

Duquesne University Duquesne Scholarship Collection

Electronic Theses and Dissertations

2004

Application of Symphonology Theory in Patient Decision-Making: Triangulation of Quantitative and Qualitative Methods

Margaret Irwin

Follow this and additional works at: <https://dsc.duq.edu/etd>

Recommended Citation

Irwin, M. (2004). Application of Symphonology Theory in Patient Decision-Making: Triangulation of Quantitative and Qualitative Methods (Doctoral dissertation, Duquesne University). Retrieved from <https://dsc.duq.edu/etd/683>

This Immediate Access is brought to you for free and open access by Duquesne Scholarship Collection. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Duquesne Scholarship Collection. For more information, please contact phillips@duq.edu.

APPLICATION OF SYMPHONOLOGY THEORY IN PATIENT DECISION-
MAKING: TRIANGULATION OF QUANTITATIVE AND QUALITATIVE
METHODS

by

Margaret M. Irwin

BA, University of Pittsburgh, 1972

BSN, Duquesne University, 1976

MN, University of Pittsburgh, 1981

Submitted to the Doctoral Faculty
of the School of Nursing in partial fulfillment
of the requirements for the degree of
PhD in Nursing

Duquesne University

2004

© Copyright by Margaret M Irwin

2004

**DUQUESNE UNIVERSITY SCHOOL OF NURSING
PhD PROGRAM**

APPROVAL OF FINAL REPORT OF DISSERTATION

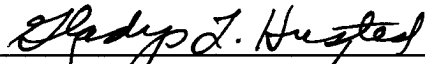

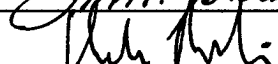
STUDENT:	Margaret Mary Irwin
DATE OF ADMISSION:	August 29, 1994
TITLE:	Application of Symphonology in Patient Decision Making: Triangulation of Quantitative and Qualitative Methods
COMMITTEE CHAIR:	Dr. Gladys Husted

The final report of the dissertation is approved by the Committee. The dissertation defense date was:


October 12, 2004

DISSERTATION COMMITTEE:

Please sign below

Chair:	Dr. Gladys Husted	
Member:	Dr. Joan Such Lockhart	
External Member:	Dr. Charles Rubin	

Approved by


Joan Such Lockhart, PhD, RN, CORLIN, AOCN®, FAAN
Professor & Associate Dean for Academic Affairs

10/12/04

Date

- Student Copy
- Chair Copy
- Student Record Copy

APPLICATION OF SYMPHONOLOGY THEORY IN PATIENT DECISION-MAKING: TRIANGULATION OF QUANTITATIVE AND QUALITATIVE METHODS

Margaret M Irwin, PhD

Duquesne University, 2004

This study tested the theory of Symphonology in two ways: 1) by determining if concepts in Symphonology were expressed in the experience of patients involved in health care decision-making, and 2) by testing the effect of an education/counseling intervention based on Symphonology, designed to facilitate decision-making. The study design was a pre-test post-test quasi-experimental design. Demographic and disease-related variables, decision-making role preference and the Bioethical Decision Making Preference Scale for Patients/Families (BDMPSP) (Husted, 2001) were measured prior to the intervention. Demographic variables that were measured included age, gender, race, marital status, years and type of education and time since diagnosis. Verbatim transcripts of semi-structured subject interviews were analyzed. The intervention provided was designed to assist subjects through the decision-making process using Symphonology. After the intervention subjects were again interviewed and they completed a post-test BDMPSP. Subject responses from post-test interviews were triangulated with results of statistical analysis testing the difference between pre and post-intervention BDMPSP scores. Relationships between demographic variables and decision-making role preference and BDMPSP scores were statistically analyzed.

The sample consisted of 30 subjects involved in a variety of decisions about health care and treatment during hospitalization in an acute care setting. Median age was 63, 75.7% were female ($n = 23$) and 53.3% ($n = 16$) had greater than a high school education. The distribution of decision-making role preferences was 40% active, 53.3% collaborative, and 6.7% passive. There were no significant relationships between demographic variables and decision-making role preference. Qualitative analysis demonstrated that patients expressed all of the concepts of Symphonology in interviews. Statistical analysis of differences in pre and post BDMPSP scores demonstrated that subjects had a more positive experience of being involved in decision-making ($p = .02$), felt more sufficiency of knowledge ($p = .013$), less frustration ($p = .014$) and more powerful ($p = .009$) after the intervention. Quantitative results were supported by qualitative findings. Findings support the validity of Symphonology theory. The theory can be used to describe the experience of being involved in decision-making and Symphonology has utility as a model for assisting patients through the decision-making process.

Dissertation Advisor: Gladys Husted RN PhD

ACKNOWLEDGMENTS

This paper is dedicated to the patients throughout the course of my career who have stimulated me to continually attempt to find better ways to provide care, as well as the patients who participated in this research. Without their time and interest, this project would not have been possible.

This work is also dedicated to the nursing profession and it is hoped that the theory testing done here can, in some small way, further the scientific basis of our practice and stimulate others to also test nursing theories.

The assistance, support and influence of the following is gratefully appreciated:

1. Gladys and Jim Husted, who wrote Symphonology theory – a theory that struck me so deeply, I felt compelled to test it.
2. The members of my dissertation committee,
 - a. Gladys Husted PhD RN, whose constant support and guidance made completion of this project possible, and who stimulated me to work on theory testing
 - b. Joanne Lockhart PhD RN, for her time, expertise, and guidance in strengthening this research
 - c. Charles Rubin, PhD, who challenged and stimulated my thinking
3. Janet Marlatt, RN, MSN, who provided critical assistance in subject recruitment and data collection, and whose constant support and positive thinking helped me complete this project.

4. Lenora Borucki, RN, MSN who helped me to get started with this study and provided assistance in data collection.
5. Chris Jones and Tami Gardner who did an outstanding job of transcribing patient interviews
6. Jefferson Regional Medical Center, especially the medical staff who supported this research with their patients, and the nursing staff who helped to identify and recruit subjects for the study.
7. My friends, loved ones and co-workers, whose support and encouragement helped me to prevail in order to complete this project.

TABLE OF CONTENTS

LIST OF TABLES	xii
LIST OF FIGURES	xiii
I. INTRODUCTION	1
A. Background of the Study	1
1. Ethical Nature of the Problem	3
B. Purpose of the Study	5
C. Study Questions	5
D. Definition of Terms	6
E. Assumptions	7
F. Limitations	7
G. Significance to Nursing	8
1. Importance of Theory Testing in Nursing	8
2. Importance of Patient Involvement in Health Care Decision-Making	9
II. REVIEW OF THE LITERATURE	11
A. Introduction	11
B. Conceptual Framework	11
1. The Nature of Man: Assumptions and Key Concepts	13
2. Nursing: Assumptions and Key Concepts	15
3. Environment: Key Concepts and Assumptions	16
4. Health: Key Concepts and Assumptions	17
5. Propositions Derived from the Theory	17
C. Importance of Autonomy to Nurses and Patients	18

D. Patient Involvement in Health Care Decision-Making.....	23
1. Decision Making Role Preferences: Personal and Disease Related Variables.	23
2. Patient Decision Making and Information	35
3. Patient Decision Making and Multiple Related Variables.....	45
4. Qualitative Studies Regarding Patient Involvement in Decision-Making.....	60
5. Interventions to Influence Patient Involvement in Decision-Making	79
E. Summary	97
III. METHODS	103
A. Design	103
1. Quasi-experimental Design	105
2. Triangulation	107
B. Setting	108
C. Sample	108
1. Sample Inclusion and Exclusion Criteria and Rationale.....	108
2. Sample Recruitment Procedures	110
D. Measurement and Instruments.....	111
1. Demographic Questionnaire	111
2. Decision-Making Role Preference	112
3. BDMPS	112
4. Patient Interview Schedule	115
E. Intervention.....	115
F. Procedures for Data Collection	116

1. Baseline Data Collection.....	117
2. Intervention.....	118
3. Post-Intervention Data Collection.....	118
G. Procedures for Protection of Human Subjects.....	119
H. Procedures for Data Analysis.....	120
1. Description of the Study Sample.....	121
2. Procedures for Qualitative Analysis of Subject Interviews.....	121
3. Documentation of the Intervention.....	122
4. Quantitative Analysis Procedures for Hypothesis Testing.....	123
5. Triangulation of Qualitative and Quantitative Results.....	123
6. Analysis of Relationships Among Variables.....	123
IV. RESULTS AND DISCUSSION.....	127
A. Sample Characteristics.....	128
1. Demographic Findings.....	129
2. Diseases, Conditions, and Types of Decisions.....	130
3. Decision-Making Role Preference.....	132
B. Study Question One.....	133
1. Fidelity.....	134
2. Freedom.....	135
3. Beneficence.....	136
4. Objectivity.....	137
5. Self-Assertion.....	138

6. Autonomy	139
C. Key Observations in Interventions.....	140
1. Uniqueness.....	141
2. Important Aspects in Life: Autonomy, Fidelity, and Freedom.....	142
3. Objectivity and Knowledge Gaps Identified	142
4. Voluntary Choice	143
5. Assessing Benefits and Impact of Alternatives	143
D. Study Question Two	145
1. Results of Quantitative Analysis: Hypothesis Testing	146
2. Qualitative Results: Post-Intervention Interviews.....	148
E. Relationships Among Independent, Intervening and Dependent Variables.....	150
1. Relationship of Demographic Variables to Decision-Making Role Preference	151
2. Clarity of the Decision and Decision-Making Role Preference.....	153
3. Relationships Among Independent, Intervening, and Dependent Variables ...	154
4. Decision Clarity and BDMPSP Scores.....	158
F. Summary and Discussion	159
1. Results of Theory Testing.....	159
2. Concepts and Themes Derived from Qualitative Analyses.....	161
3. Findings Regarding Relationships Among Variables	162
4. Role Preference Findings	166
5. Effect of the Intervention	168
V. SUMMARY AND RECOMMENDATIONS.....	171

A. Study Purpose	171
1. Results of Theory Testing	172
2. Analysis of Independent, Intervening Variables and the Outcomes.....	174
B. Sample Selection and Characteristics	175
C. The Nature of Decisions and Decision-Making.....	176
D. Limitations	179
E. Recommendations for Future Research	181
F. Implications for Nursing	182
G. Conclusions.....	183
APPENDIX A. Husted's Symphonological Bioethical Decision Making Model	186
APPENDIX B. Patient Demographic & Disease Related Questionnaire.....	187
APPENDIX C. Role Preference Tool.....	188
APPENDIX D. BDMSP	189
APPENDIX E. Pre Test Interview Schedule	191
APPENDIX F. Post Intervention Interview Schedule	192
APPENDIX G. Decision Support Intervention Guide	193
APPENDIX H. Research Approvals	196
APPENDIX I. Consent Form	200
APPENDIX J. Confidentiality Form.....	203
REFERENCES.....	204

LIST OF TABLES

Table 1. Study Variables: Variable Type, Measurement and Rationale for Inclusion ..	106
Table 2. Analysis of Relationships Among Variables: Measurement, Relationships Tested and Strategy for Statistical Analysis	125
Table 3. Sample Characteristics	129
Table 4. Health Conditions Experienced by Study Subjects.....	130
Table 5. Primary Decisions Expressed by Study Subjects	131
Table 6. Distribution of Decision-Making Role Preferences	133
Table 7. Results of Differences in Pre and Post-Intervention BDMPSP Scores.....	147
Table 8. Decision-Making Role Preference And Demographic Variables.....	152
Table 9. Association of Decision Clarity and Decision-Making Role Preference	154
Table 10. Relationships Between Demographic Variables, Decision-Making Role Preference and BDMPSP Scores	156
Table 11. Significant T-test Results for Differences in Mean BDMPSP Scores Between Subjects With Clear and Unclear Decisional Alternatives	159

LIST OF FIGURES

	Page
Figure 1. Study Design.....	105
Figure 2. Codes for Decision-Making Role Preferences.....	113
Figure 3. Schema of Relationships Examined Among Variables.....	151

I. INTRODUCTION

A. Background of the Study

In recent years the issue of patient rights has become increasingly important in health care. A variety of organizations, as well as the federal government, have addressed this issue by promulgating patients' bills of rights. Related clinical process requirements have been mandated by regulatory and accrediting agencies such as the Center for Medicare and Medicaid Services (CMS) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Each of the documents that sets forth patients' rights includes the individual's right to choice and to involvement in health care decisions.

In addition to the fact that patient involvement in decision-making is a well-recognized patient right, the literature also suggests that increased involvement of patients in making decisions regarding treatment and disease management can result in improved objective clinical outcomes (Greenfield, Kaplan, Ware, Yano, & Frank, 1988). As a result of all of these factors, there is growing attention to patient involvement in health care decision-making.

Nurses work on the front line of involving patients in a variety of decisions. In addition to practicing in the current environment that emphasizes patients' rights, nursing has long advocated principles of patient autonomy and self-determination. Research demonstrates that, among a variety of nurses, the principle of patient

autonomy is a dominant factor in ethical decision-making (Day, Drought, & Davis, 1994; Jansson & Norberg, 1989; Mattiasson & Anderson, 1995; Norberg et al., 1994).

While all of these factors encourage nurses and other professionals to increase patient involvement in health care decision-making, there is evidence to suggest that many individuals do not want to be involved in making these decisions. The desire of patients to participate in decision-making appears to be influenced by complex interactions of personal and external factors.

Age, gender, beliefs, and feelings, are some of the personal factors related to preferences about health care decision-making. There is evidence that knowledge and educational level of patients and professionals play important roles. A few studies have shown that individuals respond differently to decision-making scenarios depending upon whether or not they are personally facing an actual health related decision. The nature of the decision to be made also appears to influence the degree to which patients want to be involved.

External factors can create barriers to decision-making for both patients and nurses. Organizational constraints to ethical decision-making have been associated with feelings of conflict and powerlessness in the stories told by both nurses and patients.

Research in the area of patient involvement in health care decision-making has begun to improve our understanding of patients' desires and preferences about involvement in decision-making in different situations. Some studies have identified the type and amount of information patients want in order to make decisions. Some research has begun to identify factors that appear to influence the individual's ability

and desire to participate in health care decisions. These studies are addressed in the review of the literature.

A few studies have been done to test the effectiveness of various interventions to increase patient involvement in health care decision-making. Research in this area is somewhat limited, as the majority of these interventions have focused on provision of information. A few studies have incorporated more individualized counseling and empowerment interventions. These had more substantive results in terms of the effects on patient involvement in decisions. This research is addressed in the review of the literature.

This suggests the need for more holistic interventions and the need for patient decision support interventions that are designed according to more inclusive decision-making models. The fact that some interventions are successful in assisting patients to be involved in health care decision-making, suggests that the apparent preference for lack of involvement may reflect the need for such assistance rather than a fundamental preference. Patients are likely to need more than information and education. They may need more direct assistance with the actual decision-making process.

Ethical Nature of the Problem

From the perspective of the nursing professional, the need to provide for a patient's autonomy in a situation in which the patient is not involved in decision-making in their own health care, poses an ethical dilemma. Evidence and clinical experience suggest that involvement in decisions regarding one's own care is beneficial to the patient. Benefits derived are shown in both objective clinical terms, as well as more holistic and qualitative terms. However, in the situation where the patient does not want

to be involved in decisions, the principle of autonomy would necessitate that the patient remains uninvolved.

It appears that decision-making in health care situations is also experienced by the patient as an ethical situation. This was shown in a recent study by Husted (2001) in which patients and family members were asked to describe their experiences of being involved in bioethical decision-making. Patients and family members described a myriad of clinical decision-making situations as ethical dilemmas. Situations described by participants included deciding whether or not to undergo transplant surgery, concerns about the effectiveness of treatment, making a decision about ongoing care for an elderly grandmother with advanced dementia, and whether or not to intubate a parent with advanced chronic obstructive lung disease. Other types of decisions and situations described included decisions about how much treatment to undergo with reference to the potential impact of treatment on quality of life or survival (Husted, 2001).

If the experience of decision-making in health care is ethical in nature, examination of issues surrounding patient involvement in decision-making would be most appropriately done utilizing an ethical framework. This approach is in alignment with how health care decision-making is experienced by patients and nurses.

The conceptual framework that was used to guide this study is Symphonology theory of Husted and Husted (1991, 1995, 2001). This theory provides a holistic ethical framework that can be used to explain and facilitate patient involvement in health care decision-making.

B. Purpose of the Study

One purpose of this study was to test the theory of Husted and Husted. This was done by testing two propositions derived from the theory. These were:

1. If the theory describes the nature of man and the essential elements of ethical decision-making, then key concepts of the theory should describe the experience of individuals making health care decisions, and
2. If application of the decision-making framework provided by this theory will enable the nurse to make ethically justifiable decisions, then the same application should enable the patient to make a justifiable and satisfying decision for himself.

By testing these propositions this study determined the extent to which the theory can explain patients' experiences of being involved in health care decision-making. This study also tested the utility of the theory when used as the foundation of a decision support counseling intervention with patients.

C. Study Questions

Questions to be answered in this study were:

1. Can Symphonology be used to explain patient's experiences of being in the situation of health care decision-making?
2. Can a decision support intervention designed according to this theory, facilitate patients' decision-making? This overall question was addressed by testing the relevant null hypothesis.

D. Definition of Terms

The following terms are defined for the purpose of this study: bioethical decision-making, health care decision-making, decision-making role preference, the experience of being involved in decision-making, and decision support.

Bioethical decision-making is ethical decision-making that occurs in the context of health care. Ethical decision-making is the process of reasoning to determine what ought to be done related to vital and fundamental human goals. Bioethical decision-making concerns ethics as it relates to the provision of health care.

Health care decision-making is the process of reasoning to make choices about care and treatment that are related to an individual's health. Such decisions may involve a person's survival and affect the individual's physical and psychosocial experience of life and functioning. As such, health care decision-making involves aspects of human experience that are vital and fundamental. In this regard, all health care decision-making is bioethical.

Decision-making role preference is the patient's stated preference for degree of participation and control in decision-making as measured on a continuum from passive to active. At one end of this continuum, completely passive role preference is indicated by the patient's stated desire to leave decisions regarding care and treatment entirely up to someone else, usually the physician. At the other end of this continuum, active role preference is demonstrated by the patient's stated desire to make the final decision regarding care and treatment. In between these two ends of the continuum, decision-making preferences involve patient input or control of the decision that is shared between the patient and others.

The experience of being involved in health care decision-making is the patient's perception of the lived experience of being in the decision-making situation as expressed by the patient. The lived experience includes feelings of being involved in bioethical decision-making. Decision support is the use of tools and techniques to assist individuals to make decisions. To make decisions individuals must go through a process of reasoning and reach a conclusion or choice of action. Decision support facilitates the reasoning process and the conclusion of that process.

E. Assumptions

The following were key assumptions in this study:

1. It was assumed that subjects would respond honestly in describing their experience and in responding to approaches used in identifying preference for level of involvement and feelings.
2. There is a relationship between feelings about being involved in decision-making and sufficiency of the decision-making process. This relationship exists such that if the decision-making process is sufficient in providing an ethically justifiable personal decision, then the individual will have more positive feelings about the experience.

F. Limitations

The ability to generalize study findings is limited by the sample size, sample characteristics, the study design, and the setting of the research. Findings regarding the effect of interventions in the specific contexts in which they occur will not necessarily

be applicable to other situations and individuals. The sample characteristics and research setting are aspects of the specific context of this study. The relatively small sample size limits the statistical power to detect small differences in measurement with quantitative instruments used. The use of a quasi-experimental, rather than classical experimental design with a separate control group, limits the degree of certainty in hypothesis testing (Treece & Treece, 1973).

G. Significance to Nursing

This study is significant to nursing for several reasons. The study purpose involved testing a nursing theory, and the context in which this testing will occur involved facilitating patient involvement in decision-making. Theory testing is important for advancement of nursing knowledge. Interventions to assist patients to be involved in health care decision-making are important to enable nurses to support and promote patient autonomy.

Importance of Theory Testing in Nursing

As a scientific body of knowledge, nursing has been defined in many different ways. From the point of view of nursing as a practice discipline, it has been defined as “the body of knowledge generated and tested from the nursing perspective in order to ultimately provide relevant substantiated information for the guidance of practice” (Hinshaw, 1992, p.301)

Numerous nursing scholars have pointed to the critical need for theory and theory testing to develop knowledge in the discipline. Walker and Avant (1995) point out:

Testability of a theory and its empirical validity are of equal or greater importance in nursing as a practice discipline than to basic sciences. The public trust in a profession warrants using the very best procedures in making scientific judgments that have human import. Close interdependence between theory development and testing is essential if nursing is to build a sound body of knowledge for practice. (Walker & Avant, 1995, p.193)

This study will test a nursing theory that prescribes nursing practice through practical application of theory constructs to a clinical situation.

Importance of Patient Involvement in Health Care Decision-Making

The subject matter of this investigation is patient involvement in health care decision-making. This subject is of importance to nursing, patients, and the public at large. Nursing has historically advocated for the patient in the health care environment, and support of patient autonomy is a philosophical foundation of nursing theory and practice. Carper has identified ethics as one of the fundamental patterns of knowing in the nursing profession (Carper, 1992). The theory used in this study and the related issues to be investigated fall into this fundamental realm of nursing knowledge.

Involvement in health care decision-making is also important for patients. Making decisions is a basic way in which the individual expresses autonomy and influences his own experience. Decisions related to health care have to do with vital and fundamental goals. This research will advance our knowledge about how we can assist individuals to be actively involved in this decision-making and assist them through the decision-making process.

In the current health care environment, nurses are challenged to come up with ways to provide for the patient's right to be involved in health care decision-making. Yet, they are faced with the dilemma of dealing with patients who apparently do not want to participate in these decisions. It is unclear whether patients do not want involvement because they actually choose this approach, or whether typical interventions that focus on information are inadequate to fully facilitate the decision-making process in a health care context. This study will begin to bridge this gap in current knowledge.

II. REVIEW OF THE LITERATURE

A. Introduction

In this chapter the conceptual framework for the study, which is also the theory to be tested, will be presented. This chapter will also present the literature relevant to the subject matter of this study and evidence to support the significance of the study for nursing practice. Several research studies that demonstrate the importance of patient autonomy to nurses and patients will be reviewed. The research related to patient involvement in health care decision-making is presented. Current knowledge related to this subject consists of a variety of findings from both quantitative and qualitative research. These studies are organized according to major variables examined as follows: 1) patient decision-making and personal and disease related factors, 2) patient decision-making and information, 3) patient decision-making and multiple related variables, 4) qualitative studies of patient decision-making, and 5) interventions to influence patient involvement in health care decision-making.

B. Conceptual Framework

The conceptual framework used in this study was Symphonology (Husted & Husted, 1991, 1995, 2001). Since the purpose of this study was theory testing, the theory is presented in sufficient detail to support the propositions derived from the theory that will be tested. In this section the components of the theory - its major assumptions, concepts, and relationships among concepts are described. The

description of the theory is structured according to frameworks identified by Dickoff and James (1992) and Fawcett (1992).

Dickoff and James identify several levels of theory including: factor isolating theory, factor relating theory, situation relating theory, and situation producing theory. They describe situation producing theory, or prescriptive theory, as that level of theory that is produced to guide action. These authors further define six organizing aspects of prescriptive theory that they term a survey list. These survey list items are agency, patency, framework, terminus, procedure, and dynamics (Dickoff & James, 1992). Fawcett outlines the major structural components of theory and the essential concepts of nursing theory as person, environment, health, and nursing. Fawcett and others have agreed that nursing theory must contain one or more of these concepts (Fawcett, 1992).

Symphonology is a prescriptive theory as defined by Dickoff and James. The theoretical goal, or terminus, is for the practicing nurse to make decisions and take actions that are ethically justifiable. The prescription for achieving this goal is use of the ethical decision-making framework described in the theory. The dynamic of the theory is the ethical decision-making process. This is shown in the Husted Bioethical Decision Making Guide (Appendix A: Husted's Bioethical Decision Making Guide). This is viewed as the practical application of the reasoning process to vital and fundamental goals (Husted & Husted, 1995, 2001).

Agency can be seen in this theory as characteristic of both the nurse and the patient. This is true because the ethical decision-making process occurs at both a personal and an interpersonal level. At the personal level, the individual involved in

decision-making is an agent. At the interpersonal level the nurse is the agent for the patient.

Patency in this theory is clearly represented by the patient. This is the individual with whom the nurse has an implicit responsibility in the provision of nursing service.

Symphonology includes basic assumptions about the nature of man and of nursing. Environment and health concepts are not directly addressed in the theory, but their nature is suggested by prior assumptions and structural relationships among theory constructs.

The Nature of Man: Assumptions and Key Concepts

It is assumed that “every human being is an ethical agent” (Husted & Husted, 1995, p.18) who possesses the properties of desire, reason, life, purpose and agency. This is the nature of being human. As ethical agents, people desire things that bring them to greater perfection or preserve the self. The virtues, or qualities of the individual character that enable a person to develop or preserve the self are conceptualized in terms of the ethical standards: autonomy, freedom, objectivity, self-assertion, beneficence, and fidelity. These are key concepts in the theory (Husted & Husted, 1995).

The concept of autonomy is defined as one’s being unique, and acting from that uniqueness. Autonomy enables the individual to maintain his way of understanding himself and his world.

Freedom is conceptualized as the right and power of the person to make voluntary choices. It is the right to function as an independent being, and to initiate actions without interference.

Objectivity is the right and ability to function as reasoning being according to objective awareness. In this theory, with objectivity one is able to make decisions and take action from an objective rather than emotional stance. To have objectivity one must know the truth and the facts of a situation. Having information and understanding would be necessary components of the concept of objectivity.

Self-assertion is defined as the right and ability to control one's time and effort. This concept means self-ownership. Self-assertion also means that one has a right to not be deceived or coerced into action. One's rights to privacy, choice, consent, and confidentiality are incorporated within the concept of self-assertion used in the theory.

Benevolence is defined as the intention to help, or at least to do no harm to another. This concept has to do with action and intent to avoid any avoidable harm. For the individual, benevolence demands that one does not take action to harm oneself, or takes purposeful action to derive benefit. For the nurse, benevolence means prevention and avoidance of harm to the patient and functioning with the intent to benefit the patient.

Fidelity is defined in terms of commitment to a promise. Given the nature of man as explained by this theory, commitment to one's own preservation of desire, purpose, reason and agency is an inherent aspect of fidelity on the personal level. On the interpersonal level fidelity necessitates that the nurse fulfills the implicit agreement between the nurse and the patient. This agreement constitutes a mutually understood promise for the nurse to act in ethically justifiable ways.

These bioethical standards are key concepts of the theory that are structurally and functionally interrelated. These standards are a precondition of the implicit

agreement between the nurse and the patient. All of these standards exist together, and are intertwined with the nature of the individual and the context within which the individual exists. When all of these aspects of the individual and application of the bioethical standards are in harmony with each other and with the context of an action, that action is ethically justifiable. The interplay of all of these concepts is similar to the interplay of musical instruments in the performance of a symphony composition. In Symphonology this relationship among the bioethical standards is necessary because of the assumed nature of man and their relevance to the agreement between the nurse and the patient.

All of the aspects of the theory must be taken together in order for the process of decision-making to be sufficient in achieving an ethically justifiable decision. Taken together, these concepts form the theory construct of a bioethical decision-making model (Husted & Husted, 1995, 2001).

Nursing: Assumptions and Key Concepts

The concept of nurse is defined as the agent of a patient, "doing for a patient what the patient would do for himself if he were able" (Husted & Husted, 1995, p. 9). Nursing exists only in relationship to patients. A patient is therefore necessary for a nurse to exist.

Making decisions and taking actions that are ethically justifiable is the central focus of nursing practice. The therapeutic aspect of nursing is conceptualized as taking actions to support and facilitate the virtues of the patient. In clinical practice this can be seen to involve decision-making and nursing action that occurs on both the physical and

metaphysical realms. The nurse uses personal resources of introspection and the application of the bioethical standards in the decision-making process.

One of the key assumptions in the theory is that the relationship between the nurse and patient is founded on the existence of an implicit agreement between them. The agreement is that the nurse will function as the agent of the patient. This is an implicit understanding by both the patient and nurse. This is true because of the nature of the profession and clinical practice of nursing and the nature of human beings as ethical agents. It is important to note that the contract exists between the nurse and the patient and not between the nurse and something other than the patient.

Because the nurse and patient are ethical agents, the nurse-patient agreement presupposes the ethical standards as conceptualized in the theory. The bioethical standards are a precondition of the nurse-patient agreement. It is by using these ethical standards, which are the virtues of the patient and the nurse, that the nurse fulfills the agreement between herself and the patient. In this regard all of the decisions and actions on the part of the nurse are ethical in nature.

Environment: Key Concepts and Assumptions

Symphonology does not specifically deal with the concept of environment in the usual sense of an individual's physical surroundings or aspects of the world that exist external to the person. Environment is only relevant in this theory as the clinical practice context in which the ethical agreement between the nurse and patient exists.

As used in Symphonology the concept of ethics is "practical reason applied to vital and fundamental goals" (Husted & Husted, 1995, p. 31-32). Health care situations and decisions clearly involve vital and fundamental goals such as an individual's

functional capability, life, or quality of life. A key assumption of the theory is that ethical decision-making and ethical action are context-dependent. Ethical action cannot be separated from the context in which it occurs.

Context is seen as the interweaving of purpose, knowledge, and the facts of the situation. In ethical decision-making the context includes the reality of the situation and the relevant knowledge that decision-makers bring to that situation. It is pointed out that “the forming of a context requires that an agent become aware of his situation” (Husted & Husted, 1995, p 99.). This definition suggests relationships among knowledge, objectivity, purpose and reason that are symmetrical and mutually necessary. Knowledge and the facts of the situation are also interrelated with the bioethical standards in the individual’s experience of a given context for action. Taken together, these concepts are sufficient to form the basis of an ethically justifiable decision or action.

Health: Key Concepts and Assumptions

The concept of health is not addressed directly in the theory. However, given the nature of man as explained by the theory, health could be seen as the individual’s sustaining his existence as the person he is. The concepts of life, purpose, agency, desire and reason are mutually necessary for health.

Propositions Derived from the Theory

If the theory can be used to explain the nature of man and the essential elements of ethical decision-making, then key concepts of the theory should describe the experience of individuals making health care decisions. If application of the decision-making framework provided by this theory will enable the nurse to make ethically

justifiable decisions, then the same application should enable the patient to make the right decision for himself.

C. Importance of Autonomy to Nurses and Patients

The principle of patient autonomy has been identified as a foundation for decision-making in a number of nursing studies using hypothetical clinical situations. In these studies the principle of autonomy was ranked highly by nurses as an important factor in decision-making and was often used to justify decisions.

The concept of autonomy as used in the literature differs from the concept presented in Symphonology. As used in the literature, autonomy has to do with the right of the individual to make choices and respect of the individual's wishes. Autonomy is typically used to mean self-determination. This typical use of the term incorporates aspects of the concepts of autonomy, freedom and self-assertion found in Symphonology.

Jansson and Norberg (1989) interviewed 15 staff nurses and 5 ward sisters working at oncology, medical, and surgical clinics in Sweden. This study was done to describe the ethical reasoning of experienced nurses regarding force-feeding terminally ill cancer patients. Subjects were given a hypothetical situation of an elderly, terminally ill, and mentally alert female patient who refused food. Structured interview was used to elicit a variety of subject opinions. Subjects were also asked to rank order ethical principles in explaining their reasoning and decision-making for the hypothetical situation. Verbatim transcripts of tape-recorded interviews were analyzed for common responses and themes.

All twenty subjects chose not to feed the patient in this scenario. Eleven of the respondents, or 55%, justified their decision based on the principle of autonomy. Other respondents demonstrated use of principles of beneficence, non-maleficence, autonomy, and sanctity of life in various combinations. Autonomy was ranked as the most important ethical principle in their reasoning by 60% of subjects (Jansson & Norberg, 1989).

Day, Drought, and Davis (1994) did a similar study with 80 nurses from 4 sites for cancer care and dementia care in California and Arizona. Participants were presented with a case vignette pertinent to their field of care and interviewed regarding decisions they would make and the principles underlying their reasoning in the case.

In this study 95% of subjects stated they would not feed the patient. Among both cancer care and dementia care nurses who would not feed the terminal patient in the scenario given, most based their decision on the patient's right to refuse treatment. This is a concept inherent in autonomy. (Day, Drought, & Davis, 1994).

Mattiasson and Andersson (1995) examined principles used in the ethical reasoning of nurses from 13 different nursing homes in Sweden. Nurses were presented with a self-report questionnaire that included a vignette depicting a situation regarding the use of restraints in a patient who experienced multiple falls. In order to attempt to address discrepancies between individual views and actual behavior, subjects were asked for their personal opinion in the case as well as the clinical unit's probable decision in the case. Written responses from a total of 189 personnel were examined using content analysis techniques.

The dominant moral value expressed for both individual and unit decisions was the principle of beneficence. The principle of autonomy was ranked second for both types of decisions. About 57% of the sample indicated that they would restrain the patient “for his own good”, indicating the dominance of beneficence in their statements on the questionnaire. When staff members were asked about their own views in this case, 27% placed patient autonomy at the forefront in their thinking (Mattiasson & Andersson, 1995).

The principle of patient autonomy was a central theme in ethical dilemmas experienced by nurses in several additional studies. King and Miskovic (1996) surveyed peri-operative nurses in order to determine what they perceived as the most pressing ethical issues. A final sample of 217 respondents was obtained, representing nurses practicing in 28 different Mid-Atlantic hospitals. Subjects were asked to rank order those pressing issues that they encountered in their practice. Results of this survey indicated that the five issues identified as most pressing in peri-operative nursing practice were staffing patterns, informed consent, allocation of resources, occupational risk, and patient autonomy/advocacy. Analysis of variance did not show any significant relationship between prioritization of ethical issues and nursing position.

In 1990, a number of investigators conducted an international study of ethical reasoning associated with feeding of terminally ill cancer patients (Davidson et al., 1990). A structured interview was conducted with experienced nurses from 8 different countries. Subjects were asked to make a decision to either force feed or not force feed a hypothetical elderly patient, terminally ill with cancer, who refuses to eat. Justification and rationale for subjects' decisions were elicited during the interview, and subjects

were asked to rank order ethical principles according to their importance. All interviews were tape-recorded, transcribed verbatim, and analyzed using a consistent coding scheme. A final sample of 169 nurses was obtained.

The majority of respondents (75.8%) decided not to feed the hypothetical patient. The majority of these nurses used the principle of autonomy as justification, stating that they would support the patient's right to make her own decision. Of the remaining 37 respondents beneficence was used to justify the decision to force feed the patient by 11 individuals, and no justification was provided in 10 responses. The ethical principle that was given the most importance by the majority of respondents was autonomy. This finding was congruent with justification for decision-making that was expressed in interviews (Davidson et al., 1990).

In another international study of nursing decisions related to feeding, done by Norberg and others (1994), similar findings were reported. In this study structured interviews were done with 149 registered nurses in 7 different countries. Subjects were given a scenario in which an elderly patient with Alzheimer's dementia refused to eat. Subjects were asked whether or not they would feed the patient who seemed to refuse food and how they would justify their decision. They were also asked to rank ethical principles in order of their importance. Chi square analysis was done to determine the relationship between the decision regarding feeding and the ranking of ethical principles.

In this study 56% of subjects chose to feed the patient, and 44% chose not to feed the patient. Interviewees whose first choice was to feed the patient more often gave priority to the ethical principle of sanctity of life ($p < 0.05$). Those who chose to

withdraw feeding most often gave priority to the principle of autonomy ($p < 0.05$) (Norberg et al., 1994).

Autonomy was also found to be a driving principle for patients and families in health care decision-making. Gortner and Zyzanski (1988) reported the results of their work in developing an inventory for measurement of values based on the moral principles identified by Beauchamp and Childress. These investigators reported on the results of psychometric testing of their 16-item inventory that was administered to a sample of 65 patients undergoing first time open heart surgery. The same inventory was administered to the patients' spouses. Patients and their spouses completed the inventory postoperatively, after the decision regarding surgery was made. The instrument was a 12-item Likert scale.

Items on the scale consisted of sets of statements based on the principles of autonomy, beneficence, non-maleficence, and justice. Content validity of the instrument had previously been established by a panel of judges. Results of testing in this study were combined with analysis of data from previous testing. Instrument reliability was determined via factor analysis. Final alpha reliability for the inventory in patient samples was .69 and was .76 in family members.

In this study the investigators noted that mean scores for autonomy in patient-spouse dyads were significantly higher than the beneficence scores ($p < 0.001$). Researchers concluded that these findings indicated that families valued autonomy significantly more than beneficence. They also found that the over 70 age group had significantly higher autonomy scores than the under 50 age group ($F = 4.10, p = .02$).

Analysis of variance demonstrated no significant differences in results associated with type of surgical procedure, gender, or setting (Gortner & Zyzanski, 1988).

As evident in these studies there is substantial emphasis on the principle of patient autonomy and patient self-determination from both the patient/family and nursing perspectives. However, there is a growing body of research that suggests that not all patients want to exercise autonomy by participating in decision-making related to health care.

D. Patient Involvement in Health Care Decision-Making

A number of studies have been done to examine patients' preferences related to their involvement in health care related decision-making to identify relevant intervening variables and to explore the association of patients' preferences regarding information with their preferences regarding decision-making roles. Several qualitative studies have identified themes and patterns regarding individuals' experiences of health care decision-making. These findings and the research related to the effect of interventions designed to influence decision-making by patients is presented. Findings and implications are summarized.

Decision Making Role Preferences: Personal and Disease Related Variables

Several authors have looked at patients' decision-making role preference in health care situations or scenarios. Decision-making role preference has generally been viewed across a continuum from the preference for a passive to preference for a highly active role in decision-making. Decision-making role preference has been measured in several different ways including: structured card sort techniques,

investigator designed survey responses, and responses in structured interviews. Demographic and disease related variables have been examined for their relationship to decision-making role preference. Several investigators have shown that the majority of individuals studied did not prefer to play an active role in decision-making related to their health care. Role preference variation in relationship to age has been a fairly consistent finding among these studies. Several disease related variables such as type of illness, stage of disease, and degree of distress from physical symptoms have been examined for their relationship to decision-making role preference.

In 1988 and 1989 Degner and Sloan conducted two surveys in Manitoba to identify what roles people wanted to assume in selecting cancer treatments (Degner and Sloan, 1992). Samples used in this study were 436 newly diagnosed cancer patients and 482 individuals from the general public. Subjects with cancer were recruited from patients treated by 24 different oncologists at two treatment sites. Subjects were identified via consecutive sampling of every patient in the province over 18 years of age who had an initial diagnosis of cancer within the previous 6 months. Demographic and disease or treatment information was obtained from the patient's chart and through direct patient interview.

The sample from the general public was obtained by random selection from a city tax assessment list in order to obtain a gender-stratified sample. Standard demographic information was obtained from annual city survey data. Personal interviews were conducted with householders who were over 18 years of age.

Two measures were used in the group newly diagnosed with cancer: 1) preference about roles in treatment decision-making, and 2) the McCorkle symptom

distress scale. Individuals in the general public sample completed the same decision-making role preference measurement.

In this study the investigators developed a card sort technique to measure patient role preferences in treatment decision-making. The card sort materials consisted of two sets of 5 cards. Each card had a written description of a different role in decision-making and was illustrated with a cartoon depicting the relative control in decision-making between the physician and the patient indicated by the verbal statement. One set of cards illustrated roles that the patient and physician might assume in decision-making, ranging from the patient selecting the treatment, through a collaborative situation, to a scenario in which the physician alone made the decision. The second set of cards was designed to have the patient indicate who should make treatment-related decisions on his behalf if he became too ill to participate. In this second card set options ranged from the patient's family making the decision alone, through a collaborative model between the family and the physician, to the physician making the decision alone.

Cards used to measure patient preferences were presented to subjects in pairs and patients indicated which of the two cards they preferred. This process was repeated until all 5 cards were preferentially ordered. Patients also completed McCorkle's Symptom Distress Scale. In this instrument, 13 symptoms were rated by the patient on a 5-point Likert type scale, ranging from 1 (*no distress*) to 5 (*severe distress*). Card sort results were categorized as role preferences that were passive, (physician decision-making), collaborative (shared decision-making between the patient and physician), or active (patient decision-making).

Study findings revealed different role preferences in decision-making between those without cancer and those who were newly diagnosed with cancer. The majority of newly diagnosed subjects (59%) preferred that physicians make treatment decisions on their behalf. Twelve percent of this group indicated a preference for an active decision-making role. In contrast, 64% of householders preferred an active role, and 9% of householders indicated preference for a passive role in treatment decision-making. When these results were controlled for age these patterns did not change significantly. There was a tendency for younger people to prefer a more active role in decision-making.

Preferences shown in both card sorts were strongly correlated in cancer patients ($r = 0.72, p = 0.000$) and in members of the general public ($r = 0.54, p = 0.000$). These findings suggest that those who preferred to assume more personal control in decision-making also preferred having more control assumed by the family in the event that they were too ill to participate.

Symptom distress and stage of disease were not related to patients' role preferences. There were also no differences in decision-making role preferences among patients according to the treatment received. Results of logistic regression demonstrated that age ($r = 0.15, p = 0.000$) and male gender with reproductive cancer ($r = 0.02, p = 0.008$) were significant predictors of role preference. While these relationships were significant, the correlation coefficients were weak and the overall logistic regression model explained only 14.8% of the variance in role preference.

As shown here, the majority of individuals with cancer preferred passive involvement in decisions. This tendency was in sharp contrast to the preferences reported by individuals not diagnosed with cancer (Degner & Sloan, 1992).

Arora and McHorney (2000) reported a larger percentage of patients who preferred a passive role in decision-making. They reported results from analysis of data that was previously collected for 2197 patients with chronic disease who participated in the Medical Outcomes Study. Data collected as part of this study were analyzed using multivariate logistic regression techniques to determine the effects of socio-demographic, clinical, psychosocial, and life style characteristics on patients' decision-making role preferences.

Results of this study indicated that 69% of the sample preferred to leave their medical decisions to the physician. The odds for preferring an active role decreased significantly with age and increased with education. The likelihood of preferring an active role varied significantly across several disease related patient groupings. Individuals with mild hypertension were more likely to prefer an active decision-making role than those with severe diabetes ($p = 0.04$) or mild heart disease ($p = 0.02$). Patients with clinical depression were more likely to be active in decision-making ($p = 0.01$) than others. Women were more likely to be active than men were ($p = 0.001$).

The investigators concluded that, although the majority of individuals in this sample preferred to delegate decision-making to the physician, actual role preferences varied significantly according to a variety of patient characteristics. Age, gender, and education level were related to the degree of active participation in decision-making that was preferred. Significant differences in role preference were found among patients

with different types of health care problems. The authors concluded that health care decision-making role preferences are highly individualized, and that approaches to enhance patient involvement would need to accommodate this high degree of individuality (Arora & McHorney, 2000).

Barry and Henderson (1996) followed 7 patients with a longitudinal approach to determine if desires regarding involvement in decision-making changed with disease progression. The purpose of the study was to explore the degree to which terminal oncology patients desired participation in treatment decisions and to determine if patients were able to participate to the extent desired. Repeated in-depth interviews were used for data collection. A card sort technique similar to that described by Degner and Sloan was used to elicit preferences and feelings. Subjects all had an expected survival of less than 6 months.

The investigators found that initially patients desired a decision-making role of passiveness with input to the decision or collaborative decision-making. As their disease progressed this changed and they became desirous of more input. It was postulated that this might have occurred as a result of greater knowledge and experience as time went on and as the disease progressed.

The researchers found differences between the patients' desired and actual levels of participation in decision-making. Over the period of repeated hospital admissions patients reported an increasing discrepancy between their desired input and their perceived actual level of input into treatment decisions. The investigators reported that objective measurement of physical status did not appear to be related to the

desired level of input into decision-making. The method of measuring physical status was not described in the report (Barry & Henderson, 1996).

Ramfelt, Bjorvell, and Nordstrom (2000) also examined the preferred and actual participating roles in treatment decision-making in 86 patients with newly diagnosed colon cancer. Patients were studied in the hospital the day before their surgeries. Preferred and actual decision-making roles were measured using the card-sort technique developed by Degner and Sloan.

In this study, coping was addressed through examination of the meaning of disease and the patients' sense of coherence. They measured the meaning of disease, using a technique developed according to Lipowski's 8 categories of the meaning of disease, and measured sense of coherence using a procedure, the LCMD, designed to measure this concept.

To measure the meaning of disease, the investigators presented subjects with eight cards in random order, and patients were told to choose the one card that was closest to the meaning that they ascribed to their cancer. The eight categories of meaning were written on these cards. Categories of meaning included challenge, enemy, loss, punishment, relief, strategy, value and weakness. These eight categories were divided into two groups: the Optimistic group (challenge, relief, strategy and value) and the Pessimistic group (enemy, loss, punishment and weakness). These groupings were then used in data analysis to determine the associations between the meaning of disease and other variables of interest.

The sense of coherence was measured with the Sense of Coherence (SOC) scale, a 29-item tool that was developed by others. This was a self-administered

semantic differential scale with each item ranging from 1 to 7 between two anchoring responses. With this tool higher scores indicated stronger SOC.

In this study, 62% of subjects preferred a collaborative decision-making role, 28% chose passive roles, and 9% chose active participation. Statistical analysis showed that there were no differences between the groups with regard to age, gender, education and living status. For the actual participating role, 44% of patients achieved their preferred role, 48% achieved a more passive role, and 8% had a more active role than preferred.

Investigators examined relationships among all variables studied, using a variety of statistical techniques. They found no differences between role preference groups and SOC or meaning of disease. There were no differences in the results of these variables according to socio-demographic variables. There were also no differences in SOC or meaning of disease according to the degree of agreement between individuals' desired and actual levels of participation in decision-making.

The mean scores on the SOC scale differed significantly ($p < .05$) between Optimistic and Pessimistic groups of patients. Those with an optimistic view of their disease had a stronger sense of coherence. Demographic variables had no apparent influence on these results.

The investigators concluded that coping resources, as reflected by SOC and LCMD results, were not related to patients' preferences in treatment decision-making. They also concluded that the group showing an optimistic meaning of their disease probably experienced their disease as more comprehensible, manageable and meaningful than those with a pessimistic meaning. Factors such as age and other

demographic variables were not significantly related to overall findings (Ramfelt, Bjorvell, & Nordstrom, 2000).

Heyland and others (2003) studied the preferred role of patients in end-of-life decision-making in hospitalized patients. The investigators developed a questionnaire to assess willingness to talk about end-of-life issues, preferred decision-making role, and influence of physical symptoms. Subjects were asked about end-of-life decision-making with the presentation of 3 case scenarios of patients whose medical conditions required decisions to be made about resuscitation, mechanical ventilation, and initiation of dialysis. Decisional role preference was assessed using the card-sort technique developed by Degner and others. Symptom distress was measured with the Memorial Symptom Distress Scale. This scale evaluated symptom severity, frequency, and distress in 32 common symptoms.

In this study investigators also surveyed attending physicians and house staff most responsible for the patients if they had discussed end-of-life issues with the patient, and what role they thought the patient would want to play in these decisions. Results were analyzed to determine the agreement between the physician and patient perceptions of decision-making role preference.

The sample consisted of 135 patients who were hospitalized in a moderate sized tertiary care university-affiliated hospital in Canada. Overall 76% had previously thought about the kind of treatments they would want if they developed life-threatening illness. Most respondents preferred some sharing of decisional responsibility in the scenarios presented (72%). Forty percent preferred completely active roles.

The only variables found to be related to decision-making role preference were nausea, fatigue and memory loss. Those patients who experienced memory loss from fatigue tended to desire more passive roles ($r = -.24, p = .018$). The frequency ($r = .24, p = .007$), severity ($r = .25, p = .006$), and distress from nausea ($r = .22, p = .017$) were directly related to preferences. The actual direction of these relationships is unclear in the report, since both the effect of nausea and memory loss were stated to be associated with increasingly passive roles, despite the fact that the reported data demonstrates a direct relationship with nausea, and an indirect relationship with fatigue-associated memory loss.

The investigators found little agreement between patients' stated role preferences and the physicians' assessments of the patient's decision-making role preference. Physicians correctly identified the patient's decision-making role preference in only 19% of cases. Patients and physicians concurred as to whether or not they had had end-of-life discussions only 41% of the time.

In this study, several independent variables were analyzed in combination with other variables of interest, in order to determine the relationships among them. Independent variables included, age, sex, marital status, religion, education, income, admission diagnosis, co-morbid illness, level of symptoms and fatigue, and overall health status. There were no statistically significant relationships found between these independent variables and decision-making role preference.

The description of symptoms in the sample showed that lack of energy (84%), dry mouth (81%), and drowsiness (70%), were most frequent. Lack of energy was also found to be one of the more severe symptoms reported ($M = 2.76, SD = .83$).

Additional symptoms that were more severe in the sample were pain ($M = 2.8$, $SD = .81$), shortness of breath ($M = 2.75$, $SD = .95$), and difficulty sleeping ($M = 2.61$, $SD = .89$). Symptom severity used in this study was measured on a 5-point scale from 0 (*none*) to 4 (*high*).

Given the lack of significant relationships among demographic data, symptoms and decision-making role preferences reported, the investigators concluded that patients' preferred roles are highly variable. Their main finding was that hospitalized patients want to discuss end-of-life issues, but their actual preferred role was difficult to predict. (Heyland, Tranmer, O'Callaghan, & Gafni, 2003).

Fraenkel, Bodardus, and Wittink (2001) performed a study in patients with systemic *lupus erythematosus* who were followed in community practices in the northeast part of the United States between January and November 2000. The study was designed to assess patient treatment preferences using conjoint analysis techniques. In this study, Adaptive Conjoint Analysis (ACA), a tool utilized in marketing to elicit preferences via interactive computer methods, was used to identify patient preferences for treatment.

In ACA, the subject was presented with a questionnaire in which they were asked to rate the importance of the difference between the highest and lowest levels of pairs of attributes of various treatments. These ratings were on a 4-point scale, from 1 (*not important at all*), to 4 (*extremely important*). These ratings were used to construct estimates of the utility of each attribute to the subject. The attributes rated were: 1) benefits of medications, 2) nausea and vomiting, 3) hair loss, 4) mouth sores, 5)

infection, 6) blistering rash, 7) premature menopause and infertility, 8) bleeding from the bladder, and 9) cancer.

The ACA program used an individual respondent's answers to update and refine questions through a series of paired comparisons. The design allows for a large number of attributes to be rated "without resulting in information overload or respondent fatigue" (Fraenkel, Bodardus, & Wittink, 2001, p. 1204). In ACA, as described here, patients' relative utilities for each attribute were calculated reflecting the value placed on the attribute. Results were also used to calculate the relative importance of attributes, reflecting the degree to which differences between best and worst levels drive the decision to make a particular choice. These were then applied in computer simulations to predict preferences for treatment options and scenarios presented using least squares regression analysis.

Preferred role in decision-making was also incorporated into the questionnaire. Study findings showed that 40% preferred an active role, 52% preferred a collaborative role, and 8% preferred a passive decision-making role. Descriptive results of all attributes measured showed that efficacy of treatment and risk of infection had the highest utilities (n = 65). Simulations demonstrated a difference between pre and post-menopausal women in their choice of specific chemotherapeutic agents.

There were no associations found between demographic characteristics, clinical measures, health beliefs, preference for information, preferred role in decision-making, and medication selection. Results of this study provide information about a computerized technique that may predict specific treatment choice, but the study was

unable to provide any explanation for those choices associated with the other variables measured (Fraenkel, Bodarus, & Wittink, 2001).

Patient Decision Making and Information

Several investigators have studied patient decision-making activity and role preferences in relation to preferences about the amount and type of information individuals want about their health care situations. There have been fairly consistent relationships seen between information and decision-making role preferences. There is evidence to suggest that the format of information presented also influences patient-decision making.

Hack, Degner, and Dyck (1994) examined the relationships between patients' preferences for involvement in making treatment decisions and preferences for information about diagnosis, treatment, side effects, and prognosis. The sample for this study consisted of 35 women with stage I and stage II breast cancer recruited from two different medical and radiation oncology clinics. Patients were recruited to participate within 2 to 6 months post diagnosis in order for patient preferences to be assessed as close in time as possible to the actual time of diagnosis and treatment planning.

Patient preferences were elicited using the card sort technique developed by Degner and Sloan previously described. Decision-making role preferences were categorized as active, collaborative, or passive. A similar card sort measure was developed to examine patient preferences for diagnostic, prognostic, and treatment related information. For each type of information examined in the study, patients were asked to sort the cards into their preferred order.

Subjects also participated in semi-structured interviews to explore information needs, desired amount of treatment control, and the kind of information that they wanted to have to satisfy the degree of involvement they wanted in treatment decision-making. Content analysis was performed on the information obtained from patient interviews to identify prevalent themes.

Study findings regarding patient preferences for decision-making control indicated that 23% of patients were active, 57% were collaborative, and 20% were passive. Findings also suggested that preferences for information were a function of preferences for involvement in treatment decision-making. The degree of detail preferred by patients in disclosure of their diagnosis [Wilcoxon rank sum test ($z = 2.219$, $p < 0.05$)], disclosure of the degree of risk associated with each treatment option ($z = 3.299$, $p < 0.001$), and degree of technical detail provided in descriptions of treatment procedures ($z = 2.385$, $p < 0.01$) were positively related to the degree of active involvement they preferred.

In examining the relationships among decision-making role preference and age, education, illness severity, and treatment procedure, investigators found that only education was significantly related to decision-making role preference ($z = 2.60$, $p < 0.01$). These quantitative results were further supported by qualitative findings from subject interviews. Content analysis of interview transcripts revealed that patients who were poorly educated preferred that their physicians make treatment decisions. Data from interviews showed that these patients felt they lacked the essential knowledge for making informed, rational decisions (Hack, Degner, & Dyck, 1994).

Mazur and Hickham (1996) studied 467 patients via structured interviews to assess the level of involvement patients wanted in decision-making regarding the acceptance or rejection of an invasive medical intervention. They also examined the relationship between preference for level of involvement and the type of information individuals wanted about the risks of the procedure. Potential patient roles in decision-making were categorized as: 1) making the decision themselves, 2) physician making the decision for them, 3) shared decision-making between the patient and the physician, or 4) other than a fifty-fifty shared decision-making between the patient and physician.

Results of this study demonstrated that 68% of subjects preferred shared authority, 21.4% preferred physician authority, and 10.5% preferred patient authority alone for decision-making. With regard to information preferences, findings indicated that 98% of individuals wanted the physician to disclose information regarding risks of the intervention. In terms of the type of information preferred, 42.7% preferred qualitative probability information about risk, 35.7% wanted quantitative information, and 9.8% of subjects wanted information in both qualitative and quantitative forms. Another 9.8% of subjects had no preference regarding the format of the information disclosed. Regression analysis of patient variables showed that only younger patients, patients who had at least one stroke, and patients who preferred risk information in terms of numbers tended to prefer patient centered or shared decision authority (Mazur & Hickham, 1996).

Chee Saw, Wood, Murphy, Parry, and Hartfall (1994) evaluated patient views about informed consent. The investigators found that over half of subjects in the sample did not think that detailed information was important and trusted their doctor to

do the right thing. The sample studied consisted of 55 patients who were due to undergo transurethral resection of the prostate. Some of these patients were admitted on an elective basis and had been previously counseled regarding the procedure. Others were admitted as emergencies with acute urinary retention.

All patients were given written information and a standardized explanation of the procedure upon admission to the hospital. After explanations were given, another team member interviewed the patient prior to surgery. Patients were asked to describe what they understood about the surgery with open-ended questions and probes to elicit responses as needed. Responses were graded according to whether answers were volunteered, remembered after prompting, or not remembered at all. Subjects were also asked to complete a questionnaire about their views on informed consent before they left the hospital.

Study findings demonstrated that 90% of patients knew the purpose and description of the operation, however 18% could not remember some specific risks at all and 75% could only remember with prompting. Questionnaire results showed that 41% of patients did not mind what happened to them provided they were made better. Fifty four percent of the sample said that they trusted their doctor would do the right thing and did not think that the detailed information provided was necessary (Chee Saw, Wood, Murphy, Parry, & Hartfall, 1994).

Results from another study stand in contrast to these findings. Mazur and Hickam (1996) studied 236 consecutive patients from an internal medicine clinic to determine if patient preferences for a given treatment were changed by the way in which information was presented. Patients were asked to choose between surgery or

radiation therapy for lung cancer. Subjects were randomized to receive treatment related survival information in the form of point estimates or survival curves. The treatments were not labeled, so that subjects made selection purely on the basis of the survival information provided.

Results showed that significantly fewer patients ($p = .001$) chose treatment with better immediate survival when they were given data as comparison to 2 and 5 year survival curves than when they were given data as point estimates. Patients reported using medium range data most from survival curves in making their choice.

The investigators concluded that the amount and format of information provided could have substantial effects on preferences for type of treatment. Findings suggested that patients were more willing to take risks when they were given more complete data about treatment results. Information about midrange results appeared to be particularly important in this regard (Mazur & Hickham, 1996). Since subjects in this study were blinded to the actual treatment being selected, it is not known whether selections would have been the same if the subjects had known treatment side effects and the nature of the treatment experience. Findings are also limited because subjects were asked to respond to a hypothetical situation rather than asked to make choices that had real implications for them.

The interaction between information needs and decision-making role preference was also studied by Degner and others (1997) in women with breast cancer. In this study 1012 women were recruited from several oncology clinics in Canada. The median age of subjects was 58 years old, most subjects had less than a high school

education (42.8%), were married (66.8%), and were retired (35.1%). The majority of women had stage II breast cancer and had previously had a mastectomy.

Decision-making role preference and actual involvement in decision-making were measured using the card-sort technique described by others. Demographic and disease related data were collected via a nurse-administered questionnaire. Priorities for information were elicited by a procedure in which 9 categories of information that had been previously found to be important in women with breast cancer were arranged in pairs and presented to subjects. Every possible subset of 2 categories was presented. This procedure allowed women to choose the information category that was their highest priority while considering only 2 choices at one time.

Information from this procedure was used to develop standard normal scores for information categories, according to the proportions of the sample that preferred each item. Profiles of information needs for subgroups were then compared using a test to equality of proportions.

Investigators reported that 22% of the sample wanted to select their own medical treatment, 44% wanted a collaborative role with their physician, and 34% wanted a passive role in decision-making, wanting their physicians to make treatment decisions on their behalf. Age ($p < .001$), education ($p < .001$), marital status ($p < .01$) and type of previous surgery ($p < .001$) were related to decision-making role preference. Active and collaborative roles were more likely to be preferred by women under age 50, those with more than a high school education, those who were married, and those who had previously had a lumpectomy. There was also a trend for women with an earlier stage of disease to prefer more active roles ($X^2 = 17.14, p = .002$).

Only 42% of the sample achieved their desired role in decision-making. Profiles of categories of information prioritized by subjects differed according to age, family history of breast cancer, and time since diagnosis. For example, women who were younger placed more importance than older women (>50 years old) on information about physical attractiveness and sexuality ($p < .001$). Information about how to take care of oneself at home was more important to women over 70 years old ($p = .002$). Information about chances of cure was more important to women who wanted an active role in decision-making ($p = .04$) (Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller, 1997).

Orsino and others also reported a study that explored age and gender differences in decision-making preferences and informational needs. Their sample consisted of 197 patients with end-stage renal disease on hemodialysis. Decisions about specific treatment modalities were the focus of the study.

Data were collected with two instruments: a 69-item self-report survey developed by the investigators, and the O'Connor Decision Self Efficacy (DSES) questionnaire. Decision-making role preference was incorporated into the survey by questions regarding how much the individual wanted to participate in decisions about treatment for their disease. Possible answers ranged from completely independent to decision-making control by the health care team. The DSES was a 22-item standardized questionnaire. Data were analyzed for significant differences divided by age groups, decision-making preferences, demographic information, reasons for dialysis, knowledge of kidney condition, and information needs.

In the overall sample, 34.6% reported preference for making treatment decisions alone, 41.5% wanted equal responsibility with their health care team, and 23.9% wanted the health care team to make final decisions. There was a significant difference between reported preferences and actual involvement in decision-making ($\chi^2 = 33.8, p < .001$). The differences found showed that there was greater involvement and control by the health care team than was preferred.

Older patients in this study were more likely to prefer, and to actually have, their health care team make decisions for them ($p < .05$). Higher DSES scores were associated with experiencing more independence in decision-making ($r = -.22, p < .01$). Younger patients tended to have higher DSES scores, indicating greater self-efficacy and confidence in engaging in treatment decisions ($p < .05$).

There were no gender differences in actual or preferred involvement in decision-making. There were a number of gender differences in factors that were important in the decision to be placed on a transplant list, and in the type of information they wanted.

All patients wanted high levels of information. Perceived level of knowledge about available treatments was found to be higher in younger patients (<53 years old) ($p < .05$). The types of information that were most needed were somewhat different according to age. Younger patients wanted more information about ability to work ($p < .01$), effect of dialysis on sexual activity ($p < .01$), physical appearance ($p < .01$), flexibility in dialysis schedules ($p < .01$) and effects of dialysis on social activities ($p < .01$). Younger subjects indicated a greater use of the Internet ($p < .01$) and CD-ROMs than older people. There were no relationships found between perceived level of knowledge and decision-making role preferences.

These authors concluded that age was an important factor in the degree of involvement in decision-making since younger subjects tended to be more independent in decision-making and had higher DSES scores. Nonetheless, older subjects wanted a similar degree of information. The cutoff for identification as older or younger in this study was age 53. There were also significant differences between these two age groups in the percent who were working, length of treatment for kidney disease, and proportion of the sample that were on a kidney transplant waiting list. More older subjects were working, were on a transplant list, and had a significantly longer duration of treatment ($p < .01$) (Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003).

Davison, Parker, and Goldenberg (2004) looked at patient preferences for communications and participation in decision-making in 87 men with a prostate cancer diagnosis. The purpose of their study was to assess patient preferences about how physicians communicate information and for roles in decision-making. A secondary purpose of the study was to validate an instrument, the Measure of Patients' Preferences (MPP) designed to measure communication preferences.

Decision-making role preference was measured with a self-report tool based upon the definition of role preference originally established by Degner and others. The MPP was a 32-item questionnaire in which patients rated the importance of items presented on a 5 point Likert scale, scored from 1 (*not at all important*) to 5 (*essential*). Items included aspects of communication style as well as informational content. Factor analysis for these items on the MPP demonstrated three major dimensions on the scale: facilitation, content, and support. Internal consistency of the tool was good,

demonstrating an alpha of 0.83 for facilitation items, 0.91 for content, and 0.91 for support items in the tool.

The mean age in the sample was 62.4 ± 8.4 . Most men were married or living with a partner, and most had formal education beyond a high school diploma. The sample was recruited from outpatients at a general hospital outpatient diagnostic imaging department, where the patients had been scheduled for a first time ultrasound guided biopsy of the prostate. In order to be eligible for the study, the men had to know that this procedure was being done to diagnose prostate cancer, however the results of the test were not yet known at the time of study participation.

Most men indicated a preference for either active or shared decision-making roles. In this sample, 42.5% preferred active roles, 47% preferred collaborative roles, and 10.3% preferred passive roles in decision-making. The findings from MPP analysis indicated that the highest preferences for disclosure of a prostate cancer diagnosis had to do with physician communication about the severity of disease, treatment options, provision of up-to-date information, information about prognosis and taking time to allow for and answer questions.

These authors did not find any significant relationships between demographic variables, such as age and education level with either MPP results or decision-making role preferences in regression analysis. However, men who preferred a collaborative role placed greater importance on the content of communications ($p < .04$) as opposed to the facilitation or supportive aspects of communications by physicians. These findings demonstrated a relationship between decision-making role and informational

preferences that was not apparently influenced by age, marital status, or education (Davison, Parker, & Goldenberg, 2004).

Patient Decision Making and Multiple Related Variables

A number of investigators have evaluated multiple personal, disease related, and external variables for their relationship to the dynamics of patient involvement in health care decision-making. These studies have tended to demonstrate relationships among decision-making role preference, information, and age. Other variables examined for their relationships to decision-making preferences included gender, race, educational level, and the context of the decision-making.

Beisecker (1988) examined some of the beliefs of individuals that underlie the sense of autonomy and rights related to patient involvement in decision-making. This investigator specifically examined patient challenges to physician authority. In this study, 106 rehabilitation medicine patients were recruited from an outpatient clinic in an academic medical setting. Data collection consisted of: a socio-demographic questionnaire administered to subjects immediately prior to the physician-patient interaction, a tape recording of the doctor-patient interaction, a tape recorded interview with the patient immediately following the interaction with the physician, and a follow up opinion survey mailed to the patient 10 to 14 days following the clinic visit. The opinion survey included 5 scales designed to measure perceptions of the patient role including: right to medical information, right to medical decision-making, challenge to physician authority, locus of authority in decision-making, and desire for medical information.

Tape recordings of patient communication were analyzed by counting consumerist comments made by patients such as attempts to gain information by

asking questions, initiating a new topic to gain information, or asking the doctor for clarification. Comments that reflected assertiveness and challenge to physician authority included sarcastic comments aimed at the physician, comments that countered physician statements, degrading the doctor, requests and demands, degrading other medical personnel, and generalized complaints. Patient suggestions for treatments and alternatives were also counted and categorized. Independent coding of tape recordings by two separate judges yielded a mean correlation of 0.83 across all categories of comments.

Results showed that as age increased there was a decreased tendency to make consumerist comments and an increased tendency for the patient to desire to put decision-making in the hands of the doctor. All attitude scales showed a negative correlation with age except for the scale indicating desire for information. Although older patients desired medical information, they were less likely than their younger counterparts to believe that they had a right to this information.

Across all subjects, there was a tendency to place the locus of authority with the physician. With the measurement scale used to measure locus of authority, a score of 26 would have indicated sole authority with the patient. In this study the mean locus of authority score was 8.6, with a standard deviation of 3.4. These results indicated little variability in the strong belief in physician authority regarding medical decisions.

There were no communication variables that correlated with age. Although younger patients tended to demonstrate more consumerist beliefs as evident in survey responses, their actual behaviors in the physician interaction did not differ from those of older patients. None of the attitudinal variables measured via survey or patient

interview were correlated with actual communications by patients with the physician (Beisecker, 1988).

These findings demonstrated that the majority of the sample believed in physician authority related to health care decision-making. Findings also demonstrated that actual patient behaviors did not always reflect stated preferences regarding decision-making roles.

Ende, Kazis, Ash, and Moskowitz (1989) reported on the development of an instrument, the Autonomy Preference Index (API), to measure desires for autonomy in two dimensions: the desire to be informed and the desire to be involved in medical decisions. Results of this questionnaire and demographic information were collected from a random sample of 312 patients from a primary care group practice clinic in New England.

The API is a 23-item questionnaire that frames information questions in terms of what patients think the physician should do. For the decision-making sub-scale of the instrument items focus on what the patient feels he or she should do in regard to making decisions.

Instrument testing results demonstrated test-retest reliability of 0.84 and internal consistency of 0.82 for each instrument scale. Total scores for each of the two major scales in the questionnaire could range from 0 to 100. A score of 100 correlated with the strongest possible desire for information or involvement in decision-making, and a score of 50 indicated a neutral attitude.

The mean API decision-making score for the sample suggested an average desire for relatively low involvement ($M = 33.2$, $SD = 12.6$). The average score for

information seeking indicated a strong desire for information ($M = 79.5$, $SD = 11.5$). In univariate analysis age, education, income, and occupation were significantly correlated with API scores ($p \leq 0.001$). In stepwise regression analysis socio-demographic variables explained only 15% of the total variance in decision-making preference scores. Age was the variable with the most explanatory power ($r^2 = 0.095$). Younger age was also most explanatory of variance in desire for information ($r^2 = 0.11$).

Patients' decision-making preference scores were also correlated with scales related to health status, satisfaction, and desire for information. Stronger preference for involvement in decision-making was associated with better health condition ($r = 0.22$, $p < 0.0005$), less satisfaction with how decisions were being made ($r = -0.25$, $p < 0.0001$), and less satisfaction with medical care overall ($r = -0.28$, $p < 0.0001$) (Ende, Kazis, Ash, & Moskowitz, 1989).

Nease and Brooks (1995) used the Autonomy Preference Index (API) and the Health Opinion Survey (HOS) to measure patient desire for information and preference for involvement in health care decision-making. A sample of 167 patients with benign prostatic hypertrophy, back pain, or mild hypertension was studied. Subjects completed a survey of demographic information and both the API and HOS instruments. Both of these instruments yielded overall scores as well as scores from information and decision-making involvement sub-scales.

The API and HOS were both self-administered by subjects. The API instrument was previously described. The HOS is a 16-item questionnaire that asks what the patient usually does to seek information and assesses the patient's desire to participate in relevant decisions.

Nonparametric statistical procedures were used to determine the correlation between information and decision-making involvement scores and the correlation between data generated from both questionnaires. Analysis of variance and linear regression were used to determine those demographic and disease related variables that provided the greatest explanation of variance in information and decision-making scores.

The *desire for information* scores were higher than decision-making scores ($p < 0.001$). For both information and decision-making the scores from both instruments were significantly correlated ($p < 0.04$). Overall higher desires for information and decision-making were associated with younger age, more education, current employment, and female gender. Investigators also found that there was a substantial amount of unexplained variability among the sample in all results ($r^2 < .08$) (Nease & Brooks, 1995). These findings supported relationships among gender, education, age, and decision-making role preferences that were reported by others. However, findings also demonstrated a large amount of unexplained variability in preferences reported (Nease & Brooks, 1995).

Adams, Smith, and Ruffin (2001) modified the API in their study to examine patient decision-making role preferences in subjects with asthma. This study reported results from a cross-sectional study of 293 subjects with moderate to severe asthma recruited from participants in a longitudinal observation study of factors related to asthma outcomes. The study was done in Australia between 1995 and 1997.

In this study, the API used had been previously modified to be specific to asthma management. It was designed to measure preferences for autonomy in decision-

making in a general sense, as well as the extent to which people preferred the doctors or themselves to make specific disease management decisions in three asthma clinical vignettes. The scenarios used in these vignettes represented stable asthma management, a moderate attack, in which subjects had to respond to increased symptoms, and an acute exacerbation involving the need for hospitalization.

The patients' perceptions of the physicians' styles related to participatory decision-making were also assessed by the patient's response to three related questions. In addition, the investigators measured demographic variables and personal coping styles. Relationships among variables examined were tested by means of Analysis of Variance (ANOVA) procedures as well as correlation analysis.

The mean age of subjects in this study was 41 ± 19 years. All subjects had moderate to severe asthma as measured according to published criteria for severity of disease. Subjects completed self-report questionnaires that were mailed to them every three months for a 12-month period. Among study subjects, 28% had some education above the secondary school level, which was noted to be somewhat lower than the population at large. There was also a relatively high level of income assistance, with 54% of the sample receiving some form of government pension. This was compared to the national data in which 30% of the total population received such assistance.

Findings indicated that there was a significantly stronger preference for autonomy in the moderate scenario, than during a routine visit for stable disease or in a severe attack ($p < .001$). Stronger preferences for autonomy in decision-making, indicated by higher API scores, were associated with more education ($r = .32$), more concerns about adverse effects of medications ($r = .40$), use of more active coping

strategies ($r = .30$), a more positive evaluation of the impact of asthma on their lives ($r = .24$), greater self-efficacy in asthma management ($r = .29$), and perception of the tendency of the physician to involve them in decision-making ($r = .29$). Multiple regression analysis showed that concerns about adverse effects of medication, active coping strategies, physician style related to involvement, cost concerns that caused delays in seeking care, and education level were significantly associated with preferences for autonomy in decision-making. This model explained 48% of the variance in autonomy preference. The variables with the most explanatory power in the model were concerns about adverse drug effects and greater use of an active coping style.

The investigators concluded that patients with moderate to severe asthma did not want to be predominantly responsible for decision-making related to their care, and that patient characteristics that were significant in multiple regression analysis were most influential in determining the degree to which patients wanted autonomy in disease and treatment related decision-making. Although preferences varied across the different decision-making vignettes presented to subjects, for overall autonomy, only 37% indicated a preference for greater input into decisions than that of their physicians (Adams, Smith, & Ruffin, 2004).

Cassileth, Zupkis, Sutton-Smith, and March (1980) studied 256 cancer patients at the Hospital of the University of Pennsylvania to describe preferences for involvement in treatment related decision-making and the relationships between decision-making role preferences and performance status, desires related to information, and hopelessness. Patients in this sample had been diagnosed for an average of 10

months. Demographic, diagnosis, and treatment related information was obtained via patient interview and review of medical records. Performance status was assessed using the Eastern Cooperative Oncology Group (ECOG) performance status in which patients are rated from 0 (*capable of all normal activity*) to 4 (*completely bedridden*). Patients completed the Beck Hopelessness Scale and the Information Styles Questionnaire, an investigator developed and tested instrument. In this instrument patients were asked to: 1) describe their information preferences on a 5-point scale, from 1 (*no more details than needed*) to 5 (*as many details as possible*), 2) identify their role preferences by selecting between the two alternatives of leaving decisions up to the doctor, or participating in decisions, and 3) identify whether they needed or wanted twelve pre-selected types of disease and treatment related information

The relationships between demographic and disease related data and decision-making and information preferences were analyzed using point biserial correlation analysis. Results indicated that individuals who sought detailed information versus those who avoided it were younger ($p < 0.01$), white ($p = /<0.05$), had more formal education ($p < 0.001$), and had been diagnosed with cancer more recently ($p < 0.05$). A significant age related trend was found in decision-making and information preferences. Older patients demonstrated the tendency to desire less participation and information ($p < 0.05$). There was no relationship between information or role preference and performance status.

Across all age categories 51 to 87% of subjects indicated preference for active participation in decisions. Sixty to eighty percent of subjects wanted the maximum amount of detailed information. There was a significant correlation between the desire

for maximum information and preference for an active decision-making role ($p < 0.001$). The investigators interpreted these findings to suggest that information style and role preference were components of a single attitude or approach related to treatment decision-making.

The mean score on the Beck Hopelessness Inventory was 2.8, indicating no or minimal hopelessness. Level of hope was found to be positively correlated with medical status ($p < 0.05$), active role preference ($p < 0.05$), and desire for the maximum amount of information ($p < 0.001$). The authors reported the statistical significance of these relationships as shown here, but did not report actual correlation coefficients, in order to display the strength of the relationship (Cassileth, Zupkis, Sutton-Smith, & March, 1980).

Stiggebout and Kiebert (1997) examined whether patient preferences regarding information and participation in decision-making about treatment options were related to patient characteristics and the context of the decision. A total of 197 subjects were recruited for the study from a clinic in the Netherlands. The sample consisted of patients undergoing radiation therapy for cancer, patients evaluated in the clinic for follow up after surgery for a non-malignant condition, and persons who accompanied the patients.

Subjects completed questionnaires with items pertaining to demographic and disease related information, attitudes toward information and participation in decision-making in general, and 4 vignettes about treatment options for various diseases. Preferences for information and participation in decision-making were elicited with each vignette. For each vignette subjects were asked if they felt the information provided

was sufficient and what role they would want to play in relevant decision-making. Vignettes used were the disease conditions of *tinea* of the foot, asymptomatic gall stones, laryngeal cancer, and skin cancer.

Eighty two percent of subjects indicated they would always want to be informed about benefits and side effects of medical treatment. There were no differences among the various groups within the total sample regarding this. Slight trends related to age and education were found. Older patients indicated that they would not want all information in some circumstances. A greater proportion of individuals with higher levels of education wanted full information. These trends were not statistically significant.

Younger and more educated subjects had a greater tendency to find information provided in the vignettes to be insufficient ($p < 0.002$, $p < 0.001$). Age was also associated with decision-making role preference. Younger subjects preferred a more active decision-making role ($p = 0.006$). More women (27%) than men (15%) preferred an active decision-making role. Preferences regarding information and role in decision-making were not clearly associated with each other.

The most preferred decision-making role for patients was one in which the physician made the decision with consideration of the patient's input (38-42%). The most preferred role of individuals who accompanied the patients was a collaborative one (45%). In the collaborative role the subject made the decision with physician input. Differences in decision-making role preferences between patients and others across all 4 vignettes were statistically significant ($p = 0.03$). There were no substantial

differences in findings across the 4 separate vignettes used (Stigglebout & Kiebert, 1997).

These findings suggest that the context of being an actual patient influences information and role preferences more than the type of illness. This is in concert with findings of others who demonstrated differences in role preference between actual patients and healthy subjects.

Johnston and Pfeifer (1998) did a descriptive survey of randomly selected primary care patients and physicians in the context of end-of-life decision-making. The sample consisted of 329 patients and 272 practicing physicians in 8 different cities in the United States. Investigators administered an 83-item questionnaire in face-to-face discussions with patients and physicians. Questions were designed from previous qualitative research done by the investigators. The instrument included questions about beliefs and preferences regarding decisions about end of life care as well as demographics, health status, and Karnofsky performance status scores. Chi-square analysis was used to compare responses of physicians and patients to identical questions.

Patient ages ranged from 19 to 94, with a mean age of 50.9 years. Physician ages ranged from 27 to 90, with a mean age of 44.7 years. The majority of both patients and physicians believed that the patient should be responsible for making end of life decisions. Approximately 20% of patients felt that the patient and the physician should make these decisions. Ten percent felt that family alone should be involved. Slightly less than 5% believed that such decisions should be made solely by the physician.

Physicians were more likely to believe that the patient should make decisions, and fewer physicians believed that family or the physician alone should make end of life decisions. The difference between patient and physician views was statistically significant ($X^2 = 33.3, p < 0.001$) (Johnston & Pfeifer, 1998). These investigators did not examine or report any analysis of the relationships among demographic or functional status data and beliefs about roles in decision-making.

Deber, Kraetschmer, and Irvine (1996) also examined preferences related to the context of the type of decision in question. They surveyed 300 patients undergoing angiogram in Ontario to test the hypothesis that most patients want physicians to take responsibility for problem solving, but many want to be involved in decision-making. These investigators made a critical distinction between these two aspects of patient involvement in health care planning. Problem solving tasks were defined as those finding one right answer such as the diagnosis, probabilities of various outcomes, treatment options, and risks and benefits determination. Decision-making was defined as selecting the most desired bundle of outcomes. This involved the patient's determination of utilities of available alternatives and actual treatment choice. Survey responses were scored to indicate the individual's degree of desire for information and the individual's preference for involvement in decision-making and problem solving.

Findings from this study indicated that patients tended to prefer lower levels of involvement. Sixty-four percent of the sample gave low involvement preference scores, 19.5% gave medium scores, and 16% gave scores indicating a preference for a high level of involvement. However, when the type of involvement was separated into problem solving versus decision-making as defined in the study, the apparent patient

preferences for level of involvement changed. In areas of problem solving, 98.4% of scores reflecting preferred level of involvement ranged from shared control to physician control. In decision-making areas, score distributions showed that there was a tendency to desire more individual control. In determining actual treatment choices, the distribution of scores indicating level of involvement was essentially normal, with the majority of subjects selecting involvement of both the patient and the physician.

Study findings also suggested that patients had a high desire for information. Among individuals surveyed 20.1% had low scores, indicating little desire to ask questions and be informed. Slightly over 44% had medium range scores, and 35.3% had scores indicating a high preference for information. In this study older patients did not want as much information as their younger counterparts (Deber, Kraetschmer, & Irvine, 1996).

Blanchard and others (1988) looked at physician behaviors and patient responses in 439 interactions between 89 hospitalized adult patients with cancer and oncologists. The purpose of the research was to investigate patient preferences for a participatory role in the interaction. Performance status was examined for its relationship to decision-making role preferences of subjects.

During weekday rounds an observer used a checklist of 34 physician behaviors to record the observed occurrence or non-occurrence of each behavior. At the conclusion of each interaction with patients, observers completed two 100 mm. visual analogue scales to address the extent to which the physician addressed the patient needs that day and the extent of patient involvement in the interaction. Inter-rater reliability of these scales had been established in previous studies as 0.94 and 0.96,

respectively. Demographic data was collected via patient interview and review of records. Performance status was rated by observers using the ECOG performance status scale.

After rounds, observers returned to the patient's room to ask questions regarding patients' responses to the physician visit. Patients were asked if the specific behaviors that were on the physician behavior checklist had occurred that day. They were also assessed regarding their preferences for information and participation in decisions regarding care and treatment using methods established by Cassileth.

Ninety two percent of the sample preferred that all information be given to them. A smaller percentage, 69%, indicated that they preferred to participate in decision-making. Age and sex were significantly related to preference for involvement in decision-making. Younger patients had a higher mean preference for participation in decisions ($t = 13.24, p < 0.001$). There was a significantly greater proportion of males among those patients who preferred not to participate in decision-making ($X^2 = 7.55, p < 0.01$). When investigators analyzed differences between males and females in the overall sample, they found that among older males there was a significantly higher percentage who preferred to leave decision-making up to the physician ($X^2 = 70.79, p < 0.0001$). Since almost all of these patients were married, the investigators were unable to examine the potential impact of marital status. In their conclusions the investigators hypothesized that wives tend to play the role of negotiator in health care decisions.

Performance status was also significantly related to decision-making preferences. Lower performance status was associated with the preference to leave decision-making up to the physician ($X^2 = 20.6, p < 0.001$). Individuals who preferred

greater involvement in decisions perceived themselves as being more involved in the interactions with the oncologist during rounds, and tended to be less satisfied with the interactions than those who desired less participation in decision-making ($t = 2.03$, $p < 0.05$) (Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988).

Beaver, Luker, Owens, Leinster, and Degner (1996) studied 150 women with newly diagnosed breast cancer and 200 women with benign breast disease in order to test the hypothesis that newly diagnosed women had specific preferences about the degree of control they had over treatment decision-making. The study was conducted in a surgical clinic in Great Britain. Demographic data including level of education and financial/social class were obtained. The role preference card sort technique designed by Degner and Sloan was used to elicit data regarding decision-making role preferences.

Among newly diagnosed women, 20% wanted an active role in decision-making, 28% wanted a shared role with the physician, and 52% wanted a passive role. Among women with benign disease, 23.5% wanted an active role, 45.5% wanted a shared role, and 31% wanted a passive role. These results demonstrated that a greater proportion of women with cancer desired a more passive decision-making role. The investigators felt that these findings did lend support to the hypothesis that potentially life threatening situations may make a person more passive (Beaver, Luker, Owens, Leinster, & Degner, 1996).

Davis and Hoffman (1999) conducted a prospective study among 665 emergency department patients. Patients who presented to the emergency department during 7 nonconsecutive days were approached to participate in the study. Subjects studied

completed two 10 cm visual analogue scales to measure desire for information and desire for participation in decision-making. Patient acuity was measured according to routine triage procedures in which the triage nurses assign patients to one of four severity levels according to observed clinical criteria.

Results indicated that patients' desire for information was uniformly high and did not vary according to patient acuity. There was no difference in the desire for participation between the most acute patients and others ($p < 0.001$). Investigators found that higher levels of education ($p = 0.036$) and younger age ($p < 0.001$) were correlated with greater desire for participation and autonomy in decision-making (Davis & Hoffman, 1999).

Qualitative Studies Regarding Patient Involvement in Decision-Making

Several investigators have used predominantly qualitative approaches to examining the problem of patient involvement in health care decision-making. These studies approached the problem from a more holistic framework and used content analysis or grounded theory techniques to describe and explain this phenomenon. Results from these studies have provided information in two major areas: description of patients' experiences in decision-making and identification of constraints to decision-making with associated feelings of frustration or powerlessness. Emergent themes have tended to support quantitative findings regarding patient preferences for a more passive role in decision-making. Investigators have identified that ethical decision-making in health care tends to be associated with conflict and negative feelings.

Patient Experiences in Decision Making

Avis (1994) reported results of a qualitative study aimed at examining the patient's perspective about making choices about health care treatment. Two patient samples were used in this study. One was a convenience sample of 12 patients referred to a surgical clinic for assessment and hernia care. A second convenience sample of 10 patients was recruited within one month of having a surgical procedure for hernia repair. These subjects participated in interviews within the home setting.

Data were collected via non-participant observer techniques during clinic assessments. Patients were followed through clinical procedures, all formal and informal interactions with clinic staff were tape-recorded, and field notes were documented. Patient interviews were conducted using a method described as hierarchical focusing. In this approach, an informal interview style was used to allow spontaneous reflections by respondents within specific domains of inquiry. Domains for inquiry were established in advance of the interview process. Tape recordings of clinic interactions and patient interviews were transcribed verbatim and analyzed to identify themes. Analysis was performed concurrently with data collection so that themes and ideas that emerged from earlier observations and interviews were tested and examined in subsequent interviews.

Avis identified two main themes in this study: "being told" and "going in to get it fixed." As evident in the first theme patients were diffident about obtaining information about the repair of the hernia. The typical type of response identified was "You're the

expert,” “I’ll take your advice,” and remarks such as “I didn’t want to actually know the ins and outs of it before I went in to have it done... I didn’t want to know too much about exactly what’s involved” (Avis, 1994, p. 293).

Avis interpreted findings to indicate that respondents expected professionals to take on the responsibility of informing them. Patients perpetuated a stereotypical view of the nurse as active and controlling, and view of the patient as passive and uninformed. She also noted: “Respondents frequently remarked they had received insufficient or inadequate information. Though further investigation often revealed the information they really wanted concerned being told what to do” (Avis, 1994, p 294).

Patients in the study tended to use informal networks of family and friends who had experienced surgery for hernia repair as their main source of information about what to expect. The author points out that such informal accounts conflicted with actual experience. In some cases this left patients feeling vulnerable and confused.

Avis discussed the second theme of “going in to get it fixed” as reminiscent of the way in which people talk about getting their car fixed. Respondents presented themselves as “more helpless than they actually were” (Avis, 1994, p. 295), and their expectations of participation in decision making stopped once they had come in for assessment. These findings are similar to quantitative results in which patient assumption of a passive role related to decision-making was evident.

Avis concluded that patients in her study viewed themselves as work objects and they viewed the hernia as a thing to be fixed. Avis speculated that adopting such a passive and instrumental role may have represented a mechanism for the patient to maintain privacy and integrity. The depersonalization of the situation might enable

patients to avoid losing face and being exposed to criticism by the professional (Avis, 1994).

Caress (1997) studied preferences for involvement in decision-making among 405 renal patients recruited from an outpatient clinic in England. These results demonstrated greater preferences for involvement in decision-making and the same apparent relationship between age and role preference described by others. Results also demonstrated the variety of patient responses to these issues.

The sample included 155 patients who had identified renal problems but did not yet require dialysis, 103 patients receiving regular hemodialysis, and 147 patients with a functioning kidney transplant. Caress (1997) adapted the card sort techniques developed by Degner and Sloan to measure preferences for involvement in decision-making. Patients were also interviewed regarding their rationales for decision-making role preferences.

The most frequent preference elicited was a collaborative role in decision-making (30.9%). Slightly over 15% preferred a passive role. Role preference appeared to be related to age. Younger patients preferred more active roles. There was no relationship found between decision-making role preference and sex. There were no significant differences in decision-making role preferences among the three groups of patients in the sample.

Content analysis of patient interview data revealed a theme of trust and deference to health care professionals. Previous positive experiences with health professionals appeared to increase willingness to be passive. Some patients felt that doctors had the right to make decisions on their behalf and should not be challenged.

Another theme from this study concerned patients' feelings that they lacked adequate knowledge and received inadequate information. Patients also indicated that poor physical condition diminished desire for participation in decision-making. Some patients indicated that involvement should be related to the timing of the diagnosis. For example, one patient who had been on dialysis for 3 years considered involvement appropriate for him, but felt that passive roles were more appropriate for individuals who were newly diagnosed (Caress, 1997).

Kelly-Powell (1997) used a grounded theory approach to describe decision-making from the patient's perspective. In this study, 18 respondents aged 25 to 81 with diagnoses of heart disease, renal failure, or cancer were interviewed within 3 months of having made a treatment decision. They were interviewed again one month later. Interviews were audio-taped using an open-ended interview guide. The interview guide was revised to include questions and validate or clarify emerging themes and categories in concurrent data analysis. Theoretical sampling was used to make successive sampling and interview changes throughout the study. Verbatim interview transcripts and field notes were used in data analysis. The investigator maintained a journal of personal reflections and methodological decisions that was used to evaluate the credibility and defensibility of data interpretation.

Analysis of interviews yielded the core variable, *personalizing choices*. Choices that respondents made were:

...congruous with their views of themselves within the contexts of each of their lives. Past family and personal events, current personal views of themselves and their relationships with significant others, and anticipations of the

future, all were incorporated in the decision to pursue specific treatment options.
(Kelly-Powell, 1997, p.221)

One of the structural concepts that emerged in this study was the respondents' interpretation of the past and application of this interpretation. There were three major ways in which subjects interpreted and applied the past. These were integrating family or cultural history, incorporating past personal experience, and adopting the experiences of others.

Another structural concept was respondents' anticipation of the future. Most respondents hoped for an active future and made treatment decisions that allowed them to maintain hope and optimism. A few indicated hope for the manner of their death, or expressed hope for their children in the absence of hope for themselves. Respondents expressed trust in their health care providers to give them hope by providing treatments that would best enable them in future life and functional capabilities. Investigators commented that respondents were led to think about the future and prospects for continued life associated with various treatment options from a desire to sustain the current self.

A final theme identified was sustaining the current self. Patients tended to choose treatment options that permitted them to sustain normal lives and roles, maintain psychic integrity, and preserve personal relationships with family and friends. Individuals studied displayed a desire to maintain current lifestyles, values, and beliefs.

In study conclusions, it was pointed out that respondents made decisions based upon their understanding of how treatments would affect their bodies, their lives, and their relationships with significant others. These decisions were based on a broad set of

values, beliefs, and expectations that could have relatively little to do with the statistical effectiveness of any particular treatment. The initial focus in decision-making was on the personal self, not the treatment (Kelly-Powell, 1997).

Whittaker and Albee (1996) studied patients with end-stage renal disease to examine factors that provide a framework for their decision-making regarding treatment modality. They used grounded theory methodology with snowball sampling techniques. The sample included patients who were on dialysis less than 6 months or who had changed dialysis modality within the previous 6 months. Subjects were recruited in Nebraska and California. Patients were interviewed and asked to describe their experience in making their choice. Verbatim interview transcripts were used for data analysis.

Patients described a decision-making process that occurred in two stages. The first stage focused on the valuing and evaluating threats. The process in this stage included identification of factors considered valuable in their lives and identification of factors in each dialysis mode that were threatening to the physical self or self-identity. Subjects reported that the ability to work through this stage was based on adequacy of information, prior experience with dialysis, level of social support, availability of the particular treatment modality, and physical and medical constraints that determined the clinical appropriateness of each modality. In the second phase of decision-making, individuals weighed benefits and personal concerns regarding treatment modality against the values and threats identified.

Patients described valuing their pre-dialysis lifestyle, their ability to maintain autonomy, and their ability to maintain self-care. Pre-dialysis lifestyle factors included

work, leisure activities, social commitments, and relationships. Maintaining employment was a major concern of those employed. Retired people ranked leisure activities as the top priority. Social and family support were critical factors in this area. In many cases families pressured the patient to choose the modality that best suited the family members' desires.

Patients also valued maintaining autonomy. One group of patients exhibited passive acceptance of physician decisions regarding the treatment modality. In contrast, one group went against the doctor's advice. Investigators found that the largest group of patients listened, read, gathered information, and came to the same conclusions as the physician. Self-care perspectives described by patients ranged from rejection of self-care and the desire to be cared for by others, to desire for total self-care and total responsibility for dialysis treatments.

Informants identified that the quality and quantity of information provided to them played a major role in influencing perceptions. Timing of information was also important. If information was provided after placement of dialysis access devices, despite the implications of that information, patients tended to stay with the initial modality.

Lack of social support and strong physician preferences were identified as blocks to autonomous decision-making. It was also found that family members behaviors that appeared as sincere concern were not necessarily supportive, and that patients often described difficulty separating personal desires and needs from those of the family (Whittaker & Albee, 1996).

Berry and others (2003) reported a qualitative study in which data were collected from a sample of 15 men with localized prostate cancer via focus group discussions as well as individual unstructured interviews. The study was done in the western region of the United States. All groups and interviews were audio-taped. A grounded theory approach was used for data analysis, and qualitative findings were identified via the use of a code-based data analysis software package, the Non-numerical Unstructured Data Index Searching and Theorizing (NUDIST) program. Strict measures for ensuring the reliability of results was imposed in the study, and differences in coding were discussed until full consensus was achieved among investigators.

In this study, a core process of *making the best choice for me* was identified. This process was comprised of the steps of reflection on personal history, detection and diagnosis experiences, gathering information, consideration of outcomes and influential factors in decision-making, and making the actual decision. Influential factors included personal factors, such as age, what work and activities subjects did, priorities in life, health status, personality traits, lifestyle, experiences, philosophy and ethnicity. Influential others were also identified. Influential others included other men they had spoken with who had prostate cancer, the physician and others such as friends, business associates, family members and celebrities.

These investigators noted that

The process through which participants made their own best choice began with an initial report of who I am in various aspects, placing the rest of their story in the context of their personal experience, as if this was the most fundamental part of the experience through which everything else was interpreted...Men reported

potential outcomes of various treatments and cancer itself to inform the treatment decision. Men's interpretations of these outcomes again were based on the personal context of a particular outcome. (Berry et al, 2004, p.98.)

The authors concluded that the themes of *who I am* and *what I do* were most important for decision-making in this group of subjects throughout the process of making the best choices for themselves. They also pointed to the influence of a variety of sources of information throughout the decision-making process (Berry et al., 2003).

Biley (1992) used a modified grounded theory approach to identify how patients felt about participating in decision-making regarding nursing care. Data were obtained via unstructured interview with 4 male and 4 female informants who had undergone a surgical procedure. All subjects were interviewed 7 to 10 days following discharge from the hospital.

Subjects indicated that how much they participated in decision-making about care was according to how well they were. Informants described a continuum of progress in wellness during hospitalization. Their desire to be involved in decision-making as varied along this continuum. When they were too ill they did not want to be bothered to be involved in decisions (Biley, 1992).

Informants also described a continuum of knowledge from *the nurse knows best* to *I know best*. Informants described the type of situation in which the patient did not have enough information to make a choice and justified a passive role in decision-making as a result. These situations tended to have to do with technical issues of care such as dressing changes.

Another scenario described was the situation in which the individual did not have enough information but requested more information before a decision was made. These occurred in situations where the information was less technical but issues were still outside of the usual range of knowledge of non-nurses. An example of this type of situation was one in which a patient was encouraged to get out of bed in order to prevent leg thrombosis post operatively.

The third type of situation was one in which the patients felt they knew what was right and could completely control what they did. This type of situation had to do with areas of concern that were non-technical, such as food selection and activities of daily living.

Informants in this study also spoke about organizational constraints in the hospital that had an impact on their ability to be involved in decision-making. Subjects spoke about feeling that they had to fit in with others around them and fit in with organizational routines. This automatically restricted the amount of choice that patients had with regard to everyday activities such as hygiene, nutrition, and visitors. Informants seemed to accept that they could have little influence on these organizational constraints and justified related problems with care (Biley, 1992).

Constraints and Feelings Associated with Involvement in Decision-Making

The theme of organizational constraints to decision-making has also been described by nurses in several studies. Davis (1989) looked at responses to vignettes and semi-structured interviews with 27 nurses focusing on ethical decision-making in situations of informed consent. Content analysis of transcribed interviews was performed to identify concepts and themes in these responses. Davis found that the

most powerful variables influencing nurses' ethical decision-making in the situations presented were philosophical and structural in nature. Structural influences on ethical decision-making included job considerations such as time priorities and institutional hierarchy, and physician control and autonomy. Nurses reported that roles and behaviors of nurses and patients were constrained and patterned by the structure of the health care system (Davis, 1989)

Holly (1993) also found what she termed "staggering" environmental barriers to nurse's ability to engage in ethical decision-making situations in clinical practice. Holly recruited 65 registered nurses who were employed full time in acute care clinical practice. In this study nurses were asked to describe a work related ethical situation they had encountered and to describe their feelings about being involved in that situation. Content analysis was used to analyze written descriptions to identify patterns and themes.

Three major categories emerged from analysis: exploitation, exclusion, and anguish. Exploitation was defined as treating seriously ill patients or families without regard to their personhood. Nurses expressed concern with the aggressive treatment of the terminally ill, especially the elderly. Their stories of encounters told about what they perceived to be the use of painful and invasive procedures when the outlook for patient recovery was poor at best. Institutional policies such as those related to "do not resuscitate orders" were felt to be too vague and ambiguous to provide for any individual patient consideration.

Exclusion was defined as disregard of patients' choices to accept or reject treatment, to have their wishes acknowledged and followed, and failure to give patients

and families information that was complete enough to enable informed decisions. In some situations nurse reported that the family and physician acted in opposition to patient wishes. This was particularly true in situations where the patient was unresponsive. In these cases living wills were disregarded.

Anguish was defined as the nurses' personal feelings when involved in these situations. Feelings expressed included frustration and perceptions of ineffectiveness in resolving dilemmas. Nurses also expressed concern about the lack of available time in clinical practice to perform professional responsibilities and provide enough attention to patient teaching and counseling.

Holly concluded that environmental barriers identified by nurses precluded them from being effectively engaged in ethical situations. Barriers identified included lack of support or poorly defined mechanisms of support, time pressures, personal concerns about security, and hierarchic forces within the institution (Holly, 1993).

A number of other investigators have shown that nurses report feelings of frustration and powerlessness in being involved in ethical situations in clinical practice. Erlen and Frost (1991) studied a convenience sample of 25 nurses who were employed full or part time in a medical surgical critical care setting. The researcher conducted in-depth structured interviews with each subject. Informants were asked to describe a situation they considered to be an ethical dilemma in their practice, discuss why the situation was troubling, describe the nursing action they took, and discuss the factors they think influenced that action. Interviews were audiotaped and transcribed verbatim. Concepts and themes from review of transcripts were identified and coded

independently by the investigator and a research assistant. The inter-rater agreement in coding data was between 80 and 90 percent.

Three major themes emerged in this study: feelings of powerlessness, lack of knowledge of alternatives, and ineffectiveness of the nurse to influence the outcome or resolution of the dilemma. Feelings of powerlessness were found in nurse statements of “feeling trapped”, “helpless”, and “caught in the middle”. Nurses described situations of physician control in which physicians talked patients and families out of their original decisions or prevailed over the patient and family in situations where there was disagreement over the aggressiveness of treatment.

The theme of lack of knowledge of alternatives was seen in situations where there was little communication among various health care providers involved with the same patients and where the nurse did not have relevant knowledge about the disease process or treatment. Nurses also reported lack of knowledge about how to further pursue issues in the situation in order to take action. The issue of ineffectiveness of the nurse was evident in nurses’ descriptions of being angry, frustrated, and exhausted because of their inability to change the situation (Erlen & Frost, 1991).

Millette (1994) also reported nurses’ perceived lack of power and frustration as the most common recurring theme in her research. In this study, Millette interviewed 24 nurses regarding their experiences of moral choices in their clinical practice. Her sample was selected from respondents in a previous study based upon their answers to a questionnaire regarding advocacy. Twelve nurses who previously expressed a preference for client advocacy and 12 nurses who had expressed preference for organizational advocacy were studied.

All of the subjects participated in a semi-structured interview in which they were asked to describe a personally experienced event that involved a moral choice. Content analysis was conducted using interview transcripts. An audit trail was maintained throughout analysis.

Millette found that all subjects reported feeling inability to intervene in order to maintain the patient's well being. The stories told by nurses related events in which the nurse felt powerless and was in conflict with either the employing institution or the physician. Financial security was a factor that influenced nurses' decision-making. Another common theme in these descriptions was relationships to administration. As a group, the nurse participants did not express trust and confidence in their supervisors (Millette, 1994).

Nurse executives have also described the underlying theme of conflict in situations involving an ethical dilemma. Camunas (1994) surveyed a random sample of 500 nurse executives in acute care settings across the United States. The instrument used was a questionnaire developed by the investigators that was designed to gather demographic data and to collect information about ethical dilemmas encountered by the individual. The ethical segment of the survey was made up of closed and open-ended questions. Data were analyzed from a final sample of 315 respondents.

Camunas reported that approximately 30% of those surveyed said they had experienced conflict between their professional values of providing high quality care to all patients and the fiduciary responsibilities inherent in their administrative position. Financial issues, third party reimbursement policies, and organizational politics were also reported as sources of conflict. Ninety six percent of respondents stated that all

people, especially managers, encounter ethical dilemmas at work. Seventy percent of the sample agreed that organizations define and control situations in which decisions are made even though individuals are responsible for their own actions (Camunas, 1994).

Patients and family caregivers also describe the theme of conflict related to decision-making. Taylor, Farrell, Grant, and Cheyney (1993) studied a sample of 10 patient/caregiver dyads and their home care nurses recruited from home healthcare agencies in California. Subject selection criteria included the presence of cancer related pain for at least one month, which was expected to continue. Caregivers had to be at least 18 years old and identified as the primary caregiver.

Participants completed a demographic questionnaire and a one-on-one semi structured interview. Interviews were tape recorded and transcribed. A multidisciplinary research team performed content analysis from interview transcripts to identify themes related to decisions and ethical conflicts. The investigators set out to describe the content of ethical dilemmas and frequent decisions encountered in situations involving pain management in the home setting.

Having to make decisions about medications was reported by caregivers as resulting in conflict. Nurses reported conflict between what they perceived as poor choices by their clients, and giving their clients autonomy in decision-making (Taylor, Farrell, Grant, & Cheyney, 1993).

Husted (2001) recently investigated the experience of nurses and patients/families who were personally involved in bioethical decision-making. Phenomenological methods were used to elicit and analyze participants' reflections on

their feelings regarding the decision making process. The subjects were 15 nurses, 5 patients, and 11 family members. The analysis of data resulted in the identification of ten themes to describe the decision-making experience for each group.

For the most part, the experience was a negative one that left the participants feeling frustrated and powerless. The themes for the nurses that emerged from the data were: Absence of frustration/frustration, no guilt/guilt, no anger/anger, no sadness/sadness, confidence/no confidence, support from colleagues/no support from colleagues, ability to be an advocate/inability to be an advocate, sufficient knowledge/insufficient knowledge, content with outcome/discontent with outcome, power/powerlessness.

The themes for patients/families were: Absence of frustration/frustration, no guilt/guilt, no anger/anger, hope/no hope, ability to make decisions/no ability to make decisions, support from staff/no support form staff, control/no control, sufficient knowledge/insufficient knowledge, agreement with decisions\disagreement with decision, power/powerlessness (Husted, 2001).

Sainio, Eriksson, and Lauri (2001) did a qualitative study among cancer patients to identify how these patients perceived participation in decision-making and to identify factors that facilitated and restricted participation. Data were collected in focus group interviews with 25 patients, most of whom had breast cancer. Subjects were recruited from participants in 4 adaptation training courses for cancer patients from various geographic locations in Finland. All interviews were tape-recorded and transcribed verbatim for qualitative analysis.

The age of participants ranged from 30 to 70 years old, with a mean age of 53 years. Twenty-two subjects had breast cancer. The other subjects had lung cancer, thyroid cancer and melanoma. Twenty percent of the sample had a college level academic degree, and 20% had no training beyond vocational school level. Most subjects were married or living with a significant other. The time elapsed since the cancer was diagnosed ranged from 1 month to 6 years.

Data analysis generated three major themes: 1) patients' perceptions of participation in decision-making, 2) factors promoting participation in decision-making, and 3) factors hindering participating in decision-making. The authors noted that the concept of participation in decision-making was "alien" to the patients, and it took some time in focus group discussions before individuals could answer relevant questions.

Analysis of perceptions of participation revealed the ways in which patients participated in decision-making. These included asking questions, receiving information, and choosing between given alternatives. Subjects stressed the importance of having enough information that was accurate, reliable, and relevant to their current situations, and getting realistic answers to their questions. Participants identified that being provided with information was crucial to participation in decision-making. They also referred to being presented with different alternatives related to care and treatment. There was some criticism by subjects that physicians did not provide enough understandable information about alternatives.

The most important factor to promote participation in decision-making identified by subjects was their own active involvement. Specifically, involvement in asking questions and seeking information was identified. Subjects also said that nurses and

physicians could promote participation in decision-making in many different ways. The most important factor to promote participation identified by patients was the presence of a primary nurse who was responsible for their care. The encouragement of nurses and physicians to be involved in decision-making was also identified as an important factor to promote participation in decisions.

There were more factors identified that hinder participation in decision-making than were identified to promote participation. Patient ignorance was identified as a major factor hindering participation in decisions. Patients' physical conditions were also regarded as important. In particular anxiety and shock were seen as aspects of the patients' conditions that hindered participation in decision-making. Other obstacles identified included the tendency for nurses and physicians to treat patients as objects and to fall into routines. A number of subjects identified that they felt inferior to the nurses and physicians, and that shy people may not have the courage to "open their mouths".

Overall, this study concluded that the dissemination of information was the single most important pre-condition to patient participation in health care decision-making. Study findings also pointed to ways in which the health care team could help or hinder patient participation in decision-making. The influence of demographic variables on qualitative results found was not examined or discussed (Saino, Eriksson, & Lauri, 2003).

This body of research displays themes of conflict, organizational constraints, and feelings of being powerless or uncertain. Viewed as a whole, the research suggests that these issues and feelings are characteristic of being involved in ethical dilemmas

and decision-making. These studies also point to the importance of knowledge of alternatives and information in the decision-making process.

Interventions to Influence Patient Involvement in Decision-Making

Interest in the issue of patient involvement in decision-making has led a number of investigators to examine the effectiveness of interventions to increase patient involvement in health care decision-making. The majority of these interventions have focused on the provision of information and patient education. In several of these studies, various methods for provision of information to patients were compared. Some studies have examined the effects of additional approaches to aid patient decision-making.

Barry, Cherkin, Chang, Fowler, and Skates (1997) randomly assigned subjects who were facing treatment decisions for benign prostatic hypertrophy to use of a brochure or use of an interactive videodisc. Data were collected on an immediate post-test and at follow-up at 2 weeks, 3 months, 6 months, and 12 months. They found that knowledge in the computer group was higher after 2 weeks ($p < 0.001$), that the computer group was more satisfied ($p < 0.03$), and that the computer group had better general health and physical functioning at the end of the study ($p = 0.02$). There were no differences between the two groups in satisfaction with the treatment decision, disease specific symptoms and impact, autonomy preference, or the actual treatment decision made. Most subjects in both study groups selected watchful waiting (Barry, Cherkin, Chang, Fowler, & Skates, 1997).

Greenfield, Kaplan, and Ware (1985) conducted a randomized controlled trial in which subjects were assigned to a control counseling group or the experimental group.

The experimental group received more intensive counseling to assist in identifying relevant treatment decisions, to assist the patient to learn how to negotiate decisions, and to encourage information seeking behaviors. A pre and post-test design was used, and subjects were followed for 6 to 8 weeks. The sample consisted of 45 patients from an outpatient ulcer clinic who were not necessarily currently facing specific treatment decisions. They found that the experimental group was more involved in consultation ($p < 0.05$) and had greater desire for participation in decision-making on the post-test ($p < 0.001$). Post-test knowledge was higher in the control group ($p < 0.005$) (Greenfield, Kaplan, & Ware, 1985).

In another study Greenfield, Kaplan, Ware, Yano, and Frank (1988) conducted a randomized controlled trial of an intervention to improve patients' information seeking skills and ability to actively participate in their interactions with their physicians. The study was conducted in two outpatient clinics in a university hospital setting. The sample consisted of 54 diabetic patients, and 45 general medical ambulatory patients. Patients were randomized to receive the experimental intervention or to the control group.

The intervention consisted of individualized counseling and education regarding the disease process, identification of likely medical decisions that one would face in the future, and identification of potential treatment options. Subjects were also provided with assistance in developing and rehearsing negotiation skills and with questions and focus areas for discussion with their physician. Physician-patient interaction was assessed from audiotapes of patient clinic visits pre and post-intervention. Specific

conversational codes were assigned to all physician and patient utterances to indicate controlling behavior, communicating information, or conveying emotion.

A variety of clinical and health related quality of life outcomes were evaluated. Patient satisfaction with care was measured using a 12-item scale assessing satisfaction with the style of the physician, technical quality of care, and the care in general.

Diabetic subjects in the experimental group showed a significantly greater improvement in HbA_{1c} than those in the control group ($X^2 = 13.7, p < 0.01$). Patterns of change in quality of life data, such as days lost from work and limitations on functional status, were substantially different between the two groups ($F = 31.5, p < 0.01$).

Analysis of audiotapes demonstrated that subjects in the experimental group were twice as effective as controls in eliciting information from the physician. There were no statistically significant differences between groups in patient satisfaction (Greenfield, Kaplan, Ware, Yano, & Frank, 1988).

O'Connor et al. (1998) studied post-menopausal women who were considering hormone replacement therapy. These investigators found that patients who received a more extensive decision aid had more realistic expectations ($p = 0.001$) and lower levels of decisional conflict ($p = .04$). Subjects were randomly assigned to receive a booklet that provided information about risks and benefits of hormone replacement therapy or the booklet and an audiotape that provided exercises to assist the individual to clarify personal values.

This study demonstrated that participants found the decision aid acceptable and that after its use women felt more certain, informed, and clear about their relevant

values. This decision aid did not appear to have any impact on the actual decision made by the women regarding hormone replacement therapy (O'Connor et al., 1998).

Street, Voigt, Geyer, Manning, and Swanson (1995) evaluated the effectiveness of two pre-consultation educational interventions on increasing patient involvement in consultations to choose treatment for breast cancer. They also examined the influence of patient factors and the physicians' communication toward the patient on his or her involvement.

The research was conducted at a multi-specialty health care facility in Texas, and included 60 patients who had stage I or stage II breast cancer. After review of educational materials and consultation with physicians subjects completed a tool to assess knowledge about breast cancer treatment and optimism about the future. Knowledge was assessed using an 11-item multiple-choice test designed by the investigator. Correct responses were determined and the resulting percentage of correct responses was used as a knowledge score. Optimism was assessed with an 8-item instrument in which subjects reported their outlook regarding the future, life goals, control over life circumstances, and anticipated future enjoyment of life on a 5-point Likert scale.

Both self-reported and behavioral measures of patient involvement and physician communication were assessed. All patient-physician consultations were audiotaped. Trained coders transcribed and recorded four types of patient communications including question-asking, opinion-giving, and expression of concern or negative emotion. Each utterance of this type was identified as the unit of analysis for patient involvement behavior. Physician behaviors were categorized as patient-centered statements, such

as statements of reassurance, support, or empathy, and partnership-building statements. Partnership-building statements were those communications encouraging the patient to offer opinions, express feeling, and participate in the decision-making. Inter-rater reliability of coding was established by having coders record 15 of the same consultations. Reliability of physician and patient behavioral measures ranged from 0.68 to 0.91 (Cohen's kappa).

Patient perceptions of involvement during the consultation was assessed using a 7-item 5-point Likert scale asking the patient to report the extent to which she asked questions, offered opinions, and expressed concern when meeting with the physician. Physician facilitation of patient involvement was measured with a 5-item scale. In this instrument physicians were asked to report the extent to which they encouraged their patients to express opinions, concerns, and preferences, and the degree to which they were seen as interested in the patients' understanding of information.

Patients were randomly assigned to one of two pre-consultation education groups. One was given an interactive computerized multimedia program consisting of text, graphic display, audio narration, music, and audio-video clips from 8 women sharing reactions to the diagnosis, their biggest help in coping, and their experiences during recovery and adjuvant therapy. Other aspects of the program provided information about breast cancer and information on treatment with either mastectomy or lumpectomy with radiation.

The other group of subjects was given an 8-page brochure providing the same information about breast cancer and treatment options as the multimedia program. This

brochure did not contain material comparable to the experiences of other women provided in the other educational program.

Analysis of variance was used to determine differences among knowledge, optimism, and the experimental educational approach used. Investigators found a strong effect for time across both groups of subjects ($F = 36.35, p < 0.001$). All patients knew more after receiving the education intervention than they did before education. Knowledge scores did not increase appreciably after the physician consultation ($M = 80.7, SD = 11.29$) compared to the pre-consultation score ($M = 79.5, SD = 12.68$).

Patients in the computer group tended to learn more ($M = 75, SD = 13.64$), than the group who received the brochure ($M = 71.4, SD = 15.17$). This effect for method of education was not statistically significant ($F = 3.30, p = 0.07$). Optimism scores were not affected by timing of the assessment, the educational intervention, or the interaction between the two. Knowledge about options for treatment was the only variable that correlated with optimism ($r = 0.31, p < 0.01$).

There was no evidence that the multimedia program had any influence on greater patient involvement in consultations even when relevant data were controlled for patient age and education. Age and education were inversely related to patient involvement ($r = -0.35, p < 0.01$). Patients' perceptions of their own and the physician's communications were only mildly to moderately related to coded behaviors. Investigators reported that although older and less educated patients did not display as much involvement in consultations, they did not perceive themselves to be less involved or have less control in decision-making.

The mean perceived involvement score in younger and more educated subjects was 28.24, and the mean perceived decisional control score was 17.38. These scores in older and less educated subjects were 28.02, and 17.35, respectively. The investigators noted that these findings might indicate that physicians could have greater difficulty stimulating active participation in older patients who think that the patient's role is to listen. Alternatively, these study findings may simply indicate that, even though some patients are more talkative than others, patients generally felt they were involved and had some degree of control in decision-making.

Behavioral frequency and self reported involvement in consultations and control of decision-making perceptions of patients were directly related to the degree to which patients viewed physicians as facilitating patient involvement ($p < .05$). There were no differences in physician behaviors in any subject groupings.

The investigators concluded that education was shown to improve patient knowledge, and that computer-assisted education was effective and mildly superior to written information. Patients who were more knowledgeable were also more optimistic about the future. The type of education did not appear to influence patient involvement in decision-making or sense of control. Older and less educated patients tended to demonstrate fewer involvement behaviors than those who were younger and more educated (Street, Voigt, Geyer, Manning, & Swanson, 1995).

Liao and others (1996) examined the impact of an interactive video program on decision-making in 60 patients undergoing cardiac catheterization who were found to have significant coronary disease. The Ischemic Heart Disease Shared Decision Making Program (IHD SDP) was an interactive video program that compared medical

therapy, angioplasty and bypass surgery through a physician narrator, patient testimonials, and patient-specific outcome estimations. The program estimated mortality and 5-year survival rate with all treatment options on the basis of each patient's specific illness severity data. Relevant data were provided in several formats including survival curves and other graphic representations. The program also provided information about ischemic heart disease, treatment descriptions, and explanation of possible complications.

The study examined the SDP's influence on decision-making as measured by treatment choices before and after the patients viewed the program. Impact of the SDP on patient anxiety and changes in treatment preference were also measured. Pre-post changes were analyzed using relevant nonparametric statistical procedures.

The computer program helped 44% of initially undecided patients to select a treatment. In addition, 16% of the sample changed their initial treatment choice after viewing the program. The SDP was particularly useful for patients with no education beyond high school who were initially undecided about treatment ($p = 0.04$).

The computerized program also appeared to enhance patient agreement with physician recommendations. Before viewing the program, 86% of patients agreed with the physician's recommendation. After viewing the program 98% agreed with the physician. Effects of the program on patients' reports of anxiety were variable. Forty four percent reported an increase in anxiety, 25% reported no change, and 33% reported decrease in anxiety. Anxiety was measured by patient report on a 5-point Likert scale (Liao et al., 1996)

Rothert et al. (1997) developed and tested a decision support intervention to assist women with decision-making in the area of menopause and hormone replacement therapy. Three hundred seventy-nine women between the ages of 40 and 65 were recruited from a mid-western university community through print and television media. Participants were then randomly assigned to one of three interventions to aid in decision-making. Patients were followed for 12 months. Measurements of outcomes were performed at baseline, immediately post intervention, and at 6 and 12 months post intervention. Outcomes measured were knowledge, decisional conflict, satisfaction with decision-making, satisfaction with health care provider, and self-efficacy.

Knowledge was measured with a 24-item multiple choice and true/false test developed by the investigator. Content and face validity were established and reliability was found to be 0.85 (alpha). Decisional conflict was measured with a 3-item sub-scale of O'Connor's Decisional Conflict Scale. Satisfaction with decision-making was measured with a 6-item investigator developed scale. Satisfaction with the most recent encounter with a health care provider was measured with an encounter specific satisfaction scale with established validity and reliability. Self-efficacy related to participation in health care was measured using an 8-item, 10-point scale designed to elicit patient responses regarding their degree of confidence in several aspects of their health care that reflected decision making control and self care related to menopause.

Investigators also measured each subject's adherence to her own plan for exercise, calcium intake, and hormone replacement therapy. Related activities were marked on calendars by subjects for self-reporting of adherence to the frequency of

planned behaviors. The percentage of time that each subject adhered to her plan was calculated and averaged across the 12 months.

Subjects in this study were randomly assigned to 1 of 3 intervention groups. The first intervention consisted of a brochure addressing the physiology of menopause and self-care, advantages and disadvantages of hormone replacement therapy, and a workbook in which there were spaces provided for patients to record personal information and questions for the health care professional. The second group participated in a 90-minute lecture/discussion format presentation and question and answer session. Program content paralleled that provided in the brochure.

The third program was a personalized decision intervention consisting of three 1½-hour sessions to foster active participation and involvement in the decision process. The first session was the same as that given to group two. In the second session women were encouraged to consider their values relevant to decisions about hormone replacement therapy and were assisted to assess personal risks and values using a structured discussion and active involvement format. The final session focused on practical information to assist women to prepare for a consultation visit, prepare lists of questions and concerns, prepare to discuss relevant history, signs, and symptoms, and develop strategies to meet personal goals.

Across all groups, knowledge increased over time ($F = 554.6, p < .05$). In all groups the pattern of change in knowledge was an immediate post intervention increase of significant proportions, with the post intervention increase maintained over the rest of the study period. The increase in knowledge was greatest in the second group ($t = 3.62, p < .05$).

Decisional conflict decreased over time in all groups of subjects ($F = 27.08, p < .05$). There were no significant differences among study groups in the decrease in decisional conflict by 6 and 12 months. In the shorter term, however, decisional conflict was significantly lower in the first and second groups than in the group that received the more intensive personalized intervention. The authors did not discuss this difference in decisional conflict. The authors concluded that all interventions were successful in affecting decision-making, and that designing interventions to meet consumer needs may result in less need for costly labor-intensive approaches.

Across all experimental groups satisfaction with decision-making and satisfaction with the health care provider demonstrated the same pattern of initial increase post intervention, which was sustained over time. There were no significant differences in findings between experimental groups.

The mean adherence to the plan across the 12 month follow up period was 59% for exercise, 76% for taking adequate calcium, and 89% for adhering to personal decisions regarding hormone replacement therapy. There were no significant differences among the experimental groups in adherence to plan. These findings suggest that rather simple decision support interventions may improve patient adherence to treatment plans that require specific patient behaviors (Rothert et al., 1997).

Schapira, Meade, and Nattinger (1997) reported on their development and evaluation of a videotape decision aid that was designed to assist patients in choosing treatment options for localized prostate cancer. The videotape was developed from the input of medical experts and relevant literature. Focus groups were used to ensure the

relevance of the program content. Investigators used a convenience sample of 35 men between the ages of 50 and 85 years old without prostate cancer. Subjects took a pre-viewing knowledge and attitude test, viewed the videotape, and then repeated the knowledge and attitude test after viewing the videotape. The knowledge assessment consisted of 20 multiple-choice questions. This assessment was developed by the investigator and was based on the videotape content. Approach to decision-making was assessed by responses to open ended questions. These responses were analyzed for content and coded for the identification of major themes.

The analysis demonstrated a significant improvement in knowledge regarding prostate cancer and treatment options after viewing the videotape. Prior to viewing the videotape 28% of the subjects indicated that they would defer decision-making to the physician. After viewing the videotape only 16% reported that they would defer decision-making to the physician. These results demonstrated the usefulness of the specific intervention designed. Results also suggest that such a decision aid can improve knowledge and affect the individual's desired level of involvement in treatment related decision-making (Schapira, Meade, & Nattinger, 1997).

Wagner, Barrett, Barry, Barlow, and Fowler (1995) reported on use of a Shared Decision making Program (SDP) in patients with benign prostatic hypertrophy (BPH). The SDP was shown to men with a clinical diagnosis of BPH from 2 large group urology practices in the Southwestern United States. A total of 451 men participated in the study. The effect of the SDP on patient preferences for treatment was examined and compared to population based trends in the same geographic region. Men who were referred to the SDP also completed a baseline questionnaire that included an item

about their treatment preference. This question was re-administered immediately after viewing the SDP.

Before viewing the videodisc approximately two-thirds of the men preferred watchful waiting. After viewing the SDP this proportion increased to 79% ($p < .01$). These results suggested that method of education could influence patients' treatment choices. Investigators noted that the rates of invasive treatment such as Transurethral Prostatectomy also declined in the general population during the same period (Wagner, Barrett, Barry, Barlow, & Fowler, 1995).

Davison and Degner (1997) tested the hypothesis that assisting men with prostate cancer to obtain information would enable them to assume more active roles in treatment decision-making, and would decrease their levels of anxiety and depression. These investigators randomly assigned 60 men with newly diagnosed cancer of the prostate to receive either an intervention designed to increase their self-efficacy, or to receive only an information packet. The intervention consisted of a written information package with discussion, a list of questions that the subjects could ask their physicians, and provision of a blank audio-tape that the subject was encouraged to use to tape their consultation with the physician.

All subjects were interviewed before their initial treatment consultation in a urology clinic in Canada. During the initial interview, subjects completed a socio-demographic questionnaire, the Spielberger State-Trait Anxiety Inventory (STAI), and the Centre for Epidemiologic Studies Depression Scale (CES-D). The card-sort technique developed by Degner and Sloan was used to elicit patients' preferences for control over treatment decision-making. Most subjects (58.3%) had less than a grade

12 education, were married (86.5%), and retired (71.7%). The median age of mean was 66.5 in the intervention group and 69.5 in the control group.

All subjects were given the same written information package consisting of five brochures containing various types of information about prostate cancer, including the disease process, treatment options with advantages and disadvantages of each, diagnostic testing, and prostate specific antigen blood testing. Men assigned to the experimental group were also encouraged to think about the type of information they needed to help them decide what treatment would be best for them. This discussion was used to generate a list of questions that the men might want to ask the physician. Men in the experimental group were given an audio-tape and encouraged to use it to tape the physician consultation. These men were also specifically encouraged to participate in deciding which treatment option was best for them, and to bring their spouse or significant other to the treatment consultation.

Approximately 6 weeks after the initial interview a follow up phone interview was conducted. During this interview the men in the experimental group were asked to evaluate the intervention. The 5 statements from the role preference card sort were written on a single sheet of paper in the same order as the card presentation. These statements, the STAI, and the CES-D were mailed to participants for completion. Men were asked to select the one role preference statement that best described the way in which their treatment decisions were made.

Chi-square and t-tests were used to compare the distribution of role preferences between the groups and to analyze predictors of decisional preference. A one-tailed

multi-way analysis of variance was used to analyze pre and post-test anxiety and depression scores.

There were no differences between the two groups in pre-test role preferences and no significant differences in role preference were found based on age, education, marital status, place of residence, or employment status. A significantly higher proportion of men who received the intervention assumed a more active role in treatment decision-making than those in the control group did ($\chi^2 = 11.316, p < .001$).

Men in the intervention group had significantly lower state anxiety scores at 6 weeks as compared to their pre-test scores ($F = 9.0, p < .005$). Pre and post-test state anxiety scores were similar in the control group. Preferred decision-making role, age, and years of education were not significantly related to pre-test anxiety results. There were no differences found in mean depression scores between groups or between measurement times.

These findings indicated that patients' preferences for involvement in decision-making may be influenced by interventions designed to empower patients, and that decision-making role preference is not necessarily a static phenomenon. Study findings demonstrated that men who received the decision support intervention did assume a significantly more active role in medical decision-making, and had lower state levels of anxiety. The investigators suggested several possible explanations for these findings.

It was suggested that individuals in the experimental group were willing to assume more ownership for treatment decisions because they were able to get the information they needed to participate in decision-making. It was also suggested that

patients in the intervention group were encouraged to assume a more consumerist approach in treatment decision-making (Davison & Degner, 1997).

Gattellari and Ward (2003) examined the effects of efforts to educate men about controversies surrounding prostate cancer screening on men's estimates of lifetime risks of developing and dying from prostate cancer, having screening tests within the next twelve months and perceived ability to make an informed choice. They also examined decisional uncertainty and factors affecting decisional uncertainty, using the Decisional Uncertainty sub-scale of O'Connor's Decisional Conflict Scale. The sample size was planned to enable detection of a 0.35 difference between groups in decisional conflict with power of .80. Preferences for decisional control were recorded as active, passive, or collaborative, however, the specific method in which these were measured was not reported. Demographic variables analyzed for their relationship to other measures of interest included age, marital status, education, employment status, self-reported health status, and urinary symptoms.

The sample for this study included 248 men between the ages of 40 and 70 who were recruited by receptionists in offices of general practitioners in an urban area of Australia. Subjects completed a pre-test questionnaire prior to their physician visits. They were then given either a 32-page booklet designed to provide information about prostate screening that was previously identified by experts as essential content for informed decision-making or a pamphlet about screening developed by the government. Assignment to intervention groups was random and blinded. Baseline questionnaires for outcome measurement were then mailed to subjects within 3 days of the physician visit.

Findings indicated that knowledge scores increased significantly in the post-test period compared to pre-intervention results for both groups ($p < .001$). Compared with men receiving the government pamphlet, the experimental intervention group was significantly more likely to give a correct estimate of the lifetime risk of developing and dying from prostate cancer ($p < .001$). There was a 41-point difference between the two groups in post-test knowledge about lifetime risks, and there was a 52-point difference between the two groups in knowledge about estimated mortality from prostate cancer. The pre and post differences in knowledge were not described, and the overall possible knowledge scores were not provided in this report. There was a 2.7-point difference between the two groups in the post-test decisional conflict.

In the post-test, men who received the booklet being tested had significantly lower conflict scores on the scale used ($p < .001$) and were more likely to agree that they could make an informed choice about prostate screening ($p < .001$). There were no differences between the two groups according to men's preferences for involvement in decision-making.

This study demonstrated that an alternative educational booklet for men was more effective than a currently used tool in assisting men to correctly estimate their lifetime risks related to prostate cancer and feel that they could make an informed choice about prostate cancer screening. The more extensive educational material used also appeared to result in less decisional conflict. None of the demographic variables measured were influential in these results. Decision-making role preference was not a significant factor contributing to results reported. These findings demonstrated that the amount and type of information provided can influence patient knowledge, sense of

conflict in decision-making, and feelings of the ability to make informed choices (Gattellari & Ward, 2003).

O'Connor and others (1999) reported an integrated review of the results of 17 randomized trials of patient decision aids to improve decision-making and patient outcomes. Only randomized controlled studies comparing decision aids to controls or alternative activities were included. Two independent reviewers extracted study data using standardized forms and used consensus development procedures to resolve inconsistencies in data coding. Results of studies were analyzed individually and pooled when similar measures were used. Weighted mean effect size was calculated.

The decision aids used in these studies focused on 11 screening or treatment decisions. Across all studies decision aids improved average patient knowledge scores to options and related outcomes. This was seen to be the largest and most consistent patient benefit across all studies. Decision aids improved average knowledge scores by 13 to 25 points out of 100 (weighted mean difference = 19). Compared with simpler interventions, more intensive and complex decision aids improved average knowledge scores by a weighted mean of 3 points.

Decision aids had a positive impact on reducing decisional conflict in 2 studies of patient decision-making regarding the use of hormone therapy in prostatic cancer and in 1 other study regarding the use of prostate specific antigen testing. As calculated in this review, the effect size of decisional aids on conflict ranged from 0.2 to 0.4, with a weighted mean difference of 0.3 on a 5 point Likert-type scale. Use of a decision aid made no difference in decisional conflict in another study in which patients with ischemic heart disease were investigated.

Two studies reported that decision aids assisted patients to feel clear about personal values and supported in decision-making. In three studies that evaluated patient satisfaction with decisions and the decision-making process there were no significant differences between those who received decision aids and those who did not.

The authors noted that in studies where decision-making involved undergoing surgery, the use of decision aids appeared to effect the decision made toward preference for less intensive treatment. In a few studies, decision aids increased patient involvement in decision-making compared to usual case controls. However most studies demonstrated a relatively small effect in this regard. The reviewers suggest that the inclusion of coaching in the intervention tested by Davison may have been the reason for the relative and absolute size of the effect found in her study. Specific effect sizes related to increased patient involvement in decision-making were not reported in this review (O'Connor et al., 1999).

E. Summary

The literature demonstrates that the principle of patient autonomy is important to nurses, patients, and families (Davidson et al., 1990; Day, Drought & Davis, 1994; Gortner & Zyzanski, 1988; Jamsson & Norberg, 1989; King & Miskovic, 1996; Mattiasson & Andersson, 1995; Norberg et al., 1994). At the same time, the degree to which patients want to exercise autonomy by active involvement in health care decision-making is variable. Some studies have shown that the majority of individuals prefer passive decision-making roles. Other studies have demonstrated that the majority of the sample preferred collaborative decision-making roles.

The percentages of subjects preferring active, collaborative or passive roles across all studies are highly varied. These differences found in the literature may be the result of differences in methods of measurement as well as differences in the contexts in which studies were performed. In the majority of research, the type of decision-making examined has involved choice of medical treatment, rather than broader aspects of care (Arora & McHorney, 2000; Beaver, Luker, Owens, Leister, & Degner, 1996; Caress, 1997; Degner & Sloan, 1992; Hack, Degner, & Dyck, 1994; Mazur & Hickham, 1996; Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003).

The variability in patient preferences for involvement in decisions about their care and medical treatment has been associated with gender, educational level, and age in several studies. In these, younger and more educated patients tended to prefer greater involvement in medical decisions (Adams, Smith, & Ruffin, 2001; Arora & McHorney, 2000; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Degner et al., 1997; Degner & Sloan, 1992; Ende, Kazis, Ash, & Moskowitz, 1989; Hack, Degner, & Dyck, 1994; Mazur & Hickam, 1996; Nease & Brooks, 1995; Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995).

A few studies have shown that females tend to prefer more active roles in decision-making than men (Arora & McHorney, 2000; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Nease & Brooks, 1995; Stigglebout & Kiebert, 1997). Findings related to the relationship of marital status and time since the diagnosis of disease has been variable (Arora & McHorney, 2000; Beisecker, 1988; Blanchard,

LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Deber, Kraetschmer, & Irvine, 1996; Degner & Sloan, 1992; Ende, Kazis, Ash, & Moskowitz, 1989; Mazur & Hickham, 1996; Nease & Brooks, 1995; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning & Swanson, 1995).

Some more recent reports have failed to show the same relationships between decision-making role preference and age (Davison, Parker, & Goldenberg, 2004; Fraenkel, Nodarus, & Wittink, 2001; Gattellari & Ward, 2003; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Ramfelt, Bjorvell, & Nordstrom, 2000). It is not clear if these are real changes in the association of age and preference for level of involvement in decisions over time, or differences in findings associated with methodological differences across studies.

Information and involvement in health care decision-making appear to be interrelated in both quantitative and qualitative research findings (Avis, 1994; Barry, Cherkin, Chang, Fowler, & Skates, 1997; Biley, 1992; Caress, 1997; Davison & Degners, 1997; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; O'Conner et al., 1998; Rpthert et al., 1997; Schapira, Meade, & Nattinger, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995; Whittaker & Albee, 1996). Insufficient information and knowledge of alternatives have been shown to be important factors in decision-making to nurses as well as to patients in qualitative studies (Erlen & Frost, 1991; Holly, 1993; Saio, Eriksson, & Lauri, 2001). Qualitative studies also display the importance of patient lifestyle, sense of self, anticipation of the future, and interactions with others in the

experience of being involved with treatment decisions (Kelly-Powell, 1997; Rothert et al., 1997; Schapira, Meade, & Nattinger, 1997; Whittaker & Albee, 1996).

Themes from qualitative research had some similarities. The work by Berry and others reflected thematic content that was very similar to the concepts of freedom, fidelity, autonomy and self-assertion found in Symphonology (Berry et al., 2003; Husted & Husted, 1991, 1995, 2001). The overall decision-making process theme *making the best choice for me* in the study by Berry and others clearly reflects the concept of beneficence in Symphonology theory.

Preferences regarding one's role in decision-making appear to differ in the context of actually experiencing a health care condition versus being healthy (Beaver, Luker, Owends, Leinster, & Degner, 1996; Degner & Sloan, 1992; Stigglebout & Kiebert, 1997). The research also suggests that decision-making role preferences differ among patients experiencing different types and severity of illness, and that stated preferences may not mirror actual involvement behaviors (Beisecker, 1988). Studies suggest that health care practitioner behaviors, patient beliefs, and constraints on decision-making affect actual involvement in decisions (Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Davison & Degner, 1997; Ende, Kazis, Ash & Moskowitz, 1989; Nease & Brooks, 1995; Saino, Eriksson, & Lauri, 2001; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995).

Patients and nurses both report that health care organizations constrain and influence decision-making and contribute to situations resulting in ethical dilemmas. Patients, families, and nurses all report the sense of conflict, frustration, and lack of

power in situations involving ethical dilemmas (Davis, 1989; Holly, 1993; Erlen & Frost, 1991; Husted, 2001; Milette, 1994; Taylor, Farrell, Grant, & Cheyney, 1993). These feelings may be reflective of decisional conflict as described by O'Connor and others (O'Connor et al., 1998).

In efforts to empower patients and influence patient involvement in health care decision-making, a number of researchers have tested various types of decision support approaches. The majority of interventions to aid decision-making have been of an informational or educational nature. These have been associated with increased knowledge related to the disease and treatment alternatives (Barry, Cherkin, Chang, Fowler, & Skates, 1997; Gattellari & Ward, 2003; O'Connor, et al., 1998; Street, Voigt, Geyer, Manning, & Swanson, 1995). In one case, an educational intervention appeared to reduce decisional conflict (Gattellari & Ward, 2003). In another study, an intervention that was personalized in nature was associated with a higher level of decisional conflict than other interventions that were less personalized (Rothert et al., 1997).

The effect of decision aids on actual treatment decisions and preferences for involvement in decision-making is unclear. Some investigators have found that increased knowledge influenced treatment choice (Davison & Degner, 1997) or involvement in decision-making (Laio, et al., 1996; Schapira, Meade, & Nattinger, 1997; Wagner, Barrett, Barry, & Fowler, 1995). Others reported no change in role preference, involvement, or treatment choice as a result of an educational intervention (Rothert et al., 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995). Across studies, the greatest effect size was seen with an intervention that included individualized patient counseling along with education (O'Connor et al., 1999).

These results, along with qualitative research suggest that direct facilitation of patient decision-making, in addition to providing information, is more likely to positively influence patient decision-making roles. This suggests the need for more holistic interventions that are designed according to more inclusive decision-making models. In her review of the literature regarding patient participation in hospital care, Cahill (1998) concluded "there is also an urgent need to explore the concept in the reality of practice using more qualitative methods or a combination of both quantitative and qualitative research methods" (Cahill, 1998, p. 126).

III. METHODS

This chapter describes the purpose and methods of the study. This includes study design, setting, sample selection and recruitment, measurement and instruments used, the intervention performed in the study, procedures for data collection, procedures for protection of human subjects, and data analysis procedures.

The purpose of the study was to test Symphonology theory in two ways: 1) by determining if the experience of health care decision-making as expressed by patients reflected concepts of Symphonology, and 2) by determining whether an intervention designed to facilitate patients' health care decision-making resulted in a more positive decision-making experience. As used here, Symphonology concepts refers to the degree to which the bioethical standards that are assumed in Symphonology were expressed by subjects.

A. Design

The study was a single group, pretest-posttest quasi-experimental design, using between method triangulation of qualitative and quantitative techniques to answer study questions and test relevant hypotheses. The phenomenon under investigation and specific study questions were appropriately addressed by this combined method.

In a taped interview subjects were asked to describe and reflect upon their current experience and asked to complete instruments for measurement of study variables prior to the intervention. Subject interviews prior to the intervention were

analyzed to determine congruence of the patients' experience with Symphonology concepts. Congruence as used here refers to the degree to which concepts expressed by subjects were the same as the concepts in the theory.

The dependent variable measured to evaluate the effectiveness of the intervention was the patients' experience of bioethical decision-making. This variable was measured by both qualitative and quantitative methods. Quantitative measurement of the experience of being involved in decision-making was measured using the Bioethical Decision Making Perception Scale for Patients/Families (BDMPSP) (Husted, 2001). This tool is described in detail in the section of this chapter on measurement and instruments. Differences in pre and post-intervention findings were statistically analyzed, and results were triangulated with qualitative findings.

The intervention tested was an educational counseling session that was designed to assist patients through the decision-making process. This intervention was designed according to the decision-making theory of Symphonology (APPENDIX A: Husted's Symphonological Bioethical Decision Making Guide). The study design is displayed in Figure 1.

Independent and intervening variables measured included demographic variables that were previously associated with health care decision-making. Independent demographic variables that were measured included age, gender, ethnicity, education, time since diagnosis, and marital status. Decision-making role preference was examined as a potential intervening variable. The relationships of these variables to experiences described by subjects and observed differences in pre and post-intervention measurements were analyzed.

Study Procedures

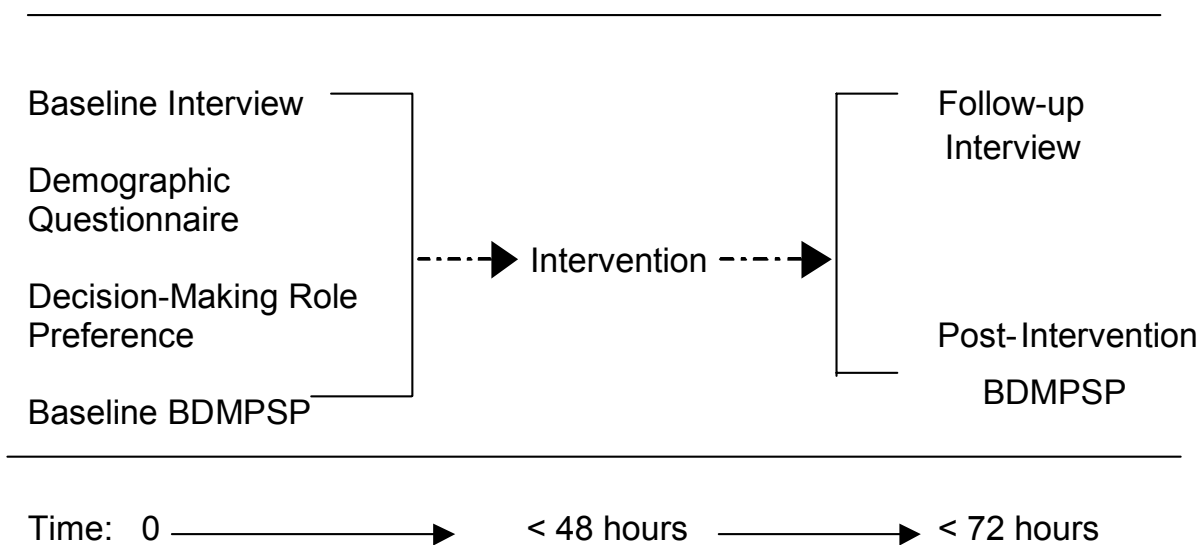


Figure 1. Study Design

All study variables and the rationales for inclusion are outlined in Table 1. Details of measurement methods and procedures for data collection and analysis are described in the following sections of this chapter.

Quasi-experimental Design

The single group pretest posttest design allows the investigator to test an intervention by obtaining baseline measurement, implementing an intervention, and then performing post-intervention measurement on the same subjects. As described by Campbell and Stanley (1963), this design is associated with several internal threats to validity. Those confounding variables that had implications for this particular study included history, testing, and reactivity. History refers to the potential uncontrolled effect

Table 1

Study Variables: Variable Type, Measurement and Rationale for Inclusion

Variable	Type	Measurement/ Instrument	Rationale for Inclusion
Experience of Health Care Decision-Making	Dependent	Quantitative: BDMSP Qualitative: Analysis of subject interviews and field notes	Measurement of the effect of study intervention Evaluation of congruence of lived experience with Symphonology concepts Triangulation with BDMSP results
Age	Independent	Demographic and Disease Related Questionnaire	Sample description Literature demonstrates relationships of age, gender, marital status, education and time since diagnosis to involvement in decision-making
Gender			
Marital Status			
Ethnicity			
Education: level and years of formal education			
Time Since Diagnosis			
Clinical Diagnosis			
Type of Decision	Independent	Qualitative analysis of subject interviews	Sample description
Perceived Constraints to Decision-Making	Intervening	Qualitative analysis of subject interviews and field notes	Literature demonstrates constraints that may influence involvement in decision-making
Decision-Making Role Preference	Intervening	Decision-Making Role Preference Tool	Literature demonstrates relationship of role preference to involvement in decision-making

of time on study observations. Between the baseline and post-intervention measurements, other change-producing events could occur in addition to the experimenter's intervention (Campbell & Stanley, 1963). In order to minimize the potential effects of history in this study, pre and post-intervention measurements were designed to be done within 72 hours. In study implementation, the actual timeframes between study procedures were within 48 hours.

Testing effects refer to the fact that subjects may learn from initial measurement. Learning may affect subsequent subject responses on the instrument used. Reactivity refers to the idea that the act of measurement itself may influence the behavior or phenomenon being measured (Campbell & Stanley, 1963). In order to reduce the potential effects of testing and reactivity, qualitative findings in this study were used to confirm quantitative results.

Triangulation

This study utilized between-method and data triangulation as described by Walz, Strickland, and Lenz (1991). Using this approach, qualitative and quantitative data were obtained simultaneously, and measurement of the dependent variable was addressed via both types of measurement. Post -intervention BDMPS scores and subjects' responses to semi-structured interviews were both used to measure the dependent variable. Qualitative data was used to elaborate findings of quantitative data. This method combination was also intended to provide a vehicle for cross-validation if findings are found to be congruent with the theory being tested (Walz, Strickland, & Lenz, 1991).

B. Setting

The study was conducted in a community hospital in the mid-Atlantic region of the United States. Patients cared for in this hospital have a median age of 69. Forty seven percent of patients are male and 53% are female. The average length of stay for acute hospitalization is 5.8 days. The hospital provides acute inpatient care to over 15,000 medical and surgical cases annually. This setting was expected to provide sufficient volume of subjects for study recruitment, and, as indicated by the average length of stay, it was expected that patients would be hospitalized long enough for completion of the intervention as well as pre and post data collection. The study was conducted between July 2002 and July 2004.

C. Sample

Findings from the literature review were used to establish specific inclusion and exclusion criteria for subject participation in this study. These criteria were used to limit some of the potential variability among study subjects in key independent variables to avoid related confounding affects on study results of primary interest.

Sample Inclusion and Exclusion Criteria and Rationale

Subjects were recruited from among hospitalized patients who met the following inclusion and exclusion criteria. Inclusion criteria for the study were:

1. Age greater than 50 years
2. Demonstration of sufficient cognitive capability to participate in the interview process, complete study instruments, and describe their

current experience. This criterion necessitated the ability to clearly verbalize thoughts and feelings in the English language.

3. Patients had to be facing a current decision regarding their health care or treatment.

Selection on the basis of age was done to limit some of the variability of this independent variable. This was done to enable greater clarity in the analysis of study findings. Previous authors identified a significant relationship between age and decision-making role preferences and involvement in health care decision-making (Arora & McHorney, 2000; Beisecker, 1988; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Deber, Kraetschmer, & Irvine, 1996; Degner & Sloan, 1992; Ende, Kazis, Ash, & Moskowitz, 1989; Mazur & Hickham, 1996; Nease & Brooks, 1995; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995).

The literature suggests that individuals have different role preferences and experiences according to whether or not they are actually facing a health care decision (Degner & Sloan, 1992; Stigglebout & Kiebert, 1997). By including only subjects who were experiencing a similar decision context, the degree of variability in this factor was limited. Limitation of this variable was done to reduce the potential confounding influence of decision context in study findings.

Participation in the decision support intervention and qualitative aspects of the study necessitated that subjects had to be cognitively and emotionally capable of relevant interactions. Patients were excluded from the study if they had a current clinical diagnosis of depression or other confounding behavioral medicine diagnosis.

The rationale for this exclusion was that the experience and participation in the decision-making process could be confounded by these clinical problems.

The sample size was 30 patients. A power analysis was conducted based on the research questions of the study and the results of pilot testing of the quantitative instrument to be used. The results of power analysis indicated that a sample size of 30 would be sufficient to detect 1 standard deviation from the mean with 99.96% certainty at an alpha of 0.05.

Sample Recruitment Procedures

When the study was begun, patients who were identified by nursing staff members as being involved in decision-making were approached by a research assistant who was also working with many of these hospitalized patients to evaluate legal competency. After the passage of the Health Information and Accountability Act (HIPAA), these recruitment procedures were changed to comply with these new requirements.

In the new procedure for subject recruitment that was implemented staff nurses involved in the care of the patients informed the patients of the nature of the study and asked if they were interested in participating or hearing more about the research. Patients who expressed interest were referred to the researcher and research assistant. Patients referred in this manner were then approached for discussion of the study and obtaining consent for participation. Specific procedures used for obtaining informed consent are outlined in the section on procedures for protection of human subjects in this chapter.

The researcher maintained a log of all study subjects according to the policy of the institution in which the study was performed. This log was required in order to provide required information about disclosure of personal health information as required by HIPAA regulations.

D. Measurement and Instruments

Measurements and instruments used in this study included: 1) a demographic questionnaire (Appendix B), 2) measurement of decision making role preference (Appendix C), 3) the Bioethical Decision-Making Perception Scale for Patient/Family (BDMPSP) (Appendix D) and 4) the patient baseline and follow-up interview schedules (Appendix E & Appendix F).

Demographic Questionnaire

Demographic data collected included, age, gender, ethnic group, marital status, disease state, and level and years of formal education. These data were collected using the demographic form provided in appendix B. (Appendix B: Demographic and Disease Related Data Form). This form was based on previous research reviewed that demonstrated relationships between these variables and decision-making role preferences and the outcomes of health care decision-making by patients. Previous research in this area has been described in detail in Chapter II. This information was used to describe the characteristics of study participants and examine the relationships between these variables and the dependent variable.

Decision-Making Role Preference

Role preference was measured as adapted from methods described by Caress (1997). In this approach, the subject selected his or her most preferred role in decision-making from a set of options of 1 to 5, from 1, completely passive to 5, completely active. This scale was designed by Caress based upon the decision-making role preferences originally described by Degner and Sloan (1992). This instrument is shown in appendix C (Appendix C: Role Preference Tool). Caress's tool was adapted in this study to include the language "or type of care I will receive" in each statement for role preference. This was done because this study was not intended to limit decisions considered to those that purely involved medical treatment alternatives, as was the case in the study by Caress.

Decision-making role preference was coded as active, collaborative, or passive according to the most preferred role identified by subjects by assigning it a rank order of 1. This method of coding is displayed in Figure 2. As shown here, subjects who ranked statement A or B as their first preference were identified as having an active role preference. If statement C was ranked as the number 1 preference, the subject's decision-making role preference was coded as collaborative. If statements D or E were identified as the first choice, the subject's decision-making role preference was coded as passive.

BDMPSP

The BDMPSP is a 10-item visual analog scale in which polar dimensions of the decision-making experience are stated. This tool is designed to measure the individual's perceptions/feelings regarding the decision-making experience.

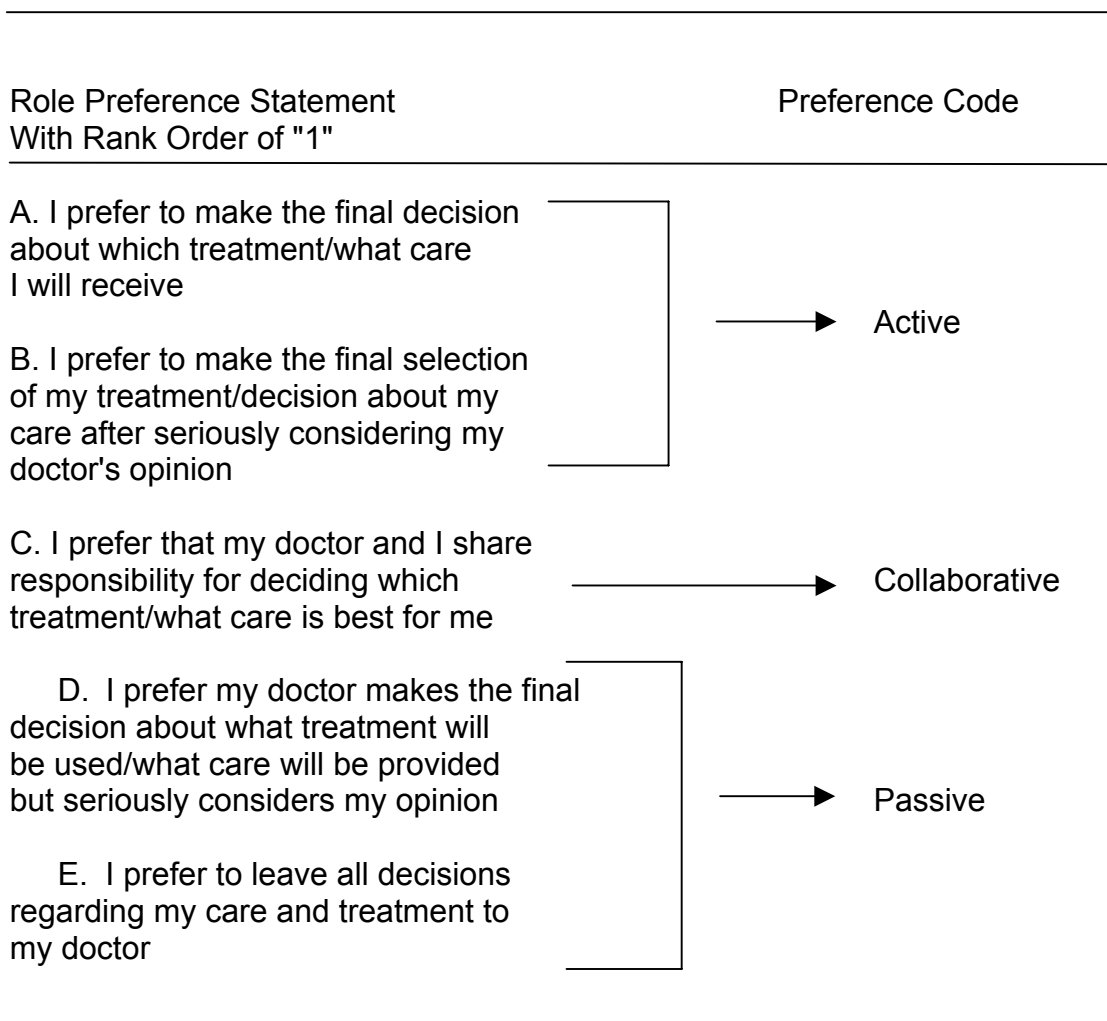


Figure 2. Codes for Decision-Making Role Preferences

The scale is a visual analogue scale that consists of ten 100 mm. lines. The 100 mm line was converted to a raw score between 0 and 100. The subject was asked to mark a vertical line across the horizontal line at the point that indicated his perception of the experience on the dimension. A plastic ruler was used to measure the distance of the vertical mark from the left end of the horizontal line. This distance in millimeters was the raw score for the individual dimension on the scale. The same ruler was used for all measurement by the same investigator in order to assure consistency of results (Walz, Strickland, & Lenz, 1991).

In addition to raw scores measured for each dimension sub-scale on the BDMPSP, total scores on the BDMPSP were calculated by summing the sub-scale scores. BDMPSP difference scores were also calculated by subtracting post-intervention scores from pre-intervention scores. These difference scores were used in statistical analysis to examine the potential relationships between independent and intervening variables and differences in pre and post BDMPSP scores found.

The selection of the dimensions on the BDMPSP scale was based on a prior phenomenological study designed to elicit patients' descriptions of this lived experience (Husted, 2001). From these data, 10 themes emerged. These themes were used to construct the dimensions of the scale. The dimensions on the visual analog scale are: absence of frustration/frustration, no guilt/guilt, no anger/anger, hope/no hope, ability to make decisions/no ability to make decisions, support from staff/no support from staff, control/no control, sufficient knowledge/insufficient knowledge, agreement with decisions\disagreement with decision, power/powerlessness (Appendix D: BDMPSP). Each of these dimensions is a sub-scale on the instrument.

The instrument has content validity, since it is based on objective evidence. This demonstrates that the tool adequately measures the concept it is intended to measure (Walz, Strickland, & Lenz, 1991). Previous reliability testing demonstrated an internal consistency of 0.82 with Cronbach's alpha (Husted, in process). This level of internal consistency reliability demonstrates that all of the questions in the tool measure the same concept.

Patient Interview Schedule

The patient interview schedule consisted of two semi-structured interviews - one to be used at baseline (Appendix E: Pre Test Interview Schedule) and one to be used after the decision support intervention (Appendix F: Post Test Interview Schedule). The pre-test interview consisted of open-ended questions to elicit patients' descriptions of their current experience and the decision to be made. Questions were prepared with probes, so that additional information could be gained in interviews as needed. Since the questions to be asked were known, but answers were not predicted, the semi-structured format with additional probes was the appropriate format for the study (Morse & Field, 1995)

The post-test interview was very brief, and was also designed in a semi-structured format. The primary goal of the post-test interview was to elicit subjects' response to questions as to whether they found the intervention to be helpful and how it was helpful.

E. Intervention

The intervention tested was an educational counseling session with the patient designed to assist the patient to use the bioethical decision-making theory of Symphonology in the decision-making process. In this session the patient was assisted to identify the following: 1) current choices involved in the decision, 2) aspects of his uniqueness, and the ways in which these aspects would be affected by alternatives (Autonomy), 3) current overall life purpose and desires and the ways in which these would be affected by alternatives (Autonomy, Freedom, and Fidelity), 4) perceived

ability to make, or barriers to, voluntary choice or expression of choice, and approaches to remove or mitigate these barriers (Self-Assertion), 5) sufficiency of current knowledge about the situation and identification of additional information/knowledge needed (Objectivity), and 6) expected benefits and negative aspects inherent in the decision (Beneficence). Where information gaps were found, the investigator worked with the subject to plan specific approaches to obtain the needed information.

Structured questions and approaches to provide this assistance were used (Appendix G: Decision Support Intervention Tool). This process was used to assist the patient through the decision-making theory, addressing all of the theory concepts in the reasoning process. During the intervention, subjects were also questioned regarding perceived constraints to their decision-making. The intervention tool was designed to allow the investigator to document the process on the tool in the form of structured field notes for later qualitative analysis.

F. Procedures for Data Collection

The procedures for collection of quantitative and qualitative data are described. This includes the description of procedures used to obtain baseline data, including descriptive information and pre-test interviews. Data collection during the intervention is described. Finally, procedures for obtaining quantitative and qualitative data in the post-intervention phase of the study are identified.

Throughout various phases of the study, qualitative data were collected by a combination of tape-recording interviews and documenting subject dialogue and verbatim statements by means of field notes. The combined use of tape recording,

documentation of patient responses and notation of subject quotations in various sections of this study reflect what Munhall and Boyd refer to as the “eclectic approach to qualitative research design” for which models can be found in educational literature (Munhall & Boyd, 1993, p. 436).

Timeframes between interactions with subjects were kept as short as possible to minimize maturation and history threats to internal validity associated with this type of quasi-experimental design. All interventions were conducted by the investigator, who was sufficiently knowledgeable about the theory of Symphonology as evaluated by the theorist. Research assistants participated in subject recruitment, obtaining informed consent for study participation, and tape recording of baseline interviews. Individual training in these processes was provided by the investigator.

Baseline Data Collection

At the time of study entry, subjects were asked to complete the demographic questionnaire, identify their decision-making role preferences, and complete the BDMPSP visual analogue scale. Data regarding disease factors were obtained by the investigator from the medical record and the baseline subject interview for completion of demographic data collection.

Patients were then interviewed in a private setting, using the interview schedule described. Interviews were recorded and transcribed verbatim. These procedures for data collection and data management have been described by Morse and Field (1995). As recommended by these authors, interviews were conducted in private settings and at times when there would be no interruptions. Tape recordings were transcribed verbatim and checked against the tape for accuracy by the transcriptionist.

Intervention

Within 24 hours of study entry, subjects were asked to participate in the decision support intervention. This session was provided in private with the patient, or with the presence of a significant other, according to individual subject wishes. The intervention tool was used to record field notes during the session. As suggested by Morse and Field, intervention tools were labeled by date and subject identification codes, and relevant subject responses and statements were recorded with both verbatim quotations and general content of the dialogue (Morse & Field, 1995).

Post-Intervention Data Collection

Within 26 hours after the intervention, subjects were approached for completion of follow-up measurement. The BDMPSP was repeated. The patient was also briefly interviewed on follow-up to elicit perceptions and evaluation of the intervention provided. In post-intervention interviews, subjects were asked if they found the process to be helpful and to explain how it was helpful.

This interview was conducted using the open-ended interview schedule previously described. Subject responses during this interview were noted by the investigator on the interview schedule for later consideration in data analysis. Specific patient comments were written verbatim at the time of the interview.

Notes recorded during the intervention and follow-up interview were used to record dialogue, and subjects' responses to questions posed. The investigator documented direct quotes wherever possible. As pointed out by Morse and Field "In field notes, it is necessary to quote what people say rather than to just summarize their

words...Another important area to record is reconstruction of dialogue” (Morse & Field, 1995, p.112).

G. Procedures for Protection of Human Subjects

The study was reviewed and approved by the Institutional Review Boards for Duquesne University and the facility where subjects were recruited prior to implementation. Institutional Review Board review included determination of compliance of study procedures with HIPAA regulations.(Appendix H: Reaserch Approval)

The information provided to potential subjects included a description of what events would occur in the study, description of the potential harms and benefits to the patient of study participation, alternatives to study participation, and the subject's right to refuse or withdraw from the study (Appendix I: Consent Form). All interviews and intervention sessions were conducted in a situation that afforded the patient privacy and confidentiality. No data by which individual patients could be identified were collected other than that required by HIPAA regulations, and all data were kept in a locked file or computer database with security against access by any one other than the investigator.

All individuals involved in data collection, transcription or analysis signed a confidentiality agreement for study involvement (Appendix J: Confidentiality Form). No information by which an individual patient could be identified was included in data for transcription and analysis, or reporting of study findings.

H. Procedures for Data Analysis

Walz, Strickland, and Lenz point out that “the primary task in analyzing data from triangulation efforts is to determine whether or not results have converged” (Walz, Strickland, & Lenz, 1991, p.376.) These authors also point out the importance of defining what will constitute evidence of consistency or congruence. In this study, congruence was evident if the direction of changes in pre and post BDMPSP was the same as the subjects' verbal responses on the post intervention interview regarding the degree to which the intervention was helpful.

Walz, Strickland, and Lenz (1991) also highlight the importance of appropriate analytical methods used for each type of data. The results, not the methods, of individual data analysis are triangulated. With this in mind, this section outlines methods that were used in qualitative data analysis and statistical procedures used for hypothesis testing with quantitative results. Data analysis included: 1) analysis of data to describe the study sample obtained from the demographic questionnaire and subjects' descriptions of the decisions in which they were involved as elicited in baseline interviews, 2) qualitative analysis of verbatim transcripts for conceptual content, 3) documentation of the intervention, 4) quantitative analysis for study hypothesis testing 5) documentation of follow-up subject interviews, 6) triangulation of qualitative and quantitative findings, and 7) examination of relationships among independent, intervening, and dependent variables.

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 11.5 and 12.0. Power analysis was conducted using SPSS Sample Power, version 1.2 (SPSS Inc., 2003).

Description of the Study Sample

Descriptive statistics were used to analyze demographic, disease-related and decision-making role preference data in order to describe sample characteristics. Frequency distributions were done for all variables, and for integer scale variables, such as age and total years of formal education, the range, representative measures of central tendency and standard deviation were determined.

Data obtained from reading verbatim transcripts of baseline interviews regarding subjects' situations and decisions were organized via content analysis to identify the types of decisions involved. The frequency of types of decisions within the sample was calculated.

Procedures for Qualitative Analysis of Subject Interviews

Qualitative analysis of verbatim transcripts was performed for identification of concepts and themes. Analysis of pre-interview transcripts was independently performed for identification of concepts and themes by the investigator using a standard procedure similar to that used by Millette to apply Gilligan's theory to the analysis of moral choices made by nurses (Millette, 1994). In this procedure, a first reading was done for a complete understanding of the story. A second reading was done to identify the narrator's personal thoughts, feelings, and beliefs that are the concepts imbedded in the story.

Two different research assistants also independently reviewed random samples of 5 transcripts for identification of overall themes and content. Research assistants had individual training sessions with the investigator for procedures in content analysis and audit trail documentation prior to their review of transcripts. The investigator and

research assistants then compared notes to identify any discrepancies in findings. An audit trail was maintained by means of notes written on transcripts. These procedures were used to address overall reliability of qualitative findings. Where discrepancies in the labeling of concepts were found, these were discussed until both reviewers reached consensus on findings.

Concepts derived from content analysis procedures were identified by the investigator and compared to the bioethical standards in Symphonology. These findings were reviewed and confirmed by the theorist in order to ensure appropriate interpretation of theoretical concepts in the data. Finally, a decision was made as to the degree to which the experience expressed by study subjects was explained by the theory.

Analysis of pre-intervention verbatim transcripts was used to answer study question 1: Can Symphonology be used to explain patients' experiences of being involved in health care decision-making? Concepts and themes expressed by study subjects were compared to the concepts in Symphonology to determine if concepts in Symphonology were expressed by subjects.

Documentation of the Intervention

As previously described, the intervention tool was used to record notes and subjects' responses to questions during the intervention. These data were analyzed to record and describe subjects' uniqueness, the important aspects of life identified, knowledge expressed and knowledge gaps identified, perceptions of constraints to decision-making and voluntary choice, and assessment of benefits and impacts of alternative choices.

Quantitative Analysis Procedures for Hypothesis Testing

Study question two was answered by testing the null hypotheses: There is no difference between pre and post-intervention feelings of being involved in decision-making. To test this hypothesis, the sum of the 10 questions in the BDMPSP scale was calculated to get a total raw score for the individual. The significance of differences in pre and post mean raw scores was determined using the t -test for paired samples. The null hypothesis was rejected at an alpha of .05. Differences in pre and post-test mean scores for each dimensional sub-scale of the BDMPSP were also tested with the t-test for paired samples in order to identify any significant differences in all dimensions of the experience. Statistical significance was determined by an alpha of .05.

Triangulation of Qualitative and Quantitative Results

Individual subject responses on the post-intervention interview were collated to determine overall subject perceptions regarding the degree to which the intervention assisted them in decision-making. Specific patient comments were reviewed. These findings, combined with quantitative results, were used to provide information about the degree to which the use of Symphonology facilitated patients' decision-making. The direction of changes in BDMPSP scores and results of statistical hypothesis testing were reviewed in combination with results of qualitative findings in order to determine if there was congruence between quantitative and qualitative results.

Analysis of Relationships Among Variables

Relationships among variables were analyzed in several ways. Data were analyzed to determine the relationships between independent demographic variables and decision-making role preference. As previously discussed, this analysis was done

because previous research reported in the literature has shown that demographic and disease related variables measured here were related to decision-making role preference.

The relationships between demographic variables, decision-making role preference, and BDMPSP baseline and difference scores were also analyzed to examine the potential impact of these variables on the experience of being involved in decision-making and changes in this experience after the intervention. This analysis was done because, as previously described, the literature has shown that demographic variables and decision-making role preference were related to outcomes measured in terms of treatment selection and post-test results in some intervention studies. The outcome measure in this study was the difference in BDMPSP scores.

Variables examined and the strategies for analysis are outlined in Table 2. Detailed discussion of statistical procedures used is provided in subsequent sections of this chapter.

Relationships Between Independent Variables and Decision-Making Role Preference

For this analysis, age was grouped according to quartiles found in the distribution. Analysis of relationships between independent variables and decision-making role preference was done using the appropriate statistical procedure according to the scale of the variables examined. The associations between age group, type of education and time since diagnosis, and decision-making role preference was evaluated using the Somers'd statistic for testing a correlation between two ordinal variables. This statistic was used because evidence from the literature has suggested a directional

Table 2

Analysis of Relationships Among Variables: Measurement, Relationships

Tested and Strategy for Statistical Analysis

Variable Measured	Strategy for Analysis	Relationship Examined
Relationships Between Independent and Intervening Variables		
Age group	Somers' d	Decision-Making Role Preference
Type of Education		
Time Since Diagnosis		
Marital Status	Pearson Chi-square	
Gender	Phi	
Relationships Between Independent or Intervening Variables and Dependent Variable		
Age	Pearson correlation coefficient	Baseline BDMPS Scores
Years of Formal Education		
Gender	Pearson Chi-square	BDMPS Difference Scores
Marital Status		
Time Since Diagnosis	Kendall's tau-b	
Decision-Making Role Preference		

relationship between age and type of education and decision-making role preferences.

The Somers'd statistic is the appropriate test for a directional relationship between ordinal variables (SPSS Inc., 2003).

The relationship between marital status and decision-making role preference was tested using the Pearson Chi-square statistic. This procedure is appropriate for testing the association between a nominal variable, in this case marital status, and an ordinal variable such as decision-making role preference (SPSS Inc., 2003). This procedure

requires the interpretation of the significance of a relationship according to the pattern of result distributions across all levels of both variables.

The Phi statistic was used to examine the relationship between gender and decision-making role preference. This procedure was appropriate for testing a dichotomous nominal variable with decision-making role preference (SPSS Inc., 2003).

Relationships Between Independent Variables, Decision-Making Role Preference and BDMPSP Scores

Analysis of the relationship between independent variables and decision-making role preference and the outcome variable of interest was performed using the Pearson correlation coefficient for quantitative variables such as raw age and total years of formal education with BDMPSP baseline and difference scores. The relationships between time since diagnosis and decision-making role preference with BDMPSP scores was done using Kendall's tau-b (SPSS Inc., 2003). This statistic was used because the investigator did not assume any particular directional relationship between these variables. Rather, statistical testing was done to identify any symmetrical patterns among the data. A potential directional relationship was not assumed since there was no previous evidence in the literature that examined relationships with BDMPSP findings. An alpha of .05 was used to determine statistical significance of all relationships tested.

IV. RESULTS AND DISCUSSION

This chapter provides results of qualitative and quantitative data analysis, as well as description of key observations recorded during the educational/counseling intervention. Findings are reported in the following areas: 1) sample characteristics, 2) study question one, 3) key observations in interventions, 4) hypothesis testing in answer to study question two, and 5) relationships between independent, intervening, and dependent variables.

Descriptive statistics are shown for age, gender, race, marital status, years and type of formal education, and decision-making role preference. The types of diseases and health conditions within the study sample are described. The types of decisions involved in the study are summarized. These findings are combined to describe the study sample in terms of demographic characteristics as well as their decision-making contexts.

Results of qualitative analysis of pre-intervention verbatim transcripts are displayed to demonstrate the reflection of concepts of Symphonology in the experience of being involved in health care decision-making expressed by subjects. Key observations about subject responses and issues identified that were recorded during the intervention are explored. These provide information about uniqueness identified by subjects, important aspects of life that were discussed, knowledge gaps identified, voluntary choice and perceived barriers, and actions planned with subjects to make decisions. The clarity of decision alternatives and the apparent impact of the degree of

clarity for decision-making on decision-making role preferences and effects of the intervention are discussed.

Findings related to study question two are presented. The results of statistical hypothesis testing for differences between baseline and post-intervention BDMPSP scores are shown. Congruence between qualitative and quantitative findings is discussed.

Finally, relationships between demographic variables, decision-making role preference and BDMPSP scores are explored. Results of parametric and non-parametric statistical analysis are provided in order to identify: 1) significant relationships between these variables and the baseline experience of being involved in decision-making, and 2) relationships to changes in this experience as measured pre-post BDMPSP difference scores.

Findings in each of these areas are summarized, and comparison of study findings to previous results reported in the literature is provided. Similarities and difference of these study findings to those reported elsewhere are discussed.

A. Sample Characteristics

Forty patients indicated initial interest in participating in the study and were approached to obtain informed consent. Thirty-five subjects gave informed consent and were entered into this study. Four subjects were lost to follow-up, and 1 subject withdrew from the study. The final sample consisted of 30 subjects. All subjects met study entry and exclusion criteria described in chapter III.

Demographic Findings

Demographic characteristics of the final study sample are shown in Table 3. As shown here, slightly over three-quarters of the sample were female and over 90% were

Table 3

Sample Characteristics (n = 30)

Gender	N	Percent
Male	7	23.3%
Female	23	75.7%
Age	Range 51 - 95	Median +/- SD 63 +/-11.99
Race	N	Percent
Afro - American	2	6.7%
Caucasian	28	93.3%
Education Type	N	Percent
Less than high school completion	2	6.7%
High school completion	12	40.0%
Some post secondary education	11	36.7%
Associate degree	1	3.3%
College/University degree	2	6.7%
Some graduate education	1	3.3%
Graduate degree	1	3.3%
Years of Education	Range 9 - 20	Mean +/- SD 13.2 +/-2.19
Marital Status	N	Percent
Single	4	13.3%
Married	13	43.3%
Divorced	2	6.7%
Widowed	11	36.7%
Time Since Diagnosis	N	Percent
< 1 month	14	46.7%
< 1 year	4	13.3%
1 - 3 years	6	20.0%
3 - 5 years	1	3.3%
> 5 years	5	16.7%

Caucasian. The median age was 63. Since the age distribution in the sample was slightly positively skewed, the median was appropriately used as the measure of central

tendency for age. Total years of formal education ranged from 9 to 20 years, with a mean of 13.2. Forty percent of subjects completed high school, and 36.7% had some post secondary education. Slightly over 13% had formal education at or above the college or university degree level.

Diseases, Conditions, and Types of Decisions

The health problems experienced by subjects are outlined in Table 4. As shown here, 30% of the sample were hospitalized and involved in decisions related to acute exacerbation of chronic diseases. Chronic diseases included arthritis, congestive heart failure, diabetes, chronic renal failure, chronic obstructive lung disease, peripheral vascular disease, and multiple sclerosis.

Table 4

Health Conditions Experienced by Study Subjects

Health Condition	N	Percent
Chronic Disease	10	33.3%
Cancer	8	26.6%
Joint Replacement	4	13.3%
Miscellaneous	8	26.6%

The second largest group of subjects had some type of cancer (26.6%). The types of cancer evident in the sample were colon, lung, rectal, and thymus cancer.

The miscellaneous category included back pain, injuries from a fall, *Guillian Barre'*, acute pancreatitis, splenic artery aneurysm, acute liver failure, and a complication of a surgical procedure. Joint replacement cases included two subjects undergoing total knee replacement, one subject who was deciding about undergoing

total hip replacement, and one subject who was deciding about whether or not to have revision of hip replacement surgery.

The types of primary decisions in which subjects were involved are shown in Table 5. The most common type of decision involved undergoing a particular type of treatment, such as cancer treatment or dialysis. The second most common type of decision had to do with living arrangements after discharge. Within this group,

Table 5
Primary Decisions Expressed by Study Subjects

Primary type of decision	N	Percent
Living arrangements or placement on discharge	10	33.3%
Type of treatment to undergo	11	36.6%
Whether or not to have a surgical or other invasive procedure	6	20%
Other	3	10%

decisions regarding placement in a skilled nursing facility versus returning to a prior home setting were most frequent.

The types of invasive procedures and surgeries that were being considered were heart valve replacement, lower extremity amputation, revision of a joint replacement, liver biopsy, and cervical myelogram. The types of decisions included in the other category in Table 5 were approaches to resolve financial problems, general lifestyle alterations, and smoking cessation.

In several cases subjects did not express discrete choices in terms of specific treatment alternatives. In these cases the decisions under consideration were more abstract, involving the idea of undergoing treatment of any type. Subjects who were newly diagnosed with cancer were thinking about cancer treatment in general, and had not yet been provided with specific plans for treatment. Seventy percent of the sample was involved in clear either-or decisions. Thirty percent of the sample was involved in decisions that were not this clear.

Most subjects (60%) were focused on a single primary decision. Twelve subjects (40%) discussed multiple decisions and issues related to their health conditions. These additional decisions and issues expressed by subjects included how to care for others such as elderly parents, planning advance directives, returning to work, financial problems due to illness, how to make necessary lifestyle alterations due to health conditions, and whether or not to have particular diagnostic testing done.

These issues and multiple decisions were interrelated and interdependent. For example, one subject was struggling with the need to make decisions about undergoing treatment with chemotherapy and/or radiation therapy for cancer. He identified that this decision would impact his ability to continue working and could create a financial hardship for him if he was unable to continue full time work. This financial hardship, in turn, would impact his ability to provide care for his elderly mother.

Decision-Making Role Preference

The distribution of decision-making role preference is displayed in Table 6. As shown here, the majority of subjects preferred a collaborative decision-making role. Only 2 subjects (6.7%) in the study sample preferred a passive decision-making role.

Table 6

Distribution of Decision-Making Role Preferences

Role Preference	N	Percent
Active <ul style="list-style-type: none"> ▪ I prefer to make the final decision about which treatment/ what care I will receive ▪ I prefer to make the final selection of my treatment/decision about my care after seriously considering my doctor's opinions 	12	40%
Collaborative <ul style="list-style-type: none"> ▪ I prefer that my doctor and I share responsibility for deciding which treatment/what care is best for me 	16	53.3%
Passive <ul style="list-style-type: none"> ▪ I prefer that my doctor makes the final decision about which treatment will be used/what care will be provided, but seriously considers my opinion ▪ I prefer to leave all decisions regarding my care and treatment to my doctor. 	2	6.7%

B. Study Question One

Study question one: are the concepts in Symphonology expressed in the experience of individuals involved in healthcare decision-making? Qualitative analysis of verbatim interview transcripts demonstrated that subjects expressed concepts of Symphonology in baseline interviews. Every subject expressed all of these concepts. The general content of interviews was similar to findings from the field notes taken during the study intervention. Examples of expressions of fidelity, freedom, beneficence, objectivity, self-assertion and autonomy are shown.

Fidelity

Fidelity was expressed by some subjects in terms of commitment to their personal desires for the future, and concern about or caring for others. “Oh, I’ve got a long line of things that I haven’t done yet and I intend to finish them all up. And I have people who need me and depend on me”. Another subject expressed fidelity in this way:

... this doctor that I have who is so understanding ...Um, we kind of have this pact, though. By two years I would quit and that kind of became my goal. From a 2 ½ to 3 pack a day smoker. During the two years since I was diagnosed, I was down probably to ½ pack a day. And then, a week ago, or maybe a little longer now, I knew that that two-year anniversary was vastly approaching. And I’m trying very hard to keep my promise. So, I have quit smoking and, um we’ll see. By the grace of God, we’ll make it this time.

Fidelity was also expressed in terms of worry about ability to assume responsibilities such as work or consideration of the input of family members in personal decision-making, out of a sense of responsibility. Another subject said “I work full time. I have to really think about working full time and to do that I’ve got to make decisions on the bills that I have”. One subject said, when asked what things he was considering, “Well, as I said, where we are financially and what we’re going to have to do to live out the rest of our life, I guess. I guess financials are the biggest things. I needed to work about five or six more years. Of course, that’s questionable now.”

In another interview, the subject responded to the same question with the following:

All, I wanna do is, like I keep telling the three of them, nobody else really means that, you know, cares how I feel. But my immediate family does. And, uh, I wanted to make it easy on them. And I don't want to be a burden. Just talking to my son this afternoon I told him "What worries me is if something does happen to me, your mother. She's my biggest concern. I'm not worried about you anymore. You have a good life. Now I'm worried about her." He said "Don't worry about her, I'll take care of her."

Freedom

Concern about freedom and frustration arising from loss of freedom was expressed by subjects involved in decisions regarding placement in a skilled nursing facility or other type of change in living arrangements after discharge from the hospital. Loss of freedom was also expressed in terms of the desire to spend time doing what the individual wanted to do. One subject said:

I know I can't go home. I have somebody at home with me six hours a day. And I was just talking with somebody and I told them, I said, "God don't want me now because he sent me back so many times." What happens to me those other 18 (hours)?

Another subject who was considering placement in a facility after discharge said:

Oh, I hate it. I hate the feeling. You have the feeling that you just tried, tried, tried, and it didn't help. I mean, there is your home you worked for. First of all, you got to pick out what little you can take there. I spent many a night, in thought, thinking, you know, what you should be working on. Things that you don't want and things that you do want.

Another subject facing the same type of decision pointed out “ I would rather be at home because I live alone, my home’s comfortable, and I’m happy where I am”. In discussing her situation, one subject said:

I’ve learned that I need to slow down. And my health comes first so I can be there for my family. And I want to have some quality of life. And I want to get back to be able to just go shopping with my daughter. Lunch. Just take a vacation again, go to a movie. I haven’t done any of those things

Freedom was also expressed in terms of the subjects' understanding of his or her right to make choices about care. One subject expressed this with these words: “Well, I think it’s my body, and my life that I should be able to make the decisions that I want.”

Both freedom and fidelity were expressed by another subject in the following statement

Well it’s a tough decision to make, you know? I don’t want my children to feel that I bugged out on everyone. You know, down the line. ‘Well she didn’t have enough strength and courage to do this or that.” You know, that would make me feel bad too. But, on the other hand, hey kids, it’s my body. You know, why should I go through all of that?

Beneficence

The concept of beneficence was expressed in terms of preservation of life, the benefit of recommended care for health or ability to function in activities of daily living, and overall benefit in treatment approaches in terms of impact on lifestyle. One subject stated, in response to a question about what was important in making this decision,

"Whatever it takes to keep me alive. As long as I'm coping, oh well, that's what I'm going to do." Another subject stated

Basically, to make the right decision. I mean, you probably only have one chance here, you know, you don't want to make a mistake and do the wrong thing. And you know the biggest thing is to get me back on my feet and everything else is kind of trivial after that.

Another subject said:

I am in a situation right now where if I don't do something about it, it's possible that I could become totally crippled because that arthritis is really going very, very hard and it's very heavy in that knee. And, um, I really think that my best bet, ah, I hate to say this, but I really do think if I get something done about it I will be much, much better off than if I don't. Because if I don't it could possible just lead to nothing but being crippled in a wheelchair for the rest of my life. And I really don't want that to start, not at this age yet.

Objectivity

Objectivity was generally expressed by subjects in terms of obtaining and using information or in terms of looking at the facts of their situations. One subject reflected this concept in the following statement:

Mostly, you know, I'd like to talk with my doctor more. To understand, to understand the problem that I have. But that's all I've got to say, you know, that I just want to talk to my doctor and puts the cards on the table and everything you know. Just let me know the odds of me coming out of it and everything is going to be all right.

The concept of objectivity can also be seen in the comment by another subject regarding what was most important in decision-making “To make the best educated decision that I can and have whatever the best available to me is.” Similarly, another subject said “ I personally feel everybody should be well informed of what’s going on.”

Objectivity in terms of acknowledging the facts of the situation can be seen in the following comment. “ Well I would rather stay on my own but its just getting too hard, because it’s hard for me. When I try to cook now, I have to hold on to the walker with one hand and try to cook with this hand.”

Self-Assertion

The concept of self-assertion was clearly expressed by this subject, who said: I will be the ultimate decision-maker. For me to agree, they’re going to have to spend a little bit of time with me eventually. Otherwise I just won’t have the surgery. If I feel fine and they say you can go and reschedule it, well, OK I’ll give you a call. Um, but I say all that because I want to be in control.

One subject who was thinking about a living will, said:

Since I’ve gotten sick and I know how precious time is, um, maybe I should consider doing a living will myself. Though my husband knows my desires and he would be the one to make those decisions, I just think it would probably be easier if there was something in writing....I want my children to know that this is not their father’s decision. That it was mine.

Another expressed self-assertion when she said “ Well, being it’s my body, and its me that has to go through this, I think I should have a very big part in decision-

making.” Another subjects expressed her self-assertion in telling her story about getting a second opinion regarding her medical care. She said her doctor was:

... very upset because I called him for a second opinion. So, he told me off in no uncertain terms. I mean he screamed at me. I looked at him and I took both of his hands and I said "Please do not yell at me. I did something I needed to do. And if you can't handle it, then that's your problem."... I have to make a big decision, and right now, today, that's where I stand. I will not make a decision that will not be for my betterment. It will have to be for me.

One subject considering post-discharge placement in a skilled nursing facility expressed self-assertion in her statement “ No, I definitely don't want to go to a nursing home.” Another subject also involved in decision-making related to placement in a skilled facility expressed the type of place she wanted.

Well, I'm thinking maybe I will find somewhere that's nice for less money. Something I can afford. Like I said, that have younger people...people within my age, you know. So that maybe when you get there, you know you have somebody that talks and you can make friends with.

Self-assertion was also often expressed as refusal to have a test or participate in planned care. One subject said “ I don't want to go to physical therapy, because, ah, my feet, I can't even walk two to four inches. The way my one foot is.”

Autonomy

Each subject expressed his or her autonomy through the unique way in which he or she approached and thought about the situation. Subjects also directly expressed the concept of autonomy as used in Symphonology in statements such as “ Well I'm

relatively young and there's financial considerations to think of and the rest of our life that we were starting to plan out." Another subject expressed it this way:

What I'm considering is trying to go home and live as normal as I can live. I'd like to do that you know, and be able to take care of him. My life. My lifestyle.

That's very important. It's always been important to us to be able to go to church and do normal things, you know. And that's what I want to do.

Another subject said " In other words, as long as I can breathe and get up in the morning. I like to get up...I wanna live a little bit, a little bit more. Become a little bit independent, not all dependent. Little bit independent." In another case the subject identified her unique view of her situation in this way: " Well I still have faith and know that I'll get better. But there is things I have to do on my own as far as getting well."

These findings demonstrate the expression of all of the concepts of Symphonology in subject interviews.

C. Key Observations in Interventions

All interventions were done between 4 and 26 hours after the initial subject interview and baseline data collection. The investigator who had not performed the initial interviews did all interventions. None of the baseline data was reviewed prior to the intervention, so that the investigator would not be influenced by this information. Subjects were requested to provide a brief overview of their situations and decisions in which they were involved at the beginning of the intervention session. The majority of subjects had the intervention done in private. Three subjects included a significant

other during this session. One of these was a spouse and the other two were children of the subjects.

Observations from field notes documented during the intervention are shown in the following sections. These findings were in response to the semi-structured intervention, previously described in chapter III. Observations and quotations from subjects are displayed that provide description of uniqueness of subjects, important aspects of life, knowledge gaps identified, perceptions of voluntary choice, and content of dialogue about assessing the benefits and impacts of choices.

Uniqueness

It was observed that most subjects had difficulty identifying what was unique about them, when directly asked. It appeared that most subjects did not think about themselves this way. Aspects of their uniqueness tended to emerge through the course of the rest of the discussion regarding important aspects of their lives and desires. As items emerged that were identified by the investigator as a part of the individual's uniqueness, these were directly validated with the subject.

Discussion of unique aspects of the individual included the importance of being in control, ability to handle things in life, determination, and a strong sense of accountability and responsibility. Several subjects spoke to the fact that they liked living alone, and the importance of being independent. Strong family ties, the importance of family, and caring for others was another theme that emerged in these discussions. Personal traits such as honesty and dependability were expressed. One individual pointed to the types of activities that provided personal reward and a sense of fulfillment

as an aspect of his uniqueness. A few subjects identified fears of isolation, loneliness, and feelings of loss due to the deaths of loved ones.

Important Aspects in Life: Autonomy, Fidelity, and Freedom

The most common important aspect of life identified by study subjects was involvement with family. This included spending time with family members, visiting with grandchildren, the need to fulfill responsibilities to care for family members, and the desire to see children or grandchildren become independent and do well in life.

It was important to subjects to be able to spend time in their lives doing the things that they enjoyed. For some, it was important to be physically active and be able to get around. Subjects expressed meeting work and financial responsibilities as an important aspect of life. For those who identified themselves as loners, living alone was a crucial aspect of life. Several subjects stated that survival and living longer was important to them.

Objectivity and Knowledge Gaps Identified

A number of subjects identified lack of knowledge of resources available for financial assistance or personal assistance in activities of daily living. Most stated that they had insufficient knowledge of the likelihood of various possible outcomes of treatment at the time of the intervention. Many of the subjects lacked knowledge about their exact diagnosis, causes of their health related problems, and specific treatment alternatives that would be available to them. These were subjects who did not have clear either-or alternatives in their decision-making.

Several individuals expressed the need for a better understanding of the impact of treatment on ability to work and resume their usual lifestyles. One subject felt that she needed to know how surgery would change her as a person.

During the intervention, subjects identified a variety of approaches to obtain the knowledge they needed. Almost all individuals identified the need to speak with their physicians to ask specific questions. Several subjects identified use of the Internet to seek additional knowledge about their condition and available treatments. Some subjects had family members or friends who were nurses or physicians who would help to explain things for them and assist them in seeking additional information. A few subjects planned to seek a second opinion or make appointments at specialized health care facilities to explore treatment alternatives.

Voluntary Choice

All but one subject stated that they felt they were able to make a completely voluntary choice. Even those subjects who recognized that they would need to take some action in order to survive, expressed that their choice was voluntary. Only one subject who needed to begin dialysis stated that her choice was not voluntary, because if she did not do this, she would die. There were no barriers or constraints to voluntary choice identified by any subject.

Assessing Benefits and Impact of Alternatives

As previously discussed, there were a number of subjects who did not have clear treatment alternatives for selection in their decision-making at the time of the intervention and interview processes. In these cases, subjects discussed the alternatives they expected, and the overall choices they were facing at the time.

Discussion of the potential impact of alternatives on the individual's uniqueness and important aspects of life appeared to be most powerful in facilitating their decision-making. For example, one subject was deciding whether or not to have a leg amputation, needed due to severe peripheral vascular disease. She did not initially want to have the surgery, since she felt so negative about it. " It makes me sick to think of it."

During the intervention it was identified that part of her uniqueness was that she was more interested in mental than physical activity and that most of the things that she enjoyed and spent most of her time doing were sedentary types of activities. When asked how she felt that the surgery would affect these, she recognized that these would not really be affected at all, since her mobility was not a factor in these activities. She decided to have the surgery.

Another subject had a major concern about his ability to alter his lifestyle as he would need to in response to disease progression and planned treatment that would reduce his stamina and ability to be physically active. Reflection and discussion illuminated numerous ways in which he had already adapted to his disease progression, while maintaining involvement with the important aspects of his life, such as visiting friends and caring for pets. This led to his realization that his ability to adjust his lifestyle to constraints imposed by his illness was already occurring, and, in fact, was an aspect of his uniqueness. With this realization he came to the conclusion that he would be able to continue to adapt to his changing needs in the near future.

Another subject, who was facing a decision whether or not to have heart valve surgery, had never had any surgery or invasive procedures in the past. One of her

aspects of uniqueness was the fact that she had not been "altered" in any way, and the importance of this to her. As she put it, when she died she wanted to be unaltered, and "go back exactly the way I came." Because she felt that heart surgery would change her in some basic and meaningful way, she decided not to have the procedure.

Another subject had an extremely strong need for independence and desire to return to living alone in her own home after discharge from the hospital. She identified this desire as a unique aspect of her personality. Because she had been severely ill, and previously confused during her hospitalization, she said that her older sister was insisting that she go to a skilled nursing facility, and that her sister and her doctor were in the process of making this decision for her. She felt that she was not being given the right to make this decision for herself. During the intervention she planned to discuss this with her sister and her doctor, explain to them how important it was to her to remain independent at home alone, and express her right to make this decision. The subject followed through with this plan, obtained agreement from her sister and her physician, and returned home.

D. Study Question Two

Study question two: does an educational/counseling intervention based upon the concepts of Symphonology have an effect on the experience of decision-making? This question was addressed with both quantitative and qualitative analysis. Quantitative analysis was performed through standard hypothesis testing regarding the difference between mean pre and post-intervention BDMPSP scores. In addition, subject responses to semi-structured interviews after the intervention were evaluated using qualitative analysis of field notes.

Results of Quantitative Analysis: Hypothesis Testing

This study question was answered quantitatively by testing the null hypothesis: there is no difference between pre and post intervention scores on the BDMPSP. Hypothesis testing was done using the t-test for paired samples using pre and post-intervention total mean scores on the instrument. Pre and post-instrument testing for reliability was performed using the alpha coefficient. BDMPSP results obtained at baseline had a standardized alpha coefficient of 0.807. The post-test standardized alpha coefficient for the BDMPSP was 0.8507. These results suggest that the instrument used in this study had good internal consistency during both times that it was administered in this study. Internal consistency findings here were also similar to those previously found in instrument testing (Husted, submitted for publication).

Pre and post mean scores for each of the 10 sub-scales on the BDMPSP were done in order to identify significant differences in the 10 dimensions of the tool. These results are shown in Table 7.

As shown in Table 7 there was a significant positive difference in the pre and post total BDMPSP scores ($t = 2.47, p = .02$) at $\alpha < .05$. The null hypothesis was rejected. This finding supports the utility of Symphonology theory.

Analysis of differences in sub-scale scores demonstrated a positive directional change with the intervention in all dimensions except guilt. Statistically significant positive changes associated with the intervention were seen in the dimensions of frustration ($t = 2.6, p = .014$), knowledge ($t = 2.66, p = .013$) and power ($t = 2.81, p = .009$).

Table 7

Results of Differences in Pre and Post - Intervention BDMPSP Total Scores

BDMPSP Dimension	Pre Mean	Post Mean	Mean Difference	T value	p
Frustration	61.43	46.48	14.95	2.612	.014
Guilt	14.03	21.70	-7.66	-1.81	.081
Anger	41.30	33.70	7.50	1.30	.203
Hope	21.67	17.77	3.90	1.32	.198
Ability to Make Decisions	14.80	14.40	0.40	0.095	.925
Support from staff	21.07	16.00	5.07	1.32	.196
Control	31.20	29.00	2.20	0.639	.528
Knowledge	38.23	28.67	9.57	2.66	.013
Agreement with Decisions	27.57	22.61	4.95	1.315	.199
Power	35.52	25.48	10.03	2.81	.009
Total score	306.82	255.82	51.00	2.47	.020

The directional change in these scores indicates that subjects felt less frustrated, more knowledgeable, and more powerful after the intervention. Power analysis of statistically significant differences demonstrated the following results. Power for the difference found between pre and post-intervention frustration was 0.74, for the difference seen in the dimension of sufficient/insufficient knowledge, the power was 0.79. Analysis of the difference between pre and post power demonstrated statistical power of 0.81. The power of the total BDMPSP score difference was 0.74.

It is interesting to note that, on average, there was only one dimension on the BDMPSP in which the directional change after the intervention was negative. This was seen with the dimension of guilt. Although the average difference was negative, not all subjects individually had a negative change. The overall difference in this sub-scale of the BDMPSP was not statistically significant.

Qualitative Results: Post-Intervention Interviews

Quantitative findings were supported by results of qualitative analysis of subjects' responses to post-intervention interviews regarding the degree to which they did or did not find the intervention to be helpful. All but 5 subjects stated they found the intervention to be helpful. Three subjects said the intervention was only somewhat helpful, and 2 subjects did not really feel that the intervention had been of any help.

Of the 3 subjects who said they only found the process to be somewhat helpful, 2 discovered that they had additional health problems that were diagnosed with additional testing between the time of the intervention and the post-test. These subjects mentioned that they had found it helpful to talk about their problems at the time, but these additional new problems caused them to feel more frustrated. The third subject in this group did not have a final diagnosis or identified cause for her health problems, and she was overwhelmed by the uncertainty of her situation. As she put it:

Well I cried all morning. Cause I'm just frustrated. Um, it just seems like nobody has any answers for me, which they don't. The doctor said he had no answer for me. He didn't know what was the matter....said that he had done 400 surgeries like mine and never has he ever had anything like what's going on with me, so it's like I'm drowning. That's how it feels to me like I'm drowning and there's no one there to stop it 'cause no one knows what's going on. It's like I'm powerless to do anything...I just want to get out of here and it seems like I can't.

The two patients who said the intervention was not really helpful both indicated that they felt they had really made their decisions prior to completing the intervention. As one subject said, " It felt good at the time, but I had pretty much made up my mind anyway."

Of those who found the intervention helpful, several subjects said that they found it helpful to just "talk things out." One subject felt that "the experience was like a catharsis." One subject stated, "I feel better about myself. I am not blaming myself as much since talking with you. I am not as angry. " Another subject stated, "It made me step back and realize that I can confer with others and make my own decision, that if we disagree I don't have to feel guilty, and I do have the power to make my own choices." Another subject said "It helped me to see and understand how I am feeling with all of this and dealing with these feelings."

Improvement in knowledge and the sense of power was also reflected in the following subject's responses. "I got some needed information and have a better understanding of what happened. Talking through things made me remember my ability to handle things." After participating in the study, one subject wrote the following to the investigator via electronic mail to express the effect the study on her decision-making experience.

I thought long and hard about the things we talked about and that knowledge is power. I armed myself with multiple references and pursued a course of IVIG, which is the standard treatment. I don't know what the future will bring...but your thought provoking discussions gave me the courage at a vulnerable time to make key decisions and forge ahead.

These effects expressed by subjects were congruent with quantitative results that demonstrate a significant positive effect of the intervention. The direction of the change in total BDMPSP scores was positive in the sample overall. In the majority of cases, subjects also expressed that they found the intervention process to be helpful.

Triangulation of quantitative and qualitative results supports the validity and utility of Symphonology theory.

E. Relationships Among Independent, Intervening and Dependent Variables

Relationships among variables were analyzed to determine 1) relationships between demographic variables and decision-making role preference 2) relationships between demographic variables and decision-making role preference, and BDMPSP scores, and 3) the association of decision clarity and decision-making role preference and BDMPSP scores. As discussed previously, the literature has reported significant associations between some of these variables and decision-making role preference and outcomes measured in the research. Since the clarity of subjects' decisions appeared to be an important factor in the decision-making process during interventions, the clarity of decisions was also analyzed to determine the association of this factor with decision-making role preference and results in the dependent variable.

Data were also analyzed to determine the associations between demographic findings and BDMPSP scores and between decision-making role preference and BDMPSP scores. Since the literature has demonstrated relationships of demographics and role preferences with involvement in decision-making, it was important to investigate the potential influence of these independent and intervening variables with subjects' experiences of being involved in decision-making in this study. The schema for testing relationships among these variables is shown in Figure 3.

 Analysis of Relationships Between Study Variables¹

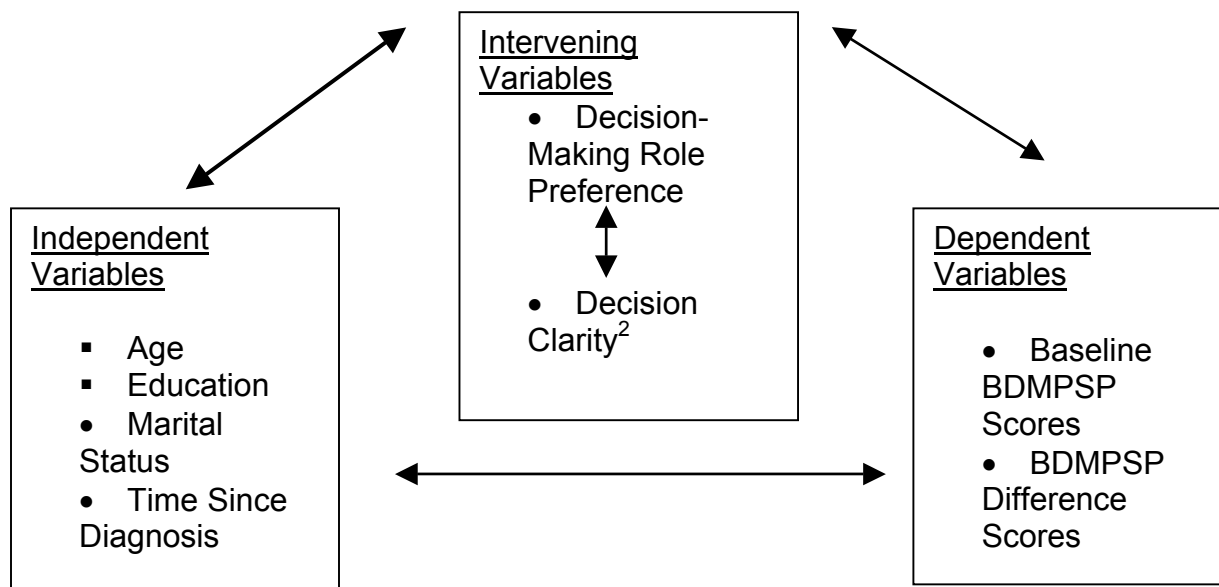


Figure 3. Schema of Relationships Examined Among Variables

¹ Arrows indicate all relationships between variables tested

² Since decision clarity emerged in the study as an important factor it was included in analysis of relationships among variables as an intervening variable

Relationship of Demographic Variables to Decision-Making Role Preference

To examine potential relationships between demographic variables and role preference, age was grouped in quartiles. Role preference by age group, type of education, marital status, gender, and time since diagnosis are shown in Table 8. This table outlines the statistical procedures used for testing relationships among all of the variables. The significance level for all statistics is provided as well.

Table 8

Decision Making Role Preference And Demographic Variables (n = 30)

	Decision - Making Role Preference (n)			Significance
	Active	Collaborative	Passive	
Age group				0.761 ¹
51 –55	3	4	0	
56 –62	1	7	0	
63 – 72	4	4	0	
76 - 95 ⁴	4	1	2	
Education Type				0.713 ¹
< High School	1	1	0	
High School	6	4	2	
Some post secondary	3	8	0	
Assoc. Degree	1	0	0	
College Degree	0	2	0	
Some graduate	1	0	0	
Graduate Degree	0	1	0	
Gender				0.572 ²
Male	2	4	1	
Female	10	12	1	
Marital Status				0.295 ³
Single	0	4	0	
Married	5	8	0	
Widowed	6	3	0	
Divorced	1	1	2	
Time since diagnosis				0.870 ¹
< 1month	4	10	0	
< 1 Year	3	1	0	
1 - 3 years	4	2	0	
3 - 5 years	0	0	1	
> 5 years	1	3	1	

¹ Statistic used was Somers'd - ordinal by ordinal variables,

² Phi statistic used for nominal scale variables,

³ Pearson Chi-square used

⁴ There were no subjects between the ages of 72 and 76.

The relationship between demographic variables and decision-making role preference was tested using Somers' d for ordinal variables, including age group ($T = -0.305, p = 0.761$), type of education ($T = 0.368, p = 0.713$), and time since diagnosis ($T = 0.545, p = 0.179$). The relationship between marital status and decision-making role preference was tested using the Phi statistic ($\Phi = 0.545, p = 0.179$). The Pearson Chi-Square was used to test the relationship between gender and decision-making role preference ($\chi^2 = 8.741, p = 0.189$).

Relationship of ethnicity to role preference was not evaluated since there were only two subjects that were not Caucasian. Since none of the subjects identified any perceived constraints to decision-making, this variable was not analyzed further. There were no statistically significant relationships between demographic variables measured and decision-making role preference.

Clarity of the Decision and Decision-Making Role Preference

Chi-square analysis was used to examine the relationship between the clarity of the decision faced by subjects and their decision-making role preferences. These results are shown in Table 9. As shown here there was a statistically significant relationship between the clarity of the decision under consideration and decision-making role preference. There was a higher than expected number of individuals who indicated preference for an active decision-making role among those subjects for whom decisions to be made involved very clear alternatives. Among subjects who were involved in less clear decisions, there were a higher than expected proportion of subjects who preferred collaborative roles, and fewer than expected who expressed preference for active decision-making roles ($\chi^2 = 8.156, p = .017$). These findings suggest that subjects who

had clear alternatives for decision-making tended to prefer more active decision-making roles.

Table 9

Association of Decision Clarity and Decision-Making Role Preference (n = 30)

Clarity of decision	Role Preference ¹		
	Active	Collaborative	Passive
Clear Alternatives			
Count	11	7	2
Expected	8.0	10.7	1.3
% within clarity of decision	55%	35%	10%
% total	36.7%	23.3%	6.7%
Unclear Alternatives			
Count	1	9	0
Expected	4.0	5.3	0.7
% within clarity of decision	10%	90%	0%
% total	3.3%	30%	0%

¹Pearson Chi-square = 8.156, p = .017

Relationships Among Independent, Intervening, and Dependent Variables

The relationships between demographic variables and decision-making role preference and BDMPSP baseline and difference scores were analyzed to evaluate the extent to which these variables may have affected the differences in pre and post-intervention BDMPSP scores. These results are shown in Table 10.

In addition, the influence of clarity of the decision was evaluated by examining the differences in BDMPSP scores between groups of subjects on the basis of decision clarity using the t-test for independent samples. These results are shown in Table 11.

Relationship of Age and Difference in BDMPSP Scores

There were significant moderate relationships between age and baseline frustration ($r = -.505, p = .004$), baseline knowledge ($r = -.415, p = .023$), baseline anger ($r = -.563, p = .001$) and total BDMPSP scores ($r = -.514, p = .004$). These results show that age was indirectly related to dimensions of frustration, anger, and knowledge as well as the total experience of being involved in decision-making. These findings suggest that older age was associated with less frustration, less anger, less feeling of having insufficient knowledge, and a less negative overall experience of being involved in health care decision-making. There was no relationship between age and BDMPSP difference scores.

These findings show that age was not related to changes in pre and post BDMPSP scores. This suggests that the changes demonstrated in post intervention BDMPSP scores were not influenced by age.

Relationship of Years of Education to BDMPSP Scores

There were no relationships between total years of formal education and baseline BDMPSP scores. Years of formal education were significantly related to total BDMPSP difference scores ($r = .398, p = .029$). Although this association was statistically significant, the relationship was somewhat weak.

Table 10

Relationships Between Demographic Variables, Decision-Making Role Preference and BDMPSP Scores

Study Variable	Relationships Tested	Statistics Used	Findings
Gender	All Baseline BDMPSP Scores All BDMPSP Difference Scores	Chi - square	No relationships
Raw Age ¹		Pearson Correlation Coefficient	Negative correlation with baseline total BDMPSP, and baseline frustration, knowledge and anger sub-scale scores
Raw Years of Education ¹		Pearson Correlation Coefficient	Direct correlation with total BDMPSP difference scores
Marital Status		Chi - square	No relationships
Time Since Diagnosis ²		Kendall's tau-b	Direct association of time since diagnosis with higher baseline control BDMPSP sub-scale scores
Decision - Making Role Preference ³		Kendall's tau-b	Indirect relationship between decision - making role preference and agreement with decisions BDMPSP sub-scale difference scores

¹ Pearson R used for quantitative variables. $p < .05$ for findings listed.

² Kendall's tau-b used for time since diagnosis as an ordinal scale. Direction of association indicates longer time since diagnosis associated with less control. $p < .05$ for findings listed

³ Kendall's tau-b used for decision-making role preference as an ordinal scale. Direction of association indicates less active the role preference is associated with less of a difference in disagreement with decisions on post-intervention BMDSP. $p < .05$ for findings listed.

There was a moderate correlation between years of education and difference scores for the BDMPSP anger sub-scale ($r = .535, p = .002$). These findings suggest

that the effectiveness of the intervention overall, was associated with total years of formal education. The more years of formal education the subject had, the greater the difference between the overall pre and post-intervention experience and the degree of anger experienced.

Relationships Between Gender, Marital Status, Time Since Diagnosis, and BMDPSP Scores

Associations between gender and marital status and BMDSP baseline and difference scores were assessed using the Pearson Chi-square statistic. There were no statistically significant relationships between gender and BMDPSP results, or marital status and BMDPSP baseline or difference scores.

There was a weak indirect relationship between decision-making role preference and the difference score for the agreement with decisions sub-scale on the BMDPSP (Kendall's tau-b, $T = 3.109$, $p = .002$). These data suggest that subjects who had a less active decision-making role preference had less disagreement with decisions. There were no other significant relationships between decision-making role preference and BMDSP baseline or difference scores.

There was a significant relationship between time since diagnosis and baseline BMDSP scores on the control sub-scale (Kendall's tau-b, $T = 3.109$, $p = .002$). Subjects who had a longer time since diagnosis had higher scores on the control sub-scale, indicating that their experiences were that of less control. Those individuals who had longer periods of time since their diagnoses were those with chronic diseases and their hospitalizations were due to disease progression and complications. These results

suggest that the longer individuals experienced chronic health problems and progression of illness, the less they felt a sense of control in the situation.

There were no statistically significant relationships between time since diagnosis and BDMPSP baseline or difference scores. This suggests that a longer time since diagnosis did not substantially influence the overall experience of being involved in health care decision-making or influence the difference demonstrated between pre and post-intervention BDMPSP scores.

Decision Clarity and BDMPSP Scores

Significant results of t-tests for differences in BDMPSP mean scores between the two groups of subjects according to the clarity of decisions are shown in Table 11. The t-test for independent samples was used for this analysis. As shown in Table 11, there was a significant difference between groups in baseline scores on the BDMPSP dimension for insufficient/sufficient knowledge ($t = -2.874, p = .008$). There were also significant differences between these two groups of subjects in BDMPSP total difference scores ($t = 2.579, p = .015$), and BDMPSP difference scores on the anger ($t = 2.207, p = .036$) and agreement with decisions ($t = 2.948, p = .006$) sub-scales.

These results demonstrate that individuals who had less clear alternatives for decision-making experienced a greater sense of having insufficient knowledge prior to the intervention. This group of subjects also appeared to experience more anger, more disagreement with decisions, and a more negative overall experience of being involved in decision-making after the intervention.

Table 11

Significant T -test Results for Differences in Mean BMDPSP Scores Between Subjects With Clear and Unclear Decisional Alternatives

BMDSP Score Item	Clear Decision Group Mean	Unclear Decision Group Mean	T	P
Baseline sufficient knowledge sub-scale	27.8	59.1	-2.874	.008
Anger sub-scale difference score	16.15	-9.5	2.207	.036
Agreement with decisions sub-scale difference score	11.92	-9.0	2.948	.006
Total BMDSP difference score	85.47	-17.95	2.579	.015

F. Summary and Discussion

In this section, results that have been presented are summarized. Similarities and differences between results of this study and findings from the literature are discussed. Summarization and discussion of study findings are provided in the areas of 1) results of theory testing, 2) concepts and themes derived from qualitative analyses, 3) relationships among independent variables, decision-making role preference, and results of the intervention, 4) role preference findings, and 5) effect of the intervention.

Results of Theory Testing

The most significant findings of this study are those that demonstrate the validity and utility of Symphonology theory. Qualitative analysis of baseline interviews of these

30 subjects demonstrated that concepts, that are the bioethical standards in Symphonology, were expressed as the experience of being involved in health care decision-making. This finding suggests that the assumption of these standards as the nature of ethical decision-making in Symphonology is valid. Since the concepts of Symphonology were expressed by subjects who were involved in making decisions about their health care and treatment, Symphonology does describe the experience of bioethical decision-making. As defined in this study, health care decision-making is bioethical decision-making.

Statistical hypothesis testing regarding the difference between pre and post-intervention BDMPSP scores demonstrated a significant positive effect of the intervention on individuals' experiences. This suggests that Symphonology theory has utility, since the intervention based upon the theory had a significant positive effect on the experience of subjects. Triangulation of qualitative and quantitative results showed that there was congruence between the different types of findings. These findings, considered together, strongly support Symphonology theory.

Post-intervention BDMPSP scores demonstrated a positive change in all dimensions but guilt. The fact that the guilt sub-scale showed a negative change is of interest, however, the difference in pre and post results was not statistically significant. In addition, there were no relationships found between guilt dimension scores and any other variable measured in this study. Rothert and others (1997) also found a higher level of decisional conflict in subjects who received a highly personalized decision support intervention in the short term. It is possible that exploration and discussion of highly personal issues may increase certain negative feelings in some individuals.

Since results in the guilt dimension scores discussed here were also not statistically significant, it is also possible that these findings occurred by chance alone.

Concepts and Themes Derived from Qualitative Analyses

The content of subject interviews and interactions during the intervention demonstrated concepts and themes that were similar to those reported in other qualitative research related to patient decision-making. The finding that many subjects identified knowledge gaps and the lack of clarity for decision-making are similar to the theme found by Caress that individuals felt that they lacked adequate knowledge (Caress, 1997).

Concepts expressed by subjects demonstrating autonomy and fidelity in this study were similar to Kelly-Powell's observation that patients made choices that were congruent with their views of themselves and the context of their lives. Themes identified by Kelly-Powell included the importance of family and personal events, relationships with others, and anticipation of the future (Kelly-Powell, 1997). The same content was found in this study in both baseline interviews and discussions during the intervention.

Whittaker and Albee identified consideration of factors that were considered valuable in their lives as a key component of decision-making in their study. These factors included lifestyle, autonomy, work, leisure, and relationships with others (Whittaker & Albee, 1996). These same factors were found to be part of the experience of subjects in this study, in their expressions of the concepts of fidelity, autonomy, freedom, beneficence, and self-assertion.

Unlike findings in the literature, this study did not demonstrate any identified barriers or constraints to decision-making perceived by subjects. All but one subject in this study indicated that they felt their choices were completely voluntary, and there were no barriers to voluntary choice. Sainio, Eriksson, and Lauri (2001) identified problems with information and lack of time in decision-making as obstacles in their study. Here, these factors were evident in the situations experienced by subjects, but were apparently not perceived by the subjects as obstacles. Rather, these factors were just experienced as part of the situation, or context, of the decisions.

Findings Regarding Relationships Among Variables

Various statistical procedures were performed to analyze the relationships among independent, intervening and dependent variables of interest in this study. This analysis was done to evaluate the ways in which variables were associated with decision-making role preference and the experience of being involved in decision-making. Previous findings reported in literature pointed to the importance of independent and intervening variables in the phenomenon of health care decision-making. Examination of interrelationships among demographic variables, decision-making role preference, baseline BDMPSP scores and BDMPSP difference scores demonstrated only a few significant relationships with age and education.

Influence of Age

Age was significantly related to baseline BDMPSP sub-scale scores for the dimensions of frustration, knowledge and anger. This was an inverse relationship, indicating that older patients tended to experience less frustration, less anger, and less feeling of having insufficient knowledge. Several authors have previously shown that

older patients tended to desire less information (Deber, Kraetschmer, & Irvine, 1996). The finding in this study that older subjects felt less knowledge insufficiency may have reflected less perceived knowledge need.

There was no relationship found between age and decision-making role preference. As discussed in the review of the literature, several studies have reported a significant relationship between age and decision-making role preference or desire for involvement in decision-making (Arora & McHorney, 2000; Beisecker, 1988; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Deber, Kraetschmer, & Irvine, 1996; Degner & Sloan, 1992; Ende, Kazis, Ash, & Moskowitz, 1989; Mazur & Hickham, 1996; Nease & Brooks, 1995; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning & Swanson, 1995).

Although relationships between age and desire for involvement in the decision-making reported in the literature were statistically significant, the correlations reported were very weak. In one study, the amount of the variance explained by age in regression analysis was only 9.5% (Ende, Kasiz, Ash & Moskowitz, 1989). Degner and Sloan reported that age was a predictor of decision-making role preference, but the correlation was weak ($r = .15$) (Degner & Sloan, 1992). Nease and Brooks reported that age was a significant predictor of decision-making involvement. However, in their study the entire prediction model, which also included current employment, gender, and education, demonstrated an r^2 of .08. Their entire model explained only 8% of the variance in decision-making involvement scores (Nease & Brooks, 1995).

The differences seen between findings of the study reported here and the literature have several possible explanations. Methods of measurement of decision-making role preference and involvement in decision-making differed somewhat in these studies. In several reports in the literature, measurement of role preference in decision-making was done using scenarios, rather than using a sample of subjects actually involved in a health care decision. Previous studies showed that role preferences and desire for involvement in health care decision-making differed when subjects were actually involved in such decisions (Degner & Sloan, 1992; Stigglebout & Kiebert, 1997). Clearly, being in the situation of involvement in an actual decision would change the context of decision-making. As pointed out in Symphonology the context of the decision is part of the experience, and an aspect that defines decision-making.

Quantitative reports in the literature generally involved much larger sample sizes and broader range of ages, than was used in the study reported here. In this study, the age range of subjects was purposefully limited in order to reduce the potential effects of age as an intervening variable. Study findings suggest that this strategy was successful.

The broader age range found in the literature may have allowed for greater differentiation of findings in association with this variable. This is a reasonable explanation, particularly keeping in mind the fact that size and strength of relationships found in published studies were weak. The sample size of 30 in this study was not large enough to produce statistically significant results for very weak relationships.

It is also possible that in more recent times, there is less influence of age on role preferences. Most of these studies from the literature are now over 10 years old. More

recent attention to patient involvement in decision-making and availability of health related information to individuals of all ages may have affected an actual change in any such relationship. This potential explanation is supported by findings from a more recent report by Ramfelt, Bjorvell, and Nordstrom in which age was not related to decision-making role preferences (Ramfelt, Bjorvell, & Nordstrom, 2000).

Influence of Education

In this study, education was significantly related to total BDMPSP difference scores. This finding suggests that the intervention was more effective in subjects who were more educated. This is similar to findings by Street and others that demonstrated younger and more educated subjects were more active participants in their intervention to increase involvement in decision-making (Street, Voigt, Geyer, Manning, & Swanson, 1995). If more educated subjects were more active in their participation in the intervention for this study, it may have been more effective for them than it was for others. Due to the nature of the intervention tested here, more active participation was likely to be more of an internal process than an observable phenomenon.

In this study there was no relationship between education level and decision-making role preference found. This is in contrast to reports by Hack, Degner, and Dyck (1994), Nease and Brooks (1995) and Mazur and Hickham (1996), who found an association between educational level or amount and decision-making role preference.

The average education level of subjects in this study was slightly higher than that reported by others. In Mazur and Hickam's study the mean years of formal education was 12.7 ± 2.73 (Mazur & Hickham, 1996), compared to the mean years of education of 13.2 ± 2.19 seen here. Nease and Brooks reported that 51% of their sample had more

than a high school education (Nease & Brooks, 1995). In this study 53% of the sample had more than a school education. It cannot be determined from these data if such small differences in this characteristic of the sample are meaningful.

Role Preference Findings

There were few differences found in the proportions of the sample that desired active, collaborative, or passive decision-making roles, from those that have been reported in the literature. Across all studies from the literature where similar methods for measuring decision-making role preference were used, the percentage of subjects who desired active styles ranged from 10.5% to 44%. The percentage of subjects who reported a collaborative role preference ranged from 28% to 68%. Reports of those who preferred a passive role in decision-making ranged from 8.9% to 80%. (Arora & McHorney, 2000; Beaver, Luker, Owens, Leister, & Degner, 1996; Caress, 1997; Hack, Degner, & Dyck, 1994; Maxur & Hickham, 1996; Orsino, Cameron, Seidl, Mendelsohn, & Stewart, 2003) In this study, 40% preferred an active role, 53.3% preferred a collaborative role, and only 6.7% preferred a passive role.

Results reported here demonstrated a smaller proportion of the sample that preferred a passive decision-making role. It is possible that, since subjects who participated in the study knew that they would be involved in interviews and an intervention, the sample was initially biased toward individuals who were interested in being involved in decision-making. Most of the studies in the literature did not involve such highly personal interactions around decision-making.

Across all studies, the variability seen in decision-making role preferences reported was broad. When studies are included that looked at preference for

involvement in decision-making with a slightly different method, the variability is even greater. Cassileth and others (1980) found that up to 87% of their sample indicated a desire for active involvement in decision-making (Cassileth, Zupkis, Sutton-Smith, & March, 1980). In their study involving end-of-life decision-making, Heyland and others concluded that the variability in patient choice could not be accounted for by demographic or symptom covariates (Heyland, Tranmer, O'Callaghan, & Gafni, 2003). This points to the complexity of this phenomenon, and the highly individual nature of actual role preference. Arora and McHorney pointed out this variability and concluded that actual role preference was highly individual and would need to be approached in an individualized way (Arora & McHorney, 2000).

Differences in role preferences seen here from those reported in the literature may also be due to the fact that the sample in this study was selected at the time of being involved in a decision. Many of these other studies did not involve this specific time point, and some measured role preference using scenarios rather than real life situations.

The setting in which this study was done is also likely to have influenced these results. In this study, subjects were hospitalized for acute care. Their decisions had immediate and long-term implications of an ethical nature. Their decisions involved important and meaningful life events, and, at the same time, many of these decisions had to be made quickly. The combination of these factors can be expected to create a high stress, high pressure situation in which decision-making cannot be avoided or delayed. The urgency of the need to make a decision may have influenced the individual's desire and need to play an active role in decision-making. Although

Heyland, and others also studied patients during hospitalization, they used decision-making vignettes for data collection, rather than actual decisions that were being considered by subjects (Heyland, Tranmer, O'Callaghan, & Gafni, 2003).

Subjects in the study reported here also had more varied situations. Studies reported in the literature were focused on groups of patients within a single type of disease, or similar type of decision. A large proportion of this study sample was making decisions about lifestyle and living arrangements after discharge. This type of decision may elicit more active involvement, since this type of decision is not technical, and may be more understandable and personal to the individual. Biley (1996) reported that patients were much more interested in being involved in these types of decisions, rather than more technical ones such as which specific drug to use or test to perform during hospitalization.

Effect of the Intervention

Overall, there was a highly significant positive change in the experience of subjects after the intervention. These results were not apparently influenced by decision-making role preference, and there were few relationships between demographic variables and BDMPSP difference scores. It did appear that the clarity of the decision that subjects were considering was influential in terms of the overall effect of the intervention.

The significant differences found in total BDMPSP difference scores between the group of subjects that had very clear alternatives from which to choose and the group of subjects for whom the decision was more abstract suggests that decisional clarity is an important variable in this phenomenon. Where subjects had clear alternatives, it was

possible to be much more specific in identifying approaches to resolve knowledge gaps and plan specific actions to aid in making the decision during the intervention. The importance of knowledge in patients' health care decision-making has been previously discussed in detail, and has been well documented in the literature. Findings regarding the importance of the clarity of the decision are in concert with results in the literature regarding knowledge. However, the concept of decision clarity as identified in this study has not been previously described.

It is difficult to compare the effects of the intervention used here with findings from other studies reported. Most interventions reported previously were purely informational or educational in nature and did not incorporate highly individualized procedures designed to assist an individual through the actual decision-making process. In addition, the outcome variable of interest that was studied here was very different from those examined by others. In this study, the outcome variable examined was the individuals' experiences of being involved in decision-making as measured via the 10 dimensions and overall experience using the BDMPSP. In other intervention studies the dependent variables measured were knowledge (Barry, Cherkin, Chang, Fowler, & Skates, 1997; Rothert et al., 1997; Schapira, Meade, & Nattinger, 1997) involvement in decision-making, (Davison & Degner, 1997; Greenfield, Kaplan, & Ware, 1985; Street, Voigt, Geyer, Manning, & Swanson, 1995), decisional conflict (O'Connor et al., 1998), or treatment choice (Liao et al., 1996).

Most qualitative reports did not involve the testing of a specific intervention. These do not allow for full comparison of results. However other research does support

the importance of highly personal and individualized interventions as were provided to subjects here (O'Connor et al., 1999).

V. SUMMARY AND RECOMMENDATIONS

In this chapter, the entire research is summarized and recommendations for future research are identified. Summarization of the research synthesizes what has been learned as well as potential explanation of study findings related to the study purpose, the sample, the nature of decisions and decision-making, study limitations and recommendations for future study in this field of inquiry. Further discussion of the study purpose reviews results of theory testing as well as the analysis of independent and intervening variables that influenced the findings. Key characteristics of the sample and sample selection procedures are reviewed. Observations and conclusions about the nature of decisions and decision-making learned in the study are discussed. Limitations of the study related to the sample, setting and study design are discussed. Finally, recommendations for future research in the area of patient decision-making are identified from what was learned in this study

A. Study Purpose

The purpose of this study was to test Symphonology theory by determining if: 1) the concepts in Symphonology were expressed as part of the experience of subjects involved in decision-making about their health care and treatment, and 2) if an educational/counseling intervention utilizing Symphonology theory would make a difference in the experience of being involved in decision-making as measured by pre and post BMDSP scores and subjects' responses in interviews regarding the

helpfulness of the intervention. Triangulation of qualitative and quantitative methods was used to answer related study questions.

This study also explored the relationships among demographic variables, decision-making role preference, the experience of being involved in decision-making, and the changes in the experience of subjects associated with the intervention. Variables that had been shown in previous research to be important correlates of involvement and role preference in decision-making were included in this study. Findings in this area differed somewhat from those seen in the literature. These differences were discussed in detail in the previous chapter. Such differences may be explained by variation in methods and sampling procedures used.

Results of Theory Testing

Qualitative analysis demonstrated that subjects did express the concepts in Symphonology in baseline interviews. Quantitative analysis demonstrated a statistically significant difference between pre and post-intervention total BDMPSP scores and a positive directional change in all but one BDMPSP sub-scale score. Most subjects also stated that they found the intervention to be helpful to them during post-intervention interviews.

These study findings supported the propositions derived from Symphonology that were initially outlined in Chapter I. As outlined in the first proposition, if Symphonology describes the nature of man and the essential elements of bioethical decision-making, then key concepts of the theory should describe the experience of individuals making health care decisions. Study subjects expressed the bioethical standards of Symphonology in their experiences in baseline interviews; therefore,

Symphonology does describe the nature of man and essential concepts in bioethical decision-making.

The second proposition originally proposed was that if application of Symphonology would enable the nurse to make ethically justifiable decisions, then it should do the same for patients. The decision-making theory would be sufficient, if its use resulted in a more positive experience of being involved in bioethical decision-making. Triangulation of quantitative and qualitative results demonstrated that overall, subjects had a positive directional change in their experiences. Overall, the intervention appeared to be sufficient. However, the use of the intervention used here did not appear to be sufficient for that subset of subjects who did not have clear alternatives for decision-making. For these subjects, the contextual component of knowledge of the situation appeared to play a major role in the degree to which the process was sufficient to improve their experience. The specificity of that knowledge, in order to yield a clear either-or choice in decision-making was a significant factor.

These results suggest that Symphonology is valid and has utility for clinical practice. The results also point to the importance of the context of knowledge within the theory and in patient decision-making. While the intervention tested here was effective for most subjects, it was not as effective with those who lacked definitive alternatives for choice. This suggests that future interventions based on Symphonology may need to be designed somewhat differently, taking this factor into account. As the decision context changes for patients continuing decision support could be provided.

Analysis of Independent, Intervening Variables and the Outcomes

Age and education were not related to subjects' preferences for active, passive, or collaborative decision-making roles in results of this research. This finding was in contrast to that of others (Adams, Smith, & Ruffin, 2001; Arora & McHorney, 2000; Blanchard, LaBrecque, Ruckdeschel, & Blanchard, 1988; Caress, 1997; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Davis & Hoffman, 1999; Degner, et al., 1997; Degner & Sloan, 1992; Ende, Kazis, Ash, & Moskowitz, 1989; Hack, Degner, & Dyck, 1994; Mazur & Hickam, 1996; Nease & Brooks, 1995; Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003; Stigglebout & Kiebert, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995).

Although age did not show the same relationships that were reported by others, in this study, age did emerge as a significant variable related to the baseline experience of being involved in decision-making overall and in a few dimensions of the instrument used. These study findings indicated that age was directly related to a more positive experience. One can speculate that the older one is, and therefore, the more life experiences and health issues one has had, the more one can accept being involved in these decisions with a less negative perspective.

Similarly, the variables of years and type of formal education did not demonstrate the same relationships seen in other reports in the literature with decision-making role preference (Adams, Smith, & Ruffin, 2004; Degner et al., 1997; Ende, Kazis, Ash, & Moskowitz, 1989; Hack, Degner, & Dyck, 1994; Nease & Brooks, 1995). Findings from this study, however, did show a relationship between education and BMDPSP difference scores. This suggests that the intervention used here may be most effective with individuals who have more formal education.

B. Sample Selection and Characteristics

The sample was planned for inclusion of a limited age range for subjects. This was done in order to reduce the potential confounding effect of age on examination of differences in the experience of being involved in decision-making before and after the intervention. It was presumed that if large age differences were included in the sample, it would be difficult to determine changes associated with the intervention versus changes associated with age.

This strategy appeared to be effective since age was not significantly related to BMDSP difference scores found in the study. The age restriction used, however, does limit the applicability of study findings and may have contributed to the fact that there was no relationship found in this study between age and decision-making role preference. This particular finding varies from the predominance in the literature in which age has often been related to role preference and degree of involvement in decision-making.

It is interesting to note that some more recent studies reported in the literature have also failed to show significant associations between age and the variables of interest in this study (Davison, Parker, & Goldenberg, 2004; Fraenkel, Bodarus, & Wittink, 2001; Gattellari & Ward, 2006; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Ramfelt, Bjorvell, & Nordstrom, 2000; Davison). This points to the possibility of a real change in society. As individuals are living longer and as there is more information in the public sector related to health care, treatments, and the importance of being involved in decisions about health care and treatment, the influence of age may be disappearing.

Previous research in the area of decision-making often involved subjects who responded to decision-making scenarios, rather than actual lived experience, and some studies suggested that involvement in decision-making was different when patients were actually involved in decisions (Degner & Sloan, 1992; Stigglebout & Kiebert, 1997). For this reason every effort was made in this research to study patients while they were actually facing decisions about care and treatment. It was felt that this situation would provide a more meaningful and realistic test of the intervention, and hence, the theory being tested. The acute care setting was used for this study, since it was expected that patients in this setting would be facing real decisions, and thus available to the investigator for recruitment. For the most part, these expectations were found to be valid, however these aspects of study design created their own difficulties and limitations.

C. The Nature of Decisions and Decision-Making

Despite the attempt to select subjects at the point of actual decision-making, not all decisions being considered involved definitive selection of one course of action versus another. The variation seen in the clarity of decisions in which subjects were involved was an unexpected and significant finding. Analysis of differences in pre and post-intervention BMDSP scores between the groups of patients with clear decision versus those for whom decisions were less clear demonstrated that the clarity of the decision was a significant variable that probably influenced the results of the intervention. This is a reasonable conclusion, since subjects who lacked definitive alternatives for decision-making were not able to make completely definitive conclusions

and plans during the intervention. Similarly, this subgroup of patients had a greater insufficiency of knowledge prior to the intervention. They did not know exactly what choices of treatment they would have, in order to make a concrete choice.

These study findings suggest that for interventions aimed at improving involvement in health care decision-making, the timing of the intervention may be critical to its effectiveness. It is likely that intervention to assist patients in making decisions can be most effective when there are clear alternatives from which to choose. Distilling health care decisions into concrete "either-or" alternatives for patients may be extremely important in order to facilitate decision-making and increase patient involvement in the process. Continuing provision of interventions to facilitate and support decision-making would also be beneficial to patients as the context of decisions changes.

The speed with which situations and decisions changed for subjects was unexpected. Even though the study was designed to attempt to minimize the effect of time on study observations, and interventions and post-intervention follow-up were consistently done within a short period of time, the situations for some subjects changed drastically within this brief time period. As new diagnostic information was received, and new problems emerged, the context of decisions was changed. In some cases, the changing context of the decision contributed to lack of clarity of decisional alternatives. This aspect of the nature of decision-making suggests that interventions to facilitate decision-making need to be ongoing, so that patient support evolves in concert with the changing context of the decision.

A few subjects were discharged from the hospital too quickly to be available for post-intervention data collection. Some subjects developed additional problems and

new diagnoses that complicated their experiences within this timeframe. This factor can be expected to have confounded study findings. However, the extent to which this was the case cannot be determined.

It is likely that this aspect of the phenomenon examined was related to the fact that the study was performed in an acute care setting. In this setting, patients are acutely ill and often unstable physiologically. With current emphasis in acute care on eliminating delays in treatment and reducing length of stay, patients move through hospitalization quickly and decisions about treatment and discharge occur rapidly. In some respects working with patients around decision-making in this setting had the flavor of crisis intervention.

Recognition of the dynamic, individual, and complex nature of health care decision-making was one of the most personally compelling observations from this study. Decision-making rarely involved a single decision, and subjects' lived experiences of decision-making involvement were expressed in terms of multiple interdependent concepts. Decision-making did not so much involve making choices at a single point in time as it involved a cascade of interrelated decisions with both present and future orientation. Even subjects who were making similar decisions, such as return to home versus placement in a skilled facility, experienced this in very different ways. The nature of decision-making was truly reflective of the individuality and complexity of human life. The use of Symphonology as the organizing framework for the intervention used in this study was particularly valuable because of the ability to provide an intervention that was highly individual and personal, incorporating the uniqueness and desires of the person at hand.

One of the main aspects in the dynamic nature of decision-making that was observed was the changing context in which decisions were being made. This was found with those subjects who found that they had additional health problems and new diagnoses between the time of the intervention and the follow-up data collection. This observation reflected the importance placed on context in Symphonology theory.

D. Limitations

This study had several limitations, some of which can be rectified in future studies. The selected age range of the sample, while useful to reduce potential confounding results, also limits the application of findings to this age group. It is likely that different age groups may demonstrate difference role preferences and effects of this type of intervention. Certainly the individuals' uniqueness, important aspects of life, desires, and experience of being involved in decision-making can be expected to differ according to age. This may be true, not so much because of age itself, but from the factors that make up one's life in different life phases that tend to go along with age. Family concerns, responsibility of caring for elderly patients, looking forward to the independence of children and grandchildren, and concerns about ability to return to work were found because subjects in this study were of the age where some were still working, their parents were now elderly and needed their help, and they were old enough to have grandchildren.

The dynamics involved in the experience of decision-making can be expected to differ according to these aspects of the individual's life. Similar results were reported by Orsino and others, who reported age related differences in the types of information that

subjects wanted. The types of information desired by different age groups in that study were reflective of the differing aspects of their lives, such as the greater interest in information about sexual activity and physical appearance in younger subjects (Orsino, Cameron, Seidl, Mendelsohn, & Stewart, 2003).

The study was also limited by the setting in which it was done. As previously discussed, the acute care hospital setting is likely to provide situations of immediacy and uncertainty as well as the sense of urgency created by the rapid change in events and decisions to be made. Individuals involved in decisions in other circumstances and settings may respond differently. The effectiveness of the intervention could have been influenced by this timing. A situation in which an individual has more time to consider the decision may yield different results.

The lack of clarity of some decisions was a limiting factor. Given the results that demonstrate significant differences between subjects grouped according to the clarity of the decision were found in total BDMPSP difference scores, it is likely that the intervention would be more effective if used in subjects who were only facing very clear choices. While the sample size used in this study was sufficient to adequately test the study questions as initially posed, if those subjects who did not have clear alternatives were removed from the analysis, the resulting sample would have been too small to detect significant differences. This limitation, from a quantitative perspective, was mitigated to some extent by the triangulation with qualitative findings used in this study.

The use of qualitative methods also carries with it some inherent limitations. As pointed out by Munhall and Boyd:

Despite the development of a variety of strategies to make the process of analysis explicit and reproducible, there remains a fundamental ambiguity that is inherent in the creativity of the process...It remains, regardless of the strategies employed to systematize it, a unique rendering of the meaning(s) of the phenomenon under study (Munhall & Boyd, 1993, p. 443).

Specific qualitative findings from this study are not necessarily applicable to other patients in other situations, making different types of decisions.

E. Recommendations for Future Research

The statistical significance of study findings points to the worth of future studies testing this type of intervention and the use of Symphonology theory. Study limitations identified point to the areas that should be considered in future research to continue to expand our understanding of the phenomenon of health care decision-making and the relationships among variables examined here in this phenomenon.

Future studies using Symphonology theory should be done in different age groups and larger samples of patients. Replication of these approaches within more defined samples according to disease type and specific decision being considered could further demonstrate the degree to which an intervention based upon Symphonology theory is useful and valid for various groups of patients. Testing the effectiveness of this intervention in an experimental design is also a logical next step.

Findings related to the effectiveness of the intervention and clarity of the decision suggest that refinement of the intervention and different timing of the intervention should be considered. There may be ways to improve the intervention in the area of assisting

patients to obtain clear alternatives for decision-making. Similarly, further study including only subjects who have clearly stated either-or choices for care and treatment would eliminate one of the limitations of this study.

Given the differences in results and approaches reported in the literature with various types of interventions to increase involvement in decision-making, it would be interesting to directly compare this intervention with others that have been tested. The power of Symphonology theory could also be explored by comparing results of this type of intervention with results of an intervention with a different theoretical basis by randomly assigning subjects to different treatment groups.

The dynamic nature of health care decision-making suggests that it may be useful to develop interventions to teach patients this decision-making process so that the individuals could use this approach without the direct involvement of a facilitator, as the decisions they are facing continue to change. Similarly, patients might benefit from ongoing facilitation of the decision-making process over a longer period of time, rather than the single point of intervention used in this study.

F. Implications for Nursing

The results of this study have implications for nursing at both the professional and practice levels. On the professional level, these findings provide support for the validity and utility of a nursing theory. These results are helpful to advance nursing science.

Findings of this research also point to a mechanism by which a nurse can fulfill the professional responsibility to function as a patient advocate and can facilitate patients' decision-making about their care and treatment. Symphonology theory, and

the intervention used in this study can provide a framework for nurses to assist patients to work through the actual decision-making process in order to have a more positive experience. On average, the intervention took less than 30 minutes, making it practical for application in clinical practice

G. Conclusions

Symphonology theory is supported by the results of this research. The use of Symphonology theory as the foundation of an intervention to assist patients in decision-making is particularly suitable because it allows for complete individualization of the intervention within an overall structure and process. Both qualitative and quantitative findings from this study and other authors have pointed to the highly variable and individual nature of decision-making as a phenomenon.

The triangulation of qualitative and quantitative methods was also particularly appropriate for investigation of this phenomenon. The ability to confirm quantitative results with qualitative findings was helpful, due to the fact that decision-making is extremely dynamic and complex. It was particularly valuable to have a quantitative tool to measure the individual's experience of being involved in decision-making that could be confirmed with qualitative findings. In addition to demonstrating support for the overall theory of Symphonology, this study also provided further evidence as to the reliability, validity and usefulness of the BDMPSP instrument.

Study findings suggest that this theory and the intervention used can be useful in clinical nursing practice. In most cases the intervention facilitated actual decision-making and resulted in a more positive experience for the subject. On average, the

intervention took less than 30 minutes, making it practical for real world application. In today's acute care environment where delays must be avoided and patient satisfaction with the health care experience is of ever-increasing importance, this type of intervention may be very beneficial.

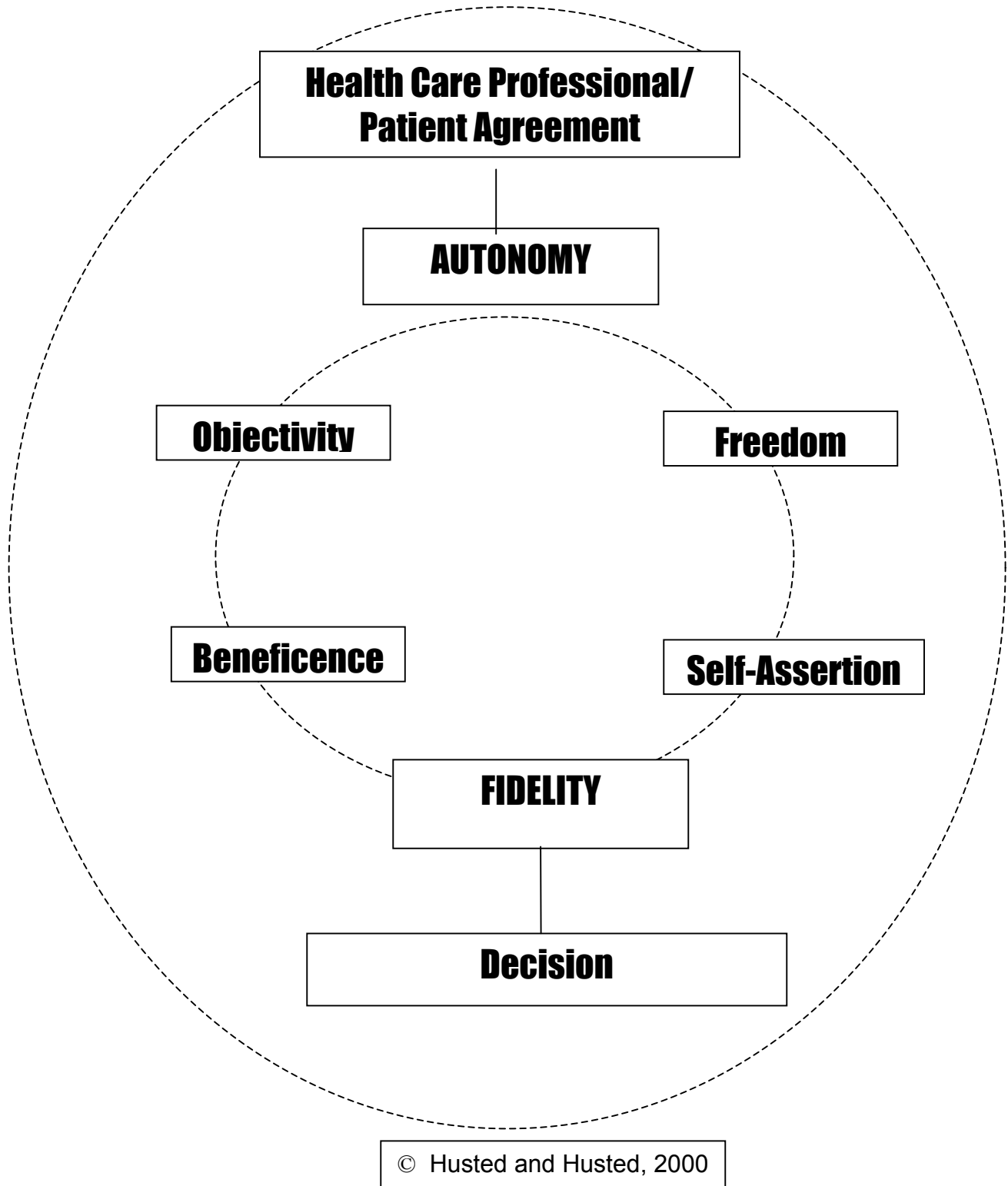
The clarity of decisions that individuals were facing was a key factor related to both decision-making role preference and the effect of the intervention used here. Study findings related to decision clarity suggest that health care providers should attempt to provide patients with clear either-or alternatives in order to facilitate patient decision-making and desire for involvement in decisions.

It is hoped that this study may provide a model that can be used by others for theory testing. Testing nursing theory is an important and essential scientific endeavor for nursing in order to advance our knowledge as a profession and apply valid theoretical concepts to clinical practice in order to benefit our patients.

APPENDICES

APPENDIX A

Husted's Symphonological Bioethical Decision Making Guide



APPENDIX B

Patient Demographic & Disease Related Questionnaire

Study Subject (study code _____)

1. Age: _____yrs.
2. Gender: M F
3. Total years of formal education: _____yrs.
4. Education Type:
 - 1)less than high school completion
 - 2) high school completion
 - 3) some post-secondary education
 - 4) associate level degree
 - 5) college or university degree
 - 6) some graduate education
 - 7) graduate level degree
5. Current Marital Status: 1)single 2) married 3)divorced 4) widowed
6. Ethnic/Race: 1) Caucasian 2) Afro-American 3) Asian- American 4) Hispanic 5) Other _____(describe)
7. Principal diagnosis _____ICD9-cm code
Code description _____
8. Time since diagnosis:
 - 1) <1 month 2) < 1 year 3) 1-3 years 4) 3-5 years 5) > 5 years

APPENDIX C

Role Preference Tool

Directions: Place a number from 1 to 5 next to each of the following statements about how you would prefer that your health care decisions are made, where **1** is your **most** preferred and **5** is your **least preferred** decision making approach.

Number/

Rank Order

_____ **A.** I prefer to make the final decision about which treatment/*what care* I will receive

_____ **B.** I prefer to make the final selection of my treatment/*decision about my care* after seriously considering my doctor's opinions.

_____ **C.** I prefer that my doctor and I share responsibility for deciding which treatment/*what care* is best for me.

_____ **D.** I prefer that my doctor makes the final decision about which treatment will be used/ *what care will be provided*, but seriously considers my opinion.

_____ **E.** I prefer to leave all decisions regarding my *care and* treatment to my doctor.

APPENDIX D

Bioethical Decision Making Perception Scale for Patient/Family (BDMPSP)

Bioethical decision making occurs in healthcare situations where choices are difficult and involve: 1) the potential for harm; 2) the difficulty of choosing the right thing to do; 3) the difficulty of selecting what is good and not good in the situation. This questionnaire will ask for you to identify the feelings that you are experiencing in regard to your current situation

Directions: There are 10 items on the questionnaire. Each item asks you to identify the feelings and the intensity of these feelings that you are experiencing as you are involved with your current healthcare situation. Each item contains two words. The words are each placed at the right or left end of a line. To identify the intensity of the feeling that you are experiencing, place a small vertical line somewhere along the horizontal line that would best describe the feeling. This is shown in the example below. Please place only 1 mark on each line and do not skip any item.

Your mark may be placed at any position on the line to describe your own personal feelings. There is no right or wrong answer. Each person who completes this tool may respond differently based on the conditions in which the experience occurs.

For example:

When I think of snakes I experience the feeling of:

No fear _____ | _____ Fear

By placing the mark at the far right end of the line it signifies that the person feels great fear when thinking of snakes.

Please turn to the next page to complete this tool.

**Patients'/Families' Feelings
Regarding Involvement with a Bioethical Dilemma (s)**

When I was involved in this difficult healthcare situation I experienced the feeling of:

- | | | |
|------------------------------|-------|------------------------------|
| 1. Absence of Frustration | ----- | Frustration |
| 2. No Guilt | ----- | Guilt |
| 3. No Anger | ----- | Anger |
| 4. Hope | ----- | No Hope |
| 5. Ability to Make Decisions | ----- | No Ability to Make Decisions |
| 6. Support from Staff | ----- | No Support from Staff |
| 7. Control | ----- | No Control |
| 8. Sufficient Knowledge | ----- | Insufficient Knowledge |
| 9. Agreement with Decisions | ----- | Disagreement with Decisions |
| 10. Power | ----- | Powerlessness |

Thank you for your help

APPENDIX F

Post Intervention Interview Schedule

This interview is to be completed within 72 hours after the intervention. The goal of this session is to obtain the patient's brief description of his current experience related to his decision making. Follow up here should include determining any outstanding information needed by the patient.

I wanted to follow up with you to find out how your are doing with your decision making, and whether or not you think our previous conversation helped or didn't help you.

1. *If relevant:* Have you been able to obtain the information you previously needed?
2. Tell me how things are going for you...what decisions have you made...what issues are you struggling with.
3. Tell me about your thoughts and feelings now, regarding being involved in this situation and regarding the decision you've made/ you are making.
4. Do you think our previous conversation about this decision was helpful to you at all in making your decision? Can you tell me more about that.....

APPENDIX G

ID

Decision Support Intervention Guide

This section is begun immediately after the pre test interview if the subject is able to continue the interview at this time. This section is not tape-recorded. If a break is needed, this section is begun within 48 hours of the initial interview. The purpose of this session is to guide the patient through the decision making theory of Symphonology.

If this session is done immediately after the pre test interview, skip to Question 2.

1. To summarize, give me an overview of the current decision you are making, and the choices you have.

Choices/ Alternatives being considered:

2. How will this decision impact you personally?

Probes;

- ◆ What are some of the things about you that you think are important and unique to you as a person? How do your current choices affect these things?

- ◆ What are the important aspects of your life - your long term desires? How does your choice affect these? (autonomy...maintaining uniqueness, freedom, fidelity)

- ◆ How do you think the alternatives would each benefit you? Are there any ways in which alternatives would harm you, or create a negative situation? (beneficence)

3. Do you feel that you are able to make a completely voluntary choice? *If relevant:* Tell me about the things that hamper your decision making? (self-assertion)

- ◆ If relevant, assist patient to identify ways in which he/she could increase own effectiveness, and remove current barriers.

Issue/Barrier	Approaches to Remove or Resolve

4. Do you think that you have all of the knowledge and information you need to make a decision that is right for you? (objectivity)

- ◆ As needed, assist patient to identify gaps in knowledge and information and define actions to be taken to obtain that information.

Knowledge/Information Needed	Approach to Obtain

5. Lets take a closer look at the specific choices/alternatives you have right now - what are the benefits and negative impacts?

Choice A _____

Benefits	Negatives	Other impacts or related issues

Choice B _____

Benefits	Negatives	Other impacts or related issues

Choice C _____

Benefits	Negatives	Other impacts or related issues

6. Is there anything else that you want to discuss at this time?



University of Pittsburgh

Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
412-578-3424
Fax: 412-578-8553

MEMORANDUM:

TO: Margaret M. Irwin, R.N., M.N.

FROM: Christopher Ryan, Ph.D., Vice Chair *CR/ay*

DATE: August 13, 2002

SUBJECT: IRB #020843
*Patient Experiences of Health Care Decision Making:
Application of Symphonology Theory*

The above-referenced proposal has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110 (7).

Approval Date: August 13, 2002

Renewal Date: August 12, 2003

Please be advised that only the IRB approved and stamped consent form can be used to make copies to enroll subjects. If you did not include an original, un-highlighted consent form with this submission, please forward one to the IRB with a copy of this letter to have it stamped.

Adverse events which occur during the course of the research study must be reported to the IRB Office. Please call the IRB Adverse Event Coordinator at 578-8569 for the current policy and forms.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the expiration date noted above for annual renewal as required by Assurance No. IORG0000196, given to DHHS by the University of Pittsburgh.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR/ay




University of Pittsburgh

Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 578-3424
(412) 578-8553 (fax)

MEMORANDUM:

TO: Margaret M. Irwin, RN, MN

FROM: Christopher Ryan, Ph.D., Vice Chair 

DATE: July 29, 2003

SUBJECT: IRB #020843: Patient Experiences of Health Care Decision Making:
Application of Symphonology Theory

Your renewal of the above-referenced proposal has received expedited review and approval by the Institutional Review Board under 45 CFR 46.110 (7).

Please include the following information in the upper right-hand corner of all pages of the consent form:

Approval Date: July 29, 2003
Renewal Date: July 28, 2004
University of Pittsburgh
Institutional Review Board
IRB #020843

Adverse events which occur during the course of the research study must be reported to the IRB Office. Please call the IRB Adverse Event Coordinator at 578-8565 for the current policy and forms.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the expiration date noted above for annual renewal as required by Assurance No. M-1259 given to DHHS by the University of Pittsburgh.

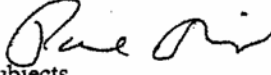
Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:cc



Duquesne University
Institutional Review Board
MEMORANDUM

To: Margaret Irwin

From: Paul Richer, Ph.D. 
Chair, IRB - Human Subjects
403 Administration Building

Re: Protocol #02/40 - "Patients' experiences of health care decision making - application of symphonology theory.

Date: July 19, 2002

Thank you for submitting your proposal to the IRB and for contributing to Duquesne's research endeavors.

Based upon the Department of Health and Human Services (HHS) regulations for the Protection of Human Subjects (45 CFR 46) as amended; 56 FR 28003, June 18, 1991), I have reviewed this research proposal in accordance with these procedures and those established and published in the Federal Register (46 FR 8392), January 26, 1981 for expedited review.

Based upon internal review, the recommendation of IRB members, Dr. Fedorka and Dr. Sekula, and my own review as Chairperson of the Institutional Review Board, I have determined that your research proposal is consistent with the requirements of the appropriate sections of the *Code of Federal Regulations* cited above re expedited review. Furthermore, the intended research involves minimal risk to human subjects. Your proposed research is hereby **approved** on an **expedited** basis.

You will be required to submit an annual report updating the IRB regarding the status of your research. In addition, any changes in the procedures involving human subjects prior the annual review must be brought to our attention by you. Please be advised that the DU IRB reserves the right to suspend or terminate the study if it is not conducted in accordance with the approved protocol or if any unexpected, adverse reactions arise. In the latter instance, either Dr. Sekula, as your DU IRB Representative, or myself, the DU IRB Chair, should be notified promptly. Once your study is complete, please provide the Board with a copy of the study results at the IRB address shown above.

Best wishes for your research.

C: Kathy Gaberson
Pat Fedorka
Kathleen Sekula
IRB Records



Human Participant Protections Education for Research

Completion Certificate

This is to certify that

Margaret Irwin

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 04/24/2002.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health
<http://www.nih.gov>

APPENDIX I

CONSENT FORM**TITLE: EFFECT OF SYMPHONOLOGY ON PATIENTS' EXPERIENCES OF INVOLVEMENT IN HEALTH CARE DECISION MAKING: A QUALITATIVE AND QUANTITATIVE STUDY****PRINCIPAL INVESTIGATOR:**

Margaret Irwin, R.N., M.N,
Director, Quality and Case Management Programs
South Hills Health System
Pittsburgh, Pa.
(412) 469-5975
PhD Student

Gladys Husted, R.N., PhD, Distinguished Professor
Chair, Dissertation Committee
Duquesne University
Pittsburgh, Pa. 15282
(412) 396-6544

SOURCE OF SUPPORT:

This study is being performed in partial fulfillment of the requirements for the doctoral degree in Nursing at Duquesne University

PURPOSE:

The purpose of this study is to determine if use of a specific decision making approach can be used to describe the experience of being involved in making decisions about your health care and treatment, and if an educational counseling intervention has an effect on this experience. You have been asked to participate because you are at least 50 years old, speak and read English, are competent to give your own consent to participate, and are currently involved in making a decision or decisions about your care and treatment.

Your participation in this study will involve completion of a brief questionnaire describing your age, years of education, length of time that you have had current health problems and other demographic information. You will also be asked to complete a tool to describe your decision making role preference and a tool to describe your experience of being involved in decision making at this time. You will also undergo an interview to discuss and describe your current experience. This interview will be tape recorded for later analysis. This process is expected to take about 30 minutes.

Initials ____ Date ____

You will then participate in an educational counseling session with an investigator, that is designed to assist you in evaluating various aspects of the choices I am facing. This session will be held in private, or in the presence of your spouse or other significant person to you, according to your choice. This session is expected to take between 30 and 60 minutes.

Within 72 hours after this session, you will again be briefly interviewed and asked to complete the tool to describe your experience of being involved in this decision making. This interview will also be tape recorded, for later transcription and analysis. This activity should take no more than 30 minutes.

RISKS AND BENEFITS:

There are no known physical risks associated with participation in this study. You understand, however, that discussing a difficult decision and your current situation may result in emotional discomfort. You may stop completing questionnaires or stop the interview at any time.

There are no known benefits to you as a result of your participation in this study. However, you may find that reflecting upon decisions facing you and participating in the counseling session are helpful to you. This research may help nurses and other health care professionals to better understand how to assist patients in making difficult decisions. This may benefit other patients in the future.

COMPENSATION:

Participation in this study will not involve any costs to you and that you will not receive any payment for your participation.

CONFIDENTIALITY:

Any information obtained in this research, including tape recordings and transcripts of interview sessions, will be kept strictly confidential. No information will be obtained by which your identity can be revealed, and any reference to information that could be used to identify you personally will be omitted or altered in order to protect your identity. Your name will never appear on any survey or research tool, report, or publication of research findings. Therefore, you are being asked to consent to the publication of this research for scientific purposes.

All written materials and consent forms will be stored in a locked file that only the investigator will have access to. Any individual involved in data collection or the transcription of taped interviews will sign a form in which they agree to maintain confidentiality of all information. At the completion of this research, all materials will be destroyed by the investigator.

Initials _____ Date _____

RIGHT TO REFUSE OR WITHDRAW:

Your consent to participate in this study is completely voluntary. You are under no obligation to participate, and you have the right to withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care or treatment in any way.

SUMMARY OF RESULTS:

A summary of the results of this research will be supplied to you at no cost, upon request.

VOLUNTARY CONSENT:

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this study.

Any questions that I have pertaining to the research have been and will be answered by Margaret Irwin (412) 469-5975. I understand that should I have any further questions about my participation in this study, I may call Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board (412-396-6326).

Participant's signature

Date

Participant's signature

Date

APPENDIX J

CONFIDENTIALITY FORM

I, _____ understand that I may have access to personal information provided by participants in the study entitled "EFFECT OF SYMPHONOLOGY ON PATIENTS' EXPERIENCES OF INVOLVEMENT IN HEALTH CARE DECISION MAKING: A QUALITATIVE AND QUANTITATIVE STUDY". As an interviewer or transcriptionist of the study, I recognize that I have an obligation to protect the confidentiality of the information acquired in the conduct of this study and that I may disclose information only with the consent of the subject and his/her representative, and of the principal investigator.

My signature below indicates my acceptance of this obligation and restriction on disclosure set forth above and that I realize that a failure on my part to fulfill this obligation can lead to appropriate disciplinary action.

Signature _____

Date _____

REFERENCES

- Arora, N.K., & McHorney, C.A. (2000). Patient preferences for medical decision making: Who really wants to participate? *Medical Care*, *38*, 335-341.
- Adams, R.J., Smith, B.J., & Ruffin, R.E. (2001). Patient preferences for autonomy in decision making in asthma management. *Thorax*, *56*, 126-132.
- Avis, M. (1994). Choice cuts: An exploratory study of patients' views about participation in decision-making in a day surgery unit. *International Journal of Nursing Studies*, *31*, 289-298.
- Barry, B., & Henderson, A. (1996). Nature of decision making in the terminally ill patient. *Cancer Nursing*, *19*, 384-391.
- Barry, M.J., Cherkin, D.C., Chang, Y., Fowler, F.J., & Skates, S. (1997). A randomized trial of a multimedia shared decision-making program for men facing a treatment decision for benign prostatic hyperplasia. *Disease Management and Clinical Outcomes*, *1*, 5-14.
- Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., & Degner, L.F. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*, *19*, 8-19.
- Beisecker, A.E. (1988). Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. *The Gerontologist*, *28*(3), 330-335.
- Berry, D.L., Ellis, W.J., Woods, N.F., Schwien, C., Mullen, K.H., & Yang, C. (2003). Treatment decision-making by men with localized prostate cancer: The influence of personal factors. *Urologic Oncology: Seminars and Original Investigations* *21*, 93-100.
- Biley, F.C. (1992). Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing*, *17*, 414-421.
- 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 in Medicine*, *27*, 1139-1145.
- Cahill, J. (1998). Patient participation - A review of the literature. *Journal of Clinical Nursing*, *7*, 119-128.
- Campbell, D.T., & Stanley, J.C (1963). *Experimental and quasi-experimental designs for research*. Boston: Houghton Mifflin Company.

- Camunas, C. (1994). Ethical dilemmas of nurse executives. *JONA*, 24, 45-51.
- Caress, A.L. (1997). Patient roles in decision-making. *Nursing Times*, 93(1), 45-48.
- Carper, B.A. (1992). Fundamental patterns of knowing in nursing. In L.H. Nicoll (Ed.), *Perspectives on nursing theory* (2nd ed.) (pp. 216-225). Philadelphia: J.B. Lippincott Co.
- 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.
- Chee Saw, K., Wood, A.M., Murphy, K, Parry, J.R., & Hartfall, W.G. (1994). Informed consent: An evaluation of patients' understanding and opinion (with respect to the operation of transurethral resection of prostate). *Journal of the Royal Society of Medicine*, 87, 143-144.
- Davis, A.J. (1989). Clinical nurses' ethical decision making in situations of informed consent. *Advances in Nursing Science*, 11(3), 63-69.
- Davis, M.A., & Hoffman, J.R. (1999). Impact of patient acuity on preference for information and autonomy in decision making. *Academy of Emergency Medicine*, 8, 781-785.
- Davidson, B., Vander Laan, R., Davis, A., Hirschfeld, M, Lauri, S., Norbert, A., Phillips, L., Pitman, E., Lin J.Y., & Ziv, L. (1990). Ethical reasoning associated with the feeding of terminally ill elderly cancer patients. An international perspective. *Cancer Nursing*, 13, 286-292.
- Davison, B.J., & Degner, L.F. (1997). Empowerment of men newly diagnosed with prostate cancer. *Cancer Nursing*, 20, 187-196.
- Davison B.J., Parker, P.A., & Goldenberg, S.L. (2004). Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU International*, 93. 47-51.
- Day, L., Drought, T, & Davis, A.J. (1994). Principle-based ethics and nurses' attitudes towards artificial feeding. *Journal of Advanced Nursing*, 21, 295-298.
- Deber, R.B., Kraetschmer, N., & Irvine, J. (1996). What role do patients wish to play in treatment decision making? *Archives of Internal Medicine*, 156, 1414-1420.
- Degner L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., Bilodeau, M.N., Watson, P., & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*. 1485-1492.

- Degner, L.A., & Sloan, J.A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology*, 45, 941-950.
- Dickoff, J., & James, P., (1992). A theory of theories: A position paper. In L.H. Nicoll (Ed.), *Perspectives on nursing theory*. (2nd ed.), Philadelphia: J.B. Lippincott Co.
- Ende, J., Kazis, L., Ash, A., & Moskowitz, M.A. (1989). Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine*, 4, 23-30.
- Erlen, J.A., & Frost, B. (1991). Nurses' perceptions of powerlessness in influencing ethical decisions. *Western Journal of Nursing Research*, 13(3), 397-407.
- Fawcett, J. (1992). A framework for analysis and evaluation of conceptual models of nursing. In L. H. Nicoll (Ed.), *Perspectives on nursing theory* (2nd ed.), Philadelphia: J. B. Lippincott Co.
- Fraenkel, L., Bodardus, S., & Wittink, D.R., (2001). Understanding patient preferences for the treatment of lupus nephritis with adaptive conjoint analysis. *Medical Care*, 1203-1216.
- Gattelari, M., & Ward, J.E. (2003). Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomized controlled trial. *Journal of Medical Screening* 10 (1). 27-31
- Gortner, S.R., & Zyzanski, S.J. (1988). Values in the choice of treatment: Replication and Refinement. *Nursing Research*, 37, 240-244.
- Greenfield, S., Kaplan, S., & Ware, J.E., (1985). Expanding patient involvement in care. Effects on patient outcomes. *Annals of Internal Medicine*, 102, 520-528.
- Greenfield, S., Kaplan, S.H., Ware, J.E., Yano, E.M., & Frank, H.J., (1988). Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine*, 3, 448-457.
- Hack, T.F., Degner, L.F., & Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science in Medicine*, 39(2), 279-289.
- Heyland, D.K., Tranmer, J., O'Callaghan, C.J., & Gafni, A. (2003) The seriously ill hospitalized patient: Preferred role in end-of-life decision making? *Journal of Critical Care*. 18 (1). 3-10.

- Hinshaw, A.S., (1992). Nursing science: The challenge to develop knowledge. In L. H. Nicoll (Ed.), *Perspectives on nursing theory*. (2nd ed.), Philadelphia: J. B. Lippincott Co.
- Holly, C.M. (1993). The ethical quandaries of acute care nursing practice. *Journal of Professional Nursing*, 9(2), 110-115.
- Husted, G.L., & Husted, J.H. (1991). *Ethical decision making in nursing*. St. Louis: Mosby.
- Husted, G.L., & Husted, J.H. (1995). *Ethical decision making in nursing*, (2nd ed.). St. Louis: Mosby.
- Husted, G.L. & Husted, J.H. (2001). *Ethical Decision Making in Nursing and Health Care*, New York: Springer Publishing Company.
- Husted, G.L. (2001). The feelings nurses and patients/families experience when faced with the need to make bioethical decisions. *Nursing Admin Q*, 25(3), 46-54.
- Jansson, L., & Norberg, A. (1989). Ethical reasoning concerning the feeding of terminally ill cancer patients. Interviews with registered nurses experienced in the care of cancer patients. *Cancer Nursing*, 12, 352-358.
- Johnson, S.C., & Pfeifer, M.P., and the End-of-Life Study Group. (1998). Patient and physician roles in end-of-life decision making. *Journal of General Internal Medicine*, 13, 43-45.
- Kelly-Powell, M.L. (1997). Personalizing choices: Patients' experiences with making treatment decisions. *Research in Nursing and Health*, 20, 219-227.
- King, C.A., & Miskovic, J.M. (1996). Ethical issues: A survey of perioperative nurses. *Seminars in Perioperative Nursing*, 5(2), 84-91.
- Liao, L., James, B.A., Jollis, G., DeLong, E.R., Peterson, E.D., Morris, K.G., & Mark, D. B. (1996). Impact of an interactive vvideo on decision making of patients with ischemic heart disease. *Journal of General Internal Medicine*, 11, 373-376.
- Mattiasson, A.C., & Andersson, L. (1995). Moral reasoning among professional caregivers in nursing homes. *Western Journal of Nursing Research*, 17(3), 277-291.
- Mazur, D.J., & Hickam, D.H. (1996). Five year survival curves: How much data are enough for patient-physician decision making in general surgery? *European Journal of Surgery*. 162, 101-104.

- Mazur, D.J., & Hickam, D.H. (1996). Patient preferences for management of localized prostate cancer. *Western Journal of Medicine*, 165, 26-30.
- Millette, B.E. (1994). Using Gilligan's framework to analyze nurses' stories of moral choices. *Western Journal of Nursing Research*, 16(6), 660-674.
- Morse, J.M., & Field, P.A. (1995). *Qualitative research methods for health professionals* (2nd ed.). California: SAGE Publications.
- Munhall, P.L., & Boyd, C.O. (1993). *Nursing research: A qualitative perspective* (2nd ed.) New York: National League for Nursing Press.
- Nease, R.F., & Brooks, W.B. (1995). Patient desire for information and decision making in health care decisions: The autonomy preference index and the health opinion survey. *Journal of General Internal Medicine*, 10, 593-600.
- Norberg, A. Hirschfeld, M., Davidson, B., Davis, A., Lauri, S., Lin, J.Y., Phillips, L, Pittman, E., Vander Laan, R., & Ziv, L. (1994). Ethical reasoning concerning the feeding of severely demented patients: An international perspective. *Nursing Ethics*, 1(1), 3-13.
- O'Connor, A.M., Rostom, A., Fiset, V., Tetroe, J., Entwistle, V., Llewellyn-Thomas, H., Holmes-Rovner, M., Barry, B., & Jones, J. (1999). Decision aids for patients facing health treatment or screening decisions: Systematic review. *British Medical Journal*, 319, 731-734.
- O'Connor, A.M., Tugwell, P., Wells, G.A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: Decision support framework and evaluation. *Patient Education and Counseling*, 33, 267-279.
- Orsino, A., Cameron, J.I., Seidl, M., Mendelssohn, D., & Stewart, D.E. (2003). Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry* 25. 324-331.
- Ramfelt, E., Bjorvell, H., & Nordstrom, G. (2000). Treatment decision-making and its relation to the sense of coherence and the meaning of the disease in a group of patients with colorectal cancer. *European Journal of Cancer Care*. 9. 158-165.
- Rothert, M.L., Holmes-Rovner, M., Rovner, D., Kroll, J., Breer, L., Talatczyk, G., Schmitt, N., Padonu, G., & Wills, C. (1997). An educational intervention as decision support for menopausal women. *Research in Nursing & Health*, 20, 377-387.
- Saino, C., Eriksson, E., & Lauri, S. (2001) Patient participation in decision making about care. *Cancer Nursing* 24. 172-179.

- Schapira, M.M., Meade, C., & Nattinger, A.B. (1997). Enhanced decision-making: The use of a videotape decision-aid for patients with prostate cancer. *Patient Education and Counseling, 30*, 119-127.
- SPSS Inc. (2003). *SPSS 12.0 guide*. Chicago: SPSS Inc.
- Stiggelbout, A.M., & Kiebert, G.M. (1997). A role for the sick role: Patient preferences regarding information and participation in clinical decision-making. *Canadian Medical Association Journal, 157(4)*, 383-389.
- Street, R.L., Voigt, B., Geyer, C., Manning, T., & Swanson, G.P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer, 76*, 2275-2285.
- Taylor, E.J., Ferrell, B.R., Grant, M., & Cheyney, L. (1993). Managing cancer pain at home: The decisions and ethical conflicts of patients, family caregivers, and homecare nurses. *Oncology Nursing Forum, 20*, 919-927
- Treece, E.W. & Treece, J.W.(1973). *Elements of Research in Nursing*. C.V. Mosby Co., St. Paul, Minnesota.
- Wagner, E.H., Barrett, P., Barry, M.J., Barlow, W., & Fowler, F.J. (1995). The effect of a shared decision making program on rates of surgery for benign prostatic hyperplasia. *Medical Care, 33(8)*, 765-770.
- Waltz, C.F., Strickland, O.L., & Lenz, E.R. (1991). *Measurement in Nursing Research*. F.A. Davis Co, Philadelphia.
- Walker, L.O., & Avant, K.C. (1995). *Strategies for theory construction in nursing* (3rd ed.). Norwalk: Appleton & Lange.
- Whittaker, A.A., & Albee, B.J. (1996). Factors influencing patient selection of dialysis treatment modality. *ANNA Journal, 23(4)*, 369-375.