

A DESCRIPTIVE STUDY TO INVESTIGATE
END STAGE RENAL DISEASE PATIENTS'
DESIRE FOR INFORMATION
AND
PREFERENCES ABOUT ROLES IN TREATMENT DECISION MAKING

by

Judith Ann Kaprowy

A Thesis
submitted to the
Faculty of Graduate Studies
in partial fulfillment of the
requirements for the degree of

MASTER OF NURSING

School of Nursing
University of Manitoba
Winnipeg, Manitoba

(c) August, 1991



National Library
of Canada

Bibliothèque nationale
du Canada

Canadian Theses Service Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-76797-9

Canada

**A DESCRIPTIVE STUDY TO INVESTIGATE END STAGE
RENAL DISEASE PATIENTS' DESIRE FOR INFORMATION
AND PREFERENCES ABOUT ROLES IN TREATMENT
DECISION MAKING**

BY

JUDITH ANN KAPROWY

A thesis 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

© 1991

Permission has been granted to the LIBRARY OF THE UNIVER-
SITY OF MANITOBA to lend or sell copies of this thesis, to
the NATIONAL LIBRARY OF CANADA to microfilm this
thesis and to lend or sell copies of the film, and UNIVERSITY
MICROFILMS to publish an abstract of this thesis.

The author reserves other publication rights, and neither the
thesis nor extensive extracts from it may be printed or other-
wise reproduced without the author's written permission.

I hereby declare that I am the sole author of this thesis.

I authorize the University of Manitoba to lend this thesis to other institutions or individuals for the purpose of scholarly research.

Judith A. Kaprowy

I further authorize the University of Manitoba to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Judith A. Kaprowy

ABSTRACT

This descriptive study examined preferences about roles in treatment decision making and desire for information in patients living with end stage renal disease (ESRD).

The conceptual framework for this study was based on the four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory of life-death decision making. The four patterns of control over decision making that were determined to be central to the descriptive theory were: patient-controlled or active decision making, joint-controlled or collaborative decision making, provider-controlled or passive decision making, and family-controlled decision making. Only the first three patterns were pertinent to this study.

A qualitative method of inquiry using a descriptive design was used to conduct this study. A nonprobability convenience sampling technique was used to select 12 patients living with ESRD. All seven physicians in Manitoba responsible for the treatment and care of ESRD patients were contacted and agreed to be interviewed.

The subjects were interviewed using two different semi-structured interview guides developed by the investigator to reflect the different experiences of the two study samples. These interview guides consisted of: an introduction, a demographic questionnaire, modified version of the Role Preferences card sort (Degner & Russell, 1988), and semi-structured questions. Interviews were tape recorded and transcribed. Data were analyzed using descriptive statistics and a method of content analysis called constant comparative analysis.

Subjects identified and described the existence of three patterns of treatment decision making: patient-controlled, joint-controlled, and provider controlled. The majority of patients preferred to assume a joint-controlled or collaborative role in treatment decision making. Congruence between ESRD patients' preferences for participation in treatment decision making and their actual experience was reported by the majority of patients. Patients identified seven factors that influenced their ability to assume preferred roles in making decisional choices. These factors included trust in physicians, social support of family and friends, hope for the future, physicians' presentation of information, lifestyle, denial of the need for treatment, and time needed to adjust to the experience. The majority of patients wanted to receive as much information as possible about their disease process and the available treatment modalities. Patients described four factors that influenced their ability to acquire information. These factors included timing of information and readiness to learn, health care experience, quantity of information, and availability and accessibility of information.

The majority of physicians identified that the ideal role for patients to assume in treatment decision making was a joint-controlled or collaborative role. Physicians indicated that the majority of patients seen in the renal ambulatory care clinics assumed either active or passive roles in treatment decision making. Physicians identified five situational and personal factors that influenced the decision making process and patients' ability to assume alternative roles. These included patients' medical or social conditions, institutional or physician biases, available resources, types of decisions being made, and trust in the physician. Physicians identified information as being central to the ESRD patients' ability to participate in the selection of

treatment modalities. They indicated that ideally patients should have as much information as they desired. Physicians identified three factors that influenced patients' ability to acquire information. These included timing of information and patients' readiness to learn, patients' health care experience, and patients' personal characteristics.

Subjects identified information as the single most significant component in ESRD patients' ability to assume their preferred roles in treatment decision making. Without knowledge and information neither health care professionals nor patients were able to effectively participate in the treatment decision making process.

The findings of this study suggest implications for nursing practice, education, and research. They contribute to nursings' knowledge and understanding of how ESRD patients' prefer to participate in the decision making process and the information they need in order to assume their preferred roles.

ACKNOWLEDGEMENTS

This study could not have been accomplished without the continued encouragement and support of many individuals. It is with great pleasure and deep appreciation that I make the following acknowledgements:

To Dr. Joan Jenkins, chair of my thesis committee, who provided me with the warmth, encouragement and support I needed to complete my thesis, I extend my heartfelt appreciation.

To Dr. Lesley Degner, whose insightful research provided the template for my inquiry, and through whose vision and example, I was able to experience an excitement for nursing research, I extend my sincere thanks.

To Professor Pat Farrell, whose insights and thoughtful contributions provided me with valuable support, I extend my sincere appreciation.

To Dr. Brian Penner, who generously shared his personal and professional experiences of patients living with end stage renal failure and whose thought provoking questions challenged me throughout this learning experience, I extend sincere gratitude.

To the participants of this study, the 12 patients and 7 physicians who willingly gave of their time, I would like to extend sincere thanks to them for so openly sharing of their feelings and thoughts.

To my friends and nursing colleagues, whose continued support and interest throughout my graduate program made the journey an adventure, I thank you from the bottom of my heart.

To my family, especially my husband Rick and our two children Kerri and Geoffrey, whose love and boundless patience sustained and bolstered me through this challenging time, I am deeply grateful. To my parents, who through their strength and love encouraged me to follow my dreams, I am extremely grateful.

Finally, to the Canadian Nurses' Foundation and to the Manitoba Branch of the Kidney Foundation of Canada, whose financial support helped to make this study possible, I extend sincere thanks.

TABLE OF CONTENTS

	Page
ABSTRACT.....	iv
ACKNOWLEDGEMENTS.....	vi
CHAPTER I INTRODUCTION.....	1
Statement of the Problem.....	1
Purposes of the Study.....	4
Significance of the Study.....	5
Definition of Terms.....	5
Assumptions.....	6
Conceptual Framework.....	6
CHAPTER II REVIEW OF THE LITERATURE.....	9
Introduction.....	9
Preference about Roles In Decision Making.....	9
Decision Making Models.....	9
Physician-Patient Interaction.....	13
Traditional Model.....	15
Consumeristic Model.....	17
Research Related To Physician-Patient Interaction.....	19
Desire for Information.....	32
Research Related To Patients' Information Seeking Behaviours.....	35
Personal Control.....	43
Conclusion.....	50
CHAPTER III METHODOLOGY.....	52
Design.....	53
Study Setting.....	53
Study Sample.....	53
Instrumentation.....	54
Acquisition of the Subjects.....	58
Procedure for Data Collection.....	59
Data Analysis.....	63
Determination of Rigor in the Study.....	64
Protection of the Rights of Subjects.....	66
Conclusion.....	68

CHAPTER IV	FINDINGS.....	69
	Introduction.....	69
	Demographic Characteristics.....	69
	Patient Participants.....	69
	Physician Participants.....	72
	Participation In Decision Making and Desire for Information.....	72
	Participation In Treatment Decision Making.....	73
	Patients' Perception of their Preferred Roles.....	73
	Patients' Perception of their Actual Roles.....	77
	Patients' Perception of the Factors Influencing Role Preferences.....	78
	Trust In Physicians.....	78
	Social Support of Family and Friends.....	79
	Hope for the Future.....	80
	Physicians' Presentation of Information.....	81
	Lifestyle.....	81
	Denial of the Need for Treatment.....	82
	Time Needed to Adjust to the Experience.....	82
	Patients' Desire for Information.....	83
	Quantity of Information Desired.....	84
	Sources of Information.....	85
	Types of Information Required.....	90
	Patients' Perception of the Factors Influencing Acquisition of Information.....	92
	Timing of Information.....	92
	Health Care Experience.....	93
	Quantity of Information.....	94
	Availability and Accessibility of Information.....	94
	Patients' Perception of Role Preferences and Desire for Information.....	96
	Physicians' Perception of Patients' Roles in Treatment Decision Making.....	98
	Physicians' Perception of the Factors Influencing Role Preferences.....	103
	Patients' Medical and Social Conditions.....	103
	Institutional or Personal Bias.....	104
	Available Resources.....	104
	Types of Decisions Made in the Clinics.....	105
	Trust in the Physician.....	106

Physicians' Perception of Patients' Desire for Information.....	107
Quantity of Information.....	107
Sources of Information.....	108
Physicians' Perception of Factors Influencing Acquisition of Information.....	110
Timing of Information.....	110
Patients' Health Care Experience.....	112
Patients' Personal Characteristics.....	113
Physicians' Perception of Information and Decision Making.....	114
Patients' Treatment Status - Six Month Follow-up Interview.....	116
CHAPTER V	
DISCUSSION.....	118
Introduction.....	118
Relationship of Findings to Conceptual Framework.....	118
Patient-Controlled or Active Decision Making.....	119
Joint-Controlled or Collaborative Decision Making.....	120
Provider-Controlled or Passive Decision Making.....	120
Relationship of Study Findings to Research Questions.....	122
Patients' Preferred and Actual Roles.....	122
Patients' Preferred Roles in Treatment Decision Making.....	123
Patients' Perception of Factors Influencing Role Preference...	126
Patients' Actual Roles in Treatment Decision Making.....	130
Congruence Between Preferred and Actual Roles.....	131
Desire for Information.....	133
Quantity of Information Desired.....	133
Sources of Information.....	135
Types of Information.....	136
Patients' Perception of Factors Influencing Acquisition of Information.....	137
Participation in Decision Making and Desire for Information.....	140
Physicians' Perception of Patients' Desire for Information and Decision Making.....	142

Physicians' Perception of Patients' Desire for Information.....	142
Physicians' Perception of Factors Influencing Acquisition of Information.....	143
Physicians' Perceptions of Patients' Roles.....	143
Physicians' Perception of Factors Influencing Decision Making.....	145
Limitations of the Study.....	148
CHAPTER VI	
RECOMMENDATIONS AND CONCLUSIONS.....	151
Introduction.....	151
Nursing Practice.....	151
Nursing Education.....	156
Nursing Research.....	158
Conclusions.....	161
REFERENCES.....	165
APPENDICES	
APPENDIX A Letter of Approval - Ethical Review Committee.....	173
APPENDIX B Letter of Access.....	174
APPENDIX C Letter of Approval for Access.....	176
APPENDIX D Letter of Approval for Access.....	177
APPENDIX E Inclusion Criteria for Subject Selection.....	178
APPENDIX F Procedure for Patient Participant Selection to be Used by Head Nurse.....	179
APPENDIX G Explanation of the Study for Patient Participants.....	180
APPENDIX H Explanation of the Study for Physician Participants...	181
APPENDIX I Consent Form for Patient Participants.....	182
APPENDIX J Consent Form for Physician Participants.....	183
APPENDIX K Patient Interview Guide.....	184
APPENDIX L Physician Interview Guide.....	186

APPENDIX M	Statements on the Role Preferences Card Sort.....	188
APPENDIX N	Psychological Dimension.....	189
APPENDIX O	Vignettes of Degrees of Control Over Treatment Decisions.....	190
APPENDIX P	Vignettes.....	191
APPENDIX Q	Outline of Study Procedure.....	196

TABLES

Table 1	Demographic Characteristics - Patient Participants.....	70
Table 2	Patients' Report on End Stage Renal Disease - Primary Cause.....	71
Table 3	Role Preferences in Treatment Decision Making.....	74
Table 4	Roles in Treatment Decision Making - Preferred and Actual.....	77
Table 5	Information Desired by Decision Making Preferences.....	96
Table 6	Patients' Treatment Status - Six Month Follow-up Interview.....	117

CHAPTER I

Introduction

Statement of the Problem

A fundamental, yet commonly underestimated, activity of patients involves their role as participants in the decision making which arises when medical treatment is required. Though few health professionals would argue with the patient's right to obtain information and make decisions, there is little consensus concerning the extent to which patients prefer to become actively involved (Pierce, 1986). Proponents of individual autonomy write that patients facing diagnosis and treatment for end stage renal disease (ESRD) are dissatisfied with the traditional medical model of health care delivery and are insisting on sharing or assuming responsibility for control over their care (Oberley & Oberley, 1979; Pierce, 1984; Ulrich, 1989). In addition, ESRD patients are "requesting more information and demanding opportunities to participate in decisions about available treatments that ultimately influence their survival and quality of care" (Starzomski, 1986, p. 325).

End stage renal disease has become a major health problem in our society today as "there continues to be increasing numbers of patients entering chronic renal programs" (Penner, Alvare, & Wong, 1988, p. S-18). The Kidney Foundation of Canada (1991) reported that the total number of patients on renal replacement therapy has increased at an average rate of 10.4% between 1981 and 1989. As of December 31, 1989 18% of the ESRD population were on peritoneal dialysis, 32% on hemodialysis, and 50% had a functioning transplant. In Manitoba, from January 1st to December 31st, 1989, new patients initiating therapy included 68 hemodialysis patients and 12 peritoneal dialysis patients. Twenty-five renal transplants had been performed.

For patients in renal failure, as the disease progresses, more functioning kidney tissue is lost and the body begins to accumulate waste products normally excreted by the kidneys. Once the disease progresses to end stage renal failure a decision is usually made to begin dialysis, hemodialysis or peritoneal dialysis, or to defer therapy. As well, the issue of renal transplantation is discussed as appropriate. In some cases there are medical, psychological, or social reasons that limit the choice. At this point in the decision making process, the context within which health care is delivered in Canada often dictates that patients now relinquish their active decision making role into the hands of a health care professional (Neufeld, 1986). According to this traditional model of the physician-patient interaction patients are obligated to assume a "passive, dependent role with nothing to do but cooperate with the physician in order to get well" (Brody, 1980, p. 718). Patients are neither responsible for their health state nor responsible for contributing to a cure. On the other hand, the physician is granted autonomy and professional dominance in the relationship (Parsons, 1951). In the vast majority of instances, the physician holds practically all of the control for making decisions related to treatment and medical care (Kalisch, 1975).

It has become increasingly obvious in recent years that a change has occurred in the public's attitude toward the medical profession and health care delivery. There appears to be a growing desire for more equality and individual autonomy. The earlier model of the patient as the passive recipient of information and treatment decisions has been replaced by a model of a partnership between the physician and patient. This change has been in response to legal, ethical, and social concerns that have escalated an interest in self determination and patient's rights as they relate to decisions about medical care (Schain, 1980; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). Philosophically, a movement away from paternalism in

health care to a belief that promotes personalism and a concept of shared or mutual responsibility between the health care professional and the patient has transpired (Brody, 1980; Degner & Beaton, 1987; Komrad, 1983; Schain, 1980; Taylor, Pickens, & Geden, 1989). This shift to a shared or mutual model advocates that the patient is a health care consumer with rights to information, interaction with health professionals, and when desired, increased control throughout the treatment decision making process (Schain, 1980).

The concept of control is a common theme presented in the nephrology literature. Patients living with ESRD experience an extreme loss of control over several aspects of their lives as the illness progresses and narrows their life style (Pierce, 1984). Patients describe how struggles over lack of control quite often result in "anger, resentment, depression, and defeat" (Lancaster, 1984, p. 63). When these patients are unable to maintain a sense of control a state of helplessness or powerlessness frequently ensues. There is increasing evidence that health care professionals can decrease the ESRD patients' state of powerlessness, enhance their sense of control and can contribute to their general wellbeing (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988). Providing ESRD patients with information and encouraging patients to make or participate in treatment decisions are strategies that are purported to facilitate the patients' sense of control. In any discussion of decision making, it is useful to consider patients' desire and willingness to exercise control over treatment choices.

As medical decisions become technically more complex and are associated with greater costs to the patient, in terms of physical and psychological resources, physicians have been increasingly encouraged to include patients in the decision making process. However, in the face of a potentially life-threatening disease some patients may want to assume an

active role in decision making while others may prefer to relinquish control and have physicians assume all responsibility. Consequently, the health care professional must ask the question: Do ESRD patients have preferences about the roles they wish to assume in treatment decision making?

Purposes of the Study

The purposes of this descriptive study were:

1. to explore ESRD patients' perception of their preferred and actual participation in treatment decision making.
2. to examine ESRD patients' perceptions of the information they desire or need to know in order for them to assume the role they prefer to play in treatment decision making.
3. to explore physicians' perceptions of the ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making.

Specifically, the research questions addressed in this study were:

1. What are the ESRD patients' perceptions of their preferred participation in treatment decision making and their actual experience?
2. What is the degree of congruence between ESRD patients' perceptions of their preferred participation in treatment decision making and their actual experience?
3. What are the ESRD patients' perceptions of the information they need in order for them to assume the role they prefer to play in treatment decision making?
4. What is the relationship between ESRD patients' preference about roles in treatment decision making and their desire for information?

5. What are the physicians' perceptions of the ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making?

Significance of the Study

This study will contribute to nursing's knowledge and understanding of ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making through description of that process as it is understood and experienced by ESRD patients in the clinical setting.

To date sparse attention has been paid to identifying ESRD patients' desire for information or their preferences about roles in treatment decision making. This knowledge would be of practical importance in nephrology programs in which the principles of autonomy are being advocated. At present there is no method for predicting which patients with ESRD would prefer little or no control over treatment decisions and which would prefer at least some degree of control over the selection of treatment alternatives. Knowledge of patients' preferences could provide a useful measure for matching patients with specific practitioners or treatment programs, or it could form the basis for choosing alternative approaches to nursing interventions that are responsive to patients' preferences. Substantial attention is required in this area to advance our scientific understanding of patients' desire for information and their preferences about roles in treatment decision making.

Definition of Terms

In this study, the following definitions apply:

Desire for information: A preference to acquire information about the disease process, diagnosis and/or treatment as a way of gaining cognitive control over a stressful situation.

Preferences about roles in treatment decision making: A desire to assume one of three alternative roles in treatment decision making: active, collaborative, or passive. Imbedded in this behaviour is the desire to exercise a degree of control over treatment decision making.

Physician: A nephrologist, attending physician, or medical resident in the clinical specialty of nephrology, who is clearly designated as having responsibility for providing information and/or making treatment decisions for the consenting patient.

End stage renal disease: Irreversible renal failure causing chronic abnormalities in the internal environment and necessitating treatment with dialysis or kidney transplantation for survival.

Assumptions

Assumptions inherent in this research problem were:

- 1) given adequate information and knowledge, most people can learn to participate in making choices about their treatment.
- 2) patients are conscious, active, and cognitively capable of participating in treatment decision making.
- 3) ESRD patients wish to have their preferences for control explicitly assessed and incorporated into the decision making process.

Conceptual Framework

The conceptual framework for this study was based on the four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory of life-death decision making. These descriptions were based on the qualitative analysis of data collected in 14 different clinical settings where treatment decisions were being made for patients with life-threatening illnesses. The four patterns of control over decision making that

were determined to be central to the descriptive theory were: provider-controlled decision making, patient-controlled decision making, family-controlled decision making, and joint-controlled decision making. The investigators differentiated between control over the design of therapy (treatment decision making) and control over the implementation of therapy (carrying out the prescribed treatment). Strategies used by patients to gain control over the design of therapy were identified. Degner and Beaton (1987) concluded that patients' and families' ability to participate in and to control treatment decisions was limited due to lack of information and assistance with interpreting their health care situation.

In provider-controlled decision making, the health care professional had final control over the design of treatment. Many patients are content to have health professionals make treatment decisions on their behalf because they may not be ready, able, or desirous of making treatment decisions. However, "while some providers of care only use this approach to decision making when the patient and family are unable or unwilling to participate, others practise the approach on a regular basis and view this as appropriate" (Degner & Beaton, 1987, p. 27). Provider-controlled decision making is the most prevalent pattern in current health care practice.

The patient, in patient-controlled decision making, exercises final control over the type of treatment to be received. "Patients are more likely to gain control over treatment design if they are given the opportunity to participate in decision making" (Degner & Beaton, 1987, p. 30). In this pattern difficulties tend to occur when a patient expects to exercise some control in making decisions about treatment and that expectation is not realized. A variety of creative strategies are used by patients in their attempt to successfully gain control.

When "control over the design of therapy is shared by one or more of the participants in decision making" (Degner & Russell, 1988, p. 368) the pattern is termed jointly-controlled decision making. In contrast to provider-controlled decision making, the exercise of joint control assumes that patients and families are capable of and willing to participate in life-death decisions.

Family-controlled decision making occurs when the family has final control over what treatment the patient receives. Sometimes a competent patient may wish to have the family mediate in treatment decision making. Two effective strategies families use to gain control are: refusing to consent to treatment of the incompetent patient and influencing health professionals to respect previously stated wishes of the patient. This pattern is not pertinent to studies of ESRD patients' preferences about roles in treatment decision making.

In the following chapter, the literature that addresses the research questions is presented and discussed.

CHAPTER II

Review of the Literature

Introduction

A review of the literature was undertaken to develop an understanding of patients' desire for information and preferences about roles in treatment decision making. A wide range of literature was reviewed, including sources from nursing, medicine, sociology, and psychology.

The literature review was organized around the three major topic areas that were brought together to provide a frame of reference for this study. These three subject areas were: preferences about roles in decision making, desire for information, and personal control.

Preferences About Roles in Decision Making

In recent years, the question of how patients approach making clinical treatment decisions when confronting a stressful event has been the subject of much debate. Empirical evidence addressing patients' preferences for playing alternative roles in treatment decision making has been conflicting and has provided health care professionals with limited guidance. To further our knowledge of the experience of the physician and the patient in the process of decision making, this section of the literature review will provide a discussion of decision making models. This will be followed by a description of the physician-patient interaction. Research relevant to these topics will then be presented.

Decision making models.

It was not until recently that scholarly attention has been devoted to the stress individuals encounter when making important life decisions (Janis

& Mann, 1977), although significant theoretical groundwork was laid more than a decade before (Festinger, 1964). This lack of development was largely because decision making was not a role attributed to patients, but rather to those health care professionals who delivered their care (Pierce, 1986). Yet, even physicians whose prime responsibility was the treatment and cure of the patient experienced difficulties in the role of decision maker. Fischhoff (1980) wrote of the dilemma confronting physicians in clinical settings,

There is no codified body of knowledge telling them when to use formal models and when to rely on intuitive judgement, how to approach decision makers and how to coax from them their true problems, which elicitation methods to use and when to trust their results, which parameters to use, and so on. Such knowledge as does exist regarding these topics is largely anecdotal. (Fischhoff, 1980, p. 28).

Decision theory has its roots in mathematics. Powerful mathematical tools, such as calculus, were formulated in the late 1600s. Probability theory was developed in the mid-1700s. These tools led many scientists to believe that even human behaviour could be explained with mathematics (Guillen, 1983). Recent publications in decision making include some aspects of probability theory (Thompson & Thompson, 1985). These are applied to the weighing of values attached to proposed actions. These include cross matrix impact analysis and decision trees that represent a quantitative approach to decision making. Decision trees and algorithms have been helpful to health care professionals in analyzing complex problems in patient care.

Decision models currently popular and widely recognized have come from the fields of business, economics, and psychology, and have been developed from simulations of decision problems in experimental laboratory studies (Pierce, 1986). This tradition of using "a hypothetical-deductive approach has produced numerous normative models of decision-making processes under varying conditions" (Pierce, 1986, p. 7).

One of the most significant normative theories is the expected utility

model. This model proposes that rational decision makers, when making deliberate choices, will take account of the values and the probabilities of the consequences to be expected from choosing each of the available alternatives (Janis, 1984). The assumption is that an individual will attempt to optimize the expected value of something defined as "utility", and that for each person a relationship between utility and dollars can be found. In other words, a rational decision maker chooses the alternative that has the highest likelihood of greatest gain. The model of expected utility model is prescriptive, designing optimal strategies for making decisions. It is not, however, a description of what people actually do.

Other prescriptive (normative) models, such as decision analysis, specify how people should make sound decisions when they have to make risky choices. The prescriptive models are occasionally applied to professional decisions made by physicians and other practitioners. However, these models are difficult to apply to personal decisions made by individual patients because "they required quantitative estimates of the desirability of each of the outcomes and of their corresponding probabilities in order to choose the course of action that maximizes expected utility" (Janis, 1984, p. 327).

Decision analysis, developed in operations research and systems analysis, has been used in making business decisions, public policy decisions, and in medical settings to aid physicians' decision making (Pierce, 1986). Decision analysis "offers a precise quantitative method for patients to express their views about the acceptability of the various risks and benefits of diagnostic and therapeutic interventions" (Eraker & Politser, 1982). This normative model involves the specification of options along with the probabilities of each outcome and the utilities or values attached to each. Expected values are then computed and an optimal choice is made. Search for the optimal outcome has been facilitated by the use of decision trees,

clinical algorithms, and cost-effectiveness/cost-utility analysis (Weinstein, Fineberg, & Elstein, 1980).

As a procedure, decision analysis is used to represent the decision maker's information and preferences concerning the uncertain, complex, unique, and dynamic features of the decision problem (Howard, 1980). Decision analysis serves to represent uncertainty in a way that the important issues are brought into consideration, structure is imposed on the numerous considerations, and the problem is personalized according to the individual's preferences and values. Therefore, decision analysis is implemented in any decision situation where individuals clearly do not know how to proceed and are overwhelmed by the task of having to make a choice when the alternatives are unclear or unknown. As Howard (1980) wryly stated "making decisions is what you do when you don't know what to do" (p. 4).

This literature review revealed that the use of decision analysis in nursing has been limited. Only five studies were found that applied aspects of decision analysis (Aspinall, 1979; Baumann & Bourbonnais, 1982, 1984; Grier, 1976). As Baumann and Deber (1989) pointed out "decision analysis fits better with a medical model than with more process-oriented approaches such as nursing" (p. 71). However, in any situation when there is not a small, finite set of mutually exclusive alternatives or when there is no a clear link between intervention and potential outcomes, the key assumptions underlying decision analysis do not hold, and the method becomes less useful. In 1980 Krischer reviewed studies of decision analysis in health care and noted 110 papers over a period of 15 years. More than half of the studies, covering a range of issues, had been reported since 1975. Most applications have been prescriptive, offering physicians an approach to diagnostic and treatment decisions (Albert, 1978; Gorry, Kassirer, & Essig, 1973; Pauker & Kassirer, 1975; Sisson, Schoomaker, & Ross, 1976; Weinstein et al., 1980).

Decision models, in vogue in other disciplines, do not adequately capture the experience of patients in life-threatening situations confronted with making treatment decisions that affect the individual's chances of optimal health and survival. In addition, the process of decision making in health care is not as clear or definitive as it is in business or industry. This is due, in part, because it is the patient's quality of life and/or the outcomes of interventions, not money, that are the appropriate measures of loss or gain.

Importing decision theories and techniques from the fields of operations research, systems analysis, or business are of limited value because they do not address the unique expression of decision problems found in clinical practice. Though the concepts of decision making under risk and uncertainty are valuable, in no way do any of the approaches consider the unique features of psychological stress, physical limitations, and the powerlessness of patients in complex health care settings.

A review of the literature on decision theory raises more questions than it answers, particularly with respect to any practical implementation. Clearly the literature lacks an explication of the decision making process when individuals confronted with stressful decisions influencing their health, and in some cases, their lives. Despite the quantity of literature about the application of decision theory to practical problems, there are neither descriptions nor prescriptions to guide our practice.

Physician-patient interaction.

To clearly understand the role of ESRD patients in the act of treatment decision making it is essential to explore the dynamics of the physician-patient interaction. In this section two approaches to the physician-patient interaction are presented: the traditional model and the consumeristic model. In the first model the patient is completely helpless and passive whereas the physician is viewed as holding all of the power and controlling all treatment

decisions. In the second model, the patient seeks to gain more control over the physician-patient interaction. Participants view each other as equals, and decisions are arrived at through a mutual or joint process involving considerable two-way communication.

In any relationship between two individuals there exists a continuum of activity-passivity, each person assumes a varying degree of passivity and activity. To maintain a sense of balance and to prevent a clash, one individual must assume a more passive role to the extent that the other individual becomes overly active. Kalisch (1975), states that "this activity-passivity continuum determines who will be in control; the passive partner giving way to the more active one" (p. 22). Control also determines the nature of the decision making process between the interacting individuals. In the traditional model of the physician-patient relationship, the patient is expected to be totally passive and immobilized as the physician assumes all of the activity and the control. "While some [physicians] use this approach to decision making only when the patient and family are unable or willing to participate" (Degner & Beaton, 1987, p. 137) others make virtually all of the decisions regarding medical treatment, issue treatment orders, and expect the patient to assume a passive, submissive role.

Moving toward the opposite end of the continuum, to the consumeristic model of the physician-patient relationship, a patient assumes a highly active role in the interaction, and the physician a more passive stance. Participants view each other as equals and decisions are arrived at through a mutual or joint process involving considerable two-way communication. This type of interaction enforces the qualities of individuality, autonomy, and personal dignity for the patient as well as preserves a high level of regard for the skills, opinions, and expertise of the physician. Thus, there is the possibility of two approaches to the physician-patient interaction: the traditional model and the

consumeristic model.

Traditional model.

According to the traditional sociological theory of the physician-patient relationship, the patient was placed in a passive, dependent sick role, a model of ideal patient behaviour (Parsons, 1951). The physician role was "to define illness, confer the sick status on potential patients,...and take the initiative in evaluating health status and controlling health problems" (Brody, 1980, p. 718). The patient was viewed as deviant (Haug & Lavin, 1981) and the physician as an agent of social control (Kalisch, 1975), thus implying that the physician-patient interaction was rooted in a power relationship (Haug & Lavin, 1981).

Historically, this particular asymmetrical relationship has been used to justify medical paternalism (Komrad, 1983), at the alleged expense of the patient's autonomy. The patient was in a dependent, subordinate position and the physician in a superordinate position. Although the degree of dependence varied according to the patient's health condition (Szasz & Hollender, 1956), social status (Brody, 1980), or culture (Kleinman, Eisenberg, & Good, 1978), both parties supposedly accepted their asymmetry as appropriate and desirable.

Brody (1980) suggested that this imbalance of power between the physician and patient that justified both the professional's assumption of authority and the client's trust and confidence, was characterized by certain types of inequalities. The least disputed inequality was that of the knowledge gap that separated physician and patient. Our society implicitly acknowledged that physicians possessed an esoteric body of knowledge acquired through academic training and leavened by a service orientation toward the patient (Brody, 1980; Haug & Lavin, 1981; Kalisch, 1975). It was the medical profession's monopoly on knowledge, not easily accessible to the public, that

has been posited as the mechanism used to preserve the physician's dominance of the physician-patient interaction. Many patients believed that the physician who regularly treated many conditions never experienced by the patient was the most knowledgeable and was best able to understand the possible outcomes and to ascertain what risks are worth taking. Because of this, some patients may be most comfortable in placing complete faith in the judgement of the physician (Eraker & Politser, 1982).

The imbalance of power has also been perpetuated by physician and patient attitudes. Physicians may think they intuitively know their patients' needs and desires without taking the patients' current thinking into account. This assumption has frequently been proven to be incorrect (Faden, Becker, Lewis, Freeman, & Faden, 1981; Haug & Lavin, 1981; Innes, 1977; Vertinsky, Thompson, & Uyeno, 1974). Patients were found to prefer far more detailed information, particularly regarding risks and alternative treatments, than physicians reported they had actually disclosed. Patients were also much more likely than physicians to believe that the final decision regarding treatment should rest with the patient.

There are several reasons for patients' acceptance of their passive role in medical decision making. When diagnosis is made suddenly in the context of a medical emergency the patient may be comforted by the belief that their physician has the knowledge and background to make decisions. "Roughly half of ESRD patients have no advance warning of impending kidney failure" (Bovbjerg, Held, & Diamond, 1987, p. 185) and hence face the difficult task of making choices, among an inherently complex set of options, when they are psychologically and physically compromised. Bovbjerg and colleagues (1987), stated that ESRD patients comprise "a 'worst case' test of patient-choice issues because...they are among the least autonomous of patients" (p. 181). ESRD patients are very sick and chronically dependent on medical technology

for mere survival - "which promotes exceptionally strong psychological dependence on doctors and passive patient behavior" (Halper, 1985, p. 67).

Consumerist model.

In the last decade a competing model, based on consumerism and authority challenges rather than authority acceptance, has received increased attention in the nursing and medical literature (Brody, 1980; Haug & Lavin, 1981; Schain, 1980). Several authors using different terms, have proposed several variations of the consumeristic model of physician-patient interaction with mutual participation as the core component. Kalisch (1975) advocated a joint participation model, whereas Brody (1980), Komrad (1983), and Schain (1980) advocated varying degrees of mutual participation. Thomasma (1983) proposed a physician conscience model that advocates consensus of mutual exchange between physician and patient.

Patient consumerism implies that the competence gap between the sick person and the health care professional has narrowed. Instead of the assumption that physicians alone are trained and sufficiently qualified to diagnose and treat, now the consumer can make the assessment "presumably on the basis of knowledge acquired through experience, patient education, or the media" (Haug & Lavin, 1981, p. 213). Physicians themselves are recognizing that the physician-patient interaction may have changed and that the traditional conceptions of professional authority is being challenged by a "more educated and more egalitarian society" (Haug & Lavin, 1981, p. 213). The implication resulting from patients' consumeristic perspective and physicians' recognition of this stance is that the physician-patient interaction itself may have changed. The interaction now seems to be based more on bargaining or mutual participation than on a dominance model.

A consumeristic stance clearly constitutes a challenge to physician authority. It focuses on patient's rights and physician's obligations, rather

than on physician rights to direct and patient obligations to follow. From a bargaining or mutual participation perspective, each individual brings to the interaction different resources and is prepared to negotiate an acceptable set of terms for the relationship. Agreements on both diagnostic tests and on medical treatment may be reached as a result of each participant sharing the other's personal expertise, knowledge, and experience. Patients are given the opportunity to increase their understanding of the medical process (Innes, 1977), particularly the logic of treatment and follow-up (Greenfield, Kaplan, & Ware, 1985). Thus, neither participant is automatically in charge.

It is generally assumed that with growing consumerism and a movement away from the traditional medical model patients wish to become more active and informed participants in decision making about their health care, the quality of survival, and even the quality of their death (Degner & Russell, 1989; Schain, 1980). While this assumption may be appropriate for some individuals, it may not be suitable for all individuals in all health situations. Some individuals would find that having information and increased control in the physician-patient relationship would be undesirable and quite stressful (Averill, 1973; Dennis, 1987; Thompson, 1981). Therefore, it is imperative that health care professionals recognize and respect their patients' individuality. As individuals, patients have the right to actively participate in the physician-patient interaction and make decisions just as they have the right to maintain a passive stance preferring to transfer the decision making power to their physician. Each patient's preference is his or her own and depends on many individual variables, modulated in many instances by illness. As Ende and colleagues (1989) stated:

The physician-patient relationship should be based not on preordained policies but rather on an accommodation to each patient's preferences and needs (p. 28).

This discussion has focused on the dynamics of the physician-patient relationship and has explored two very different models: the traditional and the consumeristic. Knowledge of these models may assist the health professional to understand the roles which patients assume when they interact with physicians.

Research Related to Physician-Patient Interaction

Much of the recent research in the field of physician-patient interaction focuses on the outcome of the interaction or patient compliance, rather than on process (Taylor, Pickens, & Geden, 1989). Several studies have linked differences in physician-patient interaction with outcomes of care including satisfaction (Ferran, Powers, & Kasch, 1987; Greenfield et al., 1985), compliance (Becker & Maiman, 1975; Davis, 1968a; Kasch & Knutson, 1985; Hayes-Bautista, 1976), and patients' increased knowledge of their disease process (Greenfield et al., 1985; Hulka, Cassel, Kupper, & Burdette, 1976).

Another series of studies examined the physician-patient interaction in an attempt to answer the question of how much involvement in their medical care patients actually desired. Analysis of these studies failed to resolve the question of patients' preferences for participation in decision making. Some researchers have found that patients want to have minimal responsibility for making treatment decisions (Degner & Sloan, 1990; Ende, Kazis, Ash, & Moskowitz, 1989; Greenfield et al., 1985; Strull, Lo, & Charles, 1984; Sutherland, Llewellyn-Thomas, Lockwood, Trichter, & Till, 1989; Vertinsky, Thompson, & Uyeno, 1974; Wetle, Levkoff, Cwikel, & Rosen, 1988), while others claim the opposite (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Faden, Becker, Lewis, Freeman, & Faden, 1981; Haug & Lavin, 1981; Thompson, 1990).

Degner and Sloan (1990), conducted two cross-sectional surveys to determine the prevalence of different preferences about roles in cancer treatment decision making, whether these preferences differed when people anticipated having cancer versus actually being diagnosed, and which demographic and disease/treatment factors were the most important predictors of preferences. The first survey examined the preferences of newly diagnosed cancer patients about roles in treatment decision making, while the second obtained a pre-disease estimate of such preferences in a general population. A sample of 436 newly diagnosed patients and 482 members of the general public participated in the study. Two measures were used to collect data. Preferences were elicited using two card sort procedures, each of which describe five different roles in decision making. The first set of roles focused on the patient-physician relationship in decision making and the second set focused on who the subject would want to make treatment decisions if illness prevented or diminished the subjects' ability to participate. The second measure was the symptom distress scale (McCorkle & Young, 1978). The scale consisted of 13 symptoms identified by patients as distressing, and each symptom was described by a card in a 5-point Likert format ranging from 1 (normal or no distress) to 5 (severe distress).

Findings revealed that preferences were situational rather than trait-like. The distributions of preferences with respect to the physician-patient decision making were reversed between the cancer patients and members of the public. Only 12% of newly diagnosed patients preferred to play an active role in treatment decision making. In contrast, 64% of householders stated that they would prefer to play an active role in treatment decision making, should they develop cancer in the future. Both samples agreed that they wanted the physician and family to share responsibility for treatment decision making if they became too ill to participate.

Univariate analysis revealed that three variables were related to preferences about roles in treatment decision making: age, education, and gender. The most important predictor of role preferences was age, with older people wanting less control in decision making. There were differences in role preferences by educational level in cancer patients, with more highly educated patients preferring more control. There was a trend for women to prefer more control than men in the cancer patient sample but not among the householders. The clinical hypothesis that patients who were sicker prefer less control in cancer treatment decision making was not supported. The researchers concluded their investigations by stating that

Individual assessment of patient preferences remains the most appropriate clinical approach given the small amount (15%) of variance in preferences that is explained by demographic and disease/treatment variables (Degner & Sloan, 1990, p. 3).

Ende and colleagues (1989), conducted a modified Delphi study to identify the key measurable dimensions of patients' preferences for autonomy. Thirteen clinicians, medical sociologists, and ethicists were recruited for their interest in the question of patient autonomy. The investigation found that:

Patients' preferences for making decisions and their desire for information emerged as the two most important dimensions for discriminating patients who seek an active role in their care from those who prefer a more passive role (Ende et al., 1988, p. 23)

On the basis of these findings, a methodological study was conducted to develop an instrument to measure patients' preference for two identified dimensions of autonomy, their desire to make medical decisions and their desire to acquire information. The final instrument, referred to as the Autonomy Preference Index (API) consisted of two scales: an eight-item scale on information seeking and a 15-item scale on decision making. The decision making scale included six general items and nine items related to one of three clinical vignettes, each vignette followed by three consecutive items. The

vignettes represented different levels of illness severity. The study used a randomized sample of 312 subjects selected from physicians' lists of general medicine patients returning to an academic hospital-based primary care clinic. To further exclude a selection bias the API was mailed to 100 patients chosen at random from those who initially had refused to participate.

Using the API the investigators found that patients' preferences for decision making was low. On a scale where zero indicated a very low and 100 indicated a very high preference for decision making, and 50 indicated a neutral attitude, the mean score for the study population was 33.2 ± 12.6 . By contrast, patients were found to have a strong interest in being well informed. On a scale where zero referred to strong disagreement with statements favouring patients' being informed, 50 to a neutral reaction to such statements and 100 to strong agreement, the mean scores for information seeking was 79.5 ± 11.5 . The investigators found that there was no correlation between the patients' decision making and information seeking preferences. Although these medical patients had a strong interest in being well informed, they preferred that decisions be made principally by their physician, not themselves.

Ende et al. (1989) state that the strong desire to be informed recorded by their population suggests that patients want to understand and be involved in decisions even if they prefer not to make the decisions themselves. The investigators found the most important positive correlate of a patient's preference for making decisions is younger age. Other sociodemographic variables associated with stronger preferences for decision making were higher education level, higher income, higher level of occupation, and a divorced or separated marital status. For the majority of patients, their desire to make decisions declined as they faced more severe illness. One limitation of the study was that participants were asked to project themselves into an illness

situation rather than using a current illness as the reference point.

In a randomized control trial, Greenfield et al. (1985) studied a Veterans Administration hospital sample of 87 patients with peptic ulcer disease. An intervention was designed by the investigators both to inform patients about the logic of the medical care process and to improve their information seeking skills so they would interact more effectively in the physician-patient relationship. Using a treatment algorithm as a guide, 23 patients in the experimental group were assisted to read their medical record and coached to ask questions and negotiate medical treatment decisions with their physicians. The intervention took place during a 20-minute session prior to the patients' scheduled doctor's appointment. Subjects in the control group attended the standard educational session of equal length in a clinic for patients with ulcer disease.

Using a four-item scale, the investigators found the 23 subjects in the experimental group more verbally active, demonstrating greater interest in the encounter and willing to become actively involved in medical decision making. The 22 subjects in the control group were found to have a passive attitude toward active involvement in clinical decision making. Several limitations of this study make it difficult to assess generalizability of the research findings. These limitations were (1) reliability and validity of the scale used for data collection were not discussed in the report, (2) the study was done among a single group of patients in the outpatient department of a teaching hospital, and (3) clinic assistants were not blind to patients' group assignments.

In a study conducted by Strull et al. (1984) the degree of involvement in medical decision making and the amount of information that 210 hypertensive patients desired and received was examined. In addition, the study examined the degree to which 50 clinicians, who represented three types of medical practice, could accurately estimate patients' preferences for

information and involvement in medical decision making. Demographic and medical factors that influenced these preferences and estimations were explored. Subjects were recruited from three different settings: a community hospital clinic, a free-standing health maintenance organization, and a Veterans Administration outpatient clinic. An investigator developed questionnaire was used to collect data.

Forty-one percent of patients stated that they preferred more information about hypertension. Clinicians underestimated patient preferences for discussion about therapy in 29% of cases and overestimated in 11% of cases. Strull et al. (1984) found that 53% of patients preferred to participate in making decisions while physicians overestimated their patients' desire for participation in decision making in 78% of cases. In actual decision making 63% of patients reported that they played a relatively passive role, leaving decision making with the physician. Only 37% of patients reported that they had participated to any extent in decisions about their hypertensive condition.

The findings indicated that 53% of patients preferred to be involved to some extent in decision making. Of these, 31% of subjects felt that the clinician should make the decisions but strongly consider their opinion, 19% felt that they wanted to share in treatment decision making, 3% felt they wanted to make the decision with or without clinician involvement. The investigators concluded that their results indicate that outpatients with hypertension desired considerable information and discussion, more than their physicians had estimated. However, these patients preferred a limited role in actual decision making and their physicians commonly overestimated these preferences. Analysis of demographic data indicated that subjects who preferred to be involved in decision making were more likely to be caucasian and attending the health maintenance organization facility.

The authors clearly defined three limitations of the study: (1) only one illness i.e. hypertension was studied in three settings therefore, the results may not be generalizable to patients with other illnesses or to other settings, (2) researchers accepted patients' and physicians' statements about decision making at face value, therefore the findings reported in this study may have differed if an observational study of these patients and physicians had been conducted concurrently, and (3) patients were asked about decision making in therapy for hypertension at only one point in time. These same patients may have revealed different preferences about other diseases and their preferences may change over time.

Sutherland and colleagues (1989) conducted a study to compare how actively patients sought information about their health status, their 'ideal' preferences for participation in decision making versus their actual experience, and the association between desire for information and perceived actual role in decision making. A convenience sample of 52 outpatients requiring post-surgical treatment for cancer participated in this study. For data collection, the investigators used the Krantz, Baum, & Wideman (1980), Health Opinion Survey, an investigator developed Information Seeking Questionnaire, and a questionnaire adapted from Strull, Lo, & Charles (1984) to assess patients' preference for participation in treatment decision making.

The investigators found that the majority of patients were active in obtaining information. This may have been the result of these patients attendance at a cancer hospital which promoted information exchange. Patients were exposed to programmes offering information, opportunities to discuss concerns with health professionals, and a patient library. The researcher suggested that there existed the possibility that patients provided socially acceptable positive responses.

Congruence between preferences for participation and actual experience was reported by 77% of the patients. Of particular interest was the fact that 63% of patients felt the physician alone, or mainly the physician, should take the primary responsibility in decision making. In addition, 27% of the subjects felt decision making should be an equally shared process, and 10% felt the patient should make the treatment decisions after considering the physician's opinion. None of the subjects indicated that the patient alone should make treatment decisions. The results of this study are compatible with the consumeristic view that believes that most patients may prefer to have their autonomy respected however, the investigators suggest that "many patients may actively seek information to satisfy an as yet unidentified aspect of psychological autonomy that does not necessarily include participation in decision making" (Sutherland et al., 1989, p. 262).

Vertinsky and colleagues (1974), using the Szasz and Hollender (1956) model of physician-patient relationships, surveyed a cross-section of 200 subjects in Vancouver to examine the physician-patient role orientations preferred by patients in clinical decision making. This study, used a technique of structured interviews centred around a clinical vignette. Subjects were asked to project themselves into the role of patient's advisor to rate a series of possible actions that the patient might take. The investigators concluded that the majority of respondents did not wish to take the entire responsibility for making their own medical decisions and they did not wish, either, to be entirely passive in the physician-patient relationship. These patients indicated a strong desire to maintain some measure of participation even though they regarded direct participation as unimportant. These results suggest that the guidance-cooperation model prescribed by Szasz and Hollender is generally acceptable to the patient. That is, in the circumstances hypothesized in the vignettes - if the "cooperation" aspect assumes a more important dimension in

the interaction. This study also suggests that for physicians who believe that congruence between physician and patient role preferences might lead to more effective treatment, one implication might be that health care providers should reduce the "mystique" in the clinical situation by allowing the patient a role in directing treatment. The investigators reported three limitations: (1) the study was not successful in delineating any variables which would provide a sufficient explanation of patients' preferences, (2) the study was not successful in providing the expected socioeconomic measures that would predict role preferences for large groups, and (3) the accuracy of the tool remains to be demonstrated and its usefulness to physicians would depend on the physicians' confidence in the tool and their perceived success in using it.

Wetle and her colleagues (1988) interviewed 198 residents, in nine long-term care facilities, and their 34 primary nurse caregivers regarding perceptions and preferences of resident participation in health care decisions. Although 40% of residents believed that they were not at all involved in treatment decisions, 80% believed that their level of involvement was appropriate. The low level of concordance between perceptions of nursing home residents and the perceptions of their nurse caregivers was a disturbing finding for the investigators. They found that caregivers overestimated the residents' level of participation in treatment decisions as compared to the residents' perceptions. The authors conclude that in general, the relatively low levels of agreement between the responses of individual residents and nurses indicates that much needs to be done to improve the level of nurses' understanding of residents perceptions and preferences.

Having reviewed the results of research studies which do not support the contention that patients want to make medical decisions it is necessary to consider published reports that strongly claim the opposite. In recent years, research studies have found that there has been a movement away from the

belief that the patient is a passive recipient of medical care to the belief that patients are active, participants in the physician-patient interaction. These studies have demonstrated that patients have a strong preference for control and participation in treatment decision making.

In a study to investigate hospitalized, adult cancer patients' preferences for information and participation in decision making, Blanchard et al. (1988), observed 439 interactions between patients and medical oncologists. The specific study objectives were to determine medical and demographic characteristics of those subjects preferring to participate in their care versus those who preferred a more traditional model of the doctor-patient relationship. In addition, physicians' behaviours toward patients were studied to determine their possible impact on patients' preferences for participation. During morning rounds physicians behaviours were assessed using the Physician Behaviour Check List (Blanchard, Ruckdeschel, Blanchard, Arena, Saunders, & Malloy, 1983) an instrument previously designed by the investigators for this purpose. Thirty-four behaviours were measured in terms of their occurrence/nonoccurrence. Behaviours included both those to measure aspects of role performance or technical competence as well as those to measure bedside manner or affective behaviours. At the conclusion of each interaction, the investigator also completed two 100 mm. visual analogue scales. One scale addressed the extent to which the physician addressed the patients' needs that day. Anchor points were 'not at all' and 'extremely well'. The second visual analogue scale was an overall measure of the patients' involvement in the interaction. The anchor points were 'not at all' and 'extremely involved'. Following rounds, patients were asked if each of a series of 17 behaviours had occurred that day. Behaviours were selected that represented each of the major categories measured by the PBCL. Patients were also asked their preference for information to be given (minimal, only if

it is good news, or all information, good or bad) and their preferences for participation in decision making (prefer doctor makes therapeutic decisions of prefer to participate in decisions).

The investigators found that 92% of the sample preferred all information, good or bad, to be given, but only 69% stated that they would prefer to participate in treatment decision making. Of those wishing all information, 75% stated that they would prefer to participate in decisions regarding their medical care and treatment and one fourth preferred a more authoritarian rather than participatory relationship with their oncologist. The investigators stated that "these findings suggest that the preference for information does not always mean that the patient then wants to participate in therapeutic decisions" (Blanchard et al., 1988, p. 1143). The investigation was limited by one methodological concern: preferences to participate were measured as a dichotomous rather than a continuous variable. Fixed response items, especially then there are only two possible alternative responses, have a major disadvantage in that they may miss some important information about the subject.

Analysis of the patient group who desired information but preferred to leave the decisions to the physician was comprised primarily of older, sicker males. Almost all of them were married. Those preferring not to participate saw themselves as less involved in the interaction than did those who preferred to participate in treatment decisions.

Cassileth and colleagues (1980) conducted a study to ascertain the preferences of oncology patients for information about their disease and their desire to participate actively in their treatment. A representative sample of 256 oncology patients participated in the study completed an Information Styles Questionnaire, developed for this study by the investigators, and the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974). They

demonstrated a strong association between preferences for information and participation in health care, particularly by younger patients (aged 20-39 years). Most patients wanted to know as much as possible about their illness and treatments with two-thirds of these patients indicating a preference for participating in decision making about their medical care and treatment. Four methodological concerns limit the interpretations of the conclusions; 1) the issues of instrument validity and reliability were not addressed, 2) a selection bias may have led to overestimation of the proportion of patients desiring control, 3) preferences for participation in decision making were measured as a dichotomous rather than a continuous variable, and 4) data on preferences were measured from two questions without any quantification of the level of participation their patients actually preferred: "I prefer to leave decisions about my medical care and treatment up to my doctor" and "I prefer to participate in decisions about my medical care and treatment" (Cassileth et al., 1980, p. 832).

A published report of a survey conducted by Faden et al. (1981) provided further support for patient participation in decision making. A convenience sample comprised of 53 adult epileptic patients, and 279 neurologists were asked their views regarding who should assume responsibility for clinical decision making. Findings revealed that patients were much more likely than physicians to believe that final decisions should rest with the patient. More than 50% of the patients held the opinion that the final decision should rest with the patient, as compared with only 7% of neurologists. While it is possible that this difference in opinion between physicians and patients may reflect in part different beliefs about outcomes, these different views may also be rooted in different assumptions about the ideal physician-patient relationship.

Haug and Lavin (1981) in a random sample of 466 members of the public and 86 physicians investigated the attitudinal variable, challenging physician authority. Their four-item scale was designed to measure consumerism, or willingness to challenge the physician's authority. The authors reported that 60% of the public took a consumerist position claiming the right to take some responsibility for clinical decision making. A major limitation of this study was that the scale contained items on information seeking and respect for physicians. These items may not relate directly to a patient's desire to make decisions. Interestingly, the authors found that their assessment of attitude failed to predict actual behaviour. The "challenge or consumeristic attitude" did not mean that the patient would be more likely to challenge the opinion of the physician, in fact, such challenges were uncommon.

In a study to describe preferences for participation in decision making and informational needs of couples undergoing investigation for infertility Thompson (1990) identified three preferred roles in treatment decision making. These roles were: 1) provider-controlled decision making, 2) joint-controlled decision making, and 3) patient-controlled decision making. A convenience sample consisting of 16 couples who were involuntarily infertile, was recruited from couples attending an infertility clinic and/or an infertility support group. A modified version of the Control Preferences Scale (Degner & Russell, 1988), an interview guide, and a demographic questionnaire were used to collect data. The investigator found that the majority of couples preferred to keep responsibility for decision making. In addition, all couples preferred to have more information than what was provided to them by their health care providers, and the majority of couples did not receive the type of information that they preferred. Incongruity between couples' preferences and their actual experiences contributed to frustration and negatively influenced

their ability to make decisions.

In summary, review of the literature revealed that although the role of patients in treatment decision making has been explored, it has not been systematically investigated. A series of studies has examined the physician-patient interaction in an attempt to answer the question of how much involvement in their medical care patients actually desire. Some researchers have found little interest in decision making among patients (Degner & Sloan, 1990; Ende et al., 1989; Greenfield et al., 1985; Strull et al., 1984; Sutherland et al., 1989; Vertinsky et al., 1974; Wetle, Levkoff, Cwikel, & Rosen 1988), while others claim the opposite (Blanchard et al., 1988; Cassileth et al., 1980; Faden et al., 1981; Haug & Lavin, 1981; Thompson, 1990). Studies did not categorize patients by the role they were actually playing in treatment decision making within the usual clinical setting. There were several limitations in the existing studies.

Desire for Information

The concept of information seeking can be found primarily in two bodies of literature: those related to consumer decisions (Newman & Lockman, 1975; Kiel & Layton, 1981; Engel, Blackwell & Kollat, 1978; Howard, 1977; Punj & Staelin, 1983) and health care utilization (Lenz, 1984; Hopkins, 1986; Messerli, Garamendi & Romano, 1980). References to information seeking activities within the health care literature were sparse until the 1960s, and those accounts were found to be predominately clinical anecdotes. Gradually however, studies have been conducted addressing the many facets of information seeking activities for consumers of health care and, of the few studies in this area, several have been conducted by nurses (Derdiarian, 1987; Dodd & Ahmed, 1987; Dodd & Mood, 1981; Lenz, 1984; Hopkins, 1986; Messerli et al., 1980).

The principle that a patient has a right to be adequately informed stems primarily from legal, ethical, social, and moral concerns. Legally, patients have the right to make decisions, based on adequate information, regarding the care and treatment of their persons: they have a right to be free of interference from other individuals, or the state, in relation to treatment without their consent (Storch, 1982). Ethically, there has been a change from a paternalistic philosophy of care to one in which autonomy and patient self-determination are promoted (Brody, 1980; Thomasma, 1984) and the provision of information is, obviously, a central issue. Socially, there has been a growing movement advocating the view that the patient is a health care consumer with rights to information, interaction with health professionals, and participation in decision making (Schain, 1980). Morally, patients have a right to be treated as autonomous persons, and to be told the truth (Storch, 1982).

The active search for health-related information is acknowledged by many to be one mechanism for coping cognitively with change, uncertainty, crisis and for gaining control over health-related events (Dennis, 1987; Hopkins, 1986; Janis & Mann, 1977; Lazarus, 1966; Lenz, 1984; McIntosh, 1974; Wallston, Kaplan & Maides, 1976). The notion that patients actively seek and acquire information to guide decisions is highly compatible with nursing theories that emphasize independent health decisions and incorporate decision making in explanations of patient health behaviour (King, 1981; Orem, 1985). The most important implication of the concept of information seeking is that it depicts the patient as an active seeker, rather than a passive recipient of health-related information.

Recently, much attention has been focused on the need for health professionals to communicate with and provide information to patients, in order that patients may participate in informed decision making regarding

their medical care (Sutherland et al., 1989).

Information is a key to understanding the problems, challenges, and frustrations with which an individual is faced throughout his or her lifespan. Information is essential in decision making and is considered by many to be a means of coping with and reducing stress (Bagley-Burnett, 1988, p. 151)

However, not all patients desire to actively seek information nor are they able to cope with complete information about their diagnosis and treatment. Forsyth and colleagues (1984) in their study of chronically ill patients who were hospitalized, found that patients sought particular types of information. These patients wanted to gain knowledge that had direct utility in solving their current problems. Burckhardt (1987) noted that "patients tend to focus narrowly on what they see as most problematic and are most receptive to learning information that enables them to make sound decisions" (p. 545).

The typical ESRD patient is seen as incapable of understanding all the issues involved in care and likely would suffer from "information overload" when showered with information (Bovbjerg et al., 1987). Physicians, when questioned, generally felt "that information and choice often tended to paralyze rather than facilitate decision making" (Bovbjerg et al., 1987, p. 185).

Some people don't want to be burdened with all the information...patients only hear about 25 to 50% of what they are told because they are often nervous, upset, and overwhelmed by their condition (Kosky, 1990, p. 23).

Forcing unwanted information on a patient is as paternalistic an act as failing to disclose the full details (Storch, 1982). Some patients may need to be allowed not to acquire information. Sometimes "preservation of uncertainty can facilitate hope, morale, and involvement with living and help the person tolerate or relieve pain and emotional distress" (Lazarus, 1982, p. 177). ESRD patients need to be given the opportunity to freely choose among options, including the option to relinquish responsibility for decision making.

Recent literature indicates that people living with ESRD and their families are requesting more information about available treatments that ultimately influence their survival and quality of life and that could possibly assist them make informed decisions (Burrows-Hudson, 1985; Lenz, 1984; Starzomski, 1986). The cardinal rule is that "the patient has the right to know" (Oberley & Oberley, 1979, p. 50). Oberley, a physician with ESRD, furthered the argument by pointing out that knowledge provides the patient with the power to make "intelligent choices" about dialysis or transplantation" (Oberley & Oberley, 1979, p. 51).

Research Related to Patients' Information Seeking Behaviours

Review of the nephrology literature reveals that despite several studies on patient education (Arsanian, 1978; Burrows-Hudson, 1985; Kutner & Brogan, 1982; Starzomski, 1986; Wynne, 1981) research has not addressed the specific question of ESRD patients' perceptions of the information they require in order for them to assume the role they prefer to play in treatment decision making.

Arsanian (1978), in a survey of one home and 96 hospitalized hemodialysis patients, found that respondents had little or no knowledge of their disease or dialysis treatment. Results of the survey prompted Arsanian to implement a patient education program based on learner needs assessment, learning goals, behavioural objectives, and an evaluation of objective achievement. Several limitations of the study were evident. The investigator did not describe how patients were exposed to ESRD education or how this knowledge was measured. In addition, the author did not include the outcome data of this well-organized program. Instead, the investigator provided a subjective assessment that patients who received instruction were less anxious and in better physical and emotional condition than patients

who had not receive the instruction. The study did demonstrate the overwhelming need to provide the patient with usable and understandable information.

Further documentation of patient need for information was confirmed by a descriptive survey conducted by ESRD Network #3 (1983) and coordinated by Burrows-Hudson (cited in Burrows-Hudson, 1985). Three surveys were conducted. The first addressed the needs of transplant patients, the second surveyed home dialysis patients, and the third surveyed the professional members of the care team. The results revealed that of all surveyed patients, 7% (N=166) had not been informed of transplantation and 22% (N=324) had not been informed of home dialysis. The results of the surveyed professionals demonstrated that with regard to transplantation, 10% of the patients either forget, deny, or are unable to comprehend the information given to them. Over 20% of the patients fall into this same category with regard to home dialysis. Problems with small sample size, lack of control for internal validity, and instrument reliability did not permit statistical analysis of the findings or the ability to generalize.

Kutner and Brogan (1982) reported on a quasi-experimental study of an educational program for new dialysis patients. These authors hypothesized that as the patients' understanding of the efficiency of the therapy increases, rehabilitation potential will also increase. This hypothesis was based on their belief that the more the patient understands the disease and treatment options the less the patient will view it as a temporary treatment that will in time restore kidney function. Using a convenience sample, matched for demographics, the subjects were randomly assigned to control and experimental groups. The actual educational program for the experimental group was not described except that a multidisciplinary team and researchers provided information on kidney disease and treatment, diet management,

vocational rehabilitation, and family and personal adjustment issues. To assess patient knowledge the experimental group was given pretests and posttests at each of the two sessions. The results of the study showed a significant increase in knowledge of kidney disease and treatment in the experimental group. No increase was noted in vocational rehabilitation, diet compliance, or personal or family adjustment. The investigators suggested several reasons for these somewhat discouraging results. Time restrictions were cited, noting that instruction given over a prolonged period time frame would have contributed to the reinforcement of the material. Sample size was small contributing to the lack of statistical significance. Finally, the investigators found that the subjects had a difficult time completing the measurement instruments.

Starzomski (1986) in an evaluation study of a patient education program established to facilitate participation of ESRD patients and families in treatment modality selection found that patients and families, generally, do want all the information possible to help them in the decision making regarding treatment choices and care planning. The patients and families in the predialysis group believed that they had the information they required to make their treatment decisions. Those respondents in the postdialysis group, however, reported that the sessions were inadequate because they came "after the fact" and that they desired more information on advantages and disadvantages of treatments. Limitations of the study include: 1) the investigator did not provide any discussion of the instrument used in the evaluation, 2) tests of reliability and validity for the patient questionnaire were not reported, and 3) results of this study cannot be generalized because of the small sample size. Results of this evaluative study emphasize the necessity of providing patients with adequate information prior to choosing a dialysis modality.

Wynne (1981) described a formal patient educational program provided to newly diagnosed patients with ESRD to: 1) reduce patient anxiety and fear and 2) allow the patient the dignity and freedom of choice. The role of the nurse in this program was to provide the patient with a detailed explanation of treatment options. This program was unique in that it incorporated conservative therapy as an option. Wynne felt strongly that patients should not be locked into a treatment option, and that death, for some, was a viable option. In the end, however, it was the professional team members who met and selected the treatment modality for the patient. It was not clear how the program achieved its goal to allow the patient freedom of choice. The author did not describe the mechanism used to assure patient learning of the printed material distributed in classes or patient input for treatment selection. This program began with established and articulated goals, however, the reality was that the patient was excluded from the decision making conference.

Several studies have documented patients' desire for information among a variety of patient populations with specific diseases, such as cancer (Blanchard et al., 1988; Cassileth et al., 1980); seizures (Faden et al., 1981); and hypertension (Strull et al., 1984) and have found that most patients reported a strong preference for information and detailed disclosure. However, despite desire and effort to acquire information, there is empirical evidence that patients often perceive that they are unsuccessful in obtaining the information they need, particularly from health professionals who may hold erroneous views of what and how much information patients desire (Faden et al., 1981; Haug & Lavin, 1981; Innes, 1977; Shapiro, Najman, Chang, Keeping, Morrison & Western 1983; Strull et al., 1984; Wetle et al., 1988).

Blanchard et al. (1988) in a study of 439 interactions between hospitalized adult cancer patients and oncologists to investigate patient preferences for information and participation in decision making found that

92% of patients do want information from their physician. The mean age of the sample, who wanted all the information given to them, was about 55 years. Slightly over half of the sample were males, and the most common diagnostic category seen was breast cancer, followed by lung cancer. Similar findings were reported by Cassileth et al. (1980). In a study to examine cancer patients' attitude toward information the investigators found that most patients wanted to know as much as possible about their illness and treatment. In addition, patients who sought detailed information versus those who avoided it were younger, white, better educated, and had had their disease diagnosed more recently.

Faden et al. (1981) in a population of physicians who treat seizures and patients who have this disorder found that patients prefer far more detailed disclosures than physicians routinely offer and that the two groups have widely different beliefs about the consequences of detailed disclosures. Patients preferred extensive disclosures, particularly regarding risks and alternative therapy. Physicians were likely to disclose only risks with a relatively high probability of occurrence and they provided little information about alternative therapies.

Strull et al. (1984) confirmed a high level of desire for information and discussion among outpatients with hypertension - more, in fact, than their clinicians believed that their patients desired. Fifty-two percent of patients reported that they had received "quite a lot" of information or "all there is to know" about hypertension and its therapy from their current physician. In contrast, physicians underestimated the amounts of information subjects reported as receiving in 38% of cases and overestimated these amounts in 16% of cases. These findings suggest that patients perceived that what their physicians had provided them with was "all there is to know" or "quite a lot", while in fact, their physicians did not feel they had provided all the

information there was to know or quite a bit of information. Forty-one percent of patients felt that they would have preferred receiving additional information about their illness, while 58% received the "right amount" and only one patient preferred less information. The relationship between preferences for additional information and assessment of what had been received was not examined. Analysis of data on demographic characteristics revealed that subjects who were likely to prefer greater amounts of discussion were more educated, had more severe hypertension and were treated at a community hospital or a health maintenance facility.

Several studies have examined the desire for information and participation in decision making from the patient's point of view (Blanchard et al., 1988; Cassileth et al., 1980; Degner & Beaton, 1987; Ende et al., 1989; Strull et al., 1984; Sutherland et al., 1989) and have found several differences.

Blanchard et al. (1988) found that the majority (92%) preferred all information be given, but only 69% preferred to participate in decision making. Of those wanting all the information, 24.9% preferred that the physician make the therapeutic decisions. This group was comprised primarily of older, sicker, married males. The findings from this study suggest that, although most patients prefer all information to be given to them, almost one-fourth of them preferred a more authoritarian, rather than a participatory relationship with their oncologist.

Cassileth and colleagues (1980) demonstrated a strong association between preference for information and participation in health care, particularly by younger patients. Most patients wanted to know as much as possible about their illness and treatment, and most preferred to participate in decisions about their care. Older patients often preferred less information and wished to depend more substantially or even completely on their

physicians for treatment decisions. Age was the only variable that consistently differentiated between persons wanting information and active involvement in decision making and those who preferred minimal information and involvement.

Degner and Beaton (1987) in their book, Life-Death Decisions in Health Care, found that, given adequate knowledge and information, most patients can learn to participate in making choices about their treatment. The assumption, so often made by health professions, that patients and families are incapable of participating in treatment decision making was not supported by their research findings. Rather, patients' participation was limited largely due to a lack of information and assistance in interpreting what was happening to them.

Ende and fellow researchers (1989) found that patients in their study wanted their physicians to be the principal decision makers and, still, they wanted very much to be informed. Their desire for information, which was high, did not correlate with their preference for decision making. Older patients had less desire than younger patients to make decisions and to be informed. These results match the findings of other investigators working with different patient populations in different settings. Strull et al. (1984) in a study of consumer preferences found that physicians, caring for hypertensive patients, overestimated their patients' desire for participation in decision making and underestimated their desire for information. Only 19% of this population wished to share equally with the clinician in decision making. Half wanted no role at all in making decisions, and only three percent wanted to make the decisions themselves. Forty-one percent of patients preferred to have more information about their disease process.

In a more recently published study conducted at the Ontario Cancer Institute (Sutherland et al., 1989) the researchers found that although many

patients actively sought information, a majority preferred the physician to assume the role of the primary decision maker. The results of this study indicated that patients may actively seek information to satisfy an as yet unidentified aspect of psychological autonomy that does not necessarily include participation in decision making. Although armed with information, some patients may choose to express their autonomy by authorizing their physicians to make all decisions, and thus decide not to decide. The results may be interpreted to indicate that professionals, in an attempt to encourage informed, autonomous decision making, may provide information which many patients may indeed desire to have. At the same time, although most patient may prefer to have their autonomy respected in relation to the provision of information, a majority may also wish to have the decision making done by others or perhaps, being well informed allows the patient to assess the decisions made by the physician.

Review of the literature on desire for information demonstrates that despite several studies on patient education, research studies have not been conducted to specifically examine the question of ESRD patients' perception of the information they require in order for them to assume the role they prefer to play in treatment decision making. Several studies have documented patients' desire for information among a variety of patient populations and have found that most patients reported strong preferences for information and detailed disclosure. However, despite desire and effort to acquire information, there is empirical evidence that patients often perceive that they are unsuccessful in obtaining the information they need.

Bagley-Burnett (1988) state that the problem today is not so much the availability of information as the identification of the type and amount of information the individual desires and under what circumstances the individual wants this information. The following suggestion is offered by

Bagley-Burnett(1988) for interpreting studies which address consumers' information seeking behaviours:

Although the results of such studies tend to demonstrate a desire on the part of consumers for more information, caution must be applied in generalizing these findings and in forming assumptions, such as: more information is better; all people desire complete information; and more information reduces stress and enhances the ability to cope with this stress. Although these assumptions may well be true, research is needed that focuses on how much information a person wants and what variables alter the amount desired (Bagley-Burnett, 1988, p. 152).

Personal Control

Perception of control is an important variable which determines if patients are willing to participate in the decisions that influence treatment choices and health care, or attribute this responsibility to others (Pierce, 1984). In the search for understanding of the concept of control scientists have studied this phenomenon extensively. Suggestions that patients be given opportunity for increased control over their health and health care is popular in current literature which predicts the belief that increasing individuals' control increases their wellbeing (Brehm & Brehm, 1981; Greenfield et al., 1985; Lefcourt, 1984). However, there is also evidence that the effects of increased control are not always positive (Averill, 1973) and that desire for control may change over time (Strull et al., 1984) and be dependent on factors such as age, education, gender, marital status, and level of occupation (Degner & Sloan, 1990; Ende et al., 1989).

In the past, a paternalistic framework of health care delivery was the norm, wherein the patient was expected to be a passive recipient of care and the physician was granted autonomy and professional dominance (Brody, 1980). This traditional view of how patients should behave in the physician-patient relationship stemmed from Parsons'(1951) concept of the sick role. The sick role conferred upon the patient certain privileges including exemption

from responsibility for one's own health state and from the performance of normal social responsibilities. The assumptions inherent in the sick role placed the patient in a passive and dependent role with nothing to do "but seek competent help and cooperate with the physician in order to get well" (Brody, 1980, p. 718). In 1956, Szasz and Hollender presented an alternative theory to Parsons' (1951) formulation of the sick role. These authors described three types of physician-patient relationships based on the degree of control of each participant: (1) activity-passivity; (2) guidance-cooperation; and (3) mutual participation. In the first model, the physician assumes an authoritative role when a patient is completely helpless and passive. It is derived from and is probably still appropriate for emergencies, trauma, and/or emergency surgery. In the second model, the patient is able to participate in a competent, rational manner by actively cooperating with the medical regimen outlined by the physician. However, while this type of interaction allows for some dialogue between participants and the opportunity for the patient to demonstrate intelligent choice, the physician is still viewed as ultimate authority. In the final model, Szasz and Hollender describe the existence of an equal participation in the delivery of health care. There exists a desire for a mutual endeavour between two parties who are dedicated to the effective management of a problem. Such an orientation requires that the "covenant" between a patient and a physician be based on mutual respect and collaborative communication. This type of interaction should reinforce the qualities of individuality, autonomy, and personal dignity for the patient as well as preserve a high level of regard for the skills, opinions, and expertise of the physician. Szasz and Hollender noted that this model might be appropriate for patients who, for varying reasons, want to participate in their decision making, especially those patients with chronic diseases.

One of the problems in the literature on control is the lack of consistent definitions. It is evident that a theoretical distinction exists between control of outcomes and control of process. In order to clearly understand this distinction one must examine and define these concepts. Control has been defined as "the ability to regulate or influence intended outcomes through selective responding" (Janis & Rodin, 1979). The crucial component of this definition makes the assumption that the individual, by selectively responding, is solely responsible for the outcomes that accrue.

In contrast, Smith, Wallston, Wallston, Forsberg, and King (1984) define control as "the ability to regulate or influence behaviour or environment in a given situation" (p. 416). This definition applies to control over the process (means) rather than control over the outcomes (ends). When patients seek to control outcomes, feelings of guilt, failure and anxiety may result if the medical treatment chosen is unsuccessful and the disease remains out of control. Control that is based on the process of treatment decision making allows patients to retain a relative sense of control even when outcomes are not favourable and seem to be controlled by other forces. One aspect of the health care process, treatment decision making, has fundamental importance as an object of control for a patient with a life-threatening disease such as ESRD, because both the patients' survival and quality of life are profoundly influenced by the type of treatment selected (Degner, 1986).

Decisional control was first described by Averill in 1973. He described "personal control" as having three different components: 1) behavioural control, 2) cognitive control, and 3) decisional control. Behavioural control is the availability of a response that can directly influence or modify an event. It is action oriented and emphasized the implementation of new behaviours. Cognitive control is the way a potentially harmful event is interpreted. Cognitive control includes "information gain, appraisal, interpretation of events

and formulation of a cognitive plan" (Dennis, 1987, p. 152). Decisional control is the opportunity to choose among several alternatives. Decisional control is having and/or executing, or contributing to the execution of a choice among alternative courses of action (Averill, 1973).

Substantial research has been done on the many facets of control in order to provide a more precise distinction between certain constructs. Investigators have examined personal control and its complex relationship to stress (Averill, 1973); the relationship between personal control and helplessness (Cohen, 1980); and the popular construct locus of control (Lefcourt, 1984). A recent focus of methodological research has been on measurement of consumer preferences and desire for control over health care (Degner & Russell, 1988; Smith et al., 1984).

Degner and Russell (1988) examined the preferences of adults with cancer about alternative roles they might play in treatment decision making. A theoretical sample of 60 ambulatory oncology patients were tested using two card-sort procedures with a total of eight vignettes describing various patterns of control over treatment decision making. The investigators were able to identify a psychological dimension of 'preferences for control over treatment decisions' using unfolding theory to scale individual preferences. Most patients preferred the pattern of shared control, and patients preferred to give control to the physician rather than a family member.

Smith and colleagues (1984), conducted a study to identify a valid instrument with which to measure patients' desire for control over their health and health care. This study was the result of the investigators' observation that many patient did not fare well under conditions in which control was available. They concluded that these patients did not, in fact, desire increased control in these specific situations. The investigators suggested that a paucity of research related to the effects of desire for control

on patients' responses to treatment approaches aimed at increasing control was due to the lack of a validated instrument to measure desire for control. Three known-groups studies were conducted in which they compared the relative utility of three measures of desire of control: a generalized measure of desirability of control (Burger & Cooper, 1979 cited in Smith et al., 1984), a health specific measure of preference toward treatment approaches (Krantz, Baum, & Wideman, 1980), and the investigator designed Desire for Control over Health Care (DCON) to measure desire for control in specific health care situations. The specific health care situations used in this study were: 1) having a baby and 2) dying of a terminal illness. These situations were compared on the basis of those who had and those who had not taken action (or indicated an intention to act). Taking childbirth preparation classes, choosing to die at home and signing a living will were considered control-enhancing actions. The best discriminator of a choice of a place to die and of the type of preparation for childbirth was the Information subscale of the Krantz Health Opinion (KHOS) Survey (Krantz et al., 1980). The Behavioural Involvement subscale of the KHOS and the situation-specific DCON were inconsistent in the discrimination among the groups. None of the measures could adequately distinguish those who had signed a Living Will (or intended to) from those who did not intend to sign one. Finally, the generalized measure did not help to discriminate among groups. The investigators suggested that situation specific measures may be appropriate for situations in which there is a large degree of experience with a specific health care setting.

Both the KHOS and the DCON are instruments developed to explore preferences for information and participation in health care processes, but are not specific to treatment decisions (Thompson, 1990). In addition, they were not developed to measure patients self perceived informational needs. The

focus of more recent studies on control in health care have addressed patients' preferences for informational control and participation preferences in relation to treatment decision making. Generally, these studies have found that not all individuals want to participate in treatment decision making and receive the same degree of information related to their medical condition (Blanchard et al., 1988; Cassileth et al., 1980; Degner & Russell, 1988; Degner & Sloan, 1990; Dennis, 1987; Ende et al., 1989; Strull et al., 1984; Sutherland et al., 1989).

Dennis (1987), using Q methodology, conducted a study to identify activities that give patients a sense of control during their hospitalization and to characterize the kinds of people who find control in various ways. The researcher identified two groups of patients: those who wanted information about diagnosis, treatment, and the life-style implications of their disease process but did not wish to be actively involved in decision making; and those patients who elected to take an active role in decision making. Dennis stressed that it is important to incorporate patients' preferences in individualized plans of care. "Although it is important to foster decisional involvement for patients who want it, it is just as important to refrain from requiring decision making by patients who do not want and cannot cope with that responsibility" (Dennis, 1987, p. 155).

This literature review revealed only two studies which examined the relationship between expectancies about control over one's health and desire for control of health care (Krantz et al., 1980; Wallston, Smith, King, Forsberg, Wallston, & Nagy, 1983). Krantz et al. (1980) constructed the Krantz Health Opinion (KHOS) Survey that was designed to operationalize preference for self care, active behavioural involvement in health care, and health-related information. It contains two subscales. The KHOS-I is a seven item subscale which measures the respondents usual information-seeking and choice

making behaviour. The KHOS-B is a nine item subscale which measures the respondents attitude towards selfcare.

Wallston et al. (1983) reported on four studies that addressed the relationship between the Krantz Health Opinion (KHOS) Survey (Krantz et al., 1980) and the multidimensional health locus of control (MHLC) scale (Wallston, Wallston, Wallston, & Devellis, 1978). Both studies conclude that preference for control as measured by the Information subscale of the KHOS (Krantz et al., 1980) was a different construct than that measured by the Health Locus of Control (HLC) Scale or the MHLC. The Locus of Control construct is conceptualized as an expectancy or belief whereas the Desire for Control is conceptualized as an attitude. Wallston et al. (1983) point out that "Expectations of control over health outcomes need not necessarily be strongly related to how much one desires control over the health care delivery process" (p. 382).

Neufeld (1986), in a descriptive study examined desire for control over health care in 43 Manitoba women, in 12 different settings, with a first time diagnosis of breast cancer. The Krantz Health Opinion Survey (Krantz et al., 1980) was administered to provide descriptive data regarding women's attitudes toward assuming an active and informed role in the health care process. The Desire for Control scale (Smith et al., 1984) was used to measure desire for control of the process of health care delivery as opposed to control of outcomes. A high desire for information was reported and respondents definitely wanted to have a say and to influence the care received. Joint control based on the assumptions of the compensatory model of helping and coping was the prevalent attitude.

Patients with ESRD have experienced an extreme loss of control over many areas of their lives as the illness progresses and diminishes their physical well-being. Indeed, the patients' entire life-style is affected, and,

though treatment makes patients feel better, they will never be well. "Diet, work pattern, finances, social activity, body appearance, family relations and sexual activity are only some of the altered life events" (Eccard, 1984, p. 30). When hospitalized ESRD patients must deal with a multitude of dependencies: "Staff members weigh the patient and calculate fluid balance. Nurses administer medications. Dieticians calculate diets. Many of the daily home activities are usurped by the hospital routine" (Fuchs, 1987 p. 11). All of these activities contribute to further loss of control for patients.

The ESRD patients' perceptions of the intrusiveness of the available treatment options and control over them has been thought to be related to the emotional impact of the disease. In one study of 70 ESRD patients undergoing renal replacement therapy (Devins, 1984), the patients' perception of the intrusiveness of the therapy and limited control over eleven life dimensions were found to correlate significantly with increased negative and decreased positive mood. In a similar study, perceived control over non-treatment life dimensions was found to be negatively related to depression (Devins, 1981). It is of interest to note that dialysis and post-transplant patients reported having a similar amount of control over non-treatment life dimensions and that control over treatment dimensions did not seem to be related to control over life in general.

Conclusion

From this selective review of the literature, it is evident that gaps exist in the state of knowledge about ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making. Previous research studies exploring the topic of patient roles in treatment decision making were limited in several aspects and none have addressed the decisional preferences of ESRD patients. None of the studies have elicited the

perceptions of treating physicians about appropriate roles in treatment decision making. Research to develop and test validated instruments that measure patients' preferences for information and participation in treatment decision making has been limited. Finally, an inductive method of inquiry has not been used in any of the studies to elicit information from patients regarding their perception of their need for information and their preferences for assuming alternative roles in treatment decision making. After a review of these studies, it is apparent that at this point not enough is known about the ESRD patients' preferences for assuming alternative roles in treatment decision making to move beyond the descriptive stage of research.

The significance of the proposed study is supported by the literature. It is evident that relatively little attention has been given to the questions: Do ESRD patients facing life threatening illness have preferences about the roles they might play in treatment decision making? and Do patients desire information about diagnosis and treatment decisions?

Knowledge of patients preferences for information and decision making would be useful for the health professional. This knowledge would also be of practical importance as nephrology programs invoking the principle of autonomy are now being advocated. These programs have been designed to make patients better informed and more involved in making decisions and consequently, they require that patients participate more actively in their own health care. This study will enable nurses to test the assumption that patients desire more information and prefer active participation in making decisions concerning their treatments.

In the next chapter, the methodology and design that were used to address ESRD patients' desire for information and preferences about roles in treatment decision making will be discussed.

CHAPTER III

Methodology

This study utilized a qualitative method of inquiry to explore, describe, and understand the ESRD patient's desire for information and preferences about roles in treatment decision making. According to Benoliel (1984), a qualitative approach can be described as "modes of systematic inquiry concerned with understanding human beings and the nature of their transactions with themselves and with their surroundings" (p. 3). Knowledge about humans is not possible without describing human experience as it is lived and as it is defined by the actors themselves. In addition, a qualitative approach is "more sensitive to and adaptable to the many mutually shaping influences and value patterns that may be encountered" (Lincoln & Guba, 1985, p. 40). The realm of human emotion, behaviour and perspective is rich in depth and diversity of meaning. The sensitivity of each individual's interpretation of their reality cannot be captured in its entirety by reducing it to small, measurable units. It is the richness and detail of the subjective data that will contribute to a deeper understanding of the ESRD patients' unique experience encountered during the decision making process.

This chapter will discuss: design, study setting and sample, instrumentation, acquisition of subjects, and the procedures used in data collection and analysis, a description of the four criteria used to determine rigor in qualitative research and ethical considerations. Finally, the limitations of the study will be addressed.

Design

A descriptive design was chosen to explore ESRD patients' desire for information and preferences about roles in treatment decision making. A review of the literature indicated that limited research examining preferences about roles in treatment decision making and desire for information, specifically in populations living with end stage renal disease, has been conducted. The use of a descriptive design allows the investigator to gain familiarity with and obtain rich, broad-ranging data on a little known phenomenon (Wilson, 1985). Therefore, a descriptive design to address the research questions was deemed appropriate.

Study Setting

The sample was selected from the Ambulatory Care Renal Clinics in two large tertiary care facilities in a midwestern Canadian city. These hospitals are the two major referral centres for ESRD patients living in Manitoba. Two settings were chosen to increase the probability of obtaining a large sample size and to ensure representativeness of treatment alternatives.

Study Sample

In qualitative research, the adequacy of the sample is based on the quality, completeness, and amount of information gathered, not on a statistical confidence level. Lincoln & Guba (1985) state that "it is usual to find that a dozen or so interviews, if properly selected, will exhaust most available information" (p. 235). A nonprobability convenience sampling technique was used to select twelve patients living with ESRD. All seven physicians responsible for the treatment and care of ESRD patients in this midwestern Canadian city were contacted and agreed to be interviewed.

Patient participants were selected from all ESRD patients referred to the two nephrology clinics. Patient volunteers who met the following criteria were included:

1. diagnosed with ESRD requiring medical intervention within six months to sustain life
2. referred to a nephrology unit for medical assessment and/or treatment
3. had a creatinine clearance of under 20 ml/min.
4. able to understand and speak English
5. no clinical evidence of confusion
6. gave consent to participate in the study

Physician volunteers who met the following criteria were included:

1. on staff at the selected facility
2. responsible for the treatment and care of ESRD patients
3. gave consent to participate in the study

The physician who served as an external member of this investigator's thesis committee was excluded from the sampling frame.

Instrumentation

Two different semi-structured interview guides were developed by the investigator based on the conceptual framework, a review of the literature, and the research questions. These semi-structured interview guides were used to elicit the qualitative data from patient participants (Appendix K) and from physician participants (Appendix L). The four sections varied across the two interview guides to reflect the different experiences of the two study samples

The four distinct sections were as follows:

Section I: An introduction.

An introduction provided a short description of the purpose of the interview and introduced participants to the kinds of questions to expect.

Section II: Demographics.

This section of the semi-structured interview guide collected demographic information on patient and physician participants in order to provide a description of the sample characteristics.

Section III: Role preferences card sort.

The role preferences card sort (Degner & Russell, 1988) consists of two sets of five vignettes which graphically depict the various roles which patients, families and physicians can play in treatment decision making. The first set of five cards (patient/physician dimension) illustrates roles that the patient and physician can assume. The second set of five cards (family/physician dimension) is designed to indicate whom the patient would want to make treatment decisions if illness prohibited the patient from participating (Appendix O & P). The roles were identified through field work (Degner & Beaton, 1987) with patients and families facing life threatening illnesses and in subsequent participant observation (Degner & Russell, 1988). These roles consisted of provider-controlled decision making, joint controlled decision making, and patient controlled decision making.

The scale (Appendix N) was developed using unfolding theory which "assumes that a psychological dimension mediates an individual's choices among a given set of alternatives and permits testing for the existence of that dimension" (Degner & Russell, 1988, p. 369). The original 8 vignettes were pretested with 10 oncology patients and reviewed by eight oncology health care professionals. The vignettes were modified to enhance discriminability and then pilot tested with a theoretical sample of 60 ambulatory oncology

patients. Preference orders of 59/60 patients were consistent with the existence of an underlying psychological dimension "preference for control over treatment decision making" (Degner & Russell, 1988, p. 367). This study concluded that most patients preferred the pattern of shared control and that when able to participate in treatment decision making patients preferred to give control to the physician rather than a family member. A subsequent pretest with 30 newly diagnosed oncology patients resulted in final changes to the card sort. This revised instrument has recently been tested in a larger project which was designed to measure the prevalence of differing preferences about roles in treatment decision making in the context of cancer (Degner & Sloan, 1990).

The role preferences card sort was selected for use in this study after review of existing literature revealed that although the topic of patients' perceptions of their preferred roles in treatment decision making has been explored (Blanchard et al., 1988; Cassileth et al., 1980) the measure of preference had not been scaled as a psychological construct and the instrument did not specifically elicit the patients' preferred and actual participation in treatment decision making. Use of the modified version of the role preferences card sort allowed for increased variability in subject response and improved on a previous approach used to elicit patient preferences about roles in treatment decision making that used only two items to dichotomously classify preferences (Blanchard et al., 1988; Cassileth et al., 1980). Furthermore, the role preferences card sort has been tested in a similar population i.e. patients with life-threatening illnesses (Degner & Russell, 1988; Degner & Sloan, 1990) and, this instrument is congruent with the four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory of life-death decision making used as the conceptual framework for this study.

The modified version of the role preferences card sort used in this study consisted of only the five cards from the patient/physician dimension. These cards were used without the cartoons that graphically depicted the alternate roles patients could assume in treatment decision making (Appendix M). The cartoons were eliminated from the original version of the role preferences card sort at the suggestion of a member of the investigator's thesis committee. Rationale for this decision was based on consideration that ESRD patients are encouraged not to see themselves in a sick role and, with the exception of a small number, are encouraged to participate in their normal activities of daily living.

These cards represented the three different roles that patients could play in treatment decision making as active, collaborative, and passive. The cards were used as a 'stimulus' to elicit a range of perceptions associated with ESRD patients' preferences for assuming alternative roles in treatment decision making.

Section IV: Semi-structured questionnaire.

A series of questions were used to elicit ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making. The interviews were structured to provide the participants with opportunities to deviate from the prepared agenda and introduce thoughts or observations that were specific to their personal perspective as the conversation unfolded (Wilson, 1985). The questions in this section were adapted with permission from Degner, Kristjanson, & Neufeld's (1990) research study and were based on the problem statement, the conceptual framework, and a review of the literature (Cassileth et al., 1980; Ende et al., 1989; Shapiro et al., 1983).

Acquisition of the Subjects

Following approval by the Ethical Review Committee at the University of Manitoba (Appendix A), a letter requesting access to the patient and physician samples and participation from staff nurses was submitted to the two tertiary care facilities (Appendix B). Upon receipt of approval from both sources (Appendix C & D) the investigator met with the nursing and medical personnel of the nephrology units in each setting to present the study's purpose, describe the methodology, and answer any questions.

In each setting, potential study patients were identified by either the Head Nurse or her delegate following review of scheduled clinic admission lists and patients' hospital records to determine which patients met the study inclusion criteria (Appendix E). At the first tertiary care facility, selected patients were approached by the Head Nurse or her delegate in the renal ambulatory care clinic while attending appointments. These patients were informed that they were potential subjects for the study and that, if they were interested in knowing what participation in the study would involve, the nurse researcher would be pleased to discuss the study with them. On the direction of the Head Nurse or her delegate, the investigator approached the patient (Appendix F). At the second tertiary care facility, selected patients were telephoned by the Head Nurse and informed that they were potential subjects for the study and that, if they were interested in knowing what participation in the study would involve, the nurse researcher would be pleased to contact them by telephone to discuss the study with them. On the direction of the Head Nurse the investigator telephoned the patient. Appointments were made to meet those patients who wished further information and expressed an interest in participating in the study.

Physicians responsible for the care of ESRD patients and who met the inclusion criteria (Appendix E) were telephoned by the investigator and invited

to participate in the study. Appointments were made, at a mutually convenient time and place, with each of the physicians who wished further information and expressed an interest in participating in the study.

A verbal and written explanation of the study was given to patients (Appendix G) and physicians (Appendix H). The explanation outlined the purpose of the study, the length of contact expected, risks to the subjects, and assured all potential participants that steps would be taken to ensure anonymity and confidentiality. Signed, informed consents were obtained from those patients (Appendix I) and physicians (Appendix J) who indicated their willingness to participate in the study. Participants were given a copy of the study's description and their signed consent.

Twelve ESRD patients and seven physicians consented to participate.

Procedure for Data Collection

Data were collected through preliminary, on-site, non-participant observations, audiotape records of face-to-face interviews with study participants using semi-structured interview guides (Appendix K & L) and follow-up telephone interviews.

Preliminary, on-site, non-participant observations were conducted in each of the study settings. "Observation...allows the inquirer to see the world as his subjects see it, to live in their time frames, to capture the phenomenon in and on its own terms, and to grasp the culture in its own natural, ongoing environment" (Lincoln & Guba, 1985, p. 273). At one tertiary care facility, the observations were conducted before the data collection period, that is, prior to patient identification and selection. Wilson (1985) designates this preliminary observational period as the "tour of limited discovery" (p. 380). The observations at this time were unstructured and were conducted to permit the investigator to expand tacit knowledge and to develop some sense of what is

seminal or salient. At the other tertiary care facility, the observations were conducted immediately prior to patient identification and selection by the Head Nurse or her delegate. The observations at this time became more focused as insights and information expanded. In each setting, the investigator arrived at the start of the day's renal ambulatory care clinics. The investigator would sit in the chairs provided for the patients and would observe physicians' and ESRD patients' activities and interactions in the clinics. Thorough field notes of observations and interactions were kept. A total of ten separate, preliminary, on-site, non-participant observational sessions were conducted by the investigator. Length of these observational sessions ranged from a minimum of two hours to a maximum of five and one half hours.

Interviews provided access to an in-depth exploration of physicians' and ESRD patients' experience in treatment decision making. According to Lincoln and Guba (1982), "The ability to tap into the experience of others in their own natural language, while utilizing their value and belief frameworks, is virtually impossible without face to face verbal interaction with them" (p. 155). The interviews were audiotaped to permit as accurate as possible a recall of the information obtained. This method of data collection permitted an opportunity to obtain information that was not biased by the researcher's memory and generated rich data.

Follow-up telephone interviews were conducted in some cases to validate concepts emerging from data analysis. In these telephone interviews the investigator validated specific themes, patterns, and categories with the subjects. Subjects were provided with the opportunity to identify other categories which they believed to be significant.

Prior to administering the instruments to the study participants the investigator asked two graduate nursing students to review the patient and

physician semi-structured interview guides and to assess whether the questions would sufficiently address the research questions. Following review by the graduate students, modifications were made to question number six of the patient interview guide. The stem of the question was left intact but the sub-questions i.e. sub-questions 'a' through to 'g' were deleted. A member of the investigator's thesis committee also expressed similar concerns with this question. Modification of the physician interview guide was not suggested.

A pre-test of the patient interview guide was then conducted with two ESRD patients known to the investigator. These pre-tests allowed the interviewer to identify whether or not respondents were able to understand the questions and articulate the information sought. In addition, the investigator was able to obtain feedback from respondents regarding their feelings and reactions to the instrument. No modifications were made to patient interview guide following the ESRD patients' pre-test. The respondents involved in pre-testing were not subsequent subjects for the study.

Once consent to participate in the study was received, arrangements were made for a mutually convenient interview time and location. Length of patient interviews varied from a minimum of one and one half hours to a maximum of two and one half hours. All seven of the physician interviews were conducted in each physician's primary practice site in one of the two health care study settings. Physician interviews took from a minimum of fifty-five minutes to a maximum of one and one half hours to complete.

Patient and physician participants were provided with a verbal explanation of the study and the interview process prior to the interview. Questions were encouraged and further explanations were given as necessary. The interview began with the demographic questions followed by the modified version of the roles preferences card sort (Degner & Russell, 1988). The investigator then asked the questions found in Section IV of the semi-

structured interview guides (Appendix K & L). The investigator supplemented the interview data with field notes made immediately after each interview. These notes contained observations made of non-verbal behaviours of the subjects, any environmental features noticed which may have contributed to an understanding of the verbal accounts, and descriptions of the investigator's own perceptions and feelings during the interviews.

The interviews were conducted without constraints in a naturalistic fashion. The interviewer chose to follow any and all leads that seemed profitable. Lincoln and Guba (1985) state that maintenance of flexibility during the questioning permits the investigator to follow up promising leads or return to earlier points that required fuller development. Probes were interjected only as necessary to elicit more information about how and why treatment decisions were made, what the subjects were thinking or concerned about, what served as their greatest source(s) of satisfaction and frustration with the decision making process, and the context of the situation. Because the investigator sought to explore and describe the subjects' lived experience during the decision making process i.e. the subjects' feelings, actions, beliefs, and the context within which these feelings, actions, and beliefs took place, it was incumbent on the investigator to create a completely permissive atmosphere. Within such an atmosphere, subjects were free to express themselves without fear of disapproval, admonition, dispute, and without advice from the interviewer.

Upon completion of the interview session each participant was thanked for their time. Additional arrangements were made so that each subject could be contacted later by telephone if clarification was required during the analysis phase.

Data were collected from May, 1990 to March, 1991.

Data Analysis

Constant comparative analysis, as described by Glaser and Strauss (1967), was used to analyze the data collected from the face-to-face semi-structured interviews. This method of analysis is objective, systematic and useful for handling qualitative descriptions of communication (Munhall & Oiler, 1986). Comparative analysis forces the investigator to expand the emerging category/construct by searching for its structure, temporality, cause, context, dimensions, consequences, and its relationship to other categories. As the data were collected from each interview the audiotapes were transcribed verbatim. Continuous and simultaneous collection and processing of the data then took place. The first rule of the constant comparative analysis method is that "while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (Glaser & Strauss, 1967, p. 106). Initially, coding and analysis took careful formulation and consideration until the categories began to emerge. By reviewing each interview as it occurred the investigator was able to confirm and explore findings in subsequent interviews. In this way, concepts and categories were enriched, verified or not supported. When all of the data had been collected the coding was reviewed in total. Incidents and pieces of the data were compared and analyzed to identify common themes, or categories that thoroughly described the data.

Codification of the data was managed by transcribing audiotapes of all interviews into computer files using the "Ethnograph" computer program (Seidel, Kjolseth, & Seymour, 1988).

Following analysis of the data collected during the first patient interview, an additional question was added to Section IV of the semi-structured patient interview guide. Congruent with a qualitative approach, it was anticipated that the interview guide may need to be refined while the

study was being conducted (Cobb & Hagemaster, 1987).

The interviews were initially coded by the investigator and were then independently reviewed by a nurse familiar with qualitative research. Categories and properties were discussed and compared to achieve consensus.

Descriptive statistics were used to analyze data collected from patients' and physicians' responses to the modified version of the role preferences card sort, the type of information that ESRD patients desired, and the demographic data. The modified version of the role preferences card sort was statistically analyzed for frequency of response in the two research groups (patients and physicians) to each of the three alternative roles in treatment decision making: active, collaborative, and passive. Differences within and between the two research groups was then determined. The types of information that ESRD patients desired required initial identification of the major coding categories followed by determination of the frequency of responses in each coded category.

Determination of Rigor in the Study

In any form of scientific inquiry validity and reliability are critical issues in evaluating research methods. When evaluating a qualitative method one looks for similar criteria commonly used in evaluating quantitative methods. Lincoln and Guba (1985) suggest that in qualitative research, these criteria require some reinterpretation. They describe four criteria that are used to establish rigor in qualitative research; truth value (credibility or internal validity), applicability (external validity or generalizability), consistency (reliability) and neutrality (objectivity). Each of these will be discussed as they applied to this research study.

Truth value seeks to establish confidence in the truth or credibility of the findings. Lincoln and Guba (1985) suggest that credibility be the criterion

against which the truth value of qualitative research be evaluated. A qualitative study's truth value is enhanced when many items of evidence are used together with a wide range of evidence which allows interpretations to be made with a greater degree of confidence. Use of a wide range and depth of evidence is consistent with the concept of triangulation, which is defined by Wilson (1985) as the use of several different collection methods to obtain as many different "slices of data" as possible on the same study question and then cross-check accounts against one another for consistency and comparability. This study's use of preliminary on-site, non-participant observations of physicians' and ESRD patients' activities and interactions in the Renal Ambulatory Care Clinics, a modified version of the role preferences card sort (Degner & Russell, 1988), and semi-structured interviews allowed the data complexities and depth to surface. In addition, member checks, peer debriefing, audiotaping and transcribing interviews verbatim provided a kind of benchmark against which later data analysis and interpretations could be tested for adequacy and credibility.

Applicability refers to whether or not the findings may be appropriately applied to other settings. According to Lincoln and Guba (1985) fittingness should be the criterion against which the applicability of qualitative research is evaluated. Fittingness is established by demonstrating that the findings of the study "fit" the data from which they are derived (Sandelowski, 1986). The responsibility of the investigator is to provide 'proper thick' descriptive data so similar analysis or judgements can be made by others. In-depth presentation of data related to demographic characteristics as well as the physicians' and ESRD patients' life experiences in the decision making process have been provided. A nurse researcher who was independent of the study and who has experience in qualitative research reviewed the themes and categories, and the description of the findings to assess the fit between the data and the findings.

At best the findings of this study are applicable only to the population studied. However, this is relevant in that it is a place from which we may go forth (Benner, 1984). Full understanding of the breadth and depth of patients' experience in the treatment decision making process has just begun.

Consistency refers to whether the research findings would be consistently repeated if the inquiry were replicated with the same subjects in the same context. Lincoln and Guba (1985) propose that auditability be the criterion of rigor or merit relating to the consistency of qualitative findings. In an effort to ensure consistency, the data was collected by one interviewer, the investigator, and later transcribed verbatim. Consensual validation of the transcribed and coded interviews by an independent nurse researcher and the members of the researcher's thesis committee familiar with qualitative research was an integral part of the data analysis.

Lastly, neutrality seeks to confirm that the findings of the study are a sole function of the subjects and conditions of the inquiry and not of the biases, motives, interests, perspectives of the investigator. Lincoln and Guba (1985) suggest that confirmability be the criterion of neutrality in qualitative research. Confirmability is achieved when auditability, truth value, and applicability are established. In this study, the strategies used to control for interpreter bias and consequently to ensure validity were: (a) consensual validation among peers with experience in qualitative research; (b) use of many items of evidence; and (c) member checking.

Protection of the Rights of Subjects

The study proposal was submitted to the Ethical Review Committee, School of Nursing, University of Manitoba. Upon ethical approval from the committee (Appendix A), a letter requesting access to the patient and physician samples and participation from staff nurses was submitted to the

two health care facilities (Appendix B). The study began on receipt of approval from both sources (Appendix C & D).

A verbal and written explanation of the study, including the rights and roles of study participants, was given to all patients (Appendix G) and physicians (Appendix H). Written consent was obtained from patients (Appendix I) and physicians (Appendix J) prior to their inclusion in the study. A copy of their signed consent was given to each participant.

Confidentiality of potential subjects was maintained by having the Head Nurses or their delegates from the nephrology units approach and inform the subjects of the study. Only those patients wishing to know more about the study were known to the investigator. This procedure for introducing the study to patients was taken in order to reduce any possibility of perceived coercion to participate on the part of the patients.

The investigator was the only person aware of the identity of the participants. The investigator did not release the names of the subjects to the staff in the study settings. Subjects were assured that any typed references to the names of physicians, health professionals, patients, and/or institutions would be designated by letter or falsified name in the interest of confidentiality. Audiotapes, transcripts, interview guides, and field notes were numerically coded and filed in a locked file drawer in an office. Only the investigator, the thesis committee, and a nurse who assessed the analysis had access to the data. Following completion of the study, audiotapes were erased and all documentation of data, excluding the final written report, was shredded.

Participants were not expected to suffer any ill effects as a result of their involvement in this study. Open discussions of their perceptions of their desire for information and preferences about roles in treatment decision making assisted patient participants to ask more questions, seek additional

information, become more aware of their preferences for participation, and as a result, some patients may be capable of assuming their preferred roles in future treatment decision making situations. Participation in this study may have provided physician participants with an opportunity to clarify some of the feelings and concerns they may have had about ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making.

Conclusion

A descriptive design was chosen to explore ESRD patients' desire for information and preferences about roles in treatment decision making. A semi-structured interview guide composed of four sections: introduction, a short demographic questionnaire, a modified version of the role preferences card sort (Degner & Russell, 1988), and semi-structured questions were used to collect data from physicians and ESRD patients. Data were analyzed using descriptive statistics and a method of content analysis called constant comparative analysis. A summary of strategies to achieve rigor in this qualitative study were presented. Measures to protect the ethical rights of subjects were identified.

In the next chapter, the findings of the study are presented. Following a description of the characteristics of the sample, the findings of this study derived from the modified version of the role preferences card sort and the semi-structured questionnaire are presented.

CHAPTER IV

Findings

Introduction

The purpose of this study was to describe end stage renal disease (ESRD) patients' desire for information and preferences for assuming alternative roles in treatment decision making. An extensive description of the study findings is presented to demonstrate the richness of the data obtained. First, the demographic characteristics of the study sample are presented. Next, data from the modified Role Preferences card sort are reported. Finally, results of the content analysis of the qualitative data are described.

Demographic Characteristics

Patient Participants

Twelve patient participants were interviewed during the data collection period from May to September 1990. The study sample included equal representation by males and females. The mean age of participants was 41.6 years for males and 54.5 years for females. The majority of participants were married, caucasian, and had completed some high school education. Three individuals had attended the Renal Education Program. One male participant had attended the Program on two separate occasions. Seven of the twelve patient participants lived in Winnipeg and five resided in rural Manitoba. It is interesting to note that the urban:rural ratio of 7:5 found in this study was representative of the larger population of ESRD patients living in Manitoba. One male participant claimed Winnipeg as his primary place of residence, however, he travelled extensively throughout Canada and the United States during the year. Table 1 describes the demographic characteristics of the participants in more detail.

Table 1**Demographic Characteristics - Patient Participants**

Characteristics	Number of Patients		
	Male	Female	Total
Number of Participants	6	6	12
Age			
Mean (years)	41.6	54.5	
Range (years)	26 - 62	44 - 63	
Marital Status			
Married/Common-law	4	6	10
Divorced/Separated	1	0	1
Single (never married)	1	0	1
Place of Residence			
Winnipeg	4*	3	7
Rural Manitoba	2	3	5
Educational Background			
Finished Some Grade School	0	2	2
Finished Some High School	3	3	6
High School Graduate	0	1	1
Trade Certificate/Diploma	1	0	1
Some University/College	1	0	1
University/College Graduate	1	0	1
Renal Education Program	2**	1	3
Racial Origin			
Caucasian	6	5	11
Native North American	0	1	1

*Primary residence located in Winnipeg, travels extensively throughout Canada and U.S.A.

**One male had attended the Renal Education Program on two separate occasions.

When asked if they knew their medical diagnosis or could describe what had caused their renal failure, the majority of patients said "yes".

One patient stated that hypertension had been the primary cause of her renal failure. Five patients responded that diabetes had contributed to their ESRD. Two of these patients also had hypertension. One male patient had diabetes, hypertension, and had had one kidney surgically removed. One patient had hypertension complicated by the congenital absence of one kidney. Three patients had long histories of chronic glomerulonephritis and one of these patients had one congenitally absent kidney. One patient had chronic pyelonephritis and had had one kidney surgically removed. One female patient stated that she did not know her diagnosis nor did she know the cause of her renal disease.

Table 2 reports data on the patients' knowledge of the primary cause of their end stage renal disease.

Table 2
Patients' Report on End Stage Renal Disease - Primary Cause

Primary Cause of Renal System Failure	Number of Patients
Diabetes	3
Hypertension	1
Diabetes and Hypertension	1
Diabetes/Hypertension/Surgical removal of kidney	1
Hypertension/Congenital absence of one kidney	1
Pyelonephritis/Surgical removal of kidney	1
Chronic glomerulonephritis	2
Chronic glomerulonephritis/Congenital absence of kidney	1
Unknown	1

The majority of patients were able to state the year in which they became ill. Only one patient could recall the month, and none of the patients could recall the exact date on which their diagnosis had been made. Only one patient was able to recall the results of his most recent creatinine clearance.

Eight patients were able to state the percentage at which their kidneys were now functioning. Three patients did not know their creatinine clearance nor did they know their degree of renal failure.

Patient participants were asked by the investigator to describe their health status using the descriptors: excellent, good, and poor. In response to this question one patient described his health status as excellent, six stated that they felt good, and three responded that their health status was poor. The majority were unable to contain their responses to these three descriptors and used unique, expressive terminology, such as " I feel good, but the truth is not as good as someone else 25 years old...I just wear out quicker than everyone else", " the shits", and " I'm just burned out" to communicate their feelings.

Physician Participants

Seven physician participants were interviewed during the data collection period. The final study sample included one female and six male participants. The mean age of the physician participants was 45.3 years. All physicians were on staff at one of the two large tertiary care facilities. The extent of involvement with ESRD patients ranged from 40 to 100% of the physicians' professional practice. All participants reported that the highest level of education they had achieved was the successful completion of the Canadian Fellowship or its equivalent.

Participation in Decision Making and Desire for Information

In the first section, the patients' perceptions of their preferred participation in treatment decision making and their actual experience are identified. Descriptions of the many factors that have an impact on patients' ability to participate in the decision making process are provided.

In the second section, the patients' perceptions of the information they needed in order for them to assume the role they preferred to play in treatment decision making are described. A variety of factors that influenced patients' ability to acquire information are presented.

In the final section, physicians' perceptions of the roles ESRD patients should assume in treatment decision making will be described. In addition, physicians' opinions of ESRD patients' desire for information are presented. Factors that impacted on patients' decisional preferences and their attainment of information are discussed.

Quotations from the transcribed interviews are used to illustrate the descriptions of patients' desire for information and preferences for assuming alternative roles in treatment decision making. Portions of the quotations were altered to protect the identification of participants and to maintain anonymity.

Participation in Treatment Decision Making

Patients' Perception of their Preferred Roles

Patients were asked to read the five cards from the modified Role Preferences card sort and then identify which one of the five cards best described the role they wanted to play in treatment decision making. Patients' responses to the modified Role Preferences card sort were categorized into three patterns of control based on research by Degner and Beaton (1987). These patterns were: 1) patient-controlled or active decision making, 2) joint-controlled or collaborative decision making, and 3) provider-controlled or passive decision making.

Table 3 illustrates the roles that patients indicated they preferred to assume in treatment decision making. Two patients preferred to assume an active role in decision making. Neither of these patients wished to have

ultimate responsibility for making the final treatment selection; both preferred to make the final selection of their treatment only after seriously considering their doctors' opinion. Seven patients stated that they preferred to share responsibility with their doctors for deciding which treatment would be best for them. Three patients wished to play a passive role in treatment decision making. Two patients preferred that their physicians make the final decision about which treatment would be used, but only after seriously considering their opinions. In contrast, the third patient preferred to relinquish all decision making to the physician.

Table 3
Role Preferences in Treatment Decision Making

Role Preference	Number of Patients		Total
	Male	Female	
A \	0	0	0
B /	2	0	2
C -----Collaborative	3	4	7
D \	0	2	2
E /	1	0	1

In patient-controlled or active decision making, patients actively participated in treatment decision making when their physicians provided extensive information and clearly outlined the various treatment alternatives that could be pursued and left the final choices to the patients.

I've had laser treatments on my eyes and I was told I should get them but it was up to me if I wanted to decide, and I decided myself, that yes, I will get them done. But I didn't decide on my own. It was listening to the doctor and he explained why you should get it done, and what a difference it would make, and everything else. And it was the same with the kidney. ...and I've decided myself which way I want to go. ...I wanted to go for a transplant or I wanted to go for peritoneal dialysis.

In this pattern, patients reported that when they believed their physician's advice about the form of treatment was inappropriate for them, they had to decide whether or not to seek alternative medical opinions, and in some cases they entertained the option of changing physicians. One patient described watching another ESRD patient hemorrhaging in a hospital bed. The experience frightened the patient. In fact, the patient was so convinced that the physician's advice about treatment was inappropriate that this patient telephoned a physician at another hospital to obtain a second opinion. This patient subsequently changed physicians and the treatment modality that initially had been chosen.

The patient next to me, I could see everything they were doing and knew that would happen to me. ...The patient was bleeding two beds full of blood! I was looking at this and I'm thinking oh my God! I've got to go through this! It could be me! The patient was hemorrhaging something terrible and ended up having to have a transfusion. So I'm watching all this and I'm thinking, oh my God!...Mentally I just couldn't take it anymore...Well, I phoned Dr. X from the hospital...I told this physician what was going on. So things got straightened out and I felt more at ease after I talked to this second physician.

In joint-controlled or collaborative decision making, patients shared control over treatment designs with their physicians. In this pattern, patients expressed a strong desire to be actively involved in making treatment decisions but did not want to be ultimately responsible for selection of a treatment modality. As with patient-controlled decision making, patients required substantial information to participate in collaborative decision making.

The decisions are discussed with me. Basically, I am well informed by the doctor of each treatment and what the effects of that are. I don't want to be totally responsible for my treatments because of knowledge for one thing...I have really been talking to the three of them [physicians in the three clinics - transplant, hemodialysis, and peritoneal dialysis]...I went and talked with them for a while and discussed the different types of dialysis.

In this pattern, patients reported that physicians spoke with them

about treatment alternatives and encouraged them to participate in making treatment decisions.

They asked me what I wanted to do. I think they give you pretty much the options. There might be a slight bias, just because that's their profession....But, other than that I think they leave it quite open for you to decide. I don't think they push you in any direction.

In provider-controlled or passive decision making, the physician made the final decision about the design of treatment. In this pattern a degree of trust or comfort must be established between the patient and physician. Two patients preferred that their physician make the final decision about their treatment, but only after seriously considering their opinions.

My opinion's the last one [I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion]. That's what you've got the doctors for. You put trust in them and that's what you do, otherwise if you don't, then that means you don't trust them. That's the way I look at it....I like to leave the decisions to my doctors, if I feel comfortable with them, like my family doctor, who I had for over thirty years. ...you want a say in it, but you know, you want to say, these are some of the things that I'd like to have considered, but then leave the doctor with the...[decision].

Patients looked to physicians for guidance, support, and information because they simply did not know how to make decisions, and they were in fear of losing their lives if they made the wrong choice. One male patient preferred to leave all decisions regarding his treatment to his doctor. In this instance, the patient trusted the physician's knowledge and relied on his judgement and decision making.

Actually for me, I'd leave everything to the doctors. The doctors know better than I do. ...I'd leave that [treatment decision making] to the doctors. I would think everything will be in their hands. I mean, what the hell do I know about it, unless they're going to kill me, then it would be different! They're out to help me, not to make things worse for me. I put myself in their hands, and what they say, I do. I don't argue with them or anything, what's the use because I don't know what I'm talking about anyway. That's why I hired them.

Patients' Perception of their Actual Roles

Patients were asked to read the five cards from the modified Role Preferences card sort and to identify which one of the five cards best described the role they actually played in treatment decision making.

Table 4 illustrates the roles that patients stated they preferred to assume in treatment decision making and compares them with the roles patients actually played in treatment decision making.

Table 4
Roles in Treatment Decision Making - Preferred and Actual

Patient	Roles in Treatment Decision Making	
	Preferred	Actual
Female024	D	D
Male036	B	B
Female048	C	C
Male060	C	C
Female072	C	B
Female084	C	C
Male096	B	B
Female108	C	A
Male120	C	C
Male144	C	E
Male156	E	E
Female178	D	C

Eight patients responded that perceptions of their preferred roles in the decision making process were identical to the roles that they actually had assumed. Three patients assumed more active roles in the actual treatment decision making process than their stated preferred roles. It became apparent to them that when the time came to make definitive decisions about the selection of treatment options, they wanted to have their opinions considered.

Seems that was always the one that I would say [hemodialysis], but when it's coming to this point now, I want the final say, that I'm not going to have it done to the blood system....I know with me and my veins, there's just no way that I will let anybody fool around with my veins. So I wanted to go the other way...I told my doctor that's the way I like it, to do peritoneal only do it at home.

One patient wanted to play a collaborative role in treatment decision making, however, hospital resources were severely limited at the time. Consequently, the choice of treatment modality was made by the physician and presented as a "best choice" to the patient. In this instance, the patient perceived being placed in a passive role with the physician controlling the decision making process. This patient was not prepared for the physician's decision and was not aware that a decision had already been made for treatment.

I would prefer to make my own decision, but...I can only have so much input right now, because of nursing and machines available. Plus there is a training period...I prefer the blood type, hemodialysis, and my doctor said well, I can't. At first I got the impression that I could have my own choice. And the next time I went all that was [different]. I was disappointed but the next time I went I understood why. I figured it all out. There's not enough nurses and people to run those dialysis things so that's fine too, and my doctor did feel that maybe the other one might be better for me, right from the start.

Patients' Perception of the Factors Influencing Role Preferences

A range of personal and situational factors influenced patients' ability to assume their preferred roles in treatment decision making including: 1) trust in physicians, 2) social support of family and friends, 3) hope for the future, 4) physician's presentation of information, 5) lifestyle, 6) denial of the need for treatment, and 7) time needed to adjust to the experience. Each of these factors will be discussed in detail.

Trust in physicians.

The fostering of a trusting relationship between patients and their physicians was crucial to the ultimate success of the decision making and dialysis experience. Whether or not patients trusted their physicians and were confident that the best decisions would be made on their behalf influenced patients' preferences to assume alternative roles in treatment decision making.

As long as they consider my opinion too, and then, you know, go from there or whatever. Because I trust my doctor now and I think, you know, my doctor's got a lot of patients. They all say my doctor's one of the best, so I think I will just let Dr. X tell me what [interventions are necessary]....I'd rather have some professional do it [hemodialysis] and then when I go in there I know I'm going to be taken care of, when I walk out I'm going to be ok.

A lack of knowledge in the initial phase of the patients' illness was a determining factor in the patients' decision to trust the physicians' judgement and delegate responsibility for treatment decision making to the physician.

So I really didn't know what was going on but I trusted the judgement of Dr. X at the time....I have people who come to me for advice, and I work with them. They trust me also. There's got to be confidence.

Social support of family and friends.

Another important element that strongly influenced patients' ability to make decisional choices was the continuation of strong ties with family and friends. There was evidence that family members wanted to be involved in the treatment decision making, they sought information for themselves and for the patient, offered advice, and participated as much as possible. The strength of the family network had influence on patients' attitudes and responses to ESRD treatment decisions.

Six patients had their spouses present in the room or within listening distance during the interviews. These spouses frequently interrupted the interviews when they felt it was necessary to voice concerns or give their interpretations of specific situations. Patients spoke of how important and necessary it was to ensure that their spouses were included in the decision making process.

They've included both of us in it. You know, like when they talk to us about transplant and all the other treatments that were available, they brought my husband into the room at the same time. So, it's been great.

Family members' desire to participate in ESRD care and assist in choosing a treatment method also had an impact.

Personally I'd just as soon [dialyze] every other day, for a few hours and have it over with instead of everyday every four hours. And the only thing would be if you did have a dialysis unit in your home, you could dialyze at night. My daughter was all gung-ho there, she thought it was a splendid idea, she made all the enquires about getting it, like she was living in a rural community at the time, so she thought this was an excellent suggestion that they had. She would get dialysis in her place, and [we would] move up there. She's still trying to convince us we should go.

Strong relationships with friends, that developed to a fuller extent when the patient became ill, helped support the patients in these times of stress.

One thing I had was my friend. I could talk to her, you know like I was talking to my mother. In fact, I couldn't even talk to my mother the way I could talk to her. ...When I was first sick she was the one that helped me, with her daughter, with the doctors and everything. She took me to the doctors and now I can tell her anything and I know it's not going to go any further.

Hope for the future.

Hope for the future was an essential factor that sustained patients in the days prior to dialysis or transplantation. Patients integrated potential treatment modalities into plans they were making for their futures. They looked at how their normal routines could be altered to ensure that their dialysis would be successful and stable. Patients spoke of re-entering a world free from overwhelming fatigue and instability once treatments began. Patients' own philosophy of life produced an impact on their ability to participate in treatment decision making.

You have to look at it this way, if you have this disease or sickness or whatever, its not that bad in a way, because you're still moving around up to a point. You're moving around freely, so you've energy problems and getting tired and a few little other things. But a guy could live with it. If this was all there was to it. Right? You can change your life to that. But I would say, I want to know because I look at it as a life-extending service.

Blending into the patients' hope for the future was an underlying sense

of despair. Aspects of their personal and private lives were on hold until treatment commenced.

Every time the phone rings I just hate it ringing. I hope it's the transplant people saying [come in]...I just want to start feeling better again, good and energetic...stop the itching and the pain. I want to get on with my life. This whole thing has actually stopped me from progressing with a career...I can't get married until this is done.

Physicians' presentation of information.

The physicians' presentation of information to patients and family was a crucial influencing factor in decision making since it allowed patients to know their options and subsequently to make an informed decision. One male patient stated that although his preferred and actual roles were congruent, he felt that his doctor had discussed neither the various treatment options nor the advantages and disadvantages of these options with him. The patient, not knowing this information, found it extremely difficult to assume a collaborative role in treatment decision making.

But I didn't get an opinion....nobody comes out and tells you. My doctor could voice an opinion without saying you have to go on this kind of system. There was no opinion....Nothing was said, actually, I don't think they pointed out the advantages and disadvantages, I shouldn't say that... But it's just that, not just the doctor, but others, they should convey their ideas more to the patients.

Lifestyle.

Patients in the end stage of renal failure have every aspect of physical, social, and psychological performance touched by the disease process. Indeed, patients' entire life-style was affected. Patients expressed the need to have physicians consider their lifestyles when treatment choices were being discussed and decided. They had a strong desire to maintain as much stability and as little disruption as possible.

My mind was kind of indirectly made up by my doctor, and by myself, because of the travelling every week, out to the farm...it's just like our second home there. So we can't miss it, it's like a magnet. And then you consider out

there, there is no hospital with dialysis machines....So, part of the decision, this is part of it, like the liquid solution I could take with me.

Denial of the need for treatment.

Five patients discussed how they coped with and adapted to the stresses of the drastically altered ESRD lifestyle by the use of denial as an adaptive mechanism. The use of denial served to guard patients from the realities of their situation and in some cases, legitimized their assumption of a passive role in treatment decision making.

I was never worried about it, because like I say, I'm not into it. For me it's twenty years down the line yet, it's not going to happen to me, that's the way I'm thinking. It ain't going to happen to me. That's the way I look at it. ...I'll cross that bridge when I come to it. I still am not sick. This is my problem. If I was really sick I'd be asking more questions or I'd worry more.

Time needed to adjust to the experience.

A patient's emotional and physical adjustment to the reality of ESRD requires a great deal of time, as does the ability to become involved in treatment decision making. The time available for patients to participate in discussions with physicians influenced the patients' ability to participate in the plan or interventions.

[I'm] more involved, more aware of my problems [now]. Originally I would just come in and do whatever they told me to. It worked great, except now that things are getting a little more serious, I am getting more involved, I want to know exactly what's going on. For a long time, I was very passive.

Patients described the time from the physicians' diagnosis of renal failure until the knowledge of pending medical intervention as a phase during which they were often shocked by the diagnosis and were quite passive in participation in decisions. In situations where life-death decisions had to be made physicians were dominant in these decisions.

People, at the Clinic, some have experienced a very traumatic change for them and really don't know what's

going on. I've been in the course, with a fellow there, that all of a sudden his kidneys just stopped working, and it can be horrible, traumatic, he was really in shock. I think, he's still in shock. So again, he hasn't been able to digest it that fast, to make a decision.

In summary, ESRD patients preferred to assume one of three roles in treatment decision making: patient-controlled or active, joint-controlled or collaborative, or provider-controlled or passive. A range of personal and situational factors influenced ESRD patients' ability to assume their preferred roles including: 1) trust in physicians, 2) social support of family and friends, 3) hope for the future, 4) physician's presentation of information, 5) lifestyle, 6) denial of the need for treatment, and 7) time needed to adjust to the experience.

Patients' Desire for Information

Information was identified as the single most significant component in ESRD patients' ability to assume their preferred role in treatment decision making. Patients acquired information they wanted about their illness and treatment modalities from a variety of sources including health care professionals, family and friends, written materials, and the media. The patients' ability to access these sources was identified as pivotal in their ability to become and remain informed about their disease process.

A variety of factors influenced the patients' ability to acquire information. Patients needed to be ready to acquire and retain information, both emotionally and mentally, before they were able to assimilate newly gained information into the decision making process. The availability of knowledgeable resource people to provide patients with the information that they needed and at an appropriate time was instrumental in the patients' ability to access information. The quantity of information available to patients

had an impact on patients' ability to participate in treatment decision making. As well, the patients' individual health care experience emerged as an important factor affecting acquisition of information and participation in treatment decision making.

Quantity of information desired.

To determine ESRD patients' perception of the information they needed in order to assume the role they preferred to play in treatment decision making patients were asked to identify which of the following statements best described their point of view: 1) I want only the information needed to care for myself, 2) I want information only if it is good news, and 3) I want as much information as possible, good or bad.

In response to the question, two patients chose the first answer, one patient replied that the second answer was the best response, and nine patients preferred to have as much information as possible, good or bad. Patients who wished to obtain only the minimal amount of information expressed that they were comfortable knowing only the necessary facts. It was an adaptive defense; a means to cope in a healthy manner with the anxiety-ridden situation. Some patients did not want to be burdened with all the information.

I think actually I know as much as I want to. You know, take it one step at a time. There's no sense in knowing all the ghastly details right down to the bitter end. I know vaguely what's going to happen, how things are going to be but I don't need to know just right yet, what's going to [happen]. I just go from day to day....You know it's not going to be a bed of roses but you don't have to know all the gory details right ahead.

In contrast, the majority of patients found that it was most helpful to obtain as much information as possible about their disease process and its treatment. Patients who were successful in their efforts to obtain information felt that they were better able to deal with their anxiety and stress; it was fear of the unknown that kept them awake worrying at night. As one patient

stated during the interview, "I found that the most disturbing thing of all is not knowing. You sit at home, you wonder, is this good?"

Sources of information.

Patients identified that they were able to acquire information from a number of individuals who were seen as having facts or knowledge about ESRD and available treatment modalities. These individuals were usually the physicians, nurses, social workers, dietitians, pharmacists, and laboratory technologists involved in their care at the Renal Ambulatory Care Clinics. These health care professionals provided patients with facts on the progress of their illness, clarified laboratory results or helped interpret information patients had received from other sources.

Strong, positive relationships with health care professionals in the clinics were described as essential ingredients that lead to mutual discussion between staff and patients. The staff's attitude toward developing a partnership with patient was most valuable.

They're very, very good [the staff] at the clinic. A really nice bunch. I haven't found any, none of them, that are surly or anything....They call you by your first name, which I find I like too. You know it makes you feel like a part of a family.

When asked who they had contacted for information, patients said that they had communicated with their physicians in the Renal Ambulatory Care Clinic. Patients relied on their physicians for information regarding their diagnosis, the treatment that was required, results from laboratory tests, and their progress.

For instance, at my last appointment, I had some questions and some information I needed to get. Well it was no problem. Dr. X signed it [a medical form] and wrote a note in my chart.

On the other hand, some patients reported that their physicians did not offer or share information easily during medical appointments for a variety of reasons. One patient described how the physician planned future dialysis

treatments while completely ignoring the fact that the patient was present in the room and wanted to play an active role in the discussion making process.

My doctor wasn't explaining anything other than just saying, well you know, we're going to have to connect you for dialysis and this and that and hey is this happening while I'm here or what?

Another patient described thwarted attempts to obtain information from several different physicians encountered in the clinics.

We've got the best information from the nurses in the hospital. Not from the doctors. Well, first of all, some of them are not very talkative and others don't have the time and the third type doesn't think about doing it.

One patient offered an explanation of the situation, stating that physicians were more than willing and able to share information only they required some clues or prompts from patients to indicate their acquiescence to accept the information.

I think the physicians are ready to give you information but I think the patient has to go with the questions to get the answers before the physician can give the information that is needed. I mean physicians have been taught to keep patients informed but if I don't ask questions then the physician can't read my mind. I think it's a big part of the patients as well.

Patients and their families repeatedly identified the nurse as being a valuable source of information. Nurses in the clinics offered explanations about diagnosis, treatments, side effects, and expected outcomes. The information that the nurses provided assisted the patients in the decision making process. Patients and families viewed the nurse as an immediate link to information.

I can ask anything if I want to know anything and they'll [the nurses] tell me. Before they do anything to me, even with taking my blood pressure or anything, they will explain everything to you. That's what I like.

Friends, relatives and family members provided patients with a great deal of informational support. Friends, who were able to offer the most information were those who had medical backgrounds or who worked in

health care institutions. These friends assisted patients in their interpretation of information given to them by health care professionals in the Renal Ambulatory Care Clinics. Many of these friends had medical textbooks that they loaned to the patients to use as references.

I talk to my friend about it [getting information]. Anything you know, and then she'll look it up. She's got some of the doctor books and she'll look it up and then she'll take the time to explain it, and if she doesn't know exactly what I am trying to tell her then she'll talk to her daughter about it. Then they'll look it up and then they'll find out.

Family members willingly conducted library searches to discover the latest trends and technologies being offered to patients living with end stage renal disease. In addition, they located recipes in books and magazines that provided nutritional substitutions for recipes presently being used. Family members frequently attended the Renal Clinics with the patients so that they could clarify and reinforce facts given to the patient.

I finally got my husband to meet Dr. X....then after, he was asking questions himself, you know. What about this and what about that. Different things like, how long is this going to go on, or how long will it take, and different things like that and he was interested in things about the kidney. It's been so hard because I don't understand a lot about it.

Patients knew that they could rely on family members to interpret and discuss information, received from the clinics, that they were unable to comprehend.

When they told me that both my kidneys are gone they gave me this one sheet, then they brought this book for me, you know, to read up on that [ESRD]. When I was reading nothing sank in, you know. I guess because I was in shock or something. Well, I said, my daughter-in-law and my son are going to help me because I just couldn't think any more.

Four patients had relatives or close friends who had been ESRD patients themselves and had either had a renal transplantation or presently were on peritoneal or hemodialysis. This knowledge base influenced their

perception of specific pieces of information and their resultant decisions about participation in the planned treatment.

I do have a girlfriend that did have that [peritoneal dialysis], and she says it's the only way to go. She thought it was great. She could go travelling and everything.

Other patients, waiting for appointments in the Renal Ambulatory Care Clinics, provided an additional source of information for the patients. In these circumstances, the information patients received ranged from scientific facts about renal disease to heresy and misinformation.

There I was sitting in the waiting room. There was an older man. I had a paper bag with my pills. He said, Oh, your lunch? A kind of relation started....I listened to the guy, he didn't know anything! I stopped the conversation and told him the few pros and cons that I know.

The majority of patients obtained information or facts about their renal disease and the available forms of treatment from reference material such as books, magazines, television, and newsletters. Written material was used by patients to clarify or interpret information they had received from health care professionals.

The source of written information most frequently used by patients was the "blue book" obtained from the Manitoba Branch of the Kidney Foundation of Canada. This manual was used as a reference to assist patients in their acquisition of information on all aspects of their illness and treatment.

They sent me this one [Kidney Foundation manual]. This is an excellent book. I wrote in, as a matter of fact, after reading this to compliment them for writing such a real, down to earth, explanation of things. By reading this book it prepared me to know some of the advantages and disadvantages and after, you know, I knew a little bit about it. That's the best knowledge a man can pick up. Right in there.

Some patients and their families used books, journals, and written documents to obtain information about treatment modalities which were viewed by some health care professions as unconventional.

There is a book at the library about a lady who had a kidney and a pancreas transplant done. Now when I read the book, she was three years with her pancreas. She could eat sweets - she's a normal person now, you know, like no insulin, no nothing....When I go for a kidney transplant, I want a pancreas transplant too.

In some instances, reading books written specifically for health care professionals caused patients to become anxious and concerned about their health. In these cases, the source of information was considered to be more harmful than beneficial.

I read a good book. It was a very good book on the market that a friend has. I read half of it and took it back. It's too scary. The whole book was called Kidney Disease. The author tells you which way you might go later on. It destroys your positive outlook. It's maybe better for young studying physicians.

Patients attending the Renal Ambulatory Care Clinics were given the opportunity to attend an educational program designed specifically for patients living with renal disease and their families. Three of the patients attended this program. One of these patients attended the program on two separate occasions. These three patients reported that the classes were informative and provided them with an excellent opportunity for discussion with health care professionals conducting the classes and other patients and their families.

Patients who felt that they had not obtained adequate information went searching for answers from a variety of sources. These patients spent a great deal of time shopping for information in their quest to determine what treatment modality would best suit their individual needs.

My physician likes hemodialysis. So I thought about that and about the bag [peritoneal dialysis] and then I was talking with another health care professional who said that's the only way to go [with peritoneal dialysis]. I enquired around with different people and different places and things like that, and I decided that maybe, that wasn't for me [peritoneal dialysis].

The majority of patients felt that they should know all there was to know about their disease and the treatment alternatives. Patients who had the benefit of being knowledgeable about kidney failure, its treatments, their limitations and their potential were better able to cope with the stresses of their disease.

Interviewer- Do you think it's good for patients to know all about their illness and their treatments?

Patient- I think it's good that they know. I think it never hurts to know. It's the unknown that's scary.

Patients expressed one concern regarding the adequacy of informational sources. They identified the need to have a patient support group established. They felt that a patient support group would be a valuable addition to the sources of information presently available to the patients.

People need people who share something in common. Everyone has a story to tell and every story has value and should be heard. There are no support groups available for patients and families and we need to talk with other people...about diet, family issues, creatinine, reactions. Perhaps once a week.

Types of information required.

Despite the fact that patients were extremely satisfied with the information they had been receiving they identified several concerns. They wanted to be educated in the reasons for diet, medications, adequate dialysis, and their relationship to complications. A number of patients and their families felt that they had not received adequate information pertaining to their renal disease and to the side effects of treatment.

I really feel that transplant patients are not prepared enough with information...I knew some facts but no one told me about the side effects - all the hair and I've gained so much weight that none of my clothes fit. They need to inform people more in preparation. It's devastating for patient and family - especially the family. It's even worse for the family members because you're not the same person. This illness affects everyone - patients and families therefore everyone needs to hear the same stuff.

Patients discussed their informational needs related to the different treatment modalities that were available.

I've always wanted to know what it's [dialysis] is going to do to me, or if it's going to work, or what's the chances or whatever.

One patient was curious about how the physician would determine when it would be necessary for her to start treatment. She wondered what it would feel like, how it would happen and how sick she would become.

The only thing I'd like to know is how it's going to happen. You know, I often wondered how am I going to get? Really, really sick before or how would they know?

Several patients voiced concerns about the inadequacy of information provided to them about the special attention they must pay to their dietary management.

I would have liked to find out that protein is bad for your kidneys. Why didn't they tell me that when I was 11. Ok, even the very first time I went to Dr. X. I was told that I've got wear and tear on my kidneys and I'll have to come back after a while and that they'll have to keep an eye on me. But I was not told right there and then that I've got to be put on a low protein diet, or I'm not to eat much protein because that's hard on my kidneys. Nobody ever told me that. (Pounded the table) Someone should have. Maybe if I'd known that my kidneys would have been [better now].

Patients discussed their need for more information about their diets, especially patients who were diabetics. They had received information about 'kidney diets' from the dietician but they had not received adequate information about diabetic diets. One patient stated that patients needed more information on combination diabetic/kidney specialist diets.

Patients who received conflicting information from separate sources became confused and irritated, not knowing which health care professional to believe. It was difficult for them to decide if they should adhere to either of the proposed dietary regimes.

The dietician would say don't eat any salt and Dr. X would turn around and say no, have some salt but don't tell her that I told you. So I mean, who do you believe - the doctor or the dietician? Who knows their business?

Patients' Perception of the Factors Influencing Acquisition of Information

Patients' acquisition of information regarding their disease, the treatment regime, and the life style changes greatly impacted on their ability to participate in treatment decision making. A variety of factors influenced patients' ability to acquire information including: 1) timing of information and patient's readiness to learn, 2) patients' health care experience, 3) quantity of information, and 4) availability and accessibility of information.

Timing of information.

Patients' readiness to acquire and retain information was dependent on their physical and emotional status, motivation to learn, and general attitude toward health care. Patients reported that when they were not physically, mentally or emotionally ready, they experienced a high degree of anxiety and apprehension when placed in situations that required them to concentrate and learn from the encounter.

They took me into where the patients were. I couldn't take that at all, I just had to get out of there. They introduced me to one of the ladies there, and she had the machine on her. Right away I thought, within the next couple of months I will be here. ...I just couldn't say anything. Then when the nurse took me out of there I was just shaking, my legs were so weak, and I just cried.

Another patient described her experience when asked to participate in the renal patient education program.

She wanted to know if I would be interested in joining in [Renal Education Program], and I told her no...at that time I wasn't ready. I had so much to take in that it seemed like every time I went there [Renal Ambulatory Care Clinic] there was always somebody with some other idea or something and I was trying to concentrate on what my doctor was telling me.

Another patient described how she had been in a daze when she was given the "tour" of the dialysis unit. She explained that it felt like the nurses had been talking with someone else and that it had not really happened to her. After this particular experience the patient expressed that it had been too

soon for her to absorb anything meaningful and that the tour should have been scheduled at a later, mutually agreed upon time.

One patient felt that the timing of the Renal Education Program came too late for her in the learning process. It would have been more beneficial for her if she had attended the Program earlier. She felt that education should take place throughout the whole course of the treatment rather than being concentrated into one short program.

I learned a lot on my own, maybe that's why I assume a lot. I learned by listening to others, watching at the Clinic, seeing what they do to others and then I took that course. But to me, I should have had that course years ago, instead of assuming for so many years.

Health care experience.

ESRD patients who had extensive health care experience were more likely to limit their widespread search for information than were patients who were facing renal disease for the first time. Patients who had been attending the clinics for an extended period quickly learned to seek out those health care professionals who were willing to talk to them and avoided those who were not as approachable.

Once I became more involved and curious I wanted more [information]....I relied on Dr. X to find out any information. If the charts were there my doctor would look it up for me. Tell me my current readings.

Several patients felt that when they first attended the Renal Ambulatory Care Clinics they were frightened and anxious. They did not want to have too much information about their health state nor did they want to ask too many questions.

I really didn't want to know too much. I felt scared, nervous but I thought well they know what they are doing. I didn't really ask any questions at that time.

The ability to ask questions during medical appointments was contingent on the patients' knowledge about what questions to ask and on their psychological states.

But there wasn't too much talk there [at the clinics on his first visit]. That was partly my fault because I didn't ask the right questions.

Many times patients came to the clinics with questions but for whatever reason they forgot to ask the question or forgot what the question was that they wanted to ask.

I've had a question that I wanted to ask and after the appointment was over my doctor walked out and I thought, oh, I was going to ask something. Then it comes to me 5 minutes later when I'm sitting in the hallway, so I try to catch my doctor. I end up asking the question in the hallway which is kind of embarrassing but you still get your answer.

Quantity of information.

Although patients reported that they had been satisfied with the quantity of information they had received from health care professionals, several described how they were unable to remember important details when they arrived home after their physician's appointment.

She [the nurse in the clinic] could talk to me for an hour at the hospital and 10 minutes after I leave I only remember a small amount of what was said. I come home and my wife says, well, what did they say? My wife just gets the bare points and that's it from what I can remember.

One strategy, used by patients to ensure that they would receive the amount and quality of information that they wanted, was to write down specific questions prior to going for an appointment at the Renal Ambulatory Care Clinic.

They say the best thing is to write down whatever you think and then when you get in there you have what you wanted to ask.

Availability and accessibility of information.

Patients reported that health care professionals in the Renal Ambulatory Care Clinics were available to talk with patients at the time of their appointments and made it quite clear that if they needed further

information or assistance with any problems they were to contact the office as soon as possible.

In addition, physicians strongly encouraged their patients to seek further information or a second opinion from physicians who had expertise in alternative forms of treatment for ESRD patients. In most cases appointments were made for the patients with the consulting physicians.

My doctor gave us a list of several doctors at the other hospital that we could go and see if we wanted to. My doctor also set it up for us to go to the other hospital for the appointments.

Patients praised physicians who took the time to contact them by telephone, after their appointments in the Renal Ambulatory Care Clinics, to report on laboratory findings. This behavior reinforced the patients' trust and respect for the physicians.

If I have problems my doctor will phone me. I'd be phoned tonight if I was there today and my potassium was high. My doctor called my brother at his work and told him that I needed this stuff and got somebody else to pick this stuff up and bring it to me at the lake.

Written information, such as easy to read, informative pamphlets were not made available to patients as they waited in the clinics for medical appointments. Several patients described how they had to write down any pertinent information given to them by health care professionals so the information would not be lost or forgotten. This information was later interpreted and explained to them by family or friends.

One strategy suggested by patients was to use the time, when patients are sitting waiting in the hallways of the Renal Ambulatory Care Clinics for appointments, to disseminate information. Regular conferences with a dietician and/or other health care professionals could be scheduled. These informal sessions would add to the patients' store of understanding.

In summary, patients' need for the exchange of information was identified as an important aspect in the illness and treatment process.

Patients expressed being extremely satisfied with the information they had received from a multiplicity of sources. The success patients experienced in acquiring information was described in relation to a variety of factors including: patients' readiness to learn and retain information, health care experience, quantity of information, and availability and accessibility of information. Patients identified several concerns they had related to the types of information they required.

Patients' Perception of Role Preferences and Desire for Information

Patients identified information as the single most significant component in ESRD patients' ability to assume their preferred role in treatment decision making. Without knowledge and information, neither health care professionals nor patients were able to participate in the treatment decision making process effectively.

Table 5
Information Desired by Decision Making Preferences (number of patients)

Decision Making Preference	<u>Types of Information Desired</u>			Totals
	Minimal	Only Good News	All	
A \	0	0	0	0
B /	0	0	2	2
C -----Collaborative	1	1	5	7
D \	1	0	1	2
E /	0	0	1	1
Totals	2	1	9	12

Table 5 shows the information and decision making preferences of the patients studied. As can be seen, nine patients preferred that all information,

good or bad, be given to them. Of those nine patients wishing all the information, five patients stated that they would prefer to play a collaborative role in the decisions regarding their treatment. Two patients wanted to be active participants in treatment decision making and two wished to play a passive role. The one patient who wanted only good news about the disease process its treatment reported a preference for assuming a collaborative or shared role in treatment decision making. Of the two patients wishing only minimal information, one preferred to play a collaborative role and the other patient wished to remain passive in treatment decision making. Patients who had received sufficient information were able to actively participate in the treatment decision making. Physicians spent time with these patients explaining the disease process and what to expect, treatment options, and consequences of each option.

The decisions are discussed with me. Basically, I am well informed by the doctor of each treatment and what the effects of that are....I have really been talking to the three of them [physicians in the three clinics - transplant, hemodialysis, and peritoneal dialysis]...I went and talked with them for awhile and discussed the different types of dialysis and I thought about it before making a decision....Being more informed, in general about renal disease helps me decide what to do.

Although the importance of information was evident as patients discussed the positive aspects of assuming their preferred roles in treatment decision making, patients expressed concern that they had not received information about treatment alternatives. Without access to this information patients experienced a difficult time participating in treatment decision making.

But I didn't get an opinion. Nobody comes out and tells you. My doctor could voice an opinion without saying you have to go on this kind of system. There was no opinion. Nothing was said, actually. I don't think they pointed out the advantages and disadvantage. They should convey their ideas more to the patients....But only after probing did my doctor tell me that this is the system they

were intending to use. That's when I went to the library and looked in a book.

Physicians had the ability to control the flow of information and could effectively hinder patients and families ability to participate in treatment decision making by failing to communicate vital information.

My doctor wasn't explaining anything other than just saying, well, you know we're going to have to connect you for dialysis and this and that, and hey is this happening while I'm here or what.

In summary, nine out of twelve patients wanted to obtain as much information as possible about their disease process. Of these patients, the majority wanted to play a collaborate role in treatment decision making. Patients identified the information exchange as being central to participation in treatment decision making. Participation in decision making became difficult when access to information was limited.

Physicians' Perception of Patients' Roles in Treatment Decision Making

Physicians were asked to read the five cards from the modified Role Preferences card sort and then identify, from a medical perspective, which of the five cards best described the role patients should assume in treatment decision making. Of the seven physicians interviewed, six identified that the ideal role for patients to assume in treatment decision making was an active role. One physician identified that patients should assume a collaborative role in treatment decision making. He stated that ideally treatment decision should be shared; patients and their physicians should discuss the situation thoroughly and then come to a joint decision.

Three of the physicians who identified that patients should assume active roles, reported that the reality of most health care situations dictated that patients and physicians needed to collaborate or share in making

treatment decisions. Another physician, who supported active decision making by patients cautioned that this was not situation specific. In situations, where decisions to initiate or not initiate care had to be made, this physician felt that the doctors needed to take control and make decisions for patients.

Physicians' responses to this question were categorized into three patterns of control based on research by Degner and Beaton (1987). These patterns were: 1) patient-controlled or active decision making, 2) joint-controlled or collaborative decision making, and 3) provider-controlled or passive decision making.

In patient-controlled or active decision making, patients' ability to assume this role was dependent on their acquisition of information. Physicians emphasized that patients who sought to actively participate in the decision making process needed to obtain information from their physician.

I'm assuming in the patient making the decision that it is an informed decision. In the sense that the doctor has communicated with the patient.

Physicians believed that patients had the right to make therapeutic choices for themselves. They had the right to make the final decision even when their choices conflicted with the physicians' advice.

In all cases the patient may decide for themselves and has the right to say, I don't wish to follow your advice. They have the final say in that....The patient ultimately has to make the decision...And that's alright.

Physicians indicated that, in disclosing all available information, they preferred not to provide patients with their opinion of which alternative would be best from a medical perspective. This allowed patients the freedom or control to chose the treatment modality that best suited their needs.

I think that with the provision that they've been given full information. So, most of the time, I don't give them an option, I give them facts. That way they can make the decision. I try to inform them that it's ok for them to decide.

Several physicians indicated that there was greater commitment to

treatment modalities when patients took an active role in making decisions and were able to make choices. Patients frequently refused to initiate therapy when they had not been involved in making the decision.

I think the patient who has chosen the best option for them wants to do it and they're going to be more cooperative. They're going to participate in their care. It's not as if the decision has been made for them. I remember trying to convince a number of people that a specific dialysis modality would be a very good option for them and they've been very insistent that they didn't want to do that and a lot of people have pulled out at the last minute.

Physicians expressed that in their care of ESRD patients they frequently encountered patients who wanted to make the final decision regarding selection their treatments. The majority of these patients spent time with their physicians. They exchanged information and the patients contemplated their physicians' recommendations prior to making treatment decisions.

Patients who assumed this role were considered to be strong, balanced, curious individuals who are interested in knowing the rationale for selection of treatment modalities.

I've had some [patients who assume active roles] and these are usually strong patients who have a very balanced view of life. These are the ones, that in fact, will actually do what I would like most people to be able to do.

In joint-controlled or collaborative decision making, there was a sharing of information between health care providers and patients. Once physicians had presented the advantages and disadvantages of each treatment modality, patients were given time to deliberate and then a decision was made together.

We are where the patient is making a decision about whether or not they will be on hemodialysis or peritoneal dialysis. And that has to be a shared decision....we will go into it with the patient to find out how it would work and then discuss it with the patient. They let us know what they think about the situation and then we'll talk it over and come to an agreement.

Patients benefited from the physicians' varied and extensive career experience when they collaborated or shared treatment decision making.

If you give them too free choice they do not have use of our input based on hundreds of patient years experience of a certain kind of person who will do well, not do well, do badly. So, they can't have a total free choice and we haven't got the ability to give them the experience I have in Nephrology.

Shared or collaborative decision making was described as an honest, relatively equal relationship. Physicians possessed more information about physiological functioning and treatment modalities but this was perceived as beneficial for the patient because the information was shared. There was time to sit and exchange information. Patients were in charge or in control of their own lives.

It's an honest, relatively as equal as it can be. You've got more knowledge than they have but you're just there as a resource for them. They're very eager to know what their latest results are and we go through it with them and sit down and chat and we'll both go through it together and go through what each knows. They get a big pat on the back for how well they've done. This is a great kind of thing.

In provider-controlled or passive decision making, physicians deliberately took control of decision making in an effort to protect patients. They took this active position to prevent patients from making treatment decisions which would not have been beneficial to their health. Physicians were also dominant decision makers in cases which involved patients' refusal to initiate treatment and those which necessitated decisions not to initiate treatment.

There are extremes to this scenario [no treatment]. One is the young individual who is otherwise well but kidneys failed. Who should start dialysis but refuses because of the effect on his lifestyle. Then I would insist somehow that he/she start on dialysis. The other end of the spectrum is the 80 year old who has multiple radical problems. You can predict that the patient will do very poorly on dialysis and you may in fact hasten their death by putting them on dialysis or if not hasten it make the time they have left horrible.

It was extremely difficult, in making life and death types of decisions, for physicians to negotiate or come to rational decisions with patients who wished to assume a passive role. Physicians struggled with patients in an attempt to determine what they wanted.

[Decisions] are more difficult when you're talking about a life and death type of situation. If you say to the patient do you want to go back on dialysis or would you want to have the operation? If the patient says well, what would you do doctor? That's more difficult because I don't know how to answer...it depends on the patient, on the individual case, what relationship you have with the patient, what you feel the patient wants.

Physicians pointed out that some patients wanted to relinquish responsibility for making treatment choices. These patients were unable or unwilling to independently make a treatment choice even after physicians had taken the time to explain treatment options in great detail. One physician indicated that many of the patients seen in the clinics were passive participants in treatment decision making.

If they chose it [passive role] that's the way it's got to be. They're asked to decide after you explained something and they say doctor you decide, I'll go along with what you think is best and so you have to accept that. I'd prefer that they made their own decision and I stay behind it but some people just function well like that.

Passive participation in treatment decision making was described as a defense mechanism. It was identified as a very common reaction used by patients as a means of dealing with the stress of their illness. It made life much simpler for patients if other people assumed many of the patients' responsibilities.

Basically it's [passive decision making] a defense mechanism. If somebody else makes the decisions then it really isn't happening to you or it's a little less on your mind. Sometimes it makes life go simpler. It's a way of dealing with stress to some extent. It's very easy for the patient to take a very passive role instead of doing everything for themselves. It's a way of gaining attention.

Discrepancies were noted in two of the physicians' verbal descriptions

of patients' roles in treatment decision making and the roles that the physicians chose from the modified Role Preferences card sort. The physicians, using the card sort, indicated that patients should assume an active role in treatment decision making however, a verbal description of this role indicated that decision making was in fact being controlled by the physician.

Quite often a choice which, if we don't think a modality will work out, the choice will not be presented [to the patient]. Do you see what I'm saying?...I guess we really do wind up having the final say, as in many kinds of treatment. But we don't inflict therapy on somebody who refuses either.

Physicians' Perception of the Factors Influencing Role Preferences

A variety of situational and personal factors influenced the decision making process and patients' ability to assume alternative roles. These included: 1) patients' medical or social conditions, 2) institutional or physician biases, 3) available resources, 4) types of decisions made in the clinics, and 5) trust in the physician.

Patients' medical and social conditions.

Patients' ability to assume their preferred roles and participate in making choices about appropriate treatment modalities was limited by their medical or social conditions. In many circumstances patients were physically unable to participate or their living conditions prohibited their selection of some treatment modalities. In these cases physicians had to make treatment decisions after carefully considering not only the patients' physical and medical status, but also the patients' individual strengths and weaknesses.

Quite often it is our decision because there are complications with certain treatment modalities. And if there are no complications then the discussion goes on such that one discusses all the ins and outs of dialysis, and then the patient thinks about it thoroughly and decides.

Institutional or personal bias.

Institutional policies or physicians' personal bias may also have limited a patient's ability to make treatment choices. Many physicians had certain biases based on their past experiences, therefore they may have favoured one type of therapy over another. Even though the patients were provided with all the treatment options sometimes one mode of therapy was emphasized.

I think there is a bias and it isn't an individual bias I think it's more like what I'd call an institutional bias. Part of this is political or it may become political because of the restriction on economics because CAPD is the least expensive.

Another physician discussed the significance of individual biases and the effect these biases had on patients' ability to participate in the decisions being made about treatment.

If hemo and CAPD are equal or CAPD may be slightly better for that individual, then there are physicians taking that and the patient is told that there is a limitation of machines. That becomes a physician's approach. It's when a patient can go either way, that's when the bias comes into effect.

Available resources.

The ability of patients to actively participate in making therapeutic choices may have been beyond some patients' reach in spite of their desire to participate in it. The reality of the situation was that overcrowded dialysis units, staff shortages, and financial restraints, as well as other factors, often determined treatment modalities without patients' input.

In ideal circumstances, it should be that the patient makes the decision. However, we are, as many places in Canada, at a crisis, in which there are not the developing amount of dialysis facilities available. And therefore, although you would love it to be a democratic world, where the patient makes the decision, unfortunately we sinners have to bully them and say I'm sorry you're not staying in the central hemodialysis unit. I have no spaces guaranteed. You have to go out to either CAPD or you have to go down to Dr2....You're nudging them towards one choice, one of two choices. But not the freedom of choice to dialysis in the hospital.

Types of decisions made in the clinics.

Two different types of decisions were made in the clinics. These were identified as life and death decisions and general 'everything in between life and death' decisions. In life or death situations in which patients may be at risk or may suffer, they were provided with extensive information and included in the decision making process. On the other hand, the physicians were dominant in the 'everything in between life and death' decisions. Patients were informed of the decision and were provided with physicians' rationale for making that particular decision.

I think that there are two types of decisions that one has to consider. Now there's the life and death type thing where I'm going to put the patient at great risk to a biopsy procedure or through an operation which I think they need. Then you explain a lot more....the doctor has to tell the patient exactly what is involved and the patient makes up their own mind. There's the everything in between. These are decisions I don't discuss with the patient. I say, for example, I think you should increase your antibiotic by one pill and they might ask why. Because I think your half a pill is not good enough for you and they'd say yes....So I think that has to be taken into account [in decision making].

Included in the life and death type of decisions were those situations in which it had to be decided whether or not treatment would be initiated for the patient. Life and death type of decisions also included those situations in which it had to be decided whether or not to terminate treatment. Physicians repeatedly stressed that in these situations they would assume responsibility for making the decisions. In accepting this responsibility patients and families were spared the burden and guilt associated with making that choice.

Sometimes you have to decide. So that in stages that the treatment is not going to be kind or fruitful you stop rather than ask the family because you don't want the family to be guilty. You don't give them a choice. If you think the chances of survival are extremely small and that if any possibility of recovery involves suffering you have to say no, it's not possible you've done what you could have done already and this is the best way....I'm reluctant [about making these decisions] and I think it over very carefully.

Trust in the physician.

Physicians stated that patients' trust in their physicians played an important role in the patients' ability to participate in treatment decision making. Patients who trusted their physicians had confidence in the information they had been given and in the decisions that were being made.

Trust obviously is a factor. There is a sort of credibility or value to one's actions. Some of the patients are passive because they've learnt to rely on their doctor or trust their doctor.

In addition, those patients who had developed a relationship with their physicians received many benefits. They were kept well informed, they felt that they were members of a team, and their outcomes improved.

To have everything up front in an honest way, you could call it a spade kind of relationship where they feel that they are part of the treatment plan and that they're going to be informed and in the end it makes my job easier because they have full trust in me....They know that they can ask questions when they want to. And, you do sort of have a relatively open chart policy. You can inform them about what they want to know about their numbers and the lab results and so on. So, I think it goes up to more open and trusting relationships and that works in both directions. It makes my job easier and their health care easier and it's good for them.

In summary, physicians identified three roles that patients should and did assume in treatment decision making: patient-controlled or active, joint-controlled or collaborative, and provider-controlled or passive. Five main situational or personal factors that influenced patients' ability to exercise control in the decision making process were identified. These were: 1) the patients' medical or social conditions, 2) institutional or individual biases, 3) available resources, 4) types of decisions made in the clinics, and 5) patients' trust in their physicians. Situational factors were identified as having the most influence in patients' ability to participate in treatment decision making.

One physician added a word of caution when one was contemplating patients' roles in making decisional choices " there are a lot of variables that

need to be considered. I think we need to obviously tread very carefully."

Physicians' Perception of Patients' Desire for Information

In the above description of the three roles patients should assume in treatment decision making, physicians identified information as being pivotal to the patients' ability to participate in the manner that they preferred. Patients' ability to successfully obtain information depended to an extent upon the quantity of information available. The sources of information were also identified as significant to the information gathering efforts. Three significant factors that impacted on the patients' ability to access information emerged.

Quantity of information.

Physicians indicated that it would be ideal for patients to have as much information as they desired. However, many factors prevented this from occurring. Sometimes it was difficult to give patients all the information they wanted because the information was not always accessible to physicians. At other times, physicians were forced to make decisions quickly without obtaining information that was available. On other occasions, physicians were unable to communicate the information to patients, for whatever reason.

It's very difficult to give all the information they want. Because the information is not there for starters. They ask how much of a risk there is. Well, I don't know because we've only done this twice and once it worked and once it didn't....Sometimes we have the information in books but we don't have it in our heads....[Sometimes] we have to make decisions quickly without the amount of information that is available on that. Sometimes we know the information but we can't communicate it for whatever reasons. In general, yes, it's better if the patients have the information.

Physicians observed that patients who obtained the amount of information that they required and desired tended to adhere to their treatment regimes, were more satisfied, had fewer complications, and had more successful outcomes than patients who had not obtained this

information.

That's what I was saying, more informed patients can control things better, will get more satisfaction, more success, fewer problems, and have fewer crisis.

Sources of information.

Physicians indicated that patients accessed many sources to obtain information about their disease process, treatment modalities, medications, and diet. These sources included physicians, nurses, families, other patients, educational sessions, and printed media.

They hear about the two kinds of treatment in the clinics and from their own physicians....Patients do talk among themselves. If there's another patient on dialysis, for example, in the community I do know that they talk. I think that when people reach end stage renal failure there's not a lot of active literature searching going on. If they're at the point of end stage renal failure their families may be doing that. Early on they may do more of that if they present very early.

The dialysis nurses were identified as playing a key role in the dissemination of information to the patients.

Actually a great deal of the input [information] comes from the dialysis nursing staff because they show the patient the different types of dialysis. They go over the mechanics and the teaching of dialysis and also they show them around the unit. She'll often see [patients] a few times and goes over things if the patient is having a lot of questions and uncertainties and difficulties in accepting the reality of the situation.

Patients were given an opportunity to attend the renal failure education programs sponsored by the hospital. However, not all patients took advantage of this opportunity.

Some go through the renal failure education program done by here. It's open to everyone but only certain people want to go through this one or two day learning.

One physician identified that the educational sessions offered to the patients required improvements. The sessions needed to be less intense, longer in length, and more people needed to be involved. However, to do this would require additional manpower and the renal program lacked this

valuable resource.

The education sessions I think could be improved. They're a little bit too intense, I mean they need to be toned down. If we could get more people, more time, more slowly and a lot more cooperative activity together with patients. We just don't have the manpower to do that. I'd love to be able to do it. I think that it would help a great deal.

Several physicians discussed the lack of resource and support professionals available to assist ESRD patients in the clinics. These individuals included a psychiatrist, psychologist, nurses, social workers, and dieticians. A shortage of funding prevented the programs from hiring these individuals.

We're wanting to have a psychology/psychiatry program for the dialysis units and for transplant. We're trying to get money for that now. We have one of the psychiatrists that's very interested. It would be good. We used to have a very good psychiatrist in a small program. Now it's a seat of the pants operation. It's interesting the hardest thing to get money for, is patient education and that kind of thing.

Physicians had not witnessed active information seeking behaviours. They believed that this was because their patients had obtained adequate amounts of information from health care professionals in the clinics.

Our nurses and social worker and home care nurse do a very good job of giving the information and describing what it is. That happens on the first visit. I guess they're given the information and maybe that's why it doesn't go on [information seeking]. Because they're given the information up front as to what the treatment is about.

Many of the patients who came to the clinics were well informed. This, was attributed to many factors including family members or friends who were on dialysis or who have had a renal transplantation. Patients often selected a particular treatment modality if they had a family member or friend who have had a positive experience with that specific treatment.

More and more patients are knowledgeable about the dialysis to some extent. The woman we saw today and I told her she could foresee CAPD she says, oh yes, my niece is on CAPD and that's the way I'm going too. Such a range in patient knowledgeability that you know we had

actually looked after her niece. The decision was almost made you know without any physician input.

Patients also decided not to chose a treatment modality if they have had a negative or unpleasant experience with someone on that therapy. Patients' choices of therapy were often based on relevant social acquaintances.

If on the other hand if you had a friend who had a terrible time on dialysis or had died on dialysis then you may back off right away. These things are so important that very often they make the decision based on the patient's relevant social contacts.

In contrast, there were those patients who did not wish to be informed or sought a minimal amount of information. These patients have been found to experience many difficulties with their dialysis at a later date because they had not understood.

People who just do the bare minimum or ask the bare minimum really end up knowing very little, they run into certain problems at home. They don't understand anything about fluid. You can train someone in dialysis but they don't really understand what swollen ankles and what 5 kilos weight gain really means until they get sick.

Physicians' Perception of Factors Influencing Acquisition of Information

Physicians reported that a variety of factors impacted on the patients' ability to acquire information. These included: 1) timing of information and patients' readiness to learn, 2) patients' health care experience, and 3) patients' personal characteristics.

Timing of information.

Patients who were continually presented with information throughout the disease process were more likely to retain this information than patients who were confronted with many details in a short period of time.

I think that somebody who has had kidney failure for a long time, who's had many discussions with their doctor is probably more likely to retain it than somebody who is just starting out and getting many new things thrown at them at a time. For example, one day, it's transplant and the next day it's the peritoneal program, and the next day

it might be that they are getting a fistula. You know it's very difficult for people and they don't [retain it], they sort of come in a daze.

Physicians discussed the many strategies they had used to assist ESRD patients acquire and retain the information they needed. One method was to gradually introduce information to the patient as early as possible.

You try to present the information early....at a reasonable point in time so that when somebody's going to need dialysis they know that they're going to have to make some major life changes. I think the best way that is done is by gradual introduction to the idea over a period of a few visits. One thing that I have done is when I see that somebody is probably going to need dialysis in about six months I'll tell them about the two different kinds of dialysis. Then we'll talk about it more next time and so you sort of plant that idea.

Another strategy, that had been proven to be successful, was the introduction of the patient to another individual who was currently being treated for renal failure. This gave patients the freedom to ask any questions that they might not otherwise have been able to ask their physicians, they could see that it was not unpleasant to be on dialysis, and there was a degree of comfort associated with actually visualizing another person undergoing treatment.

I usually try and get them to get in touch with, and I arrange it, someone who's been through exactly the same process as them who's been on one or more dialysis modality, and I sit them down, if they agree and I leave the room. I let them ask all the questions. Now they will remember that far more than the doctor saying the same thing ten times over. Just to see that machines don't bite. That it's not unpleasant to be on dialysis.

Another strategy used by physicians to reduce 'information overload' was to limit the exchange of information to one treatment modality at a time. Otherwise, it became too difficult for patients to make a choice among several

different alternatives.

When I'm talking about dialysis, I won't talk to them about the transplant thing unless they want to. Because it's a major decision they're already making.

One physician referred medical articles to patients to assist them in procuring information about their therapy.

I've referred photocopies of medical articles to the patients because they just don't have the information or the way to get it. They're confused. Perhaps I don't give them an unbiased selection of articles, but I give them the articles that might help them and give them a little piece of mind.

Several patients were encouraged to write down all the questions they had to ask the physician. They also were to include those questions that their family had to ask.

What I do is I tell them to write all their questions between now and when I see them on a piece of paper. If anyone else has questions write them down. I find that this is a better way because then they will retain the answers and they've gone out of their way to actually ask the question.

Other patients, in the care of different physicians, were not encouraged to come to their medical appointments with prepared questions. Their physicians had a completely opposite opinion.

Most of the patients that do that [write down questions] are either neurotic or obsessive compulsive until it's almost a necessity for them to do this. It's almost a badge of neuroticism. The more detailed information you give the more worries you will generate in the patient. It's a red flag almost you know, caution.

Patients' health care experience.

The patients' experience in the health care system had an impact on their acquisition of information. Chronic renal failure patients had an advantage because they had a longer time in the health care process to discuss problems, seek solutions, and to learn about the available therapies.

It's certainly very excellent because the longer they discuss the different problems they have and they get your input and sort of make a joint decision with you the better it is for the patient.

Another physician expressed concern for patients admitted to the hospital or seen in the clinics who were acutely ill and needed immediate attention.

The patient who arrives on our doorstep a month away from dialysis or two weeks away has got to do so many things and it's just horrendous. Trying to get this person used to the idea of what's going to happen. The kidneys are failing and we have to do this and that and I often think that what I say to them goes right over their heads.

Physicians reported that because of the chronic nature of their disease most patients had spent many hours over a long span of time exchanging information prior to the initiation of their treatment. Physicians tried as much as possible to ensure that patients were given adequate information about different treatment modalities that were available.

When we start someone on dialysis we try to make them aware of the different types of dialysis and the choice is there whether they want it or not. We try to provide information. We discuss the pros and cons of a specific treatment modality for 45 minutes or 1/2 hour and then they go home. We make ourselves available and we say at the beginning this is an information session. This is for you to take all of this in, take it home with you, think about it, and phone us back if you have any other questions. Sometimes we've done that twice or three times with the patients until we felt that they were sufficiently informed.

Unfortunately, despite all endeavours to prepare patients in advance by providing them with extensive information, many patients were not equipped to deal the realities of the situation. They had consumed the information but they had not retained it or had not integrated it into a form that they could use at a later date.

I think it helps to have more information. There's some people that it really doesn't help very much. There's some people that it's very difficult for them to accept what's going on. It takes them a long time and they never really accept it. I think the way we give the information is poor and I [would] very much like to improve it.

Patients' personal characteristics.

Personal factors also played an important role in the patients' ability to acquire information. Some of these personal factors included the language the

patients understood and spoke, intellectual level, and their ability to understand the information that was given to them.

How much information I give the patient depends on firstly the language. That's an important consideration here. How much they grasp and my understanding of how much they understand. I think once again because of the demographics of our patient population many patients are ill-informed. How much they grasp is part intelligence.

In summary, physicians identified information as being central to the ESRD patients' ability to participate in the selection of treatment modalities. They indicated that ideally patients should have as much information as they desired however, several factors prevented this from occurring. These factors included: 1) inaccessibility of information, 2) short time frames available for information exchange, and 3) physicians' inability to communicate information to patients.

In general, patients were able to access information from many sources including nurses, families, friends, other patients, educational sessions, and printed media. Success in obtaining information was influenced by: 1) the timing of information and the patients' readiness to learn, 2) patients' health care experiences, and 3) personal characteristics. Several strategies used by physicians to assist patients in their quest for information were described.

Physicians' Perception of Information and Decision Making

The majority of physicians reported that the ideal role for patients to assume in treatment decision making was an active role. However, the reality of most health care situations dictated that patients and physicians needed to collaborate or share decision making. In addition, physicians identified that acquisition of information was essential if patients were to exercise their preferred roles in treatment decision making. Patients required full disclosure of information in order to make informed decision. Not only was it necessary for patients to obtain information but also it was necessary that they fully

understood the information that they had been given.

I think that decision making [by patients] is ok, provided that informed consent is really there and that there is enough data and the patient understands the data.

Physicians identified several advantages associated with patients who were well informed and actively participated in treatment decision making.

The patient that is well informed is more likely to make logical decisions.... They truly are making a rational and informed decision.

Patients however did not always possess the information that they needed to make the appropriate decisions about their treatments. Most often in these situations the decisions made were not beneficial. Many different factors, contributing to these unfortunate situations, were identified by physicians.

The patient ultimately has to make the decision. But the decision at the same time may be bad [for the patient]. If either the information they received is poorly communicated or is outdated or something like that, or if the patient somehow feels able to make decisions which are not justified on the basis of what is known.

The following example helped clarify these situations:

If a patient is told incorrectly that this is a very safe medication to take or this procedure carries no risk and the patient then decides that this is what he is going to do, or the patient is told that this has a big risk, 95% risk of death and the patient understands 10% risk, those too can be bad.

In summary, physicians described the presence of a strong association between decision making and the patients' acquisition of information. Information was necessary if patients preferred to participate in making therapeutic choices in an active or collaborative role. In addition, patients needed to be provided with enough information to make them knowledgeable about the implications of the decisions they were about make.

Patients' Treatment Status - Six Month Follow-up Interview

Patients were contacted by telephone six months following the initial face-to-face interviews. At this time patients were asked to describe their present health status. The majority of patients, who had started dialysis or had a kidney transplant, reported that they had more energy and felt better than ever before. They expressed satisfaction with their treatment modality and discussed their individual successes and the milestones that had been achieved. Patients reported that they were pleased with the information they had received from the nurses after they had started their dialysis.

I'm doing so good now. I have so much more energy. I'm always asking alot of questions. The nurses give me all the information I need and I feel I have a more positive attitude. My husband and I are going on holidays and I will be able to dialyze there. I feel real good about it.

One patient stated that he did not have as much energy as he had anticipated yet he was extremely pleased with his progress.

Started dialysis and I'm managing really well....Not more energy but overall feeling well. I'm very satisfied with the amount of information I'm receiving and with dialysis ...I'm real pleased.

Another patient, who had been diagnosed with renal impairment since early childhood, was overwhelmed by the improvements experienced since initiating therapy.

I feel really healthy - more energy. Couldn't believe that you could feel that well. After first dialysis treatment I felt so well that I said to my wife "Let's go out and eat!" Wrong move - I felt terrible after, but still it felt good.

The majority discussed how satisfied they were with the amount and type of information they had received. Those patients who had not required dialysis or transplantation stated that their health status had not changed and that to date they were relatively stable.

Table 6
Patients' Treatment Status - Six Month Follow-up Interview

Treatment Modality	Number of Patients		Total
	Male	Female	
Hemodialysis	1	2	3
Peritoneal Dialysis	2	1	3
Renal Transplant	0	1	1
No Treatment Required	4	1	5

Table 6 presents information regarding the patients' treatment status at the time of the six month, follow-up telephone interview. Three patients had begun hemodialysis, three patients had been started on peritoneal dialysis, and one female patient had received a kidney transplant. Five patients had not required therapeutic interventions and they continue to attend the Ambulatory Care Renal Clinics on a regular basis.

In the next chapter, the study findings are discussed in light of the conceptual framework. The findings will be compared to research studies presented in the literature review. Limitations of the study will be identified.

CHAPTER V

DISCUSSION

Introduction

In this chapter, the findings of the study will be discussed in relation to the conceptual framework, the literature review and the identified research questions. First, the relationship of the study findings to the conceptual framework will be addressed. Next, the study's research questions will guide a discussion of the major findings of the study. Finally, limitations of the study will be identified.

Relationship of Findings to Conceptual Framework

The four patterns of control over treatment decision making described by Degner and Beaton (1987) in their descriptive theory of life-death decision making provided the conceptual framework for this study. The four patterns of control over decision making that were determined to be central to the descriptive theory were: patient-controlled or active decision making, joint-controlled or collaborative decision making, and provider-controlled or passive decision making, and family-controlled decision making. Only the first three patterns were pertinent to this study.

The findings of this study support the use of Degner and Beaton's (1987) descriptive theory. However, these findings also pointed to a weakness in the framework, particularly in defining the significance of information as it related to ESRD patients' ability to participate in and control treatment decision making. Preferences to participate in decision making appeared to occur within a broad context of informational needs. Provision of information

was not explicitly defined and addressed within each of the patterns in the descriptive theory. A discussion of the application of the findings to each of the patterns of the descriptive theory follows.

Patient-Controlled or Active Decision Making

Patients described preferences for the pattern of patient-controlled or active decision making. In this pattern, patients exercised final control over the type of treatment they were to receive. The two patients in this study who preferred to actively participate in treatment decision making wanted to have the benefit of their physicians' advice and counsel prior to making any choices.

Patients reported that they were more likely to actively participate in making treatment decisions if they were provided with extensive information about the treatment alternatives, what the consequences of each treatment would be, and what to expect should they opt to select a particular treatment modality. A variety of creative strategies were used by patients to gain control. Patients actively sought alternative medical opinions when they were convinced that their physicians were not making appropriate treatment decisions for them.

Physicians corroborated patients' need to obtain appropriate and sufficient information from health care professionals. They recognized that information was not only central to the patients' ability to assume an active role in treatment decision making but also guaranteed that the decisions being made were indisputably informed decisions. Physicians identified that when patients were actively involved in making therapeutic choices they were more committed to the treatment modality than those patients who had not been involved in the decision making process. There was evidence that patients who were dissatisfied with their physicians' selection of a treatment

modality had the right to refuse their physicians' advice; they ultimately had the right to take control and make that decision. Physicians identified that they frequently encountered ESRD patients who wanted to make the final decisions regarding selection of their treatments. The majority of these patients spent time with their physicians. They exchanged information and the patients contemplated the physicians' advice prior to making treatment decisions.

Joint-Controlled or Collaborative Decision Making

Patients described the pattern of joint-controlled or collaborative decision making. In this pattern, patients reported that they had shared control over treatment designs with their physicians. All patients who preferred to assume a collaborative role in the decision making process stated that they wanted to be actively involved but did not want to be ultimately responsible for selection of a treatment modality. As with patient-controlled decision making, patients reported that they required considerable information prior to assuming any responsibility for the decisions being made. In this pattern, patients described how physicians presented the different treatment options to them and encouraged them to share making therapeutic choices.

Physicians described joint-controlled decision making as an honest, relatively equal relationship between patients and health care professionals. There was a sharing of information and responsibility for decision making between the patient and physician. In this pattern both physicians and patients took responsibility for identifying concerns and delineating solutions.

Provider-Controlled or Passive Decision Making

Patients described provider-controlled decision making as a process wherein health care professionals exercised final control over the design of

treatment. Some patients reported that they had relinquished responsibility to their physicians because they did not know how to make decisions. They were in fear of losing their lives if they made the wrong choice. Patients described how they looked to physicians for guidance, support, and information. Other patients assumed a passive role because they trusted physicians' knowledge and relied on their physicians' judgement and ability to make decisions. Some patients described how they were forced into passive roles after being presented with a "best choice" decision when their preferred treatment modality was unavailable.

Physicians reported that they deliberately assumed responsibility for making treatment decisions to protect patients from the guilt of decision making. Physicians not only took control in life-death situations to prevent patients from undue pain and suffering, but they also took control to prevent patients from making treatment decisions that, in their opinions, would have been detrimental to the patients' health and safety. Physicians identified patients who assumed passive roles as being unable or unwilling to independently make treatment choices even after they had obtained detailed information about the treatment alternatives. Physicians described passive participation in treatment decision making as a defense mechanism. It was used by patients as a means of dealing with the stresses of their illness. It made life simpler if other people assumed many of their responsibilities including the responsibility for making therapeutic choices.

The four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory provided a useful framework for understanding the experience of ESRD patients in the decision making process. Focusing on the patients' perceptions of the roles they preferred to assume and the roles they actually played in making therapeutic choices provided a fruitful way of examining ESRD patients' experiences.

Analysis of the interview data supported the relevance of the theoretical framework. The findings of this study were congruent with Degner and Beaton's descriptive theory of life-death decision making. Three of the four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory were discussed and described by patients and physicians. Descriptions of other patterns of decision making were not evident in the findings.

There was however, one disadvantage identified in using this framework. As previously mentioned, the patients' experience in the decision making process did not fit precisely into the patterns of control over treatment decisions. Patients' desire for information as it related to patients' preferences to assume alternative roles in treatment decision making was not specifically addressed. This presented some difficulties when the interview data was being analyzed.

It was evident in the findings that information was an integral component in the decision making process. Preferences to participate in decision making appeared to occur within a broad context of informational needs. One of the purposes of this study was to examine ESRD patients' desire for information as it related to preferences to assume alternative roles in treatment decision making. Based on these facts, it may have been advisable to integrate an information search process model such as the Lenz (1984) model with Degner and Beaton's (1987) descriptive theory.

Relationship of Study Findings to Research Questions

Patients' Preferred and Actual Roles

The first research question addressed in this study was: what are ESRD patients' perceptions of their preferred participation in treatment

decision making and their actual experience?

Patients' preferred roles in treatment decision making

Patients in this study were able to identify and describe three distinct roles that they preferred to assume in the decision making process. These three roles were: 1) patient-controlled or active decision making, 2) joint-controlled or collaborative decision making, and 3) provider-controlled or passive decision making.

In this study, 2 of the 12 patients preferred to assume an active role in treatment decision making. However, they wished to keep responsibility for making decisional choices only after consulting with their physicians. These results are similar to those found by Thompson (1990) in her study to investigate preferences for participating in decision making in couples undergoing investigation for infertility. She found that the majority of couples preferred to keep responsibility for making therapeutic choices. Another study, conducted by Degner & Sloan (1990) of 436 newly diagnosed cancer patients and 482 members of the general public reported similar findings in the general public sample. Only 12% of the patients wanted an active role, whereas 64% of the general public thought they would want that role if they developed cancer.

One explanation for the similarities in these three studies is that all subjects investigated had not assumed a "sick role". These patients considered that they were still relatively healthy; they used the terms "good and stable" to describe their health status. To a great extent, their lifestyle had been stable and they had not been burdened by many of the symptoms that other ESRD patients had experienced. The couples undergoing infertility investigations (Thompson, 1990) and those members of the general public (Degner & Sloan, 1988) were also healthy, contributing adults. There were no life-death decisions being made and these individuals as Degner and Sloan

(1990) stated "may not be able to imagine how frightened and incapable of making decisions they will feel when actually facing a [life-threatening] diagnosis" (p. 17).

These findings, that patients preferred to assume an active role in treatment decision making, support the findings of other researchers who found that patients wished to be actively involved (Blanchard et al., 1988; Cassileth et al., 1980; Degner & Sloan, 1990; Faden et al., 1981; Haug & Lavin, 1981).

The majority of patients in this study preferred to assume a joint-controlled or collaborative role in treatment decision making. In choosing this pattern, patients expressed a desire to be actively involved in making decisional choices yet, they were hesitant to assume ultimate responsibility for the decisions being made. It was apparent that these patients appeared to prefer a more collaborative role in decision making, discussing at length the advantages and disadvantages of different treatment alternatives and then making shared decisions.

Shared decision making between patients and health care professionals was identified by Degner and Russell (1988) in their study of 60 adults living with cancer. They found that the majority of patients preferred the pattern of shared control over treatment decision making. A similar study was conducted by Haug and Lavin (1981) to assess the extent of reported public attitudes and behaviours that challenge physicians' traditional power. They found that a substantial portion of the public takes a consumeristic position, claiming "the right, if not to be in charge, at least to take some responsibility for medical decision making instead of leaving it entirely in the physician's hands" (Degner & Russell, 1988, p. 217).

Only three patients in this study indicated that they wanted to relinquish responsibility for decision making to their physicians. Two of these

patients preferred that their physician made the final decision about their treatment but only after seriously considering their opinions. This finding is supported by a study conducted by Vertinsky et al. (1974). These researchers found, in their study of physician/patient role orientations preferred by patients in clinical decision making, that the majority of respondents "do not wish to take the entire responsibility for making their own medical decisions...but they do not wish, either, to be entirely passive in the physician/patient relationship" (Vertinsky et al., 1974, p. 130).

One elderly, retired man who has had renal disease since childhood preferred to leave all decisions regarding his treatment to his doctor. In this case, the patient trusted the physician's knowledge and relied on his judgement and decision making. Brody (1980) suggested that this imbalance of power between the physician and patient, that justified both the professional's assumption of authority and the client's trust and confidence, was characterized by certain types of inequalities. The least disputed inequality was that of the knowledge gap that separated physician and patient. Many patients believed that the physician was the most knowledgeable and was best able to understand the possible outcomes and to ascertain what risks were worth taking. Because of this, some patients may be most comfortable in placing complete faith in the judgement of the physicians (Eraker & Polister, 1982).

Researchers have offered at least two reasons for patients' preferences for assuming passive roles in the decision making process. Vertinsky et al. (1974) suggested that increased exposure to the health care system may be related to preferences to delegate responsibility for treatment decisions to physicians. In this particular situation, in which the patient relinquished all decision making to his physician, the patient had been in the health care system since early childhood.

Blanchard et al. (1988) also suggested that elderly males were more likely to prefer not to participate as it was the females who had been the "brokers" of the health care system. One role played by the wife when she attended medical appointments with her husband was to negotiate with the health care professionals on behalf of the patient. This suggestion is interesting and insightful. However, in this study the investigator was unable to comment on this suggestion because neither did the patient describe his wife in the decision making process nor did the investigator observe the patient and wife together during a medical appointment.

These findings, that patients prefer to assume a passive role in treatment decision making, support the findings of other researchers who have studied this phenomenon and have found little interest in decision making among patients (Degner & Beaton, 1987; Degner & Sloan, 1990; Ende et al., 1989; Greenfield et al., 1985; Kristjanson, 1983; Strull et al., 1984; Sutherland et al., 1989; Vertinsky et al., 1974).

Patients' Perception of Factors Influencing Role Preference

Patients identified a range of personal and situational factors that influenced their ability to assume their preferred roles by their inhibiting or facilitating this process. These factors include: 1) trust in physicians, 2) social support of family and friends, 3) hope for the future, 4) physicians' presentation of information, 5) lifestyle, 6) denial of the need for treatment, and 7) time needed to adjust to the experience.

The fostering of a trusting relationship between patients and their physicians was an important aspect in the ultimate success of decision making for some patients. In this study, those patients who preferred to assume passive roles in making treatment decisions described having trust in their physicians. Thompson (1990) found that trust in the potential decision

maker was a factor that influenced choice of preferred role in treatment decision making. She stated that patients "who trusted their physician were more willing to give up responsibility for decision making" (p. 152).

These patients also stated that a lack of knowledge in the initial phase of their illness was a determining factor in their decision to trust the physicians' judgement and delegate responsibility for making decisional choices. Kristjanson (1983) identified that medically controlled (provider-controlled) decisions were more common when subjects relied on their physicians' knowledge of available medical interventions and trusted their proficiency in making treatment decisions.

This leads one to believe that it was more than the ESRD patients' trust in their physicians that produced an impact on these patients' preferences to assume a passive role in making decisional choices. It is apparent that lack of confidence in their own knowledge base in addition to trust in their physicians prompted patients to defer responsibility to their physicians.

The strong support of family and friends was identified as an essential component in the patients' ability to assume alternative roles in treatment decision making. The family was the major source of emotional support for most patients in this study; it helped cushion the many stresses associated with chronic illness. There was evidence that family ties were strengthened by the sharing and giving aspects of family members.

Patients in this study spoke of how important it was to them to have their spouses included in the decision making process. Angell (1984) in arguing the merits of having family members involved in treatment decision making concluded that families are important members in the discussions and "most patients would wish their families to be informed [of treatment decisions] along with themselves" (p. 1116). Oberley and Oberley (1987)

described how strong support from family members had great influence on patients' self-image and confidence. When patients did not have a sense of determination and reassurance from their family and friends they fell "into a pit of dependency" (Oberley & Oberley, 1987, p. 52).

Hope for the future was an essential factor that sustained and encouraged patients in the days prior to dialysis or transplantation. It bolstered their confidence and gave them something positive in which to believe. It helped patients think about the relationship between their potential therapy and the differences this therapy would make in their lives in the future. Cassileth et al. (1980) in a study to explore the degree to which patients prefer to become informed about and to participate in medical decisions found that those patients who preferred active involvement in decision making were more hopeful than were persons who did not want to participate. Many of the patients in this study who described their strong sense of hope also preferred to assume active or collaborative roles in the decision making process.

The physicians' presentation of information to patients and family was a crucial influencing factor in decision making since it allowed patients to know their options and subsequently to make informed decisions. Those patients who had not received adequate information described the difficulties they encountered in participating in the decision making process. The lack of information frustrated them; they became anxious and upset. There is empirical evidence that demonstrated that despite of patients' desire and efforts to acquire information, patients often perceived that they were unsuccessful in obtaining the information they need, particularly from health care professionals (Lenz, 1984; Mathews, 1983; Shapiro et al., 1983). Thompson (1990) identified that "the process of participating according to the [patients'] preferences was facilitated when they received the information that

they preferred to have from their health care provider" (p. 156).

Patients in this study reported that they had every aspect of physical, social, and psychological performance touched by their disease process. Eccard (1987) found that the impact of chronic renal failure occurred when patients realized that their symptoms had long-range meaning for subsequent life events. Patients had to adjust to the diagnosis and medical regime that accompanied chronic disease and also to the expectations that they may be dependent on dialysis for the rest of their lives, if they were unable to receive a kidney transplant. Patients' life-style was definitely affected and though patients realized that treatment would make them feel better, they would never be well.

These factors make it exceedingly important for patients to have their physicians consider their lifestyles when choices of treatment modalities are being discussed and decided. They need to be assured that their lives will not be altered any more than what is absolutely necessary. Patients have a strong desire to maintain as much stability and as little disruption as possible.

Patients in this study discussed using denial to cope with and adapt to the stresses of their drastically altered lifestyle. Kaplan De-Nour (1983) found that patients frequently used denial to handle the stresses of their chronic illness. A variety of strategies used by patients in their attempts to deny their illness were identified. Some patients often denied the presence of their chronic illness entirely. Others stated that they did not need treatment or they forgot to take medications or follow dietary restrictions. This phase varied considerably from patient to patient. It was during this time that patients found it difficult to assume responsibility for participation in the decisions being made for their care. Health care professionals need to be aware of patients' use of this coping mechanism. They need to work with those manifestations of denial in encounters with patients and at the same time

provide patients with support and reassurance. They need to assess each individual patient's need for the type and quantity of information and their preferences for participating in treatment decision making.

Patients' emotional and physical adjustment to the reality of ESRD required a great deal of time, as did the ability to become involved in treatment decision making. The time available for patients to participate in discussions with physicians influenced the patients' ability to participate in decision making. There seems to be substantial agreement that ESRD patients at first diagnosis are least likely to be in an adequate frame of mind to make good therapeutic choices. Bovbjerg (1987) explained that a diagnosis of ESRD can "easily stimulate overwhelming anxiety with its concomitants of denial and confusion" (p. 185). In addition, a complicating, if short-lived problem for ESRD patients is that after kidneys fail and before the patient's condition is stabilized through treatment, the patient has a reduced ability to think clearly or make a rational decision.

On the other hand, patients who have had chronic renal failure for an extended period of time have had the advantage of interactions with a variety of health care professionals. They have had time to discuss the various treatment modalities. These patients may be better informed and therefore may be able to assume their preferred role in treatment decision making with greater ease. Patients and physicians need to take these factors into consideration when therapeutic choices are being made.

Patients' actual roles in treatment decision making

In this study, 4 out of 12 patients indicated that they played an active role, 5 patients played a collaborative role, and 3 patients played passive roles in their actual experiences in the decision making process. Discussion of this portion of question number one, related to patients' actual roles in treatment decision making, will be provided in greater detail in the following section.

In summary, the majority of patients reported that they preferred to play a collaborative role in treatment decision making. In actual decision making, 4 out of the 12 patients interviewed indicated they played an active role, 5 patients played a collaborative role, and 3 patients played passive roles. Patients identified seven factors that impacted on their ability to assume their preferred roles in treatment decision making.

Congruence Between Preferred and Actual Roles

The second research question addressed in this study was: what is the degree of congruence between ESRD patients' perception of their preferred participation in treatment decision making and their actual experience?

Congruence between preferences for participation and actual experience was reported by 8 of the 12 patients in this study (Table 4). These findings are in accord with the findings of Sutherland et al. (1989). They conducted a study to compare ideal preferences for participation in decision making versus the actual roles assumed by a sample of 52 outpatients requiring post-surgical treatment for cancer. Congruence between the roles that patients preferred to assume in making decisional choices and their actual experiences was reported by 77% of the subjects.

Of those four patients who reported incongruence between their preferred and actual roles, three indicated that they had played a more active role in making decisional choices than their stated preferred roles. When these patients realized that treatment was imminent, they no longer were comfortable with the choices their physicians had made; they wanted to have more input into the decisions. Strull et al. (1984) found that "many patients state that although they rely on their clinicians to make initial decisions about treatment, they wish to play an active role later...when therapy becomes meaningful" (p. 2993).

One male patient felt that he was forced into a passive role from his preferred collaborative role when he was unable to have the treatment he and his physician had selected. He was presented with an alternative treatment modality by his physician without any detailed explanation or discussion. Degner and Beaton (1987) found in their study that one way physicians implement provider-controlled decision making is for the physician "to present a decision as the "best choice" to the patient and family without discussing other alternatives" (p. 28).

In this situation, the patient's choice of therapy may have been beyond his reach because of a variety of extending circumstances such as overcrowded dialysis facilities or staff shortages. As a result, the physician may have been justified in making an alternative choice for the patient. As Kosky (1990) stated "physicians aren't necessarily the bad guys...sometimes what they're doing is trying to save a patient's life. That's their priority" (p.23). However, the rationale for making the choice was not explained to the patient. The patient's frustration with the situation may have been alleviated had the physician taken the extra time to exchange this valuable information.

Incongruence between patients' preferences to participate in treatment decision making and their actual experience was reported by Degner and Beaton (1987) in their study of patients experiencing life-death decisions, and by Strull et al. (1984) in their study of hypertensive patients.

In summary, congruence between preferences for participation and actual experience was reported by the majority of patients in this study. Of those patients who reported incongruence between their preferred and actual roles, three indicated that they had played a more active role in making decisional choices than their stated preferred roles. One patient felt that he was forced into a passive role from his preferred collaborative.

Desire for Information

The third research question addressed in this study was: what are the ESRD patients' perceptions of the information they need in order for them to assume the role they prefer to play in treatment decision making?

Patients in this study were able to clearly identify the amount and types of information they required to assume their preferred roles in the decision making process. Information was identified as an essential element in decision making. Information included facts obtained through observations, discussions, and readings.

Quantity of Information Desired

In this study, 9 of the 12 patients indicated that they wanted to obtain as much information as possible about their disease process and the available treatment modalities. Only two patients indicated that they preferred having a minimal amount of information and one patient reported that she wanted only information if it was good news.

Those patients who identified that it was most helpful to obtain as much information as possible about their disease process and its treatment, also reported that they were better able to deal with their anxieties and stresses. It was fear of the unknown that had an impact on their ability to cope with their illness. Fear of the unknown has been demonstrated to be a major anxiety producer in ESRD patients. Wynne (1981) clarified this finding by stating that "ESRD patients are constantly bombarded with new threats and unknowns as well as having to cope with radical changes in lifestyle" (p. 32).

Derdiarian (1987) contends that information is functionally related to the processes of appraisal and coping, mediating both. She commented that patients developed more accurate expectations about threats of harm when

they received information regarding it. Consequently, patients coped more effectively in stressful situations when given adequate, understandable information.

No authors in the published literature on patients living with end stage renal disease have addressed the possibility that these patients may have preferences for a particular amount of information. Recent anecdotal accounts in the literature indicate that ESRD patients and their families are requesting more information about available treatments that ultimately influence their survival and quality of life and that could possibly assist them to make informed decisions (Burrows-Hudson, 1985; Starzomski, 1986). However, these authors did not define or quantify ESRD patients' preferences for amounts of information.

Several studies have documented patients' desire for information among a variety of patient populations (Blanchard et al., 1988; Cassileth et al., 1980; Faden et al., 1981; and Strull et al., 1984) and have found that most patients reported a strong preference for information and detailed disclosure. However, despite desire and effort to acquire information, there is empirical evidence that patients often perceive that they are unsuccessful in obtaining the information they need, particularly from health care professionals who may hold erroneous views of what and how much information patients desire (Faden et al., 1981; Haug & Lavin, 1981; Innes, 1977; Shapiro et al., 1983; Strull et al., 1984; Wetle et al., 1988)

In this study, there were many patients who discussed their concerns about the inadequacy of information provided to them. These patients felt that there were major gaps in the information obtained from health care professionals. Patients wanted to have more information about the different dietary management, medications, treatment modalities, and the possible side effects they may encounter.

Sources of Information

Patients identified that they were able to acquire information from a variety of sources including individuals who were seen as having facts or knowledge about ESRD and treatment modalities, family members, friends and other patients in the renal ambulatory care clinics. Health care professionals, especially physicians and nurses, in the renal ambulatory care clinics were seen as the primary information source.

In addition, patients obtained information or facts about their renal disease from reference materials such as books, magazines, television, and newsletters. The source most frequently cited as a valuable source of information was the "blue book" written by the Manitoba Branch of the Kidney Foundation of Canada. Only three patients accessed the educational program designed specifically for patients living with renal disease.

Studies of health-related searches for information indicate that personal methods, such as when information is sought from an individual known personally by the patient, are used before and in preference to impersonal methods (Kristjanson, 1983; Lenz, 1984; Vogt, 1989). However, impersonal information sources such as books, pamphlets, and information services were also used extensively and provided valuable information.

Vogt (1989) in her study to examine the information search process of climacteric women, found that all but two of the women who had searched for information had used impersonal sources of information. These impersonal sources of information included bookstores, libraries, journals and pamphlets. All subjects in that study had used personal sources of information, namely physicians and other women.

Several patients in this study described their information search as being extensive. When they felt that they had not obtained adequate

information, these patients went searching for answers from a variety of sources. These patients spent a great deal of time seeking information that would help them decide which treatment modality would best suit their individual needs. Lenz (1984) indicated that he was in favour of and supported patients who accessed all possible sources in their search for information. He stated that the use of multiple sources should result in the most extensive information acquisition.

Patients identified only one concern regarding the adequacy of informational sources. They expressed the need to have a patient support group established. They recognized the need for patients to talk with other people who had experienced many of the same things that they were presently going through.

Types of Information

Patients were able to identify the types of information they needed in order to be knowledgeable about their disease process. Those patients who identified a preference for obtaining all the information available for their specific situation, indicated that this was necessary in order for them to make an informed choice of treatment modality. Oberley and Oberley (1987) stated that "the cardinal rule is that the patient had the right to know" (p. 50). Oberley, a physician with ESRD, furthered the argument by pointing out that knowledge provides patients with the power to make intelligent choices about dialysis or transplantation. These patients identified a need to know all there was to know about their diagnosis, the diagnostic and therapeutic procedures they would undergo, and the prognosis of their disease.

On the other hand, those patients who indicated a preference for obtaining either the minimal amount necessary to care for themselves or only the good news, stated they did not want to be burdened with all the

information. This reaction would seem to be an adaptive defense mechanism; a means for patients to cope with the anxiety-ridden situation. These patients indicated a need to know only a minimal amount about their diagnosis and the meaning this diagnosis had for their health status.

Patients' Perception of Factors Influencing Acquisition of Information

Patients identified a variety of factors that influenced their ability to acquire information. These factors included: 1) timing of information and patients' readiness to learn, 2) patients' health care experience, 3) quantity of information, and 4) availability and accessibility of information.

Patients identified that their readiness to learn was largely dependent on their physical and emotional status, motivation to learn, and their general attitude toward health care. Several patients in this study reported that when they were not ready, they experienced a high degree of anxiety and apprehension when placed in situations that required them to concentrate and learn from the encounter. As Bovbjerg (1987) stressed "timing and the manner in which needed information is imparted is held to be critical...the typical ESRD patient is incapable of understanding all the issues...and likely to suffer from information overload when showered with information" (p. 185).

When ESRD patients' physiological state was unstable there was a real discrepancy between what patients needed to know and what they were capable of understanding. Several patients indicated that they had limited ability to comprehend new information. They found that they needed to concentrate on what their physicians had told them and nothing else seemed to matter. According to Kosky (1990), "patients only hear about 25 to 50% of what they are told because they are often overwhelmed by their condition" (p. 24).

Patients' past experience with the health care system played an important role in their acquisition of information. When patients first attended the renal ambulatory care clinics they had overwhelming feelings of anxiety and fear. Cassileth et al. (1980) state that "not knowing about one's clinical reality is often associated with uncertainty and unrealistic fears, a condition that patients describe as worse than knowing the facts" (p. 835). By becoming well informed over the course of their illness ESRD patients may be able to free themselves from their anxiety and fear.

These patients reported that they were too frightened to ask questions during their medical appointments. They also indicated that they felt they did not have sufficient knowledge even to know what questions to ask. Degner and Beaton (1987) also found that when patients first develop a serious illness most of them do not even know what questions to ask to elicit the data most relevant to treatment decision making. Angell (1984) offered three reasons for the occurrence of this phenomenon. He stated that some patients believe that physicians would rather not be questioned, particularly if the exchange might lead to an emotional scene, might take an appreciable length of time, or could be construed as implying lack of trust. "Some patients naturally feel very dependent on the good will of their physicians, they are loath to risk losing it" (Angell, 1984, p. 1115). It is difficult to determine why patients in this study were afraid to ask questions. Unfortunately the interviews did not delve into this aspect at any length. This information may have been important. It would have provided nurses with more information on which to base patient assessments, plan appropriate interventions to reduce patients' fear and anxiety, and ultimately to facilitate patients' learning.

Patients who had been attending the clinics for an extended period of time became more curious and involved. They wanted more information. According to Boreham and Gibson (1979) as patients become more actively

involved in the treatment of their illnesses, they are likely to be seeking more information, more precise descriptions and explanations, and detailed facts.

The quantity, availability and accessibility of information were three factors that patients identified as influential in their ability to acquire the information they desired. Although patients reported their satisfaction with the quantity of information they had received from health care professionals, patients voiced several concerns regarding availability and accessibility of some information. Patients were unable to remember information their physicians had discussed with them during their medical appointments. Patients found that they were forced to make written notes so that information would not be lost or forgotten. In addition, written information such as easy to read, informative pamphlets were not available to them as they waited in the clinics for their appointments.

Based on these findings, it would be important to have more information readily available for patients in the renal ambulatory care clinics. Since patients wait in the clinics for a considerable length of time to complete their appointments this may provide the perfect opportunity for patient teaching. It would be a time to review and reinforce information patients had received from the various health care professionals. Written material could also be given to these patients to take home and re-read at a later time with family members or friends. Any questions that patients had from their last visits could be answered and patients could be tutored as to what questions they could ask during their present appointment.

Greenfield et al. (1985) conducted an interventional study to increase patients' knowledge and involvement in medical decision making. The investigators found that those patients in the experimental group had increased involvement in their interactions with their physicians, fewer limitations imposed by the disease on the patients' functional ability, and

increased preference for active involvement in decision making.

In summary, the majority of patients wanted to obtain as much information as possible about their disease process and the available treatment modalities. Patients were able to acquire information from a variety of sources including health care professionals, family members, friends, other patients, and from the print media. Patients expressed the need to have a patient support group established. Patients identified four factors that produced an impact on their ability to obtain the information they desired.

Participation in Decision Making and Desire for Information

The fourth research question addressed in this study was: what is the relationship between ESRD patients' preferences about roles in treatment decision making and their desire for information?

In this study, the relationship between information and participation preferences was found to be intricately connected. Patients invariably identified information as an essential component of the decision making process, regardless of the degree of involvement they chose. Physicians indicated that acquisition of information was essential if patients were to exercise their preferred roles in treatment decision making. Physicians found that all patients required full disclosure of information in order to make informed decisions, regardless of the pattern of decision making they preferred.

There is empirical evidence demonstrating the association between information and participation in treatment decision making. Cassileth et al. (1984), Neufeld (1986), Blanchard et al. (1988), and Thompson (1990) found that patients preferred to have all available information and actively participate in decision making. In contrast to these studies, Sutherland et al. (1989), found that patients in their study wanted large amounts of

information even though they preferred to relinquish responsibility for decision making to their physicians. Sutherland et al. (1989) asked the question: "why did most of these patients seek information if in fact a majority preferred that physician to assume the role of primary decision maker" (p. 262).

In this study, the majority of patients indicated that they preferred to be actively involved in decision making and wanted all available information. There were also those patients who preferred to have information yet wanted to assume passive roles. Sutherland et al. (1989) suggest that patients may actively seek information to satisfy factors that do not necessarily include participation in treatment decision making. Although armed with information some patients may choose to authorize their physicians to make all the decisions, and thus decide not to decide.

These findings have implications for health care professionals. They stress the importance of making thorough assessments of patients' preferences for information and participation in treatment decision making. It is apparent that health care professionals cannot automatically assume that because patients want large amounts of information, they necessarily prefer to be actively involved in making decisional choices. It is important that health care professional avoid misunderstanding patients' wishes.

Dennis (1987) stressed that it is important to incorporate patients' preferences in individualized plans of care. "Although it is important to foster decisional involvement for patients who want it, it is just as important to refrain from requiring decision making by patients who do not want it and cannot cope with that responsibility" (Dennis, 1987, p. 155).

In summary, patients identified their preferences for information and involvement in treatment decision making. The majority of patients indicated that they actively sought information and wanted to play an active or collaborative role in treatment decision making. There were also some patients

who preferred large amounts of information yet preferred to relinquish the decision making role. It appears that patients seek information, regardless of the role they wish to assume in making decisional choices. It is apparent that information serves a purpose other than facilitating patients' involvement in treatment decision making.

Physicians' Perception of Patients' Desire for Information and Decision Making

The last research question addressed in this study was: What are the physicians' perceptions of the ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making?

Physicians' Perception of Patients' Desire for Information

In this study, all physicians agreed that it would be ideal for patients to have as much information as they desired. They recognized that information was pivotal to the patients' ability to participate, to the extent that they desired, in making therapeutic choices.

Studies have shown that physicians and patients often have remarkably different perceptions about what constitutes adequate disclosure of information (Faden et al., 1981; Strull et al., 1984). These investigators found that physicians consistently underestimated patients' preferences for discussion, whereas patients identified that they preferred far more detailed disclosures than physicians routinely offered.

The findings of this study did not support this stance. It was apparent that there had been a sharing of information between physicians and patients. Physicians indicated that, because of the nature of the patients' chronic illness, the majority had spent an extensive period of time exchanging information prior to initiation of therapy. Patients identified that they were satisfied with the quantity of information they received from physicians and

other health care professionals in the clinics.

Physicians' Perception of Factors Influencing Acquisition of Information

It was interesting to note that the factors physicians identified as having influence on the patients' ability to obtain information were similar to those identified by patients. One additional factor was described by physicians and that was patients' personal characteristics. Physicians recognized when patients' intellectual level or their ability to understand the language spoken by the physician hindered the exchange of information. In these situations, the physicians made a conscious effort to adjust their strategies to make the encounter as positive and meaningful as possible.

Physicians' Perceptions of Patients' Roles

Much of the recent research in the field of physician-patient interactions has investigated the degree of participation in decision making that patients actually prefer (Blanchard et al., 1988; Degner & Sloan, 1990; Ende et al., 1989; Sutherland et al., 1989; Thompson, 1990). However, only one study has examined physicians' perceptions of patients' preferences for involvement in decisional choices was found (Strull et al., 1984).

These investigators found that in a large majority of cases (78%) physicians believed that patients wanted to help make decisions. In only 22% of the cases did the physician think the patient wanted the physician alone to decide. In contrast, patients reported playing a relatively passive role, leaving the decision entirely up to the physician in 63% of the cases. Strull et al. state that the concept of decision making may not be familiar to patients or physicians and more importantly "physicians may truly be unable to estimate patients' preferences about decision making" (p. 2994).

In this study, physicians were interviewed and asked their perceptions of patients preferences for participating in treatment decision making. Of

those physicians interviewed six identified that the ideal role for patients to assume in the decision making process was an active role. One physician identified that patients should assume a collaborative role. Three of those physicians, who identified that patients should assume active roles, reported that the reality of most health care situations dictated that patients and physicians needed to collaborate or share in the treatment decision making. Another physician, who indicated that patients should be active in making decisional choices, reported that physicians needed to take control of decision making when "no treatment" decisions were being made.

These findings point toward what the physicians believed the "ideal" patients' roles in decision making should be in the interactions between physicians and ESRD patients in the decision making process. The findings did not address the question posed in this study: what are the physicians' perceptions of the ESRD patients' preferences for assuming alternative roles in treatment decision making? Patients' preferences were not delineated. The information obtained was limited in respect to the question asked therefore, it was difficult to make definitive statements about physicians' perceptions of patients' preferred roles. Further research is needed to probe physicians' perceptions of patients' preferences for assuming alternative roles in treatment decision making.

The findings have merit in that they provided valuable information about the roles physicians believed patients should assume in making decisional choices. The findings identified that the majority of physicians thought that patients should share in making decisional choices. This is congruent with what the majority of patients identified as their preferred involvement in the decision making process. The majority of patients reported that they preferred to collaborate with physicians when treatment decisions were being made.

These findings provided information that will guide health care professional in developing interventions to assist ESRD patients to increase their effective involvement with their physicians in the decision making process. Enhanced patient participation may result in improved outcomes, such as better treatment outcomes, restoration of patients' self-reliance, and enhancement of physicians' awareness of the patients' preferences, expectations, and needs.

Despite the physicians' belief that the ideal role for patients to assume was a collaborative role, there was little evidence in the findings to indicate that patients and physicians were, in fact, sharing responsibility for making therapeutic decisions. Physicians, in this study indicated that the majority of patients seen in the renal ambulatory care clinics, assumed an active or passive role in treatment decision making.

Discrepancies were noted in two of the physicians' verbal descriptions of patients' roles in treatment decision making and the roles that the physicians chose from the modified Role Preferences card sort. It is difficult to speculate any reasons for these discrepancies. However, one might tend to believe that the physicians' verbal reports would be quite accurate given the detailed explanations the physicians gave for their choices.

Physicians' Perception of Factors Influencing Treatment Decision Making

Physicians identified a variety of situational and personal factors influenced the decision making process and the patients' ability to assume alternative roles. These factors included: 1) patients' medical or social conditions, 2) institutional or physician bias, 3) available resources, 4) types of decisions being made in the clinics, and 5) trust in the physician. It was interesting to note that physicians, for the same reasons as patients, identified that trust had an impact on the patients' ability to become involved

in treatment decision making to the extent that they preferred.

Physicians stated that in many circumstances patients were physically unable to participate or their living conditions prohibited their selection of some treatment modalities. Kosky (1990) supports this finding by stating that "one-third to one-half of our dialysis patients are very sick when they arrive. We've never seen them before and it's too late to discuss treatment [choices] with them because they are quite uremic. We put them on the treatment we feel is best for them at the time" (p. 23). Physicians in this study have found that similar situations arise in their practices and they must do the best for the patient given the circumstances.

Personal or institutional biases may also influence the patients' ability to become involved in the decision making. Bovbjerg (1987) noted that nephrologists are experts in a particular type of treatment and therefore tend to overemphasize its advantages relative to other methods. In addition, he stated, "a nephrologist's specialty interest correlates with the type of treatment his patients' receive" (Bovbjerg, 1987, p. 185). Physicians, in this study were aware of their biases and they endeavoured to be fair and honest with patients when decisions were being made.

The ability of patients to be involved in treatment decision making may have been beyond some patients' reach in spite of their desire to participate in it. The reality of the situation was that overcrowded dialysis units, staff shortages, and financial restraints, as well as other factors, often determined treatment modalities. Unfortunately, at times, there is little one can do when these situations arise; there is no issue. However, it is incumbent on health care professionals to explain to patients, with the type and quantity of information they can comprehend, why these particular decisions have been made. Once armed with a basic understanding of the nature of the problem, patients are capable of becoming involved, to the extent that they desire, with

the making choices about other aspects of their care.

Physicians described two types of decisions that had to be made in the clinics. These decisions were life and death decisions and those general everything in between decisions. The majority of physicians stated that in life and death situations, in which patients may be at risk or may suffer, patients were provided with extensive information and included in the decision making process. However, in life death situations in which it had to be decided whether or not treatment would be initiated or if treatment had to be terminated, physicians stressed that they would assume responsibility for making the decisions. In accepting this responsibility patients and families were spared the guilt and burden associated with making the choice.

In life and death situations, in which patients may be at risk or may suffer, it was most appropriate to provide the patient with extensive information. However, it was also necessary to determine if, in fact, patients wanted to be involved in the decision making process to the extent that the physician had them involved. Physicians needed to make a thorough assessment of their patients' preferences before they arbitrarily involved them in making life-death decisions. This holds true for physicians who chose to make therapeutic choices for terminating or not initiating treatment. Physicians have an obligation to determine what roles patients and their families want to assume in making decisional choices before they take total responsibility for making the decisions for the patients.

In summary, all physicians agreed that it was ideal for patients to have as much information as they desired. It was evident that there had been a sharing of information between patients and physicians. They recognized that information was pivotal to patients' ability to participate, to the extent that they desired, in making therapeutic choices. Physicians identified three factors that influenced patients' ability to obtain the information they desired.

The majority of physicians indicated that the ideal role for patients to assume in treatment decision making was a collaborative role. These findings, although they have merit, have not addressed the research question. Physicians did not identify their perceptions of the roles that patients preferred to assume in treatment decision making. Despite the physicians' belief that the ideal role for patients to assume was a collaborative role, there was little evidence in the findings to indicate that patients and physicians were sharing responsibility for making therapeutic decisions. Physicians identified five factors that influenced patients' ability to assume their preferred roles in treatment decision making.

Limitations of the Study

There are several methodological limitations which need to be considered when interpreting data from this study. To address the purpose of this study and ensure rigor of conduct within the time frame available for completion of the study, restrictions to the design of the study were required, therefore certain limitations were unavoidable.

The conceptual framework used in this study provided a useful perspective from which to data collect and view the findings. However, the findings pointed to a weakness in the framework, particularly in defining the significance of information as it related to patients' ability to participate in and control treatment decision making. Based on the findings of this study, it may have been useful to integrate an information search process model with Degner and Beaton's (1987) descriptive theory.

The restrictive time period over which data was collected may have inhibited participants from building and maintaining trust with the investigator. Lincoln and Guba (1985) state that the existence of trust will automatically lead to credible data. Subjects are more willing to be both

candid and forthcoming if there is a degree of comfort and trust established between the investigator and subjects. The investigator spent an average of two hours with each participant, and the interviews were often emotional experiences during which participants divulged personal and confidential information. In only one of the interviews with a patient participant was there a sense that information or feelings were being withheld.

The sampling technique used in this study had limitations. The nonprobability convenience sampling method did not give each member of the population equal opportunity for inclusion. In addition, because of the sampling technique used, all categories of the subjects' experiences pertinent to this study were not identified. Theoretical sampling would have ensured that at least one patient and one physician would have fallen into each pattern of the descriptive theory.

Subject recruitment and selection by the Head Nurses or their delegates may have been biased toward ESRD patients the Head Nurses felt were the 'best' to interview. The investigator had to accept the Head Nurses' judgement that the patients, who agreed to speak with the investigator, were the only patients who met the inclusion criteria.

The volunteer nature of subject recruitment may have biased the findings. There was the possibility that data was polarized and not truly reflective of what generally tends to occur. Although some subjects were more articulate than others, they shared similar perspectives. Subjects who did not participate for a variety of reasons may have had very different perceptions of their experiences.

Patients' physical and cognitive abilities may have been impaired as a direct result of their illness. Patients fatigued easily and frequently lost their train of thought during the interviews. Patients may have forgotten or under-reported their preferences for information and participation in treatment

decision making. Therefore, the likelihood of bias was great because of systematic differences in patients' ability to recall past health-related events.

The ideal would have been to study patients' desire for information and preferences about roles in treatment decision making as it occurred in natural settings. In this study, subjects were not studied in their natural settings while patients were seeing physicians during their medical appointments. This was not done because of the possibility of the Hawthorne effect. In addition, studying subjects in their natural settings was not feasible because of time restraints; the ESRD patients' experience occurred most frequently over a protracted period of time, much longer than this study permitted.

In the following chapter, implications of the findings for nurses caring for ESRD patients in clinical settings are identified. As well, implications for education and future nursing research will be outlined. The conclusion of this study will then be presented.

CHAPTER VI

Recommendations and Conclusions

Introduction

In this final chapter, implications of the findings for nurses, as well as other categories of health care professionals who care for ESRD patients in clinical settings, are identified. Recommendations for nursing practice, education, and research will be discussed. The conclusions of this study will then be presented.

Nursing Practice

Nurses who work in ambulatory care settings play a central role in assisting ESRD patients in their quest for information and in the decision making process. Nurses' contact with patients is close and constant; meaningful relationships develop over the long term of patients' investigation for their renal disease. As a result, nurses have the opportunity to tailor nursing interventions based on their assessments of the individual learning needs of ESRD patients and their families.

Although the majority of patients identified that they wanted as much information as possible about their disease process and the available treatment modalities, 3 out of the 12 patients wished to have either a minimal amount of information or only the good news. Based on these findings, it is imperative that nurses within the ambulatory setting identify the specific amount of information that each individual patient desires. This should begin as early on in the illness episode as possible. This assessment must continue at regular intervals throughout patients' investigations in the renal clinics since patients' informational needs may change due to a number

of personal and contextual factors.

Nurses are the primary providers of information to patients and their families, and this is one of the most powerful interventions in treatment decision making. Patients and families repeatedly identified nurses as being valuable sources of information. Physicians supported patients' recognition of nurses and indicated that they believe dialysis nurses play a key role in the dissemination of information to patients. Based on these findings, nurses need to show a greater recognition of the importance of exchanging information with patients and their families. They have to take more opportunities to provide patients with the information that they need and desire.

Patients spend an inordinate amount of time sitting in the clinics waiting for their appointments. At this time they have nothing to do other than talk with friends and other patients, or read a variety of popular press magazines. This time would provide nurses, patients and their families with a "golden opportunity" for health care teaching. Regularly scheduled, short, informal, educational sessions could be planned that provide patients with information on diet, health risks, kidney disease, treatment modalities, medications, and personal/family adjustment issues.

These educational sessions would be structured to meet patients' individual learning needs. Nurses would take into account the identified needs of those patients who are experienced in the health care system and who are knowledgeable about renal disease and also of those patients new to the system who have little knowledge. The sessions could be planned on the days that patients attend the renal clinics. Patients would not be obligated to attend if they did not feel they were ready or if they felt they have obtained the information from a different source.

Friends, relatives and family members provided patients with a great deal of informational and decisional support. Therefore, when planning educational sessions, it would be essential to determine if patients would want to have these individuals accompany them to the sessions being offered in the clinics. All educational sessions should be open to all patients and their guests. If some patients and their families are unable to attend group educational sessions, for whatever reasons, family conferences or sessions should be planned to meet their individual needs.

Educational pamphlets specific to the needs of ESRD patients need to be developed and readily available for patients. Physicians could provide patients with these pamphlets while discussing treatment alternatives. Nurses, if necessary, could review these pamphlets with patients before they leave the hospital. Patients attending the clinics should be recruited to help develop these pamphlets. Only those patients with personal experience with renal disease can truly define and identify informational needs of ESRD patients. Involvement of patients in the development of these educational resources is highly recommended.

Videotapes, to be used by patients for educational purposes, need to be developed. Patients could view the tapes while they wait in the clinics or, if they wish, they could take the tapes home. Content of the tapes could be levelled to meet patients' identified needs at specific points in the investigation process. These tapes could focus on a variety of topics pertinent to the health and care of renal patients.

Patients spoke of the invaluable knowledge other dialysis or transplant patients have to share. Patients also expressed a need to "tell their story" to the investigator. These findings indicate that there appears to be a need for a neutral support person/group for ESRD patients to ventilate their concerns and frustrations. The establishment of a support group would give patients an

excellent opportunity to share experiences, discuss problems and seek solutions. It would be important to have health care professionals, preferably nurses, facilitate the sessions. Nurses would ensure that information being shared was accurate and reliable. Interpretations of information could be clarified and discussed with members of this support group to ensure accuracy of message transmission.

Patients require some form of preparation to improve their ability to ask the right questions, in the right way, and at the right time. One of the main obstacles in the exchange of information is patients' reluctance to ask questions. Another is that when physicians are willing to answer questions, patients are so ineffective at interviewing that they might elicit little more than reassuring answers biased in the direction that the physicians think the patients want to hear. Nurses can assist patients learn to be more effective in the physician-patient interaction. Nurses can coach patients prior to their appointments by getting patients to describe any concerns or problems they may be having. Nurses can then instruct patients on what questions they need to ask and what information they need to obtain from their physicians.

Nurses responsible for the care of ESRD patients could formulate a series of general questions to guide patients during their initial interactions with health care professionals in the clinics. These questions could assist patients in their endeavour to obtain basic information about their lab results, diets, medications, physical symptoms, and possible lifestyle changes. Simple questions such as "what are the results of my lab tests?" "what does it mean to have renal failure?", "what are my treatment options?" would help patients obtain the information they desire. After patients complete their appointments with members of the health care nurses could review any questions asked during the appointments and could reinforce answers given to the patients.

Nursing practice must maintain continuous vigilance in evaluation of patients' learning capabilities and readiness, experience with the health care system, perceptions, and biases, as well as, level of learning and comprehension. Armed with knowledge of these factors, nurses will be in a position to plan and implement patient education programs that will meet the ever changing needs of the nephrology patient population.

Nurses have a central role in identifying patients' preferences for participation in treatment decision making and in providing support through assessment skills and patient advocacy. Nurses can facilitate patients' preferred participation by representing patients' views to other health care professionals and by educating the public regarding their rights and responsibilities before they enter the health care system.

Initial and ongoing exploration of patients' preferences for information and participation in treatment decision making is essential. Nurses in clinical practice need to recognize that patients may desire all available information even though they may prefer to relinquish decision making to their physicians. It is also important that nurses recognize that patients may vary in their need for information and involvement at the various points in the investigation process.

Nurses need to educate patients to exhibit informed consumer behaviour and encourage physicians to recognize the value of patients' participation. As Neufeld (1986) suggests, when patients and health care professionals arrive at mutual patterns of decision making the needless expenditure of energy in trying to control, overcome communication barriers and establish ones self as a credible partner in the health care process can be avoided. Such collaborative endeavours could result in increased patient satisfaction, reduced burden for physicians, and preserved patients' feelings of individuality, autonomy and senses of personal dignity.

Nurses caring for ESRD patients need to be aware of the personal, situational, and contextual factors that influence patients' ability to obtain information and assume their preferred roles in treatment decision making. An awareness of these factors will facilitate nurses' ability to plan and implement strategies to address the complexity and diversity of patients' needs in the decision making process.

These recommendations have implications for nursing administration. Allocation of resources to assist nurses working in ambulatory care settings to meet the educational needs of ESRD patients is imperative. These resources would include educational materials and equipment, additional nursing staff to develop and implement educational programs, clerical support to assist in the preparation of the program, adequate supplies, and a physical environment that would be conducive to teaching and learning. Without administrative support to ensure that these resources were available and in place the education of ESRD patients would be difficult, if not impossible.

Nursing Education

The findings of this study have identified several areas in which nursing education can evolve in order to prepare nurses to meet the needs of patients facing the arduous task of making decisional choices.

The role of the nurse as a patient advocate is an integral component in contemporary nursing practice. The nurse as a patient advocate assists patients to discuss their needs and interests and to make choices congruent with their identified preferences. Educators need to recognize that in order for nurses to be effective patient advocates it is imperative that they are provided with the appropriate educational background.

Helping patients to make decisions has not been claimed as a legitimate nursing function in nursing education or practice. Yet, it is the

nurse who must comfort patients, ease concerns, and answer their questions. It is time, now with the impact of burgeoning technology and emerging claims for patients' rights, that nursing education programs move toward the incorporation of patients' roles in treatment decision making and patient advocacy into their curriculums. Clearly, for nurses to adequately meet patients' decision making needs, advanced education and experience is needed. As nurses search for ways to structure information to teach, counsel, and support patients through the decision process they can begin to address the needs of patients who face decision problems.

Patients in this study identified that the family played a central role in their ability to obtain information and assume their preferred roles in decision making. Nurses' ability to include families in the decision making process hinges on their knowledge and comfort in dealing with families. Lack of knowledge in family interactions may prevent some nurses from including families in the exchange of information and in the decision making process. Educators ought to recognize the need for a sound knowledge base in family needs and behaviours, and specific interventions to bridge the gap between patients, families, and health care professionals.

Communication is an integral component in the decision making process and in the exchange of information between patients and health care professionals. Educators need to acknowledge the important role communication plays in these interactions. Nursing students need to develop assertive communication skills which will assist them to advocate for patients, exchange valuable information, and respond in an appropriate manner when patients are faced with decisional uncertainties.

The need for ongoing education for nurses working with ESRD patients in ambulatory settings is strongly recommended. To effectively meet the needs of patients involved in the decision making process nurses need to maintain

their knowledge and level of competency. To remain in touch with the current trends in nursing practice, nurses must be provided with and be allowed to attend continuing education sessions. Continuing education sessions for nurses caring for ESRD patients in ambulatory care would focus on the decision making process, the role of the nurse as a patient advocate, family-centered nursing care, and communication skills.

Nursing Research

The findings of this study have identified that further research is needed to advance nursings' knowledge of the ESRD patients' experience in the decision making process.

Patients' comfort with the qualitative research method of inquiry employed in this study coupled with patients' need to "tell their story" raises important potential implications for future research involving ESRD patients. A more intensive longitudinal study of ESRD patients' lived experience from entrance into the health care system until initiation of a therapeutic modality may warrant further investigation. The rich and potentially insightful data collected in this study using qualitative research methods is valuable for generating knowledge about ESRD patients' experience in the decision making process. Future studies using this qualitative methodology are strongly recommended.

Patients attending the renal ambulatory care clinics were given the opportunity to participate in an educational program designed specifically for patients living with renal disease and their families. Only three patients in this study attended. It is recommended that the reasons for low attendance should be investigated. One physician stated that the program needed improvements. This physician indicated that the program needed to be less intense, longer in length, and more people needed to be involved. An

evaluation study to investigate these issues should be conducted.

Further research is required to define appropriate intervention techniques for patients faced with making decisional choices. An intervention designed to alter the traditional patient role in the physician-patient interaction can be developed. Patients living with ESRD would be coached to ask questions and negotiate medical decisions with their physicians, in a session with their nurse prior to attending their regularly scheduled appointments. The goal of this intervention would be increased involvement in the interaction with the physician, increased level of health knowledge, and increased ability to assume preferred roles in treatment decision making.

A comparison study should be conducted to investigate the differences in patients' desire for information and preferences about roles in treatment decision making between patients with acute/life-threatening illnesses and those patients with long-term illnesses. A qualitative methodology, similar to that used in this study should be employed. This study should also investigate the situational and contextual variables that influence these patients' ability to obtain the information they desire and assume the roles they prefer to play in treatment decision making.

Review of the literature and findings from this study describe a trend toward patient involvement in health-care decisions emphasizing the necessity for adequate information for patients prior to choosing a treatment modality. A needs assessment should be conducted to investigate ESRD patients' requirements for information during the investigation phase of their illness. Results from this assessment could be used to plan and implement a patient education program.

The findings of this study indicate that desire for information and preferences for participation are intricately linked. However, the relationship appears to be complex and multifaceted and not well understood. It is

strongly recommended that the relationship between patients' preferences to acquire information and to assume alternative roles in treatment decision making be further investigated. Knowledge of the relationship is necessary if health care professionals expect to competently and effectively assist ESRD patients through the decision making process.

Further exploration of the patterns of control over treatment decision making (Degner & Beaton, 1987) is required. Based on the findings of this study, it is recommended that this descriptive theory be integrated with an information process model such as Lenz (1984). An integrated framework may assist nurses to understand the relationship between patients' desire for information and their preferences for participation in making decisional choices.

A research project using a longitudinal design needs to be conducted to identify the extent to which ESRD patients' desire for information and preferences about roles in treatment decision making remain constant over time, from entrance into the health care system to initiation of therapy. The same subjects should be used to supply the data at two or more points in time. Because the same patients will be contacted at different time intervals, the investigator can identify the subjects who did and did not change and then can isolate the variables of the subgroups in which changes occurred.

In summary, several implications for nursing practice, education, and research were identified from this study. These implications pinpoint changes that are needed to improve the overall quality of patients' involvement in the decision making process. Nurses caring for ESRD patients must be knowledgeable regarding the amount and types of information patients and their families require during their investigation in the renal clinics. Nurses also need to be aware of ESRD patients' preferences for involvement in the decision making process. Furthermore, nursing students should be educated

to be effective advocates for ESRD patients when they have preferences for information and participation in making decisional choices. Additional research is imperative if nursing is to advance its knowledge of patients' preferences for roles in the decision making process.

Conclusions

The goal of this descriptive study was to gain a better understanding of ESRD patients' perceptions of their experiences in the process of treatment decision making. The study was directed by two main purposes. The first was to explore ESRD patients' preferences for participation in treatment decision making. The second purpose was to examine ESRD patients' desire for information as it related to their preferences to assume alternative roles in treatment decision making. Five research questions were addressed: 1) what are ESRD patients' perceptions of their preferred participation in treatment decision making and their actual experience, 2) what is the degree of congruence between ESRD patients' perceptions of their preferred participation in treatment decision making and their actual experience, 3) what are the ESRD patients' perceptions of the information they need in order for them to assume the role they prefer to play in treatment decision making, 4) what is the relationship between ESRD patients' preferences about roles in treatment decision making and their desire for information, and 5) what are the physicians' perceptions of the ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making? The range of answers to these questions was described in the preceding chapter.

The conceptual framework for this study was based on the four patterns of control over treatment decisions found in Degner and Beaton's (1987) descriptive theory of life-death decision making. The four patterns of control provided a useful framework for understanding the experience of ESRD patients in the decision making process. Focusing on the patients'

perceptions of the roles they preferred to assume and the roles they actually played in making therapeutic choices provided a fruitful way of examining ESRD patients' experiences. The findings however, pointed to a weakness in the framework, particularly in defining the significance of information as it related to ESRD patients' ability to participate in and control treatment decision making. Based on the findings it may have been advisable to integrate an information search process model such as the Lenz (1984) model with Degner and Beaton's (1987) descriptive theory.

From a selective review of the literature, it was evident that gaps exist in the state of knowledge about ESRD patients' desire for information and preferences for assuming alternative roles in treatment decision making. Previous research studies exploring the topic of patient roles in treatment decision making were limited in several aspects and none have addressed the decisional preferences of ESRD patients. None of the studies have elicited the perceptions of treating physicians about appropriate roles in treatment decision making. Use of an inductive method of inquiry to elicit information from patients regarding their perceptions of their need for information and their preferences for assuming alternative roles in treatment decision making has been limited. Deficiencies in the existing literature led to the selection of a qualitative research approach.

Subjects were interviewed by the same investigator using two semi-structured interview guides developed to reflect the different experiences of the two study samples. The interview guides consisted of four parts: an introduction, a short demographic questionnaire, a modified version of the Role Preferences card sort, and semi-structured questions. Data were analyzed using descriptive statistics and a method of content analysis called constant comparative analysis.

Patients identified and described the existence of three patterns of treatment decision making: patient-controlled, joint-controlled, and provider-controlled. The majority of patients preferred to assume a joint-controlled or collaborative role in treatment decision making. Congruence between ESRD patients' preferences for participation in treatment decision making and their actual experience was reported by the majority of patients. A range of personal and situational factors influenced ESRD patients' ability to assume their preferred roles including: 1) trust in the physician, 2) social support of family and friends, 3) hope for the future, 4) physicians' presentation of information, 5) lifestyle, 6) denial of the need for treatment, and 7) time needed to adjust to the experience.

The majority of patients indicated that they wanted to receive as much information as possible about their disease process and the available treatment modalities. Patients' need for the exchange of information was identified as an important aspect in the illness and treatment process. Patients expressed extreme satisfaction with the information they received from a multiplicity of sources. The success patients experienced in acquiring information was described in relation to a variety of factors including: patients' readiness to learn and retain information, health care experience, quantity of information, and availability and accessibility of information. Patients identified several concerns they had related to the types of information they required.

Physicians identified and describe the existence of three patterns of treatment decision making: patient-controlled, joint-controlled, and provider-controlled. The majority of physicians identified that the ideal role for patients to assume in treatment decision making was a joint-controlled or collaborative role. Physicians indicated that the majority of patients seen in the renal ambulatory clinics assumed either active or passive roles in treatment

decision making. Physicians identified five situational or personal factors that influenced the decision making process and patients' ability to assume alternative roles. These included patients' medical or social conditions, institutional or physician biases, available resources, types of decisions being made, and trust in the physician.

Physicians identified information as being central to the ESRD patients' ability to participate in the selection of treatment modalities. They indicated that ideally patients should have as much information as they desired. Physicians identified three factors that influenced patients' ability to acquire information. These included timing of information and patients' readiness to learn, patients' health care experience, and patients' personal characteristics.

Patients and physicians identified information as the single most significant component in ESRD patients' ability to assume their preferred roles in treatment decision making. Without knowledge and information neither health care professionals nor patients were able to effectively participate in the treatment decision making process.

The findings of this study suggest implications for nursing practice, education, and research. They contribute to nursings' knowledge and understanding of how ESRD patients' prefer to participate in the decision making process and the information they need to assume their preferred roles.

REFERENCES

- Aspinall, M.J. (1979). Use of a decision tree to improve accuracy of diagnosis. Nursing Research, 28(3), 182-185.
- Albert, D.A. (1978). Decision theory in medicine: A review and critique. Milbank Memorial Fund Quarterly, 56, 362-401.
- Angell, M. (1984). Respecting the autonomy of competent patients. New England Journal of Medicine, 310(17), 1115-1116.
- Arsanian, J. (1978). The need for patient education. Journal of the American Association of Nephrology Nurses and Technicians Annual Meeting Proceedings (pp 71-75). Park Ridge: American Association of Nephrology Nurses and Technicians.
- Averill, J.R. (1973). Personal control over adverse stimuli and its relation to stress. Psychological Bulletin, 80, 286-303.
- Bagley-Burnett, C. (1988). Measuring information-seeking behaviors. In M. Frank-Stromborg (Ed.), Instruments for clinical nursing research (pp. 151-169). Norwalk: Appleton & Lange.
- Baumann, A., & Bourbonnais, F. (1982). Nursing decision making in critical care. Journal of Advanced Nursing, 7(5), 435-446.
- Baumann, A., & Bourbonnais, F. (1984). Rapid decision making in nursing: A case study method for nurses. Toronto: McGraw-Hill Ryerson.
- Baumann, A., & Deber, R. (1989). The limits of decision analysis for rapid decision making in ICU nursing. Image: Journal of Nursing Scholarship, 21(2), 69-71.
- Beck, A.T., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The hopelessness scale. Journal of Consulting Clinical Psychology, 42, 861-865.
- Becker, M.H., & Maiman, L.A. (1975). Sociobehavioral determinants of compliance with health and medical care recommendations. Medical Care, 13 (1), 10-14.
- Benner, P. (1984). From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, California: Addison-Wesley.
- Benoliel, J.Q. (1984). Advancing nursing science: Qualitative approaches. Western Journal of Nursing Research, 6, 1-8.
- Blanchard, C.G., Labrecque, M.S., Ruckdeschel, J.C., & Blanchard, E.B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. Social, Science and Medicine, 27(11), 1139-1145.
- Blanchard, C., Ruckdeschel, J., Blanchard, E., Arena, J., Saunders, N., & Malloy, D. (1983). Interactions between oncologists and patients during rounds. Annals of Internal Medicine, 99, 694-699.

- Boreham, P., & Gibson, D. (1979). The informative process in private medical consultations: A preliminary investigation. Social Science and Medicine, 12, 409-416.
- Bovbjerg, R.R., Held, P.J., & Diamond, L.H. (1987). Provider-patient relations and treatment choice in the era of fiscal incentives: The case of the end-stage renal disease program. Milbank Quarterly, 65(2), 177-202.
- Brehm, S.S., & Brehm, J.W. (1981). Psychological reactance: A theory of freedom and control. New York: Academic Press.
- Brody, D. S. (1980). The patient's role in clinical decision-making. Annals of Internal Medicine, 93(5), 718-722.
- Burckhardt, C.S. (1987). Coping strategies of the chronically ill. Nursing Clinics of North America, 22(3), 543-549.
- Burrows-Hudson, S. (1985). Assuring informed choice: A literature review. ANNA Journal, 12(3), 177-180.
- Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. Annals of Internal Medicine, 92, 832-836.
- Cobb, A., & Hagemaster, J. (1987). Ten criteria for evaluating qualitative research proposals. Journal of Nursing Education, 26(4), 138-143.
- Cohen, S. (1980). After effects of stress on human performance and social behavior: A review of research and theory. Psychological Bulletin, 88, 82-108.
- Davis, M.S. (1968a). Physiologic, psychological and demographic factors in patient compliance with doctor's orders. Medical Care, 6, 115.
- Degner, L.F. (1986). Measurement of preferences for control over treatment decisions among adults with cancer. (Unpublished research proposal, National Cancer Institute).
- Degner, L.F., & Beaton, J.I. (1987). Life-death decisions in health care. New York: Hemisphere Publishing.
- Degner, L.F., Kristjanson, L., & Neufeld, K. (1990). Factors associated with patients' playing alternative roles in cancer treatment decision making: A feasibility study. (Unpublished research proposal).
- Degner, L.F., & Russell, C. (1988). Preference for treatment control among adults with cancer. Research in Nursing and Health, 11, 367-374.
- Degner, L.F., & Sloan, J.A. (1990). Decision making during serious illness: What role do patients really want to play? (unpublished research report).
- Dennis, K.E. (1987). Dimensions of client control. Nursing Research, 36(3), 151-156.
- Derdiarian, A. K. (1987). Information needs of recently diagnosed cancer patients: A theoretical framework. Cancer Nursing, 10(2), 107-115.

- Devins, G.M., Binik, Y.M., Hutchinson, T.A., Hollomby, D.J., Barre, P.E., & Guttman, R.D. (1983-84). The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. International Journal of Psychiatric Medicine, 13, 327-343.
- Devins, G.M., Hollomby, D.J., Barre, P.E., & Guttman, R.D. (1981). Helplessness and depression in end-stage renal disease. Journal of Abnormal Psychology, 90, 531-545.
- Dodd, M.J., & Ahmed, N. (1987). Preference for type of information in cancer patients receiving radiation therapy. Cancer Nursing, 10(5), 244-251.
- Dodd, M.J., & Mood, D.W. (1981). Chemotherapy: Helping patients to know the drugs they are receiving and their possible side effects. Cancer Nursing, 4(4), 311.
- Eccard, M. (1984). Adjustments and psychosocial impact of end stage renal disease: Nursing interventions. In L. Lancaster (Ed.), The patient with end stage renal disease (pp.29-48). Toronto: John Wiley & Sons.
- Ende, J., Kazis, L., Ash, A., & Moskowitz, MA. (1989). Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. Journal of General Internal Medicine, 4, 23-30.
- Engel, J.F., Blackwell, R.D., Kollat, D.T. (1978). Consumer behavior. Hinsdale: Dryden.
- Eraker, S.A., & Polister, P. (1982). How decisions are reached: Physician and patient. Annals of Internal Medicine, 97(2), 262-268.
- Faden, R.R., Becker, C., Lewis, C., Freeman, J., & Faden, A. I. (1981). Disclosure of information to patients in medical care. Medical Care, 19(7), 718-733.
- Ferrans, C.E., Powers, M.J., Kasch, C.R. (1987). Satisfaction with health care of hemodialysis patients. Research in Nursing and Health, 10, 367-374.
- Festinger, L. (1964). Conflict, decision and dissonance. Stanford, Calif: Stanford University Press.
- Fischhoff, B. (1980). Decision analysis: Clinical art of science? In L. Sjobert, T. Tyszka, & J. Wise (Eds.). Decision analysis and decision processes. Lund, Sweden: Doxa.
- Forsyth, G.L., Delaney, K.D., & Gresham, M.L. (1984). Vying for a winning position: Management style of the chronically ill. Research in Nursing and Health, 7, 181-188.
- Fuchs, J. (1987). Use of decisional control to combat powerlessness. ANNA Journal, 14(1), 11-13.
- Glaser, B.G., & Strauss, A.L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine.

- Gorry, G.A., Kassirer, J.P., & Essig, A. (1973). Decision analysis as the basis for computer-aided management of acute renal failure. American Journal of Medicine, 55, 473-484.
- Greenfield, S., Kaplan, S., & Ware, J.E. (1985). Expanding patient involvement in care. Annals in Internal Medicine, 102(4), 520-528.
- Grier, M.R. (1976). Decision making about patient care. Nursing Research, 25(2), 105-110.
- Guillen, M.A. (1983). Behavior by the numbers. Psychology Today, 17(11), 77.
- Halper, T. (1985). Life and death in a welfare state: End stage renal disease in the United Kingdom. Milbank Memorial Fund Quarterly, 63, 52-93.
- Haug, M.R., & Lavin, B. (1981). Practitioner or patient-Who's in charge? Journal of Health and Social Behavior, 22(September), 212-229.
- Hayes-Bautista, D.E. (1976). Modifying the treatment: Patient compliance, patient control and medical care. Social Science and Medicine, 10, 233-238.
- Hopkins, M.B. (1986). Information seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. Cancer Nurse, 9(5), 256.
- Howard, J.A. (1977). Consumer behavior: Application of theory. New York: McGraw-Hill.
- Howard, R.A. (1980). An assessment of decision analysis. Operations Research, 28, 4-27.
- Hulka, B.S., Cassel, J.C., Kupper, L.L. & Burdette, J.A. (1976). Communication, compliance and concordance between physicians and patients with prescribed medications. Journal of Public Health, 66(9), 847-853.
- Innes, J.M. (1977). Does the professional know what the client wants? Social Science and Medicine, 11, 635-638.
- Janis, I.L. (1984). The patient as decision maker. In W.D. Gentry (Ed.), Handbook of behavioral medicine (pp. 326-368). New York: Guilford Press.
- Janis, I.L., & Mann, L. (1977). Decision making: A psychological analysis of conflict, choice and commitment. New York: The Free Press.
- Janis, I.L., & Rodin, J. (1979). Attribution, control and decision making: Social psychology in health care. In G.C. Stone, F. Cohen, & N.E. Alder (Eds.), Health psychology. San Fransico: Jossey-Bass.
- Kalish, B.J. (1975). Of half gods and mortals: Aesculpiian authority. Nursing Outlook, 23(1), 22-28.

- Kaplan De-Nour, A. (1983). An overview of psychological problems in hemodialysis patients. In N.B. Levy (Ed.), Psychonephrology: Psychological Problems in Kidney Failure and Their Treatment (pp. 3-14). London: Phenum Medical Books.
- Kasch, C.R., & Knutson, K. (1985). Patient compliance and interpersonal style: Implications for practice and research. Nurse Practitioner, 10(3), 52-56, 64.
- Kidney Foundation of Canada. (1991). Canadian Organ Replacement Register:1989 Report. Canada: Kidney Foundation of Canada.
- Kiel, G.C., & Layton, R.A. (1975). Dimensions of consumer information seeking behavior. Journal of Market Research, 18, 233.
- King, I. (1981). A theory for nursing: Systems, concepts, process. New York: John Wiley & Sons.
- Kleinman, A. Eisengerg, L., & Good, B. (1978). Culture, illness and care: Clinical lessons from anthropologic and cross cultural research. Annals of Internal Medicine, 242, 344-346.
- Komrad, M.S. (1983). A defense of medical paternalism: Maximising patients' autonomy. Journal of Medical Ethics, 9, 38-44.
- Kosky, M. (1990). Dialysis decisions: Whose choice is it anyway? The Renal Family, 12, 23-25.
- Krantz, D.S., Baum, A., & Wideman, M.V. (1980). Assessment of preferences for self-treatment and information in health care. Journal of Personality and Social Psychology, 39(5), 977-990.
- Krischer, J. (1980). An annotated bibliography of decision analytic application to health care. Operations Research, 28(1), 97-113.
- Kristjanson, L.J. (1983). Family decision making in terminal cancer: A descriptive study. Unpublished master's thesis, University of Manitoba, Winnipeg, MB.
- Kutner, N.G., & Brogan, D.R. (1982). Evaluation of an experimental education program for new dialysis patients. AANNT Journal, 9(6), 22-25.
- Lancaster, L.E. (1984). The Patient with End Stage Renal Disease (2nd ed.). Toronto: John Wiley & Sons.
- Lazarus, R.S. (1966). Psychological stress and the coping process. New York: McGraw-Hill.
- Lazarus, R.S. (1982). Stress and coping as factors in health and illness. In J. Cohen, S.W. Cullen & L.R. Martin (Eds.). Psychosocial aspects of cancer (pp. 170-179). New York: Raven Press.
- Lefcourt, H. (1984). Research with the locus of control construct. (Vol. 3). Orlando: Academic Press.
- Lenz, E.R. (1984). Information seeking: A component of client decisions and health behavior. Advances in Nursing Science, April, 59-72.

- Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. London: Sage.
- Mathews, J.J. (1983). The communication process in clinical settings. Social Science Medicine, 17(18), 1371-1378.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. Cancer Nursing, 1, 373-378.
- McIntosh, J. (1974). Processes of communication, information seeking and control associated with cancer: A selective review of the literature. Social Science and Medicine, 8, 167-187.
- Messerli, M.L., Garamendi, C., & Romano, J. (1980). Breast cancer: Information as a technique of crisis intervention. American Journal of Orthopsychiatry, 50(4), 728.
- Munhall, P.L., & Oiler, D.J. (1986). Nursing research: A qualitative perspective. Norwalk: Appleton-Century-Crofts.
- Neufeld, K.R. (1986). Desire for control over health care in Manitoba women with a first time diagnosis of breast cancer. Unpublished thesis, University of Manitoba.
- Newman, J.W., & Lockman, B.D. (1975). Measuring prepurchase information seeking. Journal of Consumer Research, 2(3), 216.
- Oberley, E.T., & Oberley, T.D. (1984). In L. Lancaster (Ed.), The patient with end stage renal disease (pp. 49-57). Toronto: John Wiley & Sons.
- Orem, D.E. (1985). Nursing concepts of practice (3rd ed.). New York: McGraw-Hill.
- Parsons, T. (1951). The social system. New York: The Free Press.
- Pauker, S.G., & Kassirer, J.P. (1975). Therapeutic decision making: A cost-benefit analysis. New England Journal of Medicine, 293, 229-234.
- Penner, B.S., Alvare, G.C., & Wong, T.A. (1988). Renal failure patients: Our perception of their psychological symptoms. Kidney International, 33(Supplemental 24), S18-S20.
- Pierce, P.F. (1984). Decision counselling for nephrology patients. In L.E. Lancaster (Ed.), The patient with end stage renal disease (pp. 59-71). Toronto: John Wiley & Sons.
- Pierce, P.F. (1986). Decision making of women with early stage breast cancer: A qualitative study of treatment choices (Doctoral dissertation, University of Michigan, 1986). Dissertation Abstracts International, 46, 3784B.
- Punj, G.N., & Staelin, R. (1983). A model of consumer information search behavior for new automobiles. Journal of Consumer Research, 9, 366-380.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

- Schain, W.S. (1980). Patients' rights in decision making: The case for personalism versus paternalism in health care. Cancer, 46, 1035-1041.
- Shapiro, M.C., Najman, J.M., Chang, A., Keeping, J.D. Morrison, J., & Western, J.S. (1983). Information control and the exercise of power in the obstetrical encounter. Social Science Medicine, 17(3), 139-146.
- Seidel, J.V., Kjolseth, R., & Seymour, E. (1988). The ethnograph: Version 3.0. Littleton: Qualis Research Associates.
- Sisson, J.C., Schoomaker, E.B., & Ross, J.C. (1976). Clinical decision analysis: The hazard of using additional data. Journal of the American Medical Association, 236, 1259-1263.
- Smith, B.S., Wallston, B.S., Wallston, K.A., Forsberg, P.R., & King, J.E. (1984). Measuring desire for control of health care processes. Journal of Personality and Social Psychology, 47(2), 415-426.
- Starzomski, R.C. (1986). Patient and staff involvement in decisions for ESRD treatment. ANNA Journal, 13(6), 325-328.
- Storch, J. (1982). Patients' rights: Ethical and legal issues in health care and nursing. Toronto: McGraw-Hill Ryerson.
- Strull, W.M., Lo, B., & Charles, G. (1984). Do patients want to participate in medical decision making? Journal of American Medical Association, 252(21), 2990-2994.
- Sutherland, H.J., Llewellyn-Thomas, H.A., Lockwood, G.A., Tritchler, D.L., & Till, J.E. (1989). Cancer patients: Their desire for information and participation in treatment decisions. Journal of the Royal Society of Medicine, 82, 260-263.
- Szasz, T.S., & Hollender, M.H. (1956). A contribution to the philosophy of medicine: The basic models of the doctor-patient relationship. Archives of Internal Medicine, 97, 585-592.
- Taylor, S.G., Pickens, J.M., & Geden, E.A. (1989). Interactional styles of nurse practitioners and physicians regarding patient decision making. Nursing Research, 38(1), 50-55.
- Thomasma, D.C. (1983). Beyond medical paternalism and patient autonomy: A model of physician conscience for the physician-patient relationship. Annals of Internal Medicine, 98, 243-248.
- Thompson, J.E. & Thompson, H.O. (1985). Bioethical decision making for nurses. Norwalk, Conn.: Appleton-Century-Crofts.
- Thompson, L.A. (1990). Preferences for participation in treatment decision making and informational needs of couples undergoing infertility investigation. Unpublished master's thesis, University of Manitoba, Winnipeg, MB.
- Thompson, S.C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. Psychology Bulletin, 90(1), 89-101

- Ulrich, B.T. (1989). Nephrology nursing: Concepts and strategies. Norwalk: Appleton & Lange.
- Vertinsky, I.B., Thompson, W.A., & Uyeno, D. (1974). Measuring consumer desire for participation in clinical decision making. Health Services Research, Summer, 121-134.
- Vogt, C. (1989). The information search process in climacteric women. Unpublished master's thesis, University of Manitoba, Winnipeg, MB.
- Wallston, B.S., Wallston, K.A., Kaplan, G.D., & Maides, S.A. (1976). Development and validation of the health locus of control (HLC) scale, Journal of Consulting Psychology, 44, 580-585.
- Wallston, K.A., Smith, R.A., King, J.E., Forsberg, P.R., & Nagy, V.T. (1983). Expectancies about control over health: Relationship to desire for control of health care. Personality and Social Psychology Bulletin, 9(3), 377-385.
- Weinstein, M.C., Fineberg, H.V., & Elstein, A.S. (1980). Clinical decision analysis. Philadelphia: W. B. Saunders.
- Wetle, T., Levkoff, S., Cwikel, J., & Rosen, A. (1988). Nursing home resident participation in medical decisions: Perceptions and preferences. Gerontologist, 28, Supplement, 32-8.
- Wilson, H.S. (1985). Research in nursing. Don Mills: Addison-Wesley Publishing.
- Woods, N. & Cantazaro, M. (1988). Nursing research: Theory and practice. St. Louis: C.V. Mosby.
- Wynne, A.B. (1981). Patient management - predialysis education. AANNT Journal, 8(6), 32-33.

APPENDIX A
Letter of Approval - Ethical Review Committee

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEE

Proposal Number N#90/08

Proposal Title: "A Descriptive Study to Investigate End Stage
 Renal Disease Patients' Desire for Information and
 Preferences about Roles in Treatment Decision Making."

Name and Title of

Researcher(s): Judith Kaprowy, R.N., B.N.

Graduate Student, Master of Nursing Program

University of Manitoba

Date of Review: April 02, 1990

Decision of Committee: Approved: Apr. 23/90 Not Approved: _____

Approved upon receipt of the following changes:

APPROVED with changes and corrections submitted on
April 18, 1990.

Date: April 25th 1990

Theresa George, RN, PhD Chairperson
Associate Professor
University of Manitoba

Position

NOTE:

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

APPENDIX B
Letter of Access

(Date)

503 Bower Blvd.
Winnipeg, MB. R3P 0L7

*Dr. Dan Harper
Director of Research
Health Sciences Centre
820 Sherbrook Street
Winnipeg, MB

Dear Dr. Harper:

Re: Request for Nurse Research Access

I am writing to request your assistance in accessing, for my nursing study, end stage renal disease (ESRD) patients and the physicians responsible for their treatment and care. The study is in partial fulfilment of the requirements for the degree of Master of Nursing, University of Manitoba, School of Nursing.

The purpose of this research project is to explore and describe ESRD patients' desire for information and their preferences for assuming alternative roles in treatment decision making. I request access to conduct this study in the Renal Ambulatory Care Unit located on E4 at the Health Sciences Centre. (in the Renal Ambulatory Unit located in the Ambulatory Care Facility at St. Boniface General Hospital).

This thesis proposal has been approved by members of my thesis committee. The committee includes three members from the University of Manitoba, School of Nursing, Dr. Joan Jenkins, Chair, Dr. Lesley Degner, Professor Pat Farrell, and one external member, Dr. Brian Penner.

The study is supported by a Canadian Nurses Foundation Fellowship and by a grant from the Manitoba Branch of the Kidney Foundation of Canada.

Ethical and scientific approval to conduct this study is being sought from the University of Manitoba Nursing Ethics Committee, who will review my proposal on April 2, 1990. Subject recruitment and data collection is expected to commence in May 1990 or as soon as I receive approval from the Nursing Ethics Committee, University of Manitoba as well as approval for access to the Health Sciences Centre (St. Boniface General Hospital).

All information obtained from participants will be treated confidentially and names will not be identified in any reports of the study. Participation in the study is not expected to pose any personal risk to the patients or to the physicians. While participants may receive no direct benefit from the study, it is anticipated that the information obtained may increase understanding and enhancement of the decision making process in the physician-patient relationship.

Briefly, your assistance is requested to obtain consent to access, through the Renal Ambulatory Unit of your hospital, ESRD patients and the physicians responsible for the treatment and care of these patients. Upon completion of the study, I would be pleased to provide you with a summary of the findings. I would also be pleased to meet with you to discuss any questions you may have.

If you would like to speak with me concerning my application, please call me at 889-8232. Dr. Joan Jenkins can be reached at the University of Manitoba, School of Nursing at 474-6627.

Thank you for your interest and consideration of my research proposal. I look forward to a reply at your earliest convenience.

Sincerely,

Judy Kaprowy, R.N., B.N.
Graduate Student
School of Nursing
University of Manitoba

cc. Dr. J. Jenkins

*A Letter of Access would also be sent to:

Dr. Eleanor Adaskin
Director, Nursing Research
St. Boniface General Hospital
409 Tache Avenue
Winnipeg, MB R2H 2A6

APPENDIX C
Letter of Approval for Access
HEALTH SCIENCES CENTRE

DATE: MAY 3, 1990

FROM: Dr. D. Harper, Director of Research, H.S.C.

TO: MS. J. KAPROWY

SUBJECT: Research Protocol Approval

NO: NURSING (N#90/08)

TITLE: A DESCRIPTIVE STUDY TO INVESTIGATE END STAGE RENAL
DISEASE PATIENTS' DESIRE FOR INFORMATION AND PREFERENCES
ABOUT ROLES IN TREATMENT DECISION MAKING.

The above study has been reviewed by the appropriate H.S.C. Research Committee and has been approved.

COMMENTS: _____

Dr. D. Harper, Director of Research

May 3, 1990
Date: /

APPENDIX D
Letter of Approval for Access



Hôpital Général - St. Boniface - General Hospital

409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

May 10, 1990

Ms. Judy Kaprowy
503 Bower Blvd.
Winnipeg, MB R3P 0L7

Re: Access to SBGH Approval

Dear Ms. ^{Handwritten initials}Kaprowy:

I am pleased to inform you that your project:

A descriptive study to investigate end stage renal disease patients' desire for information and preferences about roles in treatment decision-making

has been approved for access to St. Boniface General Hospital patients, according to the protocol you have outlined. Approvals have been received from Dr. A. Fine, Mrs. V. Mann, myself, and Mrs. Jan Dick, VP Nursing.

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

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

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

Sincerely,

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

EA/mj

APPENDIX E
Inclusion Criteria for Subject Selection

Patient Participants

1. Diagnosed with ESRD requiring medical intervention within 6 months to sustain life.
2. Referred to a nephrology unit for medical assessment and/or treatment.
3. Has a creatinine clearance of under 20 ml/min.
4. Able to understand and speak English.
5. Consent to participate in the study is given.

Physician Participants

1. On staff at the selected institution.
2. Responsible for the treatment and care of ESRD patients.
3. Consent to participate in the study is given.

APPENDIX F
Procedure for Patient Participant Selection
to be Used by Head Nurses

1. Identify possible patient participants

Selection Criteria include:

1. Diagnosed with ESRD requiring medical intervention within 6 months to sustain life.
2. Referred to a nephrology unit for medical assessment and/or treatment.
3. Has a creatinine clearance of 20ml/min.
4. Able to understand and speak English.

2. Approach possible patient participants

State that a nursing study is currently being conducted with end stage renal disease patients. Inform them that they are a potential participant in the study and ask them if they are interested in having a nurse explain what participation in the study would involve. IN ORDER NOT TO BIAS RESPONSES IT IS VERY IMPORTANT THAT YOU DO NOT USE THE WORDS DESIRE FOR INFORMATION OR PREFERENCES ABOUT ROLES IN TREATMENT DECISION MAKING WHEN APPROACHING A POSSIBLE PARTICIPANT. IT IS BEST TO ATTEMPT TO DESCRIBE THE STUDY.

3. Receive verbal consent from the potential participant to release name to the investigator.
4. Inform the investigator of potential patient participant.

THANK YOU FOR YOUR COOPERATION AND PARTICIPATION

APPENDIX G
Explanation of the Study for Patient Participants

My name is Judy Kaprowy. I am a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba. As part of my nursing program, I am conducting a study to learn about renal disease patients' perceptions of their desire for information and their preferences for playing different roles in treatment decision making.

One of the nurses in the Renal Unit suggested your name as someone who might be interested in learning more about this study. I would like you to participate in this study.

If you agree to participate, I will interview you on two occasions for approximately one half to one hour, to discuss your perceptions about your participation in treatment decision making. I will also ask you some questions about yourself: where you live, educational background, length of time since you have known about diagnosis, and extent of your illness. The initial interview will be held in the Renal Unit at a time convenient to you and me. If you have no objections, I would like to have your permission to tape record the interview. I will make a follow up telephone call, after I review the tape recording, to share my findings with you and to determine if the information I have taken from the tape recording adequately reflects what has been said during the interview.

Participation in this study is completely voluntary. Your decision whether or not to participate will not affect your care in any way. If you agree to participate, you do not have to answer any questions that you do not wish to answer.

If you do agree to participate, your involvement in the study will remain strictly confidential. The information you provide will be identified by a code number. Your identity will be known only to the investigator. At the completion of the study, audiotapes will be erased and all written material, excluding the final written report, will be destroyed. The written report of this study will describe only group information and no single individual will be referred to or will be identifiable.

Participation in this study will result in no direct benefits to you but it may provide you with an opportunity to clarify some of the feelings and concerns you might have about assuming alternative roles in treatment decision making and the information you have received or wish to receive. The study is designed to be risk free and should not pose any distress to you.

If you choose to participate, I will read a consent form with you and if you have any questions, please feel free to ask me about them. Your signature on the consent form indicates your willingness to participate in the study. You are free to withdraw at any time, without harm to you or your care.

I will be happy to answer any questions you have about this study. I can be reached at 889-8232. If you wish to speak with my study supervisor, Dr. Joan Jenkins, you can call her at the School of Nursing, University of Manitoba (474-6627). Thank you for your time and attention.

APPENDIX H
Explanation of the Study for Physician Participants

My name is Judy Kaprowy. I am a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba. As part of my nursing program, I am conducting a study to learn more about end stage renal disease (ESRD) patients' desire for information and their preferences for assuming alternative roles in treatment decision making.

You are invited to participate in this study. If you agree to participate, I will be conducting two interviews with you, for approximately one half to one hour in length, to discuss your perceptions about ESRD patients' desire for information and participation in treatment decision making. I will also ask you some questions about yourself: educational background, practice site, and extent of your medical experience associated with ESRD patients. The initial interview will be held at a time and location that is convenient to you and me. If you have no objections, I would like to have your permission to tape record the interviews to aid in recall. I will make a follow up telephone call, after I review the tape recording, to share my findings with you, to determine if I have captured the essence of what you intended, and to seek your assistance if I am unclear about what has been said in the interview.

Participation in this study is completely voluntary. Your decision whether or not to participate will not affect you in any way. If you agree to participate, you do not have to respond to any questions that you do not wish to answer.

If you do agree to participate, your involvement in the study will remain strictly confidential. The information you provide will be identified by a code number. Your identity will be known only to the investigator. Tapes and code numbers will be destroyed at the completion of the study. The written report of this study will describe only group information and no single individual will be referred to or will be identifiable.

Participation in this study will result in no direct benefits to you but it may provide you with an opportunity to clarify some of the feelings and concerns you might have about ESRD patients' desire for information or about their preferences for assuming alternative roles in treatment decision making. The study is designed to be risk free and should not pose any distress to you.

If you choose to participate, I will ask you to read the consent form. If you have any questions, please feel free to ask me about them. Your signature on the consent form indicates your willingness to participate in the study. You are free to withdraw at any time.

I will be happy to answer any questions you have about this study. I can be reached at 889-8232. If you wish to speak to my study supervisor, Dr. Joan Jenkins, you can call her at the School of Nursing, University of Manitoba (474-6627). Thank you for your time and attention.

APPENDIX I
Consent Form for Patient Participants

I, _____ agree to participate in the study conducted by Judy Kaprowy who is a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba.

I understand that the purpose of this research is to investigate renal disease patients' perceptions of their desire for information and their preferences for assuming alternative roles in treatment decision making.

I agree to participate in two interviews to discuss my perceptions of my participation in treatment decision making. I understand that during the interviews I will be asked questions about myself: where I live, educational background, length of time since I have known about my diagnosis, and the extent of my illness. I understand that my participation in each interview will involve one-half to one hour of my time.

I understand that the initial interview will be tape recorded. I understand that I have the right to refuse to have taped all or part of the interview.

I understand that participation in this study is completely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to terminate at any point. Whether or not I decide to participate, my care will not be affected in any way. If I decide to participate and then later want to withdraw, I am free to do so without any effect on the quality of my medical care.

I have been assured that my involvement in the study will remain strictly confidential. I understand that only the investigator will know my identity and that the information that I provide will be identified by a code number. I understand that the written report and any further publication coming out of this study will describe only group information and will not identify me in any way. Tapes and code numbers will be destroyed at the completion of the study.

I understand that participation in this research study will result in no direct benefits. I am also aware that this study is designed to be risk free and should not pose any distress to me.

If necessary, I am aware that I may contact Judy Kaprowy at 889-8232 or her study supervisor, Dr. Joan Jenkins, at 4474-6627 at the School of Nursing, University of Manitoba.

My signature below indicates my willingness to participate in the study.

Date: _____
(Participant) (Investigator)

I would like a summary of the results of this study: Yes____No____

Mail to:

APPENDIX J

Consent Form for Physician Participants

I, _____ agree to participate in the study conducted by Judy Kaprowy who is a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba.

I understand that the purpose of this research is to investigate end stage renal disease (ESRD) patients' desire for information and their preferences for assuming alternative roles in treatment decision making.

I agree to participate in two interviews to discuss my perceptions about ESRD patients' desire for information and participation in treatment decision making. I understand that during the interviews I will be asked questions about myself: practice site, educational background, and extent of my medical experience associated with ESRD patients. I understand that my participation in each interview will involve one-half to one hour of my time.

I understand that the initial interview will be tape recorded. I understand that I have the right to refuse to have taped all or part of the interview.

I understand that participation in this study is completely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to terminate at any point. Whether or not I decide to participate, my position as a physician will not be affected in any way. If I decide to participate and then later want to withdraw, I am free to do so without any harmful effects.

I have been assured that my involvement in the study will remain strictly confidential. I understand that only the investigator will know my identity and that the information that I provide will be identified by a code number. I understand that the written report and any further publication coming out of this study will describe only group information and will not identify me in any way. Tapes and code numbers will be destroyed at the completion of the study.

I understand that participation in this research study will result in no direct benefits. I am also aware that the study is designed to be risk free and should not pose any distress to me.

If necessary, I am aware that I may contact Judy Kaprowy at 889-8232 or her study supervisor, Dr. Joan Jenkins, at 474-6627 at the School of Nursing, University of Manitoba.

My signature below indicates my willingness to participate in the study.

Date: _____
(Participant) (Investigator)

I would like a summary of the results of this study: Yes___No___

Mail to:

APPENDIX K
Patient Interview Guide

Introduction

The purpose of this interview is to explore your perception of your desire or need for information and your preference for assuming alternative or different roles in treatment decision making. I would like you to describe for me any feelings or concerns that might have about your experiences with making treatment decisions with your physician.

Demographics

1. Where do you live? (urban, rural)
2. What is the highest grade or level of education you have completed? (primary, high school, university)
3. Have you attended the Renal Education Program? (yes, no)
4. What is your medical diagnosis?
5. How long have you known your medical diagnosis? (month, day, year)
6. What is the extent of your illness? (i.e. creatinine clearance)
7. How would you describe your health status? (poor, good, excellent)

Modified Version of the Role Preference Card Sort

Directions: I would like you to take these 5 cards describing 3 different roles that patients with renal disease can play when decisions are being made about how to treat their illness. Please read each one of the cards carefully. Now:

1. Which one of these 5 cards best describes the role you wanted to play in treatment decision making? (record choice)
2. Which one of these 5 cards best describes the role you actually have been playing in treatment decision making? (record choice)

Guide for Questions

1. You chose this card (indicating card) to represent the role you wanted to play in treatment decision making. Can you describe for me, in your own words, why you made this choice?
2. Have you always wanted to play this role when you have been in a situation where decisions were being made about how to treat your illness or is this desire a recent occurrence?
3. (If there is a discrepancy between the preferred and attained roles) What would have helped you or what could have been done to assist you to play the role you wanted to play?

APPENDIX K (Cont'd)

4. (If provision of information is not a response) Many people believe that if they are given adequate information they are better able to play the role they want to play in treatment decision making. Has this been your experience? If so, could you describe your experience regarding this?
5. (If provision of information is a response) You mentioned information as one factor which would have helped you play the role you wanted to play in treatment decision making. Please describe the types of information which you feel would have helped you play your preferred role.
6. Now, I would like you to describe a recent situation in which treatment decisions were being discussed with you by your doctor. Think carefully about the discussion that took place.

Did you:

- a. find it hard to talk about your problem(s)
 - b. feel silly asking questions
 - c. wish you could talk your problems over with the doctor
 - d. feel that bringing up a question was too hard
 - e. find it just too difficult to ask too many questions
 - f. feel that there were many more questions you would have liked to ask the doctor
 - g. seem to have a lot of unanswered questions
7. Knowing what you know now, what advice would you give to another patient like yourself who is facing choices about their treatment?
 8. Are there any questions I can answer for you about this study?

APPENDIX L
Physician Interview Guide

Introduction

The purpose of this interview is to explore your perceptions about end stage renal disease (ESRD) patients' desire for information and their preferences for assuming alternative roles in treatment decision making. I would like you to describe for me any feelings or concerns that you might have about your experiences with making treatment decisions with your ESRD patients.

I will first start with some questions about yourself.

Demographics

1. Where is your primary practice site? (hospital, nephrology unit)
2. What is the highest level of education you have completed? (medical school, residency, fellowship)
3. What is the extent of your involvement with ESRD patients?

Modified Version of the Role Preferences Card Sort

Directions: I would like you to take these 5 cards describing 3 alternative roles that ESRD patients can assume in treatment decision making. Please read each one of the cards carefully. Now:

1. From a medical perspective, which of these 5 roles do you think it is best for an ESRD patient to assume in treatment decision making? (record response)

Guide for Questions

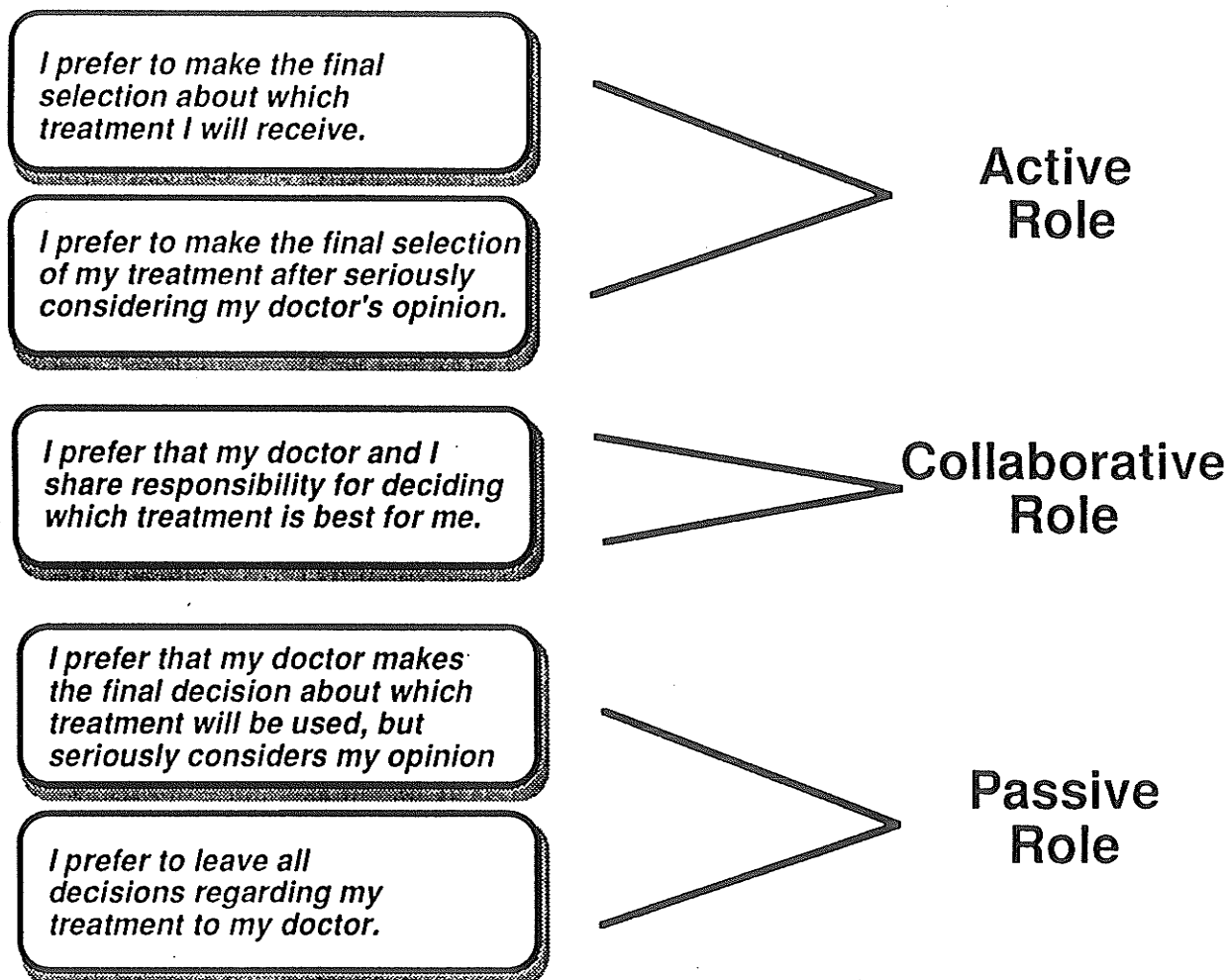
1. Could you give me a description of a patient you treated recently who assumed this role?
2. Given that this role is assumed by the patient in treatment decision making, what information do you think the patient will want to know in order to successfully assume this role?
3. Now, let's consider the other two potential roles that patients could play. Could you describe a patient you treated recently who assumed this role (one of the roles not selected)? What information do you think this patient will want to know in order to successfully assume this role?
4. Could you describe a patient you treated recently who assumed this final role in decision making (the other role not selected)? What information do you think this patient will want to know in order to successfully assume this role?
5. Given that you might encounter patients who wish to play different roles in treatment decision making, which type of patient would you personally find the easiest to care for?

APPENDIX L (Cont'd)

6. If you were to develop ESRD, what role would you like to play in treatment decision making?
7. Do you find yourself using any clues given by the patient during the interview to assess the patient's role preferences? If so, which of these clues do you find to be most helpful?
8. Are there any questions I can answer for you about this research project?
9. Are there any other suggestions you have related to this research project?

(Adapted from Degner, Kristjanson, & Neufeld, 1990)

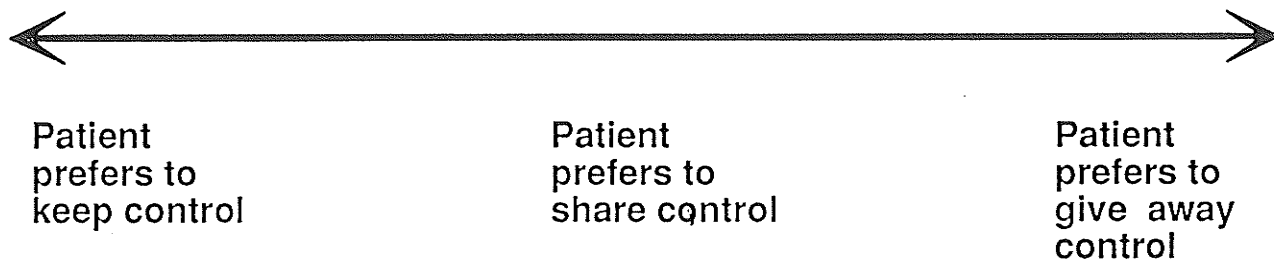
APPENDIX M
Statements on the Role Preferences Card Sort



(Degner & Sloan, 1990)

APPENDIX N
Psychological Dimension

There exists a single psychological dimension such that:



(Degner & Russell, 1988)

APPENDIX O
Vignettes of Degrees of Control Over Treatment Decisions

I. Patient-Physician Alternative

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

II. Patient-Family Alternative

- A. I prefer that my family makes the final decision regarding which treatment I will receive.
- B. I prefer that my family makes the final selection of my treatment but considers my doctor's opinion.
- C. I prefer that my family and my doctor together select which treatment is best for me.
- D. I prefer that my doctor makes the final selection of my treatment but considers my family's opinion.
- E. I prefer that my physician alone makes all of the decisions regarding my treatment.

(Degner & Russell, 1988)

APPENDIX P
Vignettes

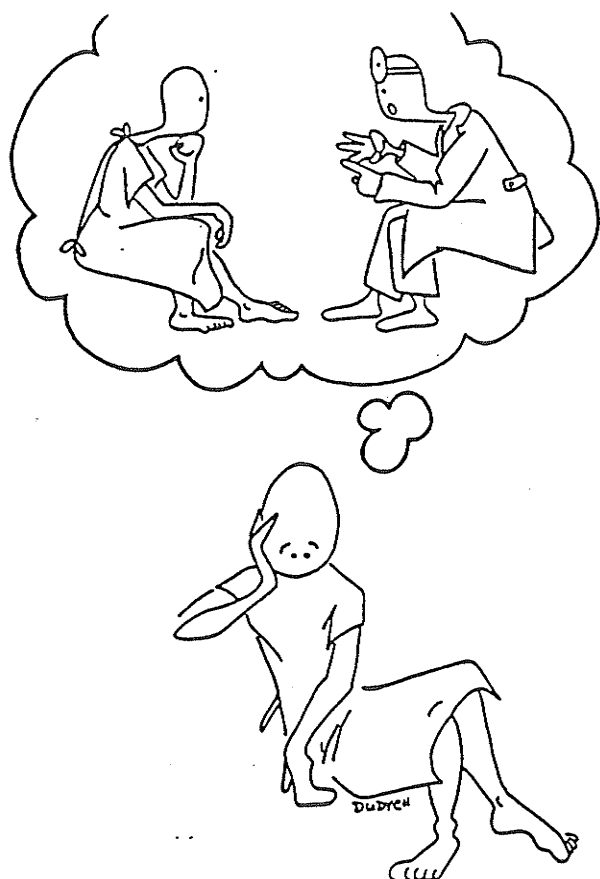
Patient-Physician Alternatives



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

(Degner & Russell, 1988)

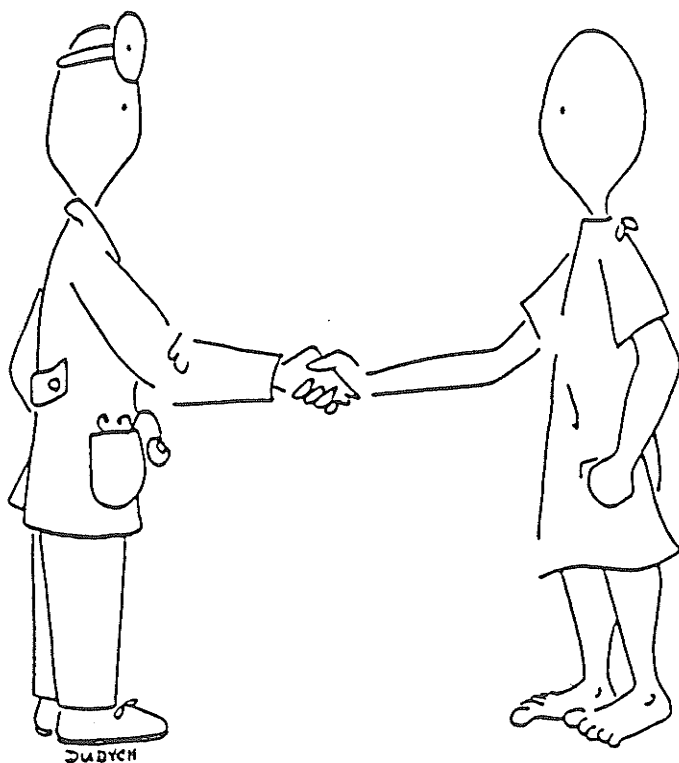
APPENDIX P (Cont'd)



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

(Degner & Russell, 1988)

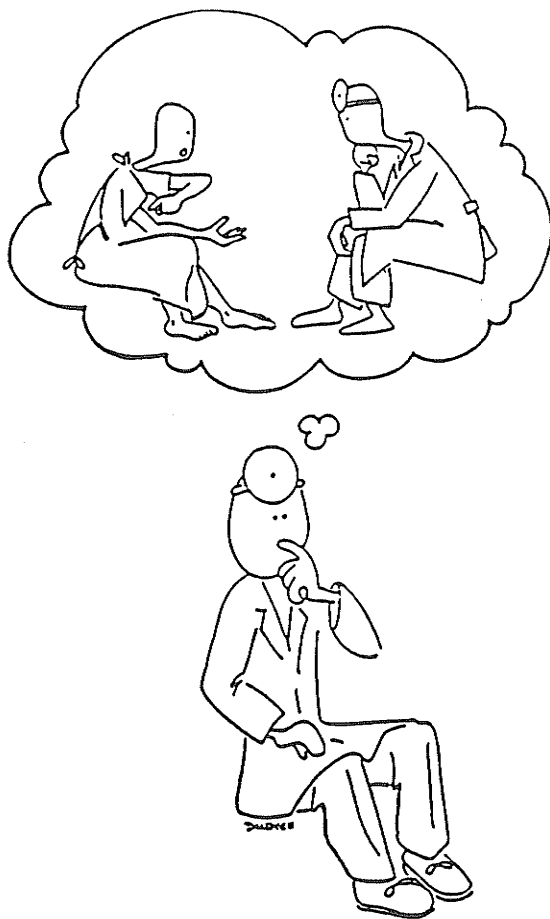
APPENDIX P (Cont'd)



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

(Degner & Russell, 1988)

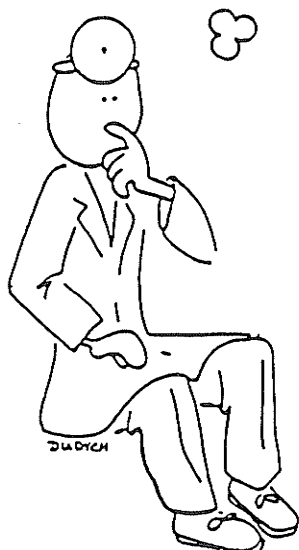
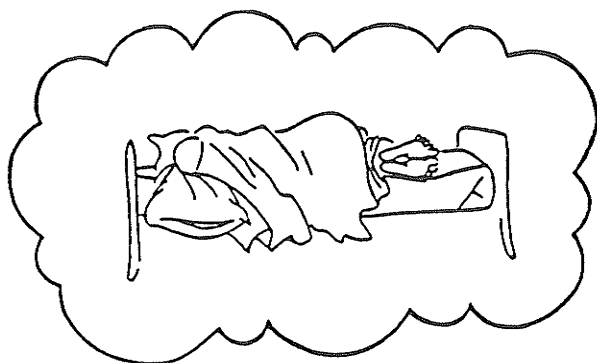
APPENDIX P (Cont'd)



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

(Degner & Russell, 1988)

APPENDIX P (Cont'd)



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

(Degner & Russell, 1988)

APPENDIX Q
Outline of Study Procedure

- STEP 1: Obtain approval from Ethical Review Committee, University of Manitoba, School of Nursing.
- STEP 2: Obtain permission for access to patient and physician samples and participation from Head Nurses of the Ambulatory Care Nephrology Units at the Health Sciences Centre and St. Boniface General Hospital according to institutions' policy.
- STEP 3: Explain the study to staff nurses and Medical Directors of the Nephrology Units at each setting.
- STEP 4: Identify patients meeting the eligibility criteria during the data collection period.
- STEP 5: Approach eligible patients with letter of explanation of study.
- STEP 6: Explain the study to interested patients, answer questions.
- STEP 7: Obtain written, informed consent from patients willing to participate in the study.
- STEP 8: Recruit a minimum of 10 patients for the study.
- STEP 9: Physicians responsible for the treatment and care of the consenting patient participants will be invited to participate in the study.
- STEP 10: Obtain written, informed consent from physicians willing to participate in the study.
- STEP 11: Collect data for the study.
- STEP 12: Analyze data.
- STEP 13: Disseminate study results to those study participants requesting a copy.