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PERCEIVED ACTIVE PARTICIPATION IN DECISION-MAKING REGARDING BACK SURGERY AFTER EXPOSURE TO THE LUDANN EDUCATIONAL PROCESS

By

PATRICIA LOUISE BEMENT

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER of SCIENCE in NURSING

COLLEGE OF NURSING

1994

ABSTRACT

PERCEIVED ACTIVE PARTICIPATION IN DECISION-MAKING REGARDING BACK SURGERY AFTER EXPOSURE TO THE LUDANN EDUCATIONAL PROCESS

By

PATRICIA LOUISE BEMENT

This descriptive study sought to answer the research question: Is there a change in the patient's perception of active participation in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process? Active participation in decision-making was defined as being comprised of desire to participate, perception that participation was possible, and a perception that participation had occurred. Decision-making also included the sub-concepts of expectation, role clarification, accountability and shared information. A 24 item Likert Scale was developed and administered to sixteen subjects before and after exposure to the Ludann Educational Process. Statistical analysis of the data revealed an overall positive response to the intervention. However, the clinical significance was negligible since the participants agreed both before and after the intervention only increasing the strength of their agreement, rather than clarifying their original perception. Implications for nursing research and practice are presented.

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Patricia Louise Bement, RN, B.A.

1994

To the friends and faculty who never
gave up on me, staying with me all
the way through completion.

ACKNOWLEDGEMENTS

This research would not have been completed without the valuable assistance of many people. I am especially grateful to Dr. Barbara Given, R.N., Ph.D for her expertise in the research process and serving as the chairperson of this thesis committee. I owe special thanks to Jackie Wright, R.N., M.S.N. who helped me enormously and without whom I could not have done this very difficult task. I also want to thank the other committee members Rachel Schiffman, R.N., Ph.D, and Brigid Warren, R.N., M.S.N. for their infinite patience and good will through this project. Their guidance and support is greatly appreciated.

I express my gratitude to the people who kept me company during the lonely process of writing; Char Groot, Richard Bird, Cindy Brunsman, Mary Ann Desmond, Kate Peters, my sister Marcie Beck and my other sister Susan Rechner. I am especially grateful to Georgia Cecil and Megan Bronson whose patience, compassion and support allowed me to find the internal place that knew how to complete such a complex project.

I also thank Dr. Oliver Grin, M.D. and Dorothy Bouwman, R.N., M.S.N. for their generosity and creativity. Lastly, I am deeply grateful to Carol Roberts, R.N., M.S.N. for her constant enthusiasm, support, advice, and mentoring throughout the entire project. Carol, I am truly grateful. I hope I can do for another what you have done for me.

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Chapter I

The Problem

Introduction of the Study

Active participation by patient and family in health care decision-making is becoming more important. Health care consumers are demanding a greater opportunity to be heard. A growing number of health care providers realize the importance of patient's and family's active participation in the complex issues involved in health care decision-making today. Since both the consumers and portions of the health care industry know the importance of opening up the decision-making process, research that describes the patient's perception of active participation in decision-making will produce results helpful in designing and evaluating programs, models, and interventions.

The role of advanced nursing practice in both primary care and specialties is particularly important in the discussion of increasing patient and family participation in decision-making. The Clinical Nurse Specialist has traditionally promoted the patient and family as central to the health care process Nursing theory and research have promoted scholarly discussion adding to the literature related to decision-making.

The goal of this study was to describe the absence or presence of a change in the patient's perception of active participation in decision-making related to lumbar surgery after exposure to the Ludann Educational Process. The study described the patient's perception of his/her active participation. Though many factors enter into such perception (e.g. locus of control) it was not within the scope of this study to address all possible variables.

Nursing literature is rich in the description of the current revolution in health care and the resultant need for increased active participation in decision-making by patient and family. This health care revolution is being driven by a constellation of factors; the increasingly chronic nature of disease, issues of health resource constraint, profound ethical concerns associated with high technology medical care (Giloth, 1990). The late twentieth century has also seen a growing number of elderly and indigent needing care and the advent of care intensive disease processes such as AIDS and substance addicted newborns (Bramlett, Gueldner & Sowell, 1990). Estimated health care costs are projected to reach 15% of the gross national product by the end of the century (Meisenheimer, 1991). These and other authors (Orr, 1990; Conway-Rutkowski, 1982; Krouse & Roberts, 1989; Matheis-Kraft, 1990) believe changes in American health care require increased patient and family participation. Nursing scholarship and practice are charged with the mandate to develop effective and efficient interventions promoting active participation in decision-making.

Primary care is the point of entry for the patient and family into the health care system and provides a continuous on-going relationship. Fagin (1980) describes primary care as stressing effective, accessible, affordable, family oriented care that is integrated into the community. Lytle (1980) expands the definition to the following: illness prevention, happy productive parenting, growth promoting strategies, problem solving, action alternatives and mobilization of resources to live and die in harmony with self and others. Lytle (1980) states the involvement of nursing in primary care comes at the level of clinical nurse specialist. Advanced learning is required to prepare the CNS to provide specialty practice (primary care), administration and research capabilities.

Promoting active patient and family participation is of special interest to the advanced practice clinical nurse specialist in primary care. Jacobs (1990) states that the CNS offers a different and unique kind of health care service to the public. Primary care clinical nurse specialists are assumed to operate from a patient-centered model, thus providing an alternative to traditional medical practice. The general belief is that the CNS brings an additional ingredient to primary care because of her/his interest and skill in health counseling, interpersonal relationships, family dynamics, and psycho-social problems. Jacobs (1990) found that all the advanced practice nurses in her study recognized the importance of involving patients in their care. Loretta Ford (Jacobs, 1990) sees the practice of involving patients in their care as a means of helping patients become more competent to care for themselves. Jacobs (1990) summarizes that for a long time nursing practice has expressed concern that patients should be involved in their care.

Since promoting active participation is a vital and unique quality to the services provided by the primary care CNS, the research process must examine interventions which anecdotally claim to increase patient participation in decision-making. The purpose of this study is to explore a system designed to increase patient participation in decision-making. The Ludann Educational Process was developed by a neurosurgeon and Clinical Nurse Specialist to educate patients and their families about their health problems plus the surgical and recovery experience. The Ludann Educational Process also serves as a communication tool between patients and health care professionals. Ludann's education system attempts to bridge the communication gap and address patient management as opposed to disease management. The goal of the Ludann Educational Process is to put the patient at the center of his/her health care decisions through a comprehensive, structured process of appropriate illustrated monographs, pre- and post-surgical patient/family conferences, role-clarification, disease-specific models, professional education primers and teaching videos. The Ludann Educational Process is significantly linked to the Clinical Nurse Specialist's practice of primary care with a patient-centered philosophy promoting active patient and family participation in decision-making.

The Ludann Educational Process was created to promote the patient and family as active participants in decision-making and the process utilizes modalities designed to enhance patient understanding. The developers of Ludann purport to extend patient and family knowledge, allowing effective communication and collaboration among all members of the health care team. The goals are to lessen anxiety related to surgery and speed recovery. The Ludann Educational Process hopes to lessen the adversarial relationships often found among those involved in health care, and promote a collaborative alliance restoring trust between team members and the patient/family. The system is designed to promote optimal health care outcomes facilitating proactive risk management, patient adherence and accountability. The developers also state the outcomes of the process are fundamentally based on the patient's and family's increased perception of being well informed, active participants in their decision to have or not have surgery.

The purpose of this study was to describe the degree of perceived active participation in decision-making by patients exposed to the Ludann Educational Process. The research question stated: Is there a change in the patient's perception of active participation in decision-making to have lumbar surgery or not after exposure to the Ludann Educational Process?

A Likert Scale measuring the patient's perceived degree of active participation in decision-making was administered at the time of referral prior to the patient's participation in the Ludann Educational Process and after exposure to the intervention.

Background of Problem

Historically health care providers and the health care system have held a paternalistic attitude toward patients and families regarding decision-making. Bramlett et al., (1990) describe the advocacy behaviors of the 1970's as reflecting this paternalistic history in which both physicians and other health care providers (such as nurses) possessed knowledge which was selectively shared with the patient when it was judged to be necessary and desirable, much as parents would decide what is best for their children. The view of paternalism centered around authority figures who determined what was best for the patient. Information necessary for decision-making was selectively distributed or withheld in order to lead the patient to the desired decision. Coercion by direct or implied threat could also be involved. In either case, interference with the patient's decision-making and the actions taken relative to that decision represent a paternalistic view of the patient. In recent years the paternalistic approach to health care of patients has met increasing resistance. A better informed public now demands greater input and control regarding their health care, both individually and collectively. Although paternalistic advocacy may have been well intentioned, it is no longer consistent with the emerging demands of an informed consumer oriented public.

Modern life has become more complex. As the complexity increases, individuals experience less control of their lives and events. Nowhere is this more evident than in modern health care. Several developments have contributed to this increasing lack of control; the high degree of specialization, the increasing reliance on advanced technology, the subsequent segmentation of care among an array of health care providers who are often strangers to the patient. As the system of acute health care becomes more complex, the patient and family become increasingly disenfranchised and peripheral to the decision-making process. Ironically, the multifaceted complexity of modern health care requires increased informed responsible decision-making by patient and family rather than diminished involvement. The medical-legal community has attempted to address this paucity of involvement by developing the concept of informed consent (Holzer, 1989; Katz, 1992; Green, 1988). Fundamentally, informed consent is based on respect for the individual, and in particular, for each individual's capacity and right both to define his or her own goals and to make choices to achieve those goals (President's Commission, 1982; Holzer, 1989; Green, 1988; Katz, 1992).

Though identified as both a legal and ethical right, informed consent has not proven to be the vehicle for the desired increase in shared decision-making. Legal author Jerry Green (1988) clarifies the difference between "informed consent" which is a hybrid tort concept and "shared decision-making" which is characteristic of contractual relationships. Attempts at obtaining consent actually seek compliance rather than informed choice, while a contract involves shared decision-making and choice. Katz (1992) expands this concept by observing that providers' conversations with patients and families are not conducted in the spirit of inviting the sharing of the burdens of decision-making. Without such a commitment, dialogue is reduced to monologue with providers unwittingly attempting to shape the disclosure process so that patients will comply with their recommendations.

Green's study (1988) found that patients seeking meaningful participation in health care decision-making were often faced with health care providers urging compliance rather than active participation. The dissonance between the patient's desire for an active role in decision-making and the health care provider's desire for passive compliance on the part of the patient caused many patients and families to lose confidence in and respect for the provider. The patients and families became suspicious and distrustful of their relationship with the health care provider. The providers became defensive and insecure. The patients and families often perceived the outcomes of intervention to be less than optimal.

Holzer's study (1989) similarly describes the distinction between the "event" model and the "process" model of consent. The "event" model confuses the documentation of consent with the actual process of decision-making to undergo treatment, surgery, or participate in a therapeutic regimen. The "event" model contains no on-going process between patient and health care provider designed to establish realistic expectations, role clarification, and eliminate magical thinking. Research on litigation in surgical practice found that, nationally, general surgeons currently win 75% of their malpractice claims (Holzer, 1989). These cases, however, are still costly to doctors and insurers in terms of litigation expense, lost time and forced participation in an adversarial process that benefits neither provider nor patient. Improved communication and shared clinical decision-making would have a favorable impact on decreasing the frequency of these claims and promote improved perceived outcomes by the patient. Holzer, (1989), also recommends shifting the focus from the legal doctrine of consent as a single event to consent as an ongoing process of shared information and decision-making. Health care providers must begin to work in collaboration with patients and families to eliminate subjective factors that trigger a significant percentage of malpractice claims. Both authors (Holzer, 1989; Green, 1988) describe effective collaborative decision-making as an on-going process of shared information, mutually set achievable goals, realistic expectations, role clarification and shared accountability. This collaborative on-going decision-making process would benefit patients and families by promoting increased trust between patient/family and provider and increased patient/family ownership of outcomes through increased participation in decision-making.

Today's health care professionals are witnessing an era in which patient attitudes have shifted from passive acceptance of doctor's diagnoses and recommendations to more strident demands for high quality medical care and involvement in decision-making (Matheis-Kraft & George, 1990). Greenfield, Kaplan & Ware, (1985) point out that despite a developing history of increased patient involvement in medical care and evidence that patients want more information about health care and health care issues, few attempts have been made to change the traditionally passive patient role. Patients usually do not and are not expected to take part in the medical decisions arrived at during an office visit. These authors point out that the passive patient who remains relatively uninformed and takes little part in medical care may be less prepared to translate treatment plans into a workable daily routine of health management and problem-solving (Greenfield et al., 1985).

Another trend in the past two decades has been reframing the role of patient into health care consumer. Meisenheimer (1991) states the focal point in the health care system is the consumer. The patient or recipient of health care is the "raison d'être" of all health care providers. Despite this reality, the role played by consumers has historically been minimal. The views, beliefs, and values of the consumer are often considered external to the health care delivery process. The system has been based on the premise that providers, not consumers, are best prepared to make health-related decisions. Meisenheimer (1991) states a "quality revolution" fostered by economic, political, social, ethical and legal pressures commencing in the sixties have placed the patient/family more central in the decision-making process.

Inlander (1990) states the coming decades will see the most important revolution in medical history: the empowered consumer.

> No longer will medical and health knowledge be solely in the hands of providers. No longer will the language of medicine be a cryptic code. No longer will the treatment and care of people be in the hands of a small group of practitioners who own the machines and journals. The empowered consumer (who knows where to find answers to medical questions) is the trend of the future. (p. 115)

In the decades ahead, Inlander writes, medical consumerism will develop so rapidly and dramatically as to make the health care delivery of the early 1990's to look "archaic."

Bramlett et al., (1990) propose a consumer-centric advocacy model with three central components:

1. Maximum transfer of knowledge to the patient.
2. Prominent patient participation in decision-making.
3. Patient freedom to implement decisions.

These authors state the involvement of the patient as an informed participant is the most critical element of this model. Nurses who subscribe to this model would use their own power to promote the implementation of decisions and acts that patient would pursue for themselves if they were able. Nurses would also promote the restoration of the individual's decision-making and participation abilities as quickly as possible. Such activities are well within the role of nursing and are consistent for practice within the nursing conceptual framework of theorists like King. As nursing evolves into the 21st century the traditional approach to advocacy, with its patriarchal emphasis on loyalty and obedience to institutions and physicians will no longer be acceptable. Consumers are demanding participation in the decisions affecting their health care at both individual and group levels (Bramlett et al., 1990).

Krouse and Roberts (1989) state changes in society's perception of health care have fueled an emerging self-care movement in the last two decades. Major instigators of this movement have been: (a) the increased "medicalization" of processes previously controlled by self-and-family, and (b) the evolution of the "medical model". Both of these factors took decision-making away from the patient, placing it in the hands of professionals. Individuals who criticize a health care system based solely on the medical model offer self-care as an alternative structure. Changing the patient-provider relationship to resemble a negotiation process is one way to encourage greater participation by the patient.

Krouse and Roberts' research (1989) found that an actively negotiated process had a positive impact on the patient's feelings of control and power within a simulated treatment setting. These findings are particularly important for nurses who are interested in increasing patient perceptions of decision-making and ownership of care. Feelings of power and control over one's destiny may also be found to influence factors such as compliance with treatment, following other health care practices, and a general satisfaction with health professionals.

Purpose and Research Question

Polit and Hungler (1987) describe two broad classes of non experimental research. Applicable to this study was their discussion of descriptive research. The purpose of descriptive research is to observe, describe, and document aspects of a situation. Experimental designs are not required in descriptive research since the intent of descriptive research is not to explain or understand the underlying causes of the variables. Before conducting an experimental design using the Ludann Educational Process, it was important to first describe an accurate portrayal of the specific variables involved in the phenomenon of perceived patient participation in decision-making.

Therefore the purpose of this study was to describe the perceived active participation in decision-making by patients exposed to the Ludann Educational Process. The research question asks: *Is there a change in the patient's perception of active* *participation in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process*? A Likert scale was administered to measure the patient's perception of active participation in decision-making prior to the patient's exposure in the Ludann Educational Process (at the time of referral) and after exposure to Ludann's education interventions.

Overview

This descriptive study was designed to obtain data on the degree of perceived active participation by patients in decision-making about whether or not to have lumbar surgery after exposure to the Ludann Educational Process. Data was gathered on the perceptions of the subjects in order to best describe the relationship between their perceptions and involvement in Ludann. The introduction, background of the problem, statement of purpose, and the research question were discussed in Chapter I. Definition of the concepts within the study question and the relationships among the conceptual variables are contained in Chapter II. Imogene King's open systems nursing theory is also discussed in Chapter II. The pertinent literature accompanied by critique and analysis is reviewed in Chapter III. The methodology for this study is described in Chapter IV. Data analysis and a description of the results are reported in Chapter V. Data results, interpretations, summaries and conclusions are discussed in Chapter VI. Based on the data collected, the discussion focuses on implications for advanced nursing practice and primary care, as well as areas for further study. In conclusion, the research problem and purpose is tied to the conceptual framework and previous research. It is hoped that this thesis provides direction for future research on the experience of the patient's perception of participation in decision-making and other educational interventions.

Chapter II

The Conceptual Framework

Overview

Discussed in the following chapter are the concepts found in the research question: Is there a change in the patient's perception of active participation in decision-making of whether to have lumbar surgery or not after exposure to the Ludann Educational Process? The conceptual definition of perceived active participation in decision-making is explored and how this definition is operationalized through the model of consumer-centric advocacy and the Ludann Educational Process is defined. The points of decision-making and action for the patient with lumbar pain considering laminectomy are reviewed. Imogene King's theory of Nursing and the consumer-centric advocacy model guide the conceptual framework for this study.

King cites specific assumptions about nurse-patient interactions which are relevant to the advanced practice of the Clinical Nurse Specialist (Fitzpatrick & Wahl, 1983). These assumptions are:

1. Both nurse and patient perceptions influence the interaction process.
2. Goals, needs, and values of nurse and patient influence the interaction process.
3. Individuals have a right to knowledge about themselves.
4. Individuals have a right to participate in decisions that influence their life, their health, and community services.
5. Health professionals have a responsibility to share information that help individuals make informed decisions about their health.
6. Individuals have a right to accept or reject health care.
7. Goals of health professionals and goals of recipients of health care may be incongruent.

The following assumptions guide the Ludann Educational Process:

1. Mutual decision-making between patient and nurse about treatment interventions (e.g. whether to have back surgery) is superior to decisions made in isolation by health care providers.
2. The patient should be at the center of any decision-making process.
3. The patient when appropriately educated and informed is inherently capable of actively participating in decision-making regarding his/her treatment plan (e.g. whether to have lumbar surgery).
4. Active patient participation in informed decision-making can maximize health care outcomes and recovery.
5. Increased patient involvement in decision-making regarding treatment interventions promotes greater ownership of outcomes and increased responsibility for actualizing optimal outcomes.
6. Active patient participation in decision-making regarding treatment interventions, role clarification, and discussion of realistic expectations promotes trust between patient and health care provider. (Roberts & Wiley, 1990).

The consumer-centric advocacy model assumes the following three central components (Bramlett et al., 1990):

1. Maximum transfer of knowledge to the patient.
2. Prominent patient participation in decision-making.
3. Patient freedom to implement decisions.

In order to depict a conceptual framework for the research question the following assumptions must be considered. The assumptions which guide King, the Ludann Educational Process, and the consumer-centric advocacy model share many similarities. These similarities provide an integrated framework to guide the interactions between the Clinical Nurse Specialist and the patient involved in a decision-making process. The assumptions collectively state the patient has a right to information about his/her health, that such information is important in the patient's ability to participate in the decision-making process, that the patient should play a prominent role in this process, and that the patient has the freedom to choose which option is most appropriate. The assumptions differ in that King also emphasizes the nurse's interaction with the patient. Ludann places special emphasis on the impact mutual decision-making has on outcomes of health care interventions. The consumer-centric advocacy model speaks to the patient's position alone and does not consider the nurse's interaction or outcomes. Given the similarities and differences these three sets of assumptions complement each other in forming the basis for the following conceptual framework outlined in this study (see Figure 1.).

Conceptual Definition of Clinical Nurse Specialist

The concepts which require definition are; the role of the Clinical Nurse Specialist, patient, relative environmental factors, absolute environmental factors, patient perception of active participation, and measurable outcomes of Ludann which relate to patient's perception of active participation health related decisions (i.e. whether to have lumbar surgery or not). The Clinical Nurse Specialist delivering primary care emphasizes wellness, promotion of patient's and family's ability to cope with illness, adjustment and adaptation to disability and incapacitating illness, and supports and enhances the patient's own strengths and assets (MSU, 1991). Specific role characteristics define how the Clinical Nurse Specialist operationalizes his or her practice. For the purpose of this study the Clinical Nurse Specialist is viewed in the patient advocacy role. The role characteristic of patient advocate is defined as one who works to promote a transfer of responsibility to the patient by creating a climate of mutuality in which the nurse assists the patient in exercising his/her rights and in improving self-care abilities (MSU, 1991).

The consumer centric advocacy model defines the role of the Clinical Nurse Specialist as that role which promotes maximum transfer of knowledge to the patient (Bramlet et al., 1990). The Ludann Educational Process defines the role of the Clinical Nurse Specialist as that role which promotes mutual decision-making between patient and health care provider, placing the patient at the center of the decision-making process.

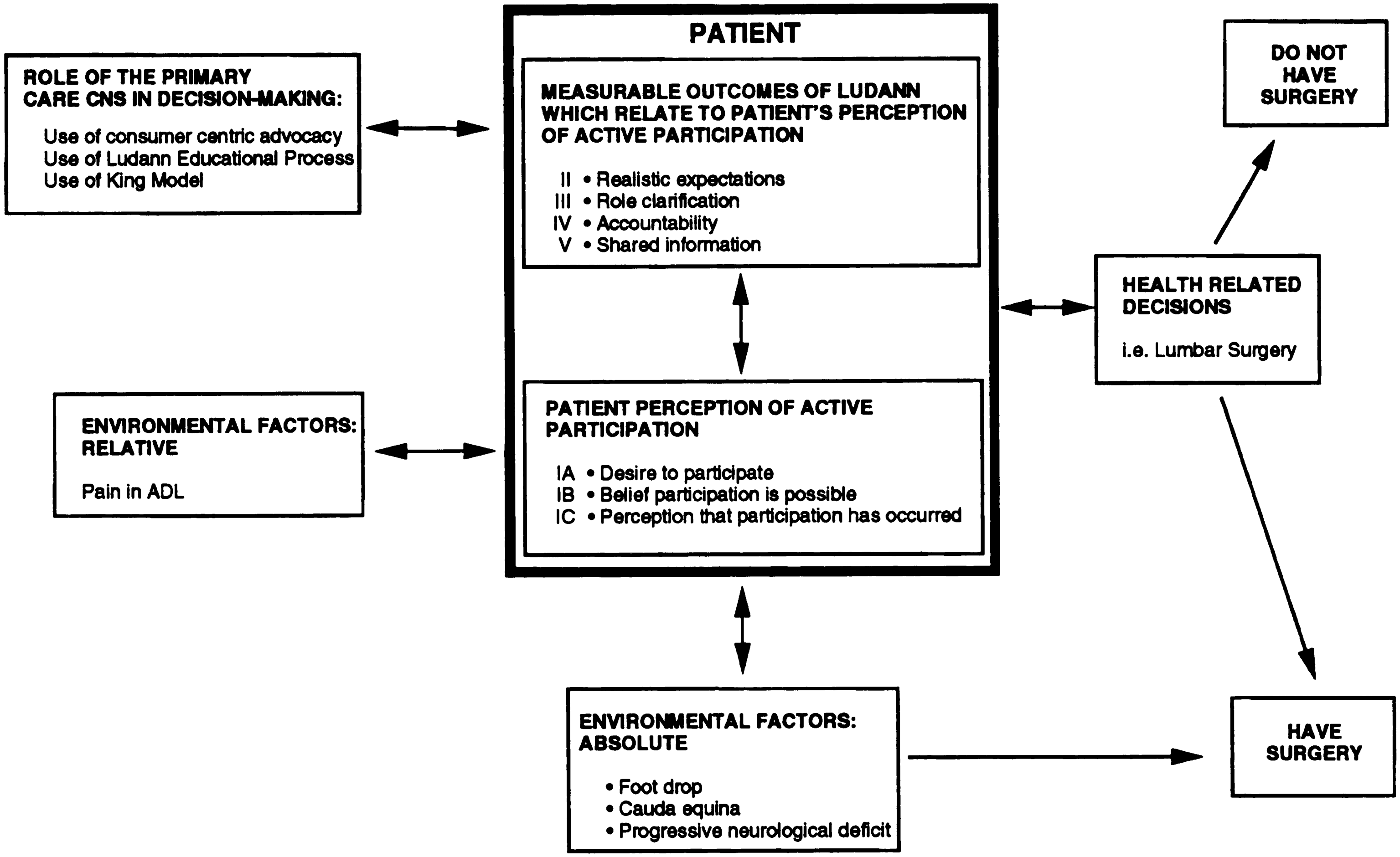


Figure 1: A conceptual framework for the study; the relationship of the primary care CNS to the patient; the relationship of the patient with the variables involved in decision-making.

King defines the role of the Clinical Nurse Specialist as an open system interacting with the environment (which includes the patient). Both the environment and the Clinical Nurse Specialist exhibit permeable boundaries permitting an exchange of matter, energy, and information (Fitzpatrick & Wahl, 1983). King defines the Clinical Nurse Specialist as a health professional having the responsibility to share information that helps patients make informed decisions about their health.

Conceptual Definition of Patient by King

For the purposes of this study, King's definition of person was used to describe the concept of patient. King defines patient (person) as an open system interacting with the environment, each exhibiting permeable boundaries permitting an exchange of matter, energy and information (Fitzpatrick & Wahl, 1983). King defines environment as an open system exhibiting permeable boundaries, permitting an exchange of matter, energy, and information with human beings. According to King individuals are called personal systems. Each human being is conceptualized as an unique total system, the care of whom is the focus of nursing practice. King further explains her philosophy of persons as being rational, sentient, social, reacting, and perceiving. These characteristics in King's definition identify a person capable of active participation in decision-making and a person who can describe any perceived change.

Conceptual Definition of Perceived Active Participation in Decision-Making

Perceived active participation in decision-making described in this study will be based on the work of Wallston et al., (1991). Active participation presumes three things; (a) there exists a desire to participate in a situation, (b) a belief that participation is possible, and (c) a perception that participation has taken place. Therefore the conceptual definition of perceived active participation in decision-making must include these stated presuppositions; (a) the desire for participation, (b) the belief that participation is possible and (c) the perception that participation has occurred.

Holzer (1989) and Green (1988) describe active participation in decision-making as an interaction between patient and provider operationalized by the sharing of information, the setting of realistic expectations related to treatment, the clarification of roles, and the sharing of accountability for treatment outcomes.

As with Holzer and Green, the Ludann Educational Process relates to patient's participation in decision-making through an educational intervention which includes; (a) sharing information regarding the diagnosis and treatment options, (b) discussing realistic expectations related to treatment outcomes, (c) clarifying the roles of the team, specifically the roles played by the patient/family, the Clinical Nurse Specialist, and the neurosurgeon, (d) discussing the shared accountability between patient/family and health care provider for the recovery process. These provide measurable outcomes which relate and interact with the patient's perception in actual participating in decision-making.

Conceptual Definition of Relative and Absolute Environmental Factors Regarding Having a Laminectomy

A lumbar laminectomy for a herniated disc involves the removal of the laminae of the bony vertebrae and removal of a portion of the disc. The purpose of the surgery is to remove pressure on the exiting nerve root that was producing either neurological symptoms or pain. The indications for surgical intervention in the treatment of a ruptured intervertebral disk fall into two categories: (1) symptoms that indicate progressive cauda equina compression and surgical intervention is definitely required; and (2) symptoms of incapacitating pain that has not been helped by conservative treatment and which may be helped by surgery. Indications for laminectomy are summarized in Figure 2 (Chapman, 1988; Crenshaw, 1992).

I. Absolute

  A. Bladder or bowel paralysis (cauda equina syndrome).

  B. Marked muscular weakness.

  C. Progressive neurological defect despite complete bedrest.

II Relative

  A. Pain unrelieved by complete bedrest.

  B. Major alteration in activities of daily living because of pain.

  C. Recurrent episodes of incapacitating sciatica.

Figure 2: Indications for lumbar laminectomy; the difference between absolute and relative indicators.

Though the lumbar pain patient who presents with absolute (I) indications for laminectomy can still decide not to have surgery, the presence of motor symptoms indicate an emergent need for removal of the ruptured disc to prevent permanent damage to nerve fibers. Symptoms which would indicate an emergent need for removal of the ruptured disc are categorized as "absolute" and include; bowel and bladder paralysis (cauda equina syndrome), marked muscle weakness, and progressive neurologic defect despite complete bedrest. The patient with lumbar pain who presents with the relative (II) indications more easily has alternative action or choices. "Relative" indications include pain unrelieved by complete bedrest, major alteration in activities of daily living because of pain, and recurrent episodes of incapacitating sciatica. Patients in both absolute (I) and relative (II) categories require diagnostic study that clearly show a ruptured disc (Crenshaw, 1992; Chapman, 1988). The points of decision-making for these patients are different. The patients in the second category do not require surgical intervention but may be helped by surgery. These are patients in whom the primary symptom of pain is intolerable or unrelieved by usual methods.

Health Related Decisions

For the purpose of this study, health related decisions meant the decision the patient made to consent or not to consent to having lumbar surgery. The population that has this option most clearly is the population that presents "relative" indicators. Those who present "absolute" indicators (i.e. foot drop) can still elect not to have surgery as it is unethical to deny any population its right to decide. However, this population was not included in the scope of this study.

Interactions within the Conceptual Framework

The Ludann Educational Process was created to promote the patient and family as active participants in decision-making and utilizes modalities designed to enhance patient understanding. Figure 1 depicts the conceptual framework of this study and the interaction of the components. The primary care Clinical Nurse Specialist brings to the CNS-patient interaction the influences of Imogene King, consumer-centric advocacy, and the Ludann Educational Process.

Guided by King, the Clinical Nurse Specialist realizes that the perceptions, goals, needs, and values of both nurse and patient influence the interaction process. The practice of the Clinical Nurse Specialist is also informed by King's direction that individuals have a right to knowledge about themselves, a right to participate in decisions that influence their life, and a right to accept or reject health care. King further informs the Clinical Nurse Specialist's interaction with patients through her assumptions that health care professionals have the responsibility to share information that promotes informed decision-making by patients and that the goals of the patients and the goals of the health care professionals may not be the same.

The consumer-centric advocacy model guides the interaction of the Clinical Nurse Specialist and patient in three ways. First, the Clinical Nurse Specialist is to promote maximum transfer of knowledge to the patient. Second, the patient is to have prominence in the decision-making process. Third, the patient has the freedom to implement decisions or not.

The Ludann Educational Process directs the Clinical Nurse Specialist to interact with the patient through the activities of sharing information, describing realistic expectations, clarifying roles, and promoting shared accountability for treatment outcomes. These measurable outcomes interact with the patient's perceptions of actively participating in decision-making. The patient is influenced by the role of the Clinical Nurse Specialist, the environmental factors (absolute or relative) and the perception of active participation. The role of the Clinical Nurse Specialist is to put an informed patient and family at the center of the decision-making process. Relative environmental factors influence patient interaction by driving a perceived need to explore treatment options relative to increasing pain and discomfort. Absolute environmental factors drive the patient interaction by the presence of actual motor or neurologic deficit. Though the patient has options in either case, the presence of motor or neurologic deficit may alter the patient's perception as to how much freedom he/she has to chose "no surgery" in the decision-making process.

The patient's interaction is also influenced by his/her own desire to participate, belief that such participation is possible, and the perception that such participation has occurred. Therefore, health related decisions (in this instance whether or not to have lumbar surgery) are influenced by the interaction between the role of the Clinical Nurse Specialist and the patient, the patient's interaction with environmental factors, and the patient's interaction with his/her perception of perceived active participation.

Summary

Discussed within this chapter have been the concepts found in the research question: *Is there a change in the patient's perception of active participation in the decision-making process of whether to have lumbar surgery or not after exposure to the Ludann Educational Process?* A model for this study was illustrated and defined. Assumptions of the conceptual framework were listed. The purpose of this framework is to provide a solid foundation upon which to work in describing the patient's perceived active participation in the health related decision of whether or not to have lumbar surgery.

Chapter III

Review of the Literature

Overview

The review of empirical and conceptual literature relevant to patient perceptions in the decision-making process, the Clinical Nurse Specialist as advocate, and the Ludann Educational Process are discussed in this chapter. Included in each section is a critique of the research. This critique provided direction and purpose for the present study. A brief review and discussion of lumbar disc herniation and potential treatment modalities is included.

Lumbar Disc Herniation

Spengler (1988) and Crenshaw (1992) state that although back pain is common from the second decade of life on, intervertebral disc disease and disc herniation are most prominent in otherwise healthy people in the third and fourth decades of life. Spengler (1988) describes the typical patient with a lumbar disc herniation to be a 35 year old man with a 2 to 3 month history of lower back pain and a 4 to 6 week history of gradually increasing, radiating pain in the lower extremity. Both authors conceptualize the occurrence of a lumbar disc herniation as the result of a cyclic loading phenomenon, wherein the biologic reparative processes are exceeded by the rate of progression or extrusion of the disc through the limiting annulus fibrosus. Non-operative management strategies combine short-term bedrest with mild anti-inflammatory agents. The majority of patients who experience lumbar disc herniation find relief in this way.

Spengler (1988) states the indications for surgical management of a symptomatic lumbar disc herniation, exclusive of any urgent/emergency presentation, are unresponsiveness to non-operative management and a reasonable rapport with the patient. Crenshaw (1992) observes the reason that surgery is not done on all patients in whom pain is the overriding symptom is that surgery is not successful in all cases. Reports show that surgery is unsuccessful in 10% to 50% of cases. Researchers generally feel that the success of surgery for the relief of pain can be improved if the patient is carefully evaluated for both the physical and psychological basis of pain and if pain can be clearly judged to be physiogenic in nature (Crenshaw, 1992).

The Clinical Nurse Specialist in Decision-Making

The Clinical Nurse Specialist operationalizes her role of decision-making through patient advocacy. The role of patient advocate is widely described in the nursing literature. Nelson (1988) traces 3 major themes in the historical evolution of this role: nurse as advocate for or on behalf of another, nurse as mediator, and nurse as protector of patients' self-determination. Cocoran (1988) defined advocacy as helping patients to be autonomous, informed decision makers. That author describes one aspect of the advocacy role as helping another person decide.

Curtain (1989) describes advocacy as the philosophical foundation and ideal of nursing where nurse-patient relationships involve nurses and patients as whole, unique persons. Both nurses and patients have concern for patients' right to self-determination. Patients are recognized and respected as unique individuals in their entirety. Nurses participate in the decision-making process as whole persons.

Subsequent authors (Bramlett et al., 1990) have defined the concept of advocacy as consumer-centric advocacy. These authors observe that the current health care system is undergoing continuous change. Fiscal constraints and changing demographics of patients are factors driving the reorganization of the health care system. In addition, the public has become better informed concerning health and is seeking new approaches to the delivery of health care services. Since the largest group of health care providers is nurses, and the shortage of registered nurses continues to grow, nurses must develop new strategies to maximize their impact on the health care system. These strategies must be designed to meet the needs of consumers as well as protect the integrity of the nursing profession.

Clarification of the nurse's traditional role as advocate can enhance the development of such strategies (Bramlett et al., 1990).

Nursing leaders have historically assigned the role of patient advocate to the nurse. Florence Nightingale, Lillian Wald, and Lavinia Dock have all advanced the role of nurses as advocates by concern for the environment and social issues affecting public health, expressing concern over human rights and dignity, and promoting social and health care reform (Bramlett et al., 1990). Implementation of advocacy was delayed earlier because of the old value of loyalty and obedience to the physician. Advocacy's implementation was further delayed by the more contemporary admonition for nurses to consider themselves as team players, with physicians and hospital administrators as the other members (and implied leaders) of the team (Pagana, 1987).

Adherence to loyalty and obedience to other health care team members has led to a well-meaning but potentially harmful paternalistic view of advocacy. This view centers around authority figures who determine what is best for the patient. A paternalistic approach to health care is increasingly meeting more resistance. The public is better informed and demands more input and control over their health care, both at the individual and collective level (Carter & Mowad, 1988). The public's desire for increased input and control over their health care requires health care providers to be interactive with consumers as opposed to directive. Paternalistic paradigms do not lend themselves to such interactive relationships. Paternalism disenfranchises the consumer from self-determination, encouraging passive compliance. The paternalistic paradigm is becoming increasingly anachronistic (Carter & Mowad, 1988).

Consumerism is a related and perhaps more contemporary construct than advocacy. No longer acceptable is the traditional approach to advocacy, emphasizing loyalty and obedience to institutions and physicians. Consumers, both individuals and groups are demanding increased participation in the decisions which affect their health care. Involving the patient as an informed participant is a critical element of consumer-centric advocacy.

Consumerism may be simply defined as “the promotion of the consumer’s interests” (Carter & Mowad, 1988, p. 74). Consumerism is a process that emerges from the desires of the patient. Although the theoretical basis of consumerism is obscure in the literature, several related concepts are implied in traditional usage. Hibbard and Weeks (1987) include knowledge and attitudes as essential concepts. Within their view, knowledge becomes the commodity which allows the consumer to make informed choices. Attitude is the component that determines the consumer’s ability and willingness to question or challenge authority. Attitude is closely related to issues surrounding the phenomena of compliance or noncompliance. Haug and Lavin (1983) emphasize the important perspective of consumerism as the power relationship between the consumer and the health care professional that presents the potential for choice and negotiation.

The consumer, within Haug and Lavin’s view, becomes an inquisitive and active participant in health care rather than a passive recipient of care. The health care provider is accessed by empowered consumers as a source of information upon which to base his/her own decisions (Hibbard & Weeks, 1987). Empowering and supporting patients in their decision-making is consistent with the care components of consumer-centric advocacy (Bramlett et al., 1990). In this study the definition of advocacy is based on the work of Bramlett et al., (1990). These authors propose a consumer-centric model with three central components:

1. Maximum transfer of knowledge to the patient.
2. Prominent patient participation in decision-making.
3. Freedom to implement decisions.

The Clinical Nurse Specialist’s role in knowledge transfer is to assure that the patient has all the information needed to make an informed decision. The information must be presented in an understandable form. After adequate knowledge transfer the patient becomes an active participant in decision-making, and the ultimate decision rests with him/her. In this consumer-centric model the patient’s decision may not always be the preferred decision of the health care provider. The role of the Clinical Nurse Specialist is to support the patient's decision regardless of its degree of congruence with the established values of the health care system. The decision is generally followed by actions. The Clinical Nurse Specialist and the patient work to determine appropriate actions, however, the final choice of action is made by the patient. The role of nursing practice is to assist the patient to manifest the actions required to operationalize the decision (Bramlett et al., 1990).

The involvement of the patient as an informed participant is the most critical element of this model. Knowing participation requires the individual have full knowledge specific to the situation and available options. In addition, the patient must feel free to select any option and to act on said choice (Bramlett et al., 1990). These authors acknowledge, however, that because of extenuating circumstances, some patients may be less capable of such knowing participation than others (e.g. comatose patient). Bramlett et al., (1990) state in this situation the Clinical Nurse Specialists who subscribe to this model of patient support would use their own power to: (a) promote the implementation of decisions and acts that patients would pursue for themselves were they able, and (b) to promote the restoration of the individual's decision-making and participative abilities as quickly as possible. Such activities are well within the role of the Clinical Nurse Specialist and are consistent for practice within the nursing conceptual framework of nursing theorists like Imogene King. As nursing practice evolves into the 21st century the traditional approach to advocacy, with its patriarchal emphasis on loyalty and obedience to institutions and physicians, will no longer be acceptable (Bramlett et al., 1990).

Active Participation in Health Care Decisions

In many different clinical settings patients are faced with making choices about alternative actions. These actions cover a wide range of considerations, which include but are not limited to; choices regarding treatment plans, changes in life style patterns, family planning, and when to initiate emergency care. Ward and Heidrich (1989) define decision-making as the process of choosing between alternative courses of action or inaction. Holzer

(1989) and Green (1988) both describe effective collaborative decision-making as an on-going process of shared information, mutually set achievable goals, realistic expectations, role clarification, and shared accountability. McFarland and McFarlane (1989) describe decisional conflict as uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values such as personal health, family relationships, career, finances, or other life events.

Krouse and Roberts (1989) state the actual decision regarding the treatment plan represents the culmination of an interactive process between patient and health provider and results from information exchange. The way options are stated and focused can greatly influence patient preference and selection. Krouse and Roberts (1989) observe that changes in society's perception of health care have fueled an emerging self-care movement in the last two decades. Major instigators of this movement have been: (a) the increased "medicalization" of processes previously controlled by self-and family, and (b) the evolution of the "medical model." Both factors took decision-making away from the patient and placed it in the hands of professionals. Changing the patient-provider relationship to resemble a negotiation process is one way to encourage greater participation by the care-seeker. The negotiation process requires an interaction between two parties. When the patient and health care provider negotiate the patient actively participates in that process through the exchange of information. The sharing of information creates the foundation for the patient to take an action. In this study the action was deciding whether or not to have lumbar surgery.

Krouse and Roberts (1989) conducted an experimental study to test and refine an actively negotiated process of decision-making. The 84 subjects were randomly assigned to 1 of 3 treatment groups. The study compared 3 different styles (active negotiation, partial negotiation and traditional approach). These 3 styles were studied to determine if individuals experienced differing degrees of power and control, agreement with treatment, and feelings of satisfaction. Results were analyzed using chi-square, one-way analysis of variance, and analysis of co-variance for each factor. Significant effects remained on control versus powerlessness between the active negotiation and the other two styles even when using time as a covariate.

Krouse and Roberts' research (1989) found that an actively negotiated process had a positive impact on the patient's feelings of control and power within a simulated treatment setting. These findings are particularly important to the CNS who is interested in increasing patient perceptions of decision-making and ownership of care. Feelings of power and control over one's destiny may also be found to influence factors such as compliance with treatment, following other health care practices, and a general satisfaction with health professionals.

Authors caution, however, that not all patients want a high degree of participation in decision-making. Waterworth and Luker's research (1990) raised the point that some patients may not wish to be involved in health care decision-making. They advise that promoting individualized care is not synonymous with active patient participation. Watersworth and Luker (1990) conducted qualitative research using an interviewed convenience sample of 12 patients. One major theme emerged from the data and that was "toeing the line." The data suggested that some patients are more concerned about doing what is right than participating in decisions concerning care. These authors state that individualized care should be based on determining what degree of active participation the patient desires. Those patients who prefer "toeing the line" to actively participating in decision-making should be given more traditional directive care and not forced to make decisions. True patient advocacy is based on meeting patients' actual wants and desires not those presumed by the health care provider.

Degner and Beaton's qualitative research (1990) provided descriptions of many patients who seemed to prefer little or no involvement in treatment decisions. However, when Degner and Russell (1988) studied 60 adults from oncology clinics, those authors found that most patients preferred the pattern of shared control. The qualitative procedure directed the patients to order eight written vignettes developed by the investigators. Each vignette described various degrees of control over treatment decisions. The content for the vignettes was derived from the hypothesis that patients have preferences about keeping, sharing, or giving away control over decision-making. These authors found that most patients preferred the pattern of joint control, particularly with the patient and physician as participants; and that patients preferred to give control to the physician rather than a family member. While this study had several limitations, Degner and Russell's findings (1988) do indicate the need for further research.

Wallston et al., (1991) found that for most people loss of control was distressing. However, there are differences among people in the degree to which control over one's health care is an important or salient concern. Wallston et al., (1991) studied 74 chemotherapy patients from both out-patient and in-patient settings. They tested the interaction between presence/absence of choice of anti-emetic treatments and the level of desire for control of health care. Patients were randomly assigned to choice or no-choice groups and were followed for 4 sessions using multiple dependent measures. The 4 measures administered were the desire for control, perceived control, emotional distress, and physical distress.

While few patients seemed to want complete control over their treatment, the amount of control desired varied from patient to patient (Wallston et al., 1991). The authors found that persons with a moderate desire for control (DFC) over their health care responded better when given choice over some aspect of their care than when they were not given choice. Those patients with high DFC who were given a choice did not differ from high DFC patients who were not given a choice. Low DFC patients did not report feeling better when not "forced" to make a choice compared to when they were asked to select which anti-emetic treatment they wanted to receive. Matching treatment approaches to preferences for the amount of control desired in clinical decision-making is a more rational response to consumerism than advocating increased control for everyone regardless of preferences (Haug and Lavin, 1981). Degner and Russell's review (1988) of the literature suggests that the general public may prefer a pattern of shared decision-making rather than a total abdication or having complete control. The consumer movement in health care has fostered the assumption that most people desire some degree of control or participation in decision-making regarding treatments which will influence their quality of life (Degner and Russell, 1988; Waterworth & Luker, 1990; Bramlett et al., 1990; Meisenheimer, 1991; Roter, 1987; Inlander, 1990).

The Ludann Educational Process

The Ludann Process is an educational model based on patients and families actively participating in health care decision-making. Mutual decision-making is superior to decisions made in isolation by health care providers alone. The founders of Ludann eschew the paternalistic models of health care decision-making preferring to place the patient at the center. At present there have been no empirical studies using the Ludann Educational Process as an intervention. Thus, this section will review Ludann's purported basis for their educational process. A transcript of the Ludann Educational lumbar laminectomy teaching video is included in Appendix B.

Ludann purports that the patient, when properly educated, is capable and responsible for being in charge of the health care team. A person who makes the decisions on his own behalf is ultimately responsible for those decisions. Ludann believes patients are consumers who are capable of the ultimate responsibility for health care decision-making. Active participation in informed decision-making can maximize health care outcomes and recovery. Adults expect to have choices and be involved in those choices. When a patient has more involvement and greater ownership of outcomes, the patient is more likely to assume responsibility for actualizing those outcomes. Furthermore, Ludann believes that active participation in decision-making, role clarification and the discussion of realistic expectations promotes trust between patient and health care provider. The most positive outcome of this process is the establishment of trust and rapport. Finally the founders of the Ludann Educational Process propose that the patient's active participation in health care decision-making will enable patients to choose better health behaviors when they feel accountable for that choice and accountable for the outcomes (Roberts & Wiley, 1990).

The tenets of the Ludann Educational Process closely parallel the consumer-centric advocacy model of Bramlett, Gueldner and Sowell. Ludann's Educational Process theoretically promotes maximum transfer of knowledge to the patient, promotes patient participation in decision-making, and encourages the patient's freedom to implement those decisions. The Ludann Process also shares concepts with the definition of decision-making used in this study. This definition is described by Holzer (1989) and Green (1988) involving the patient and provider in the process of shared information, realistic expectations, role clarification and shared accountability

Summary

A review of both empirical and conceptual literature was presented in this chapter. Patients' perceptions in the decision-making process, the Clinical Nurse Specialist as advocate, and the Ludann Educational Process were reviewed. Pertinent research relative to this topic was critiqued. Because there is an absence of research using the Ludann Educational Process, or the overall process in general, data from this thesis is needed. The literature review provided the basis and evidence that this study will add to the existing body of knowledge related to a consumer's perception of actively participating in health care decision-making.

Chapter IV

Methods

Overview

Presented in this chapter are the methods and procedures used for collecting data regarding the change in the patient's perception of active participation in decision-making to have lumbar surgery or not after exposure to the Ludann Educational Process. Specifically addressed in this chapter are: (a) the study design with a description of the population, subjects, sampling techniques, patient accrual and operational definition of concepts; (b) the instrument; (c) the data collection procedures and intervention process; (d) protection of human subjects; (e) analysis of data; and (f) a summary.

Study Design

The purpose of this study was to describe the perceived active participation in decision-making by patients exposed to the Ludann Educational Process. The research question states: Is there a change in the patient's perception of active participation in decision-making to have lumbar surgery or not after exposure to the Ludann Educational Process. The methods included the collection of data at the time of referral for a sample of patients considering lumbar surgery. A Likert scale, designed to measure perceived active participation in decision-making, was administered pre- and post-exposure to the Ludann Educational Process. The standard statistical technique of the paired t-tests was used to describe the statistical significance of any change in perception. Cronbach's alpha was used to determine the subscale and full scale reliabilities.

Sample

The target population for this study was comprised of men and women who had no history of previous lumbar surgery and had the option of whether or not to chose lumbar surgery at the time of the study. The sample was a convenience sample of 16 subjects from a neurosurgical practice associated with a 550 bed tertiary care facility in a large midwestern city. This neurosurgical practice provides a collaborative approach to decision-making through an educational intervention, addressing the needs of lumbar patients and their families. Each subject met the following criteria:

1. Male or female with lumbar pain.
2. Referred from a primary care physician.
3. May be seeking workmen's compensation.
4. May have underlying medical problems.
5 May be on anti-depressants or mood-altering drugs.
6. Did not present with absolute indications for laminectomy (i.e. bladder or bowel paralysis [cauda equina syndrome], marked muscular weakness and/or footdrop, progressive neurological deficit (despite complete bedrest).
7. Was able to read and write in English.
8. Was not a minor.

There were no limits placed on age (other than patient could not be a minor), gender or educational background. Subjects were enrolled according to their availability and willingness to participate.

Active Participation

Active participation was conceptualized to be the combination of a desire to participate, a belief that participation was possible, and a perception that participation had occurred. Immediate outcomes of the Ludann Educational Process which were measurable and related to the patient's perception of active participation included realistic expectations, role clarification, accountability, shared information. On both pre- and post-test instruments, parallel questions were used to measure active participation and the related immediate outcomes. See Appendix C for a detailed presentation of the specific questions which measure active participation and the related measurable outcomes of expectation, role clarification, accountability, and shared information.

The Ludann Educational Process consisted of patients viewing the teaching video: Lumbar Laminectomy. The sample was tested prior to viewing the video and afterwards. The test prior to viewing the video was done at the time of referral on the initial visit. The patient was sent home with the video. After viewing the video at home, the patient filled out the post-test and sent the questionnaire directly to the primary investigator. A transcription of the Ludann Educational teaching video in included in Appendix B.

The Instrument

The questions of the instrument were designed to collect data reflecting perceived active participation, shared information, realistic expectations, role clarification and accountability. The pre- and post-test instruments used parallel questions which were a combination of measures of perceived control (Wallston et al., 1991), demands of illness (Woods, Haberman & Packard, 1987), and six questions designed specifically for this study. Questions 1, 2, 3, 4, 5, 7, and 8 on the amount of control that the patient perceives having came from Wallston et al., (1991). Questions 11, 12, 13, 14, 15, and 16 were taken from the *Demands of Illness Inventory*. Questions which were designed specifically for this study included questions 10, 22, and 23 used to measure desire for participation; question 24 used in the measurement of participation having occurred; questions 17, 19, and 20 used to measure the outcome of role clarification; question 18 was created to be used in the measurement of the outcome of realistic expectation; question 6 was designed to be used in measuring the outcome of shared information.

The pre-test instrument was a two part questionnaire designed to collect data on patient's perceived active participation in decision-making to have lumbar surgery or not prior to exposure to the Ludann Educational Process. The first part was designed to collect demographic data such as age, sex, education, occupation, employment status, degree of activity or functional limitation, and current treatment plan. The remainder of the pre-test instrument was made up of 24 items designed to obtain data on perceived active participation, shared information, accountability, realistic expectations, and role clarification. Readability was tested with the Flesch formula for reading ease. The Flesch formula is widely used by the insurance industry to check the readability of insurance policies. The formula grades writing on a score from 0-100. The higher the number, the easier the reading. A good value is 40 or above. The Flesch reading ease score of this tool is 76.6 with a reading grade level of 7.3. The tool was also reviewed by a panel of masters prepared nurse clinicians. Their feed back was incorporated into the tool. The subsequent changes improved the flow of the text, made all verb tenses consistent and eliminated all demographic data not pertinent to the research question.

A six point Likert scale was used, scoring strongly disagree as "1", mildly disagree as "2", disagree as "3", agree as "4" mildly agree as "5" and strongly agree as "6". The post-test instrument contained the same 24 items and was scored on a six point Likert Scale in the same way. The responses were scored in such a way that endorsement of positively worded statements, and non-endorsement of negatively worded statements were assigned a higher score. Table 1 illustrates the scoring of this tool. The "+" in the first column of the table signifies that this is a positively worded item. A higher score is assigned to the person agreeing with this statement than to someone disagreeing with it. Since the scale has a maximum of 6 points, the score of 6 is given to someone strongly agreeing, a score of 5 to someone mildly agreeing, and so forth. When an item was negatively worded, the scoring was reversed, assigning a score of 1 to those who strongly agree, and so forth. This reversal is necessary to allow a high score to consistently reflect positive attitudes.

Data Collection Procedures

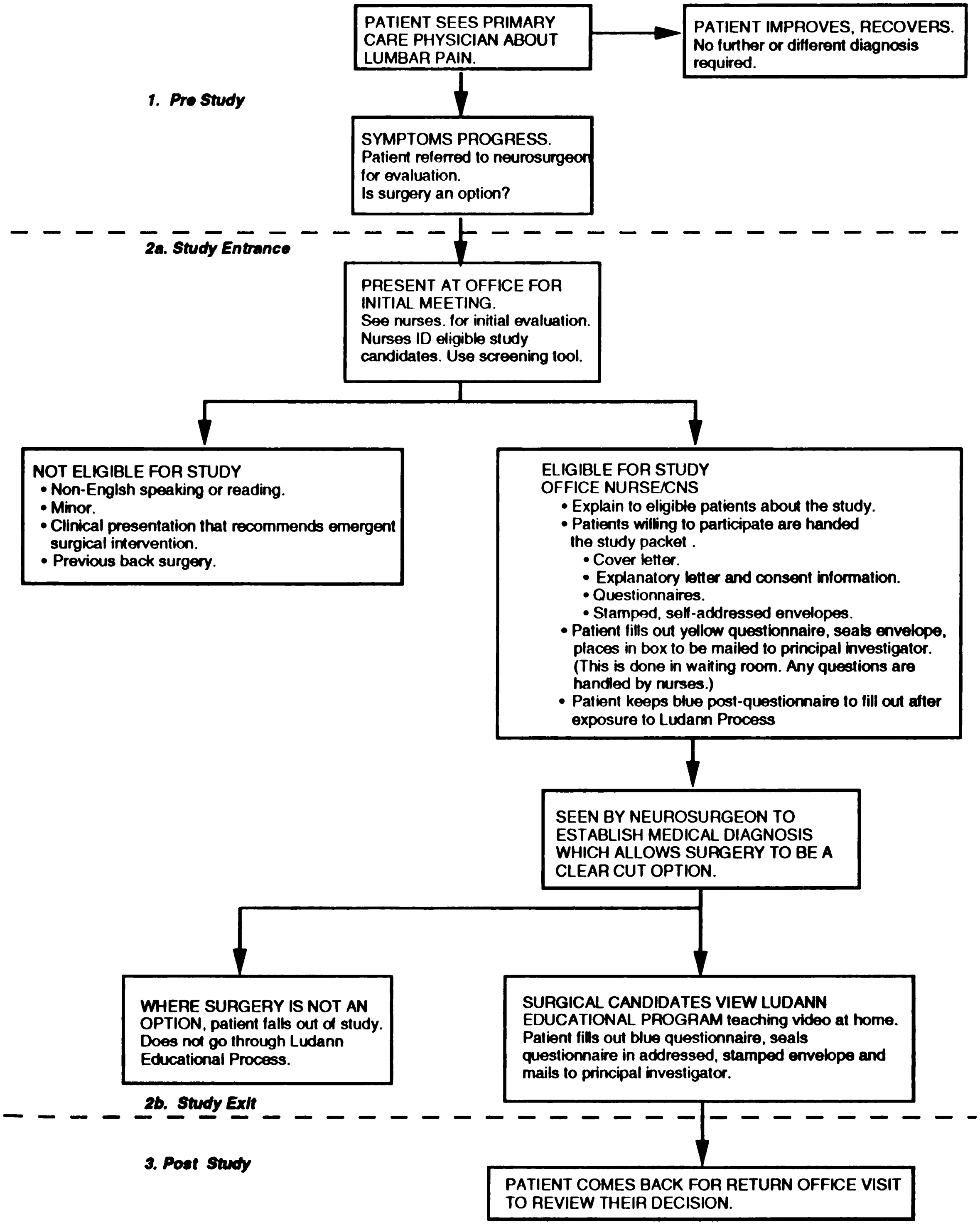
The methods and procedures of the study were reviewed by the primary investigator with the Clinical Nurse Specialist and the office nurse responsible for data collection in the office. Data was collected between April 1993 and August 1993. The sequence of events for the data collection process (Figure 3) was given to the office nurse to guide the procedure. When the potential subjects presented at the neurosurgeon's office for initial

Table 1.

Explanation of Likert scale values for each question.

Direction of Score	Question				Value of Scores		
		SD*	MD*	D*	A*	MA*	SA*
	Since my referral for back pain, I felt ...						
–	1. That I am unable to influence the treatment I received.	6	5	4	3	2	1
+	2. That I am in control of the situation.	1	2	3	4	5	6
–	3. That I am just told what to do.	6	5	4	3	2	1
+	4. That I can get all of my questions answered.	1	2	3	4	5	6
+	5. That I am allowed to play an active role in my health care.	1	2	3	4	5	6
+	6. That the health care providers are sensitive to my feelings and opinions.	1	2	3	4	5	6
	Since I began this referral for back pain, I also felt...						
+	7. Very much "on top" of the situation.	1	2	3	4	5	6
–	8. At a loss to know what to expect	6	5	4	3	2	1
+	9. I know what the treatment will do for me.	1	2	3	4	5	6
	As I experience my back pain I...						
+	10. Want to be more involved about deciding whether to have surgery.	1	2	3	4	5	6
+	11. Realize I was initially unclear about the treatment I'd receive.	1	2	3	4	5	6
–	12. Am dissatisfied with progress of my treatment.	6	5	4	3	2	1
–	13. Felt my problem is incorrectly managed.	6	5	4	3	2	1
	As the result of my medical treatments I...						
–	14. Now have new physical symptoms.	6	5	4	3	2	1
	At times, some of my health care providers...						
–	15. Do not tell me the truth about changes in my health.	6	5	4	3	2	1
–	16. Do not thoroughly explained my health status to me.	6	5	4	3	2	1
	As a result of meeting with my health care providers...						
+	17. I clearly understood my part in making the decision to have surgery.	1	2	3	4	5	6
+	18. I clearly understood what the surgery can and cannot do.	1	2	3	4	5	6
+	19. I clearly understood what the surgeon's job is.	1	2	3	4	5	6
–	20. I am not clear about my part in the recovery process.	6	5	4	3	2	1
+	21. I have an important part to play in my recovery.	1	2	3	4	5	6
–	22. The surgeon was responsible for my decision.	6	5	4	3	2	1
+	23. I am responsible for making my own decision about surgery.	1	2	3	4	5	6
–	24. I feel I did not play a part in deciding to have surgery	6	5	4	3	2	1

*SA=strongly agree, MA=moderately agree, A=agree, D=disagree, MD=moderately disagree, SD=strongly disagree



<u>Figure 3</u>: The sequence of events in the data collection process.

evaluation and intake procedures by the Clinical Nurse Specialist and office nurse, the Clinical Nurse Specialist and office nurse determined eligibility.

For eligible patients the Clinical Nurse Specialist and office nurse explained the study. Patients interested in participating were handed the study packet which included the cover letter, explanatory letter and consent information, questionnaires and stamped envelopes addressed to principal investigator. The patient filled out the questionnaire, sealed the envelope and placed it in a box to be mailed or mailed it directly to the principal investigator. This procedure was done in the waiting room and any questions were handled by the Clinical Nurse Specialist or the office nurse.

At this visit the subject was seen by the neurosurgeon to establish the medical diagnosis of ruptured disc which allowed surgery to be a potential intervention. When surgery was not an option, the patient was excluded from the study. Surgical candidates were exposed to the Ludann Educational Program by viewing the teaching video at home. The patient filled out the post questionnaire after the educational intervention, sealed the envelope and mailed the sealed envelope to the principal investigator. All the subjects completed the pre-and post-questionnaire at different points in time.

Protection of Human Subjects

This study was non-invasive and non-intervention. Each subject was given a description of the study. Anonymity was guaranteed by having all subjects return the packet in the mail to the principal investigator. No names were written anywhere on the questionnaire. No staff member or health care provider had knowledge of who completed the questionnaire. The explanation of the study also included statements regarding risks and benefits of participating in the study. Since this study was a non-invasive, non-intervention study, there were no known potential risks or danger from harm either physically, socially or economically. Some patients may have experienced psychological stress from decision-making, however, none should have experienced psychological harm. Participation in the study did not effect the subject's care. Benefits included increasing the knowledge base regarding health care decision-making. This study was approved by the University Committee on Research Involving Human Subjects (UCRIHS). See Appendix D for document of approval.

Data Analysis

Descriptive statistics for the sample's demographic information were calculated. The scores of the total questionnaire and subscales were subjected to statistical analysis which measured the central tendency (the mean), whether any change was statistically significant and not due to chance (the paired t-test).

Limitations of the Study

The methodology of this study was limited in the following ways.

1. Parts of 2 different tools had been combined and six additional questions were created. The tool in its current form had not been tested for reliability prior to the study.
2. Other variables not tested (e.g. locus of control) may have affected the outcomes more than the Ludann Educational Process.
3. It was a one time descriptive study so it may not have captured the entire process of decision-making..
4. Since the study sample was a small convenience sample, rather than a representative sample, no generalizations can be made.

Summary

Contained in this chapter was the description of the study methodology. The methodology was designed to gather data about perceived participation in health care decision-making. The following were described and defined; design, population and subject sampling technique, operational definitions of concepts, the instrument, data collection procedures, method for protection of human subjects and analysis of reliability of the tool.

Chapter V

Results of the Study

Overview

This chapter presents the study findings. The contents of the chapter include; 1) profile of the sample, 2) analysis of quantitative data, and 3) summary.

Profile of the Sample

As can be seen in Table 2, the majority of the subjects were between 31-40 (31.25%) and 41-50 (25.0%) years of age. There were 6 (37.5%) males and 10 (62.5%) females. Most of the subjects indicated at least a college education completed. Among the respondents the primary occupations were identified as health care (n=4, 25.0%) and blue collar jobs (n=4, 25.0%). The majority of subjects worked outside the home either full time (n=9, 56.25%) or part-time (n=4, 25.0%).

Eleven participants (68.75%) stated they had received medical treatment for the back pain prior to this episode, while 5 (31.25%) indicated they had not. The treatments described included chiropractor, traction, pain meds, x-rays, rest, and physical therapy. None of the subjects indicated they had undergone previous surgery for this back problem before. As seen in Table 3, all subjects reported limitation in more than one ADL with athletics being the most frequently identified. A majority of the subjects reported problems with walking, working, sleeping and outside care.

As seen in Tables 4 and 5, most subjects lost 7 or fewer days of work. Only one subject was seeking workman's compensation. The modal response for length of treatment was 4-5 weeks (n=5, 31.25%). Most subjects reported being treated with anti-inflammatory and/or non-narcotic pain medications and bedrest.

Most of the subjects were not under a doctor's care for any other medical problem. Breathing problems (asthma), "high blood pressure", and "back pain" were reported

Table 2

Demographic Characteristics of the Sample (n=16)

Characteristics	Frequency	Percentage
Age		
Less than 20	1	6.25
21-30	2	12.50
31-40	5	31.25
41-50	4	25.00
51-60	3	18.75
Over 60	1	6.25
Education Completed		
Elementary	0	0.00
High school	4	25.00
Junior college	2	12.50
College	5	31.25
Graduate studies	5	31.25
Occupational Group		
Health care	4	25.00
Educators	3	18.75
Business	2	12.50
Blue collar worker	4	25.00
Student	1	6.25
Other	2	12.50
Employment Status		
Fulltime	9	56.25
Unemployed	1	6.25
Part-time	4	25.0
Homemaker	1	6.25
Retired	1	6.25
Disabled	1	6.25
Seeking employment	0	0.00

separately by three participants. Nine subjects (56.25%) reported not taking any medications while three subjects (18.75%) wrote in "pain pills" under "other". "High blood pressure pills", "water pills", and "breathing pills" were each identified once. "Estraderm", "synthroid", and "tetracycline" were written in under "other".

Table 3

Frequency and Percentage of ADL-limitation (n=16)

ADL	Frequency	Percentage
Athletics	15	93.75
Outside household care	12	75.00
Sleeping	11	68.75
Working	10	62.50
Inside household care	9	56.25
Walking	8	50.05
Driving a car	7	43.75
Sitting	7	43.75
Sexual relations	7	43.75
Personal care	3	18.75
"Standing"[a]	1	6.25

Note. Subjects were allowed to check more then one. The percentages total more than 100%

[a] Write-in response

Table 4

Frequency and Percentage of Work Lost and Length of Treatment for This Episode of Back Pain (n=16)

Characteristic	Frequency	Percentage
Days Lost		
0 days	5	31.25
1-7 days	5	31.25
8-14 days	3	18.75
15-21 days	1	6.25
"5 months"[a]	1	6.25
"Just started new job and had to put it off"[a]	1	6.25
Length of Treatment		
0-2 weeks	3	18.75
2-3 weeks	2	12.50
4-5 weeks	5	31.25
6-7 weeks	1	6.25
Other[a]:		
"one year"	1	6.25
"off and on 15 years"	1	6.25
"since 1970"	1	6.25
"21 weeks"	1	6.25
"off and on for years"	1	6.25

[a] Write-in response

Table 5

Frequency and Percentage of Current Treatments for This Episode of Back Pain (n=16)

Treatment	Frequency	Percentage
Non-narcotic pain meds	7	43.75
Anti-inflammatory pain meds	12	75.00
Bedrest	8	50.00
Other:		
Chiropractor	1	6.25
Tylenol #3	1	6.25
Massage	1	6.25
None	4	25.00

The Research Question Answered

The scores of the total questionnaire and subscales were subjected to statistical analysis which measured the central tendency (the mean),whether any change was statistically significant and not due to chance (the paired t-test), and whether the instrument could be said to be internally consistent or homogeneous to the extent that all of the subscales measured the same characteristic. For these computations a t-test greater than 2.97 was statistically significant with the level of significance being $p<.01$. See Appendix C for quantitative analysis of subgroups per item. Table 6 summarizes data per research question and subgroups.

The research question stated: Is there a change in the patient's perception of active participation in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process? The null hypothesis states there is no change in the perception of active participation in the decision to have lumbar surgery or not after exposure to the

Table 6

Summary of Quantitative Analysis

		Mean Before Treatment	Mean After Treatment	t-test
I	Active Participation Alpha = .57 Questions 1, 2, 3, 4, 5, 7, 10, 22, 23, 24	Mean 4.12 S.D. 1.02 Range 1-6	Mean 4.44 S.D. .82 Range 1-6	3.28**
IA	Desire to Participate Alpha = .86 Questions 10, 22, 23	Mean 4.31 S.D. 1.05 Range 1-6	Mean 3.89 S.D. .93 Range 1-6	6.89**
IB	Participation is Possible Alpha = .85 Questions 1, 3, 4, 5	Mean 4.03 S.D. .88 Range 1-6	Mean 4.83 S.D. .65 Range 1-6	4.84**
IC	Participation Occurred Alpha = .86 Questions 2, 7, 24	Mean 4.17 S.D. 1.12 Range 1-6	Mean 4.69 S.D. .89 Range 3-6	3.74**
II	Expectation Alpha = .67 Questions 8, 9, 12, 13, 18	Mean 4.05 S.D. .94 Range 1-6	Mean 4.65 S.D. .78 Range 2-6	3.49**
III	Role Clarification Alpha = .85 Questions 17, 19, 20	Mean 4.04 S.D. 1.12 Range 1-6	Mean 4.75 S.D. .94 Range 2-6	3.00**
IV	Accountability Alpha = .95 Questions 14, 21	Mean 4.47 S.D. 1.02 Range 1-6	Mean 4.94 S.D. .89 Range 3-6	1.77
V	Shared Information Alpha = .91 Questions 6, 11, 15, 16	Mean 4.16 S.D. .56 Range 1-6	Mean 4.39 S.D. .60 Range 1-6	1.63

** = $p < .01$

Ludann Educational Process. The conceptual framework defined "active participation" as the combination of the desire to participate, the perception that participation was possible, and the perception that participation had occurred. Table 6 shows the sample's mean for "active participation" changing from 4.13 prior to Ludann to 4.44 after exposure to the Ludann Educational Process. Since the t-test was 3.29 with p<.01, it is probable that the change is statistically significant and not due to chance. Therefore the null hypothesis can be rejected with a high degree of probability of not committing a Type I error (p<.01). The internal consistency of the portion of the tool which measured "active participation" was .57 indicating that not all itmes on this portion of the questionnaire contributed consistently to the overall measure of "active participation."

The alternative, or research, hypothesis states that the perception of active participation in decision-making before and after exposure to the Ludann Educational Process will not be the same. Following the above discussion of statistical measurements, the results indicate that a change in the means did occur, and therefore, the research hypothesis is supported. No conclusion can be drawn as to whether the Ludann intervention had a correlative or causal relationship to the change in means. The data only supports that a change did occur and this change seemed to move in a positive direction.

Discussion of the Subscales

The subscale "desire to participate" had an alpha coefficient of .86. The null hypothesis states there is no change in the desire to participate after exposure to the Ludann intervention. This subscale's mean did change from 4.31 before to 3.89 after the Ludann Educational Process. The change in means was statistically significant (t=6.89 with p<.01). Therefore the null hypothesis can be rejected with a high probability of not committing a Type I error. The alternative, or research, hypothesis states the desire to participate before and after the Ludann Educational Process will not be the same. The statistical measurements indicate that a change in the means occurred, therefore, the research hypothesis is supported. No conclusion can be drawn as to whether the Ludann intervention had a correlative or causal relationship to the change in means. The data only shows that a change in means occurred and the change seemed to move in a negative direction.

The subscale "participation is possible" had an alpha co-efficient of .85. The null hypothesis stated there would be no change before and after exposure to the Ludann intervention in the subject's perception that participation was possible. The subscale's mean changed from 4.03 before to 4.83 afterwards. The change in means was statistically significant ($t=4.84$ with $p<.01$) allowing the null to be rejected. The research hypothesis states there will be a change in the perception that participation is possible. The data shows that a change in means occurred and this change seemed to be in a positive direction.

The subscale "participation occurred" had an alpha co-efficient of .86. The null hypothesis states that there would be no change in the perception that participation had occurred before and after the Ludann intervention. The means changed from 4.17 before to 4.69 afterwards. The change in means was statistically significant ($t=3.74$ with $p<.01$), allowing the null hypothesis to be rejected. The data supports there was a change in the two means and that the change was in a positive direction.

The conceptual framework stated there were 4 measurable outcomes of the Ludann Educational process which were related to the patient's perception of active participation. These outcomes are discussed as the subscales expectation, role clarification, accountability and shared information. The subscale "expectation" had the lowest alpha co-efficient .67 of the subscales. The null hypothesis stated that there would be no difference in the perceptions of expectations before and after the Ludann Educational Process. The means changed from 4.05 to 4.65. The change in means was statistically significant ($t=3.49$ with $p<.01$) allowing the null to be rejected. The data supports there was a change in the two means and that the change was in a positive direction.

The subscale "role clarification" had an alpha co-efficient of .85. The null hypothesis stated there would be no change in the perceptions related to role clarification before and after the Ludann intervention. The means changed from 4.04 to 4.75. The change in means was statistically significant (t=3.00 with p<.01) allowing the null to be rejected. The data supports there was a change in the two means and that the change was in a positive direction.

The subscale "accountability" had an alpha co-efficient of .95. The null hypothesis stated there would be no change in the perception of accountability before and after the Ludann intervention. Though the means changed from 4.47 before to 4.94 afterwards, the change was statistically insignificant (t=1.77 with p<.01). The null hypothesis cannot be rejected.

The subscale "shared information" had an alpha co-efficient of .91. The null stated there would be no change in the perception of information having been shared before and after the Ludann Educational Process. Though the means change from 4.16 to 4.39, the change was not statistically significant (t=1.63 with p<.01). The null hypothesis cannot be rejected.

Summary

This chapter reviewed the data from the study questionnaire which assessed if there were a change in the patient's perception of active participation in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process. Sixteen participants responded to the questionnaire. The following areas of data presentation and analysis were given; 1) description of the sample and 2) the study question answered with analysis of subscale means and analysis of paired t-tests. Quantitative analysis demonstrated a mostly positive response to the intervention. Exposure to the Ludann Educational Process produced a positive increase in perceptions in the subscales of participation being possible, participation having occurred, expectations having been clarified, and roles having been clarified. The responses in the subscale desire to participate moved in a negative direction. The responses in the subscales of accountability and shared information were statistically insignificant.

Chapter VI

Summary and Implications

Overview

In Chapter VI the study findings are summarized and interpreted. The implications for future research and nursing practice are discussed. The chapter includes 1) summary of findings, including the research question answered, 2) interpretation of study findings, including discussion of reliability and validity measures, the relationship of findings to previous literature and the study model, and 3) implications for nursing practice and future research.

Summary of the Study

A descriptive study was designed to assess if there was a change in the patient's perception of active participation in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process. The conceptual definition of perceived active participation included desire to participate, perception that participation was possible, and a perception that participation had occurred. Measurable outcomes of the Ludann Educational Process which related to the patient's perception of active participation included; 1) expectations (the setting of realistic expectations related to treatment), 2) role clarification, 3) accountability (sharing of accountability for treatment outcomes), and 4) the sharing of information.

Interpretation

This descriptive study sought to answer the research question: Is there a change in the patient's perception in the decision to have lumbar surgery or not after exposure to the Ludann Educational Process? Active participation was defined as being comprised of the desire to participate, the perception that participation was possible, and a perception that participation had occurred. Related to the patient's perception of active participation were the measurable outcomes of Ludann's intervention, namely; expectation, role clarification, accountability, and shared information. A 24 Likert scale was developed using parallel questions in the pre-and post-tests. The instrument was administered to sixteen subjects before and after exposure to the Ludann Education Process. Though the data supported that participants moved in a positive direction in many aspects of the model after exposure to the Ludann intervention, the clinical significance was negligible. In the majority of the 24 items on the questionnaire participants reported the same perception ("agree") before the intervention as afterwards with only a slight increase in the strength of their perception (e.g. a before-response of 4.25=agree and after-response of 4.56=agree). So, though there was a statistically significant overall movement towards the positive, the before- and after-response category remained unchanged. Speculations regarding why this data occurred are discussed later in the chapter.

Critique of Study Results

Spengler (1988) and Crenshaw (1992) stated that although backpain is common from the second decade of life on, intervertebral disc disease and disc herniation are most prominent in otherwise healthy people in the third and fourth decades of life. Spengler described the typical patient with a lumbar disc herniation to be a 35 year old man with a 2 to 3 month history of lower back pain and a 4 to 6 week history of gradually increasing, radiating pain in the lower extremity. The sample in this study resembled Spengler and Crenshaw's description. Five participants (31.25%) of the study were between the ages of 31-40. Six of the respondents (37.5%) were male. Eleven patients (68.75%) reported having had medical treatment before with five participants (31.25%) indicating 4-5 weeks of treatment for this episode of backpain. Eight subjects described themselves as being limited in 8 or more of the listed ADL's. Thirteen respondents (81.25%) reported "none" when asked if they were currently under a doctor's care and are presumed to be healthy but for their back problem.

A cornerstone of the conceptual framework was Bramlett et al.(1990) consumer-centric model. The three central components of their model are; 1) maximum transfer of knowledge to the patient, 2) prominent patient participation in decision-making, and

3)freedom to implement decisions. Applicable to "maximum transfer of knowledge" subjects' responses moved towards the positive in the sub-scales of role clarification, expectation, and shared information. In regards to the perception of patient participation in decision-making and the freedom to implement decisions respondents moved towards the positive in the sub-scales of participation having been possible and participation having occurred. Analysis of the data was ,therefore, reflective of the three central components which describe the consumer-centric model.

Multiple authors described decision-making as the process which lays the foundation to take a course of action (Ward & Heidrich,1989; McFarland & McFarlane, 1989; Krouse & Roberts,1989). In this study, the course of action was deciding whether or not to have lumbar surgery. In the design of the study specific assumptions were made. The assumptions collectively stated the patient had a right to information about his/her health, that such information was important in the patient's ability to participate in the decision-making process, that the patient should play a prominent role in this process, and the patient has the freedom to choose which option is most appropriate.

The foundation assumption was the patient had a decision to make. Here a potential flaw of this research study was revealed. The research question assumed there was a decision to be made, however, this may have been an error. Two participants wrote unsolicited remarks on their post-intervention questionnaires stating their pain was so intense that they did not perceive to have any choice as to whether or not to have surgery. For these two subjects the course of action was not whether to have lumbar surgery. Their decision was already made. Though only two participants clearly stated they "had no decision to make," it is not unreasonable to assume others may have reported the same perception if asked directly.

Though the tool wasn't designed to elicit this information ("do I have a choice?"), data which supports this new assumption that they may not have perceived a choice includes is 8 of the 16 subjects indicating limitations in greater than 6 of the 10 listed

ADL's. A reasonable assumption would be that pain was a limiting factor in the functioning of a given ADL. Though the data did not confirm that these 8 participants felt they had no choice, it would have been interesting to correlate the perceived level of choice with the perceived level of ADL limitation and the perceived level of pain. In future studies the tool should be designed to clearly ask if the subject perceives there is truly a choice regarding whether or not to have surgery. The study was flawed as it did not test whether the foundation assumption was true: i.e. did the patient perceive he/she had a decision to make. This flaw formed the basis for changing the conceptual framework to guide future studies. The changes in the conceptual framework are detailed later in the chapter.

The implications for primary care are important. If the decision to have back surgery was not being made in the neurosurgeon's office, where was the decision being made? The decision-making was most likely being made in primary care. Spengler (1988) stated the majority of patients who experience lumbar disc herniation find relief from non-operative management strategies which combine short-term bedrest with mild anti-inflammatory agents. Indications for surgical management of a symptomatic lumbar disc herniation, exclusive of any urgent/emergency presentation, are unresponsiveness to non-operative management and a reasonable rapport with the patient (Spengler,1988). In this area between perceived "relief" and "unresponsiveness" lie the challenges and opportunities for primary care. It is unmanageable, rather than unrelieved, pain (with the companion of increasing limitations in ADL's) which causes a patient to present for lumbar disc surgery.

Primary care can help patients manage discomfort and promote increased tolerance for ADL's. Primary care providers need to continue to embrace alternative and adjunctive therapies for pain management. Relaxation techniques, bio-feedback, imagery and visualization exercises are supportive to traditional therapies of anti-inflammatory medications and short-term bedrest. It is important for primary care providers to help move patients towards an increased efficacy in self-care.

Krouse and Robert's research (1989) found that an actively negotiated process had a positive impact on the patient's feelings of control and power within a simulated treatment setting. Wallston et al.(1991) found that for most people loss of control was distressing. Though few patients wanted complete control, the amount of control varied from patient to patient with most patients preferring a pattern of joint control and shared decision-making. Feelings of power and control over one's destiny may also be found to influence factors such as compliance with treatment, following other health care practices, and a general satisfaction with health professionals. After exposure to the Ludann intervention the participants reported an increase in the perception of being "in control" or "on top of the situation", an increase in understanding their role in recovery and the degree of importance they play in that process. The data revealed subjects increased their positive perceptions regarding being able to influence their treatment and being allowed to play an active role in their health care. Again, though the decision to have surgery may have already been made, the participants described positive attitudes regarding aspects the literature describes as part of decision-making. Statistical analysis revealed all of the aforementioned increases in positive perception were statistically significant and not due to chance. However, the changes were clinically insignificant since the participants followed the trend of agreeing prior to the Ludann intervention and only strengthening their original perception of agreement and not actually changing their position.

Holzer (1989) and Green (1988) both described effective collaborative decision-making as an on-going process of shared information, mutually set achievable goals, realistic expectations, role clarification, and shared accountability. Though the Ludann Educational Process is not an on-going process nor does it focus on mutual goal-setting, after exposure to the intervention subjects increased their positive perceptions in the sub-scales of expectations and role clarification. The data in this study reflects a statistically significant positive increase in aspects of Holzer's and Green's description of collaborative decision-making, though the clinical importance was negligible since participants agreed before and after the intervention without truly changing their position. Participants only strengthened the degree of their original position.

A major strength of the literature rests in the consistency of multiple authors' calling for an interactive negotiating process between patient and provider. Another strength lies in the authors' abilities to articulate why this interactive process needs to take place which include the rise of consumerism, the changing role of advocacy, the increasing complexity of required decisions related to the management of chronic disease. Though the literature is strong in describing what is needed (interactive negotiating process) and why (consumerism, advocacy, and complexity of chronic disease), the literature is extremely weak in describing how to operationalize this interactive negotiating process in a 15 minute primary care office visit. Nursing research in primary care must start to explore designs which promote the interactive decision-making process. Such designs might include, but are not limited to, using the office visit to identify the need for decision-making and then bringing patients back for classes in health care decision-making and one-on-one counseling specific to their individual problem. Continued research and design are required to meet the demands of increasingly complex decision-making.

The model proposed an interactive relationship between the patient and the patient's perception of active participation. Active participation was comprised of desire to participate, belief that participation is possible, and a perception that participation has occurred. Statistical analysis of the data revealed the respondents' increased positive perception in regards to participation being possible and having occurred. Again, following the previously described trend, these positive changes were clinically insignificance since the participant agreed both before and after the intervention. Data regarding the desire to participate was inconclusive and should be studied more adequately in the future.

The conceptual model described the final outcome of the interaction of all these factors to be a health related decision, in this case whether to have lumbar surgery or not. As described earlier this may not be an accurate description of the end result as the decision to have lumbar surgery may have been made prior to presenting at the neurosurgeon's office.

As noted before, the study's conceptual framework was not supported. The framework should be changed to reflect the actual points of decision-making which take place in primary care. The framework should also describe the strategies for and patient's reported response to symptom management which takes place in primary care. The patient's exposure to the Ludann Educational Process would not promote increased patient participation in decision-making, rather, the Process would promote the outcomes of increased knowledge of the surgical experience, the patient's role in recovery, and ownership of subsequent restoration outcomes. In retrospect, possible additions to the theoretical underpinnings of the conceptual model might be the literature describing locus of control and its relationship to decision-making. The new conceptual framework is detailed in Figure 4.

Though the data supports that participants moved in a positive direction in many aspects of the model after exposure to the Ludann intervention, the clinical significance is negligible. In the majority of the 24 items on the questionnaire participants reported the same perception before the intervention as afterwards with only a slight increase in the strength of their perception (e.g. a before-response of 4.25=agree and an after-response of 4.56=agree). So, though there was a statistically significant overall movement towards the positive, the before- and after-response category remained unchanged.

Why this occurred can only be discussed at the level of speculation. Perhaps the decision-making process had occurred in primary care and the patients came with a level of perceived active participation already established which, though strengthened, remained essentially unchanged after their exposure to the Ludann Education Process. Another possible explanation might include a patient's perceived locus of control and the interaction of that locus with this specific decision. For example, patients who perceive themselves to

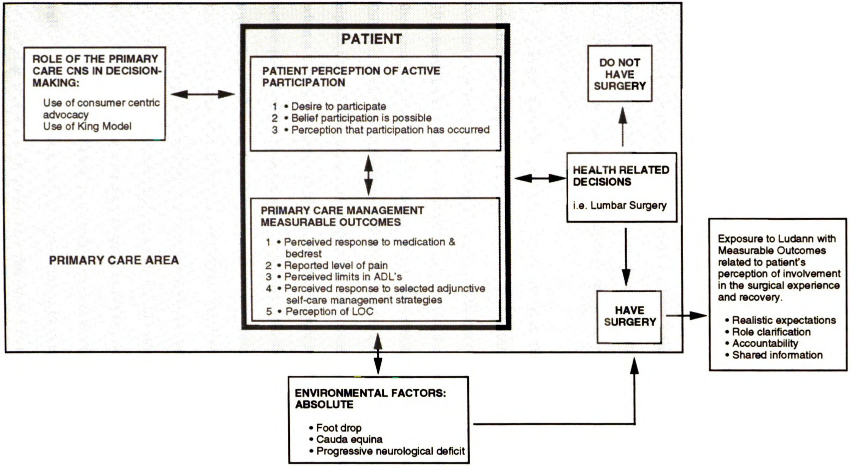


Figure 4: Redeveloped conceptual framework for future study; the relationship of the primary care CNS to the patient; the relationship of the patient with the variables involved in decision-making.

always make their own decisions may not change their initial perceptions after a specific intervention.

Another possible reason the before and after response remained unchanged is related to the tool itself, specifically, measurements regarding the tool's reliability and validity. Since most of the sample was probably in pain at the time they filled out the questionnaire, equivalence measures of reliability (completing two alternate form questionnaires at the same time) would have been a hardship as the length of time required to complete the process would have been prohibitive. Therefore, the tool was only subjected to one measure of reliability, specifically Cronbach's alpha coeffecient, to establish internal consistency.

Internal consistency refers to the extent to which all parts of the measurement technique are measuring the same concept. Ten questions were developed to measure the concept of active participation. The alpha coefficient of these 10 questions was .57. These 10 questions were then re-arranged to measure the 3 subscales hypothesized to comprise the concept of active participation. The 3 subscales and their alpha coefficients were as follows; desire to participate, alpha=.86; perception that participation was possible, alpha=.85; and perception that participation had occurred, alpha=.86. What does it mean when a total scale (active participation) has a lower reliability than the subscales? First, active participation is not a single construct and, therefore, does not lend itself to a unidimensional scale. Second the items do not measure what they were designed and intended to measure (active participation) and, therefore, the tool is not valid.

Though face validity was established via the mechanism of other nurse researchers reviewing the tool, content and construct validity were not estblished prior to this pilot study. The data supports the importance of the tool being tested and revised before any further use in future studies. Especially important would be measures to establish construct validity since the data suggests the theory, proposition, hypothesis, and principles underlying this research study may not have been valid. To test construct validity comparisons need to be made with a number of other instruments that test for constructs similar to perceived active participation in decision-making. Content validity involves comparing the content of the measurement technique of this study's tool to the known literature on the topic of perceived active participation in decision-making and validating the fact that the tool does represent the literature accurately.

Implications for Nursing Practice

There is an emerging recognition among policy makers, providers, and patients that our health care system is in need of reform. While there is no clear consensus regarding what kind of reform is needed all proposals reflect a common awareness of the challenge to increase the value obtained for our health care dollars. Additional research is needed in the biobehavioral environment of primary care. The role that patients play in framing problems and deciding on therapy is critical to achieving effective health care (Hibbard & Nutting, 1991).

The Primary Care CNS is uniquely qualified to meet the challenges of promoting effective health care in this era of reform. This study demonstrated the importance of decision-making in primary care. Specific to the sample of this study the Primary Care CNS could decrease the number of surgeries by mutually designing strategies with the patient that promote improved patient perception in relation to pain management, increased function in ADL's, and enhanced sense of self-efficacy in self-care and symptom management. Such adjunctive therapies as therapeutic touch, biofeedback, visualization and imagery, and effective relaxation techniques are important skills for the CNS to use in his/her practice.

Another area of importance for the Primary Care CNS is in developing an expertise promoting patient involvement in the area of health care decision-making. The most significant contribution of this study to advanced nursing practice in primary care lies in the development of the new research question: when did the decision to have back surgery occur? The new hypothesis is decision-making occurred in primary care during the process of interaction between patient and primary care provider as they attempted to manage the symptom of pain and its impact on the level of ADL function.

This new hypothesis generates many implications for advanced nursing practice in primary care. If indeed the majority of decision-making is made in primary care as an outcome of the interaction between the variables of perceived pain, perceived level of ADL function and perceived choice of whether to have surgery or not, than primary care providers need to create an environment where such decisions can be made. The literature uniformly describes optimal decision-making to be the outcome of a negotiated interactive process which occurs over time between patient and health care provider.

The traditional 15 minute office appointment does not lend itself to such a process. Another approach would be to take the interactive decision-making process out of the 15 minute visit and place it in the environment of an educational focus group. Just as diabetic education, cardiac rehabilitation, and pre-natal support groups have been designed to meet needs of specific patient populations, a group could be designed to promote interactive decision-making in primary care. Potential participants could be identified and invited to attend the "classes". The primary are CNS would design and facilitate these class/meetings.

Possible topics for discussion and participation would be;

What is decision-making?, How does the patient prefer to make decisions regarding health care?, What specific decision is the patient currently faced with (e.g.lumbar surgery)?, What does the patient perceive to be his/her current and future choices?, What does the patient believe he/she needs to know to make this decision?, and,finally, What decision does the patient chose to make at this time? The CNS could help patients and family members to come to their own conclusions through administering evaluation tools, promoting group discussion, facilitating one-on-one interactions, and negotiating choices with mutually designed follow-up mechanisms.

Though it is true this type of process does not lend itself to the 15 minute office visit, the process does lend itself to the environment of the interactive focus group. Of all the primary care providers (physician, P.A., Bachelor's prepared Nurse Practitioner,and Masters prepared CNS) it is the advanced practice CNS who is uniquely qualified to design, implement, and evaluate such a program. The CNS is also prepared to write grant proposals to generate the funds and design research to describe the outcomes.

The CNS must develop a tool which assesses the patient's desire for participating in health care decision-making and match the patient's style accordingly. True patient advocacy is found in promoting individualized care which is not always synonymous with active patient participation. The CNS needs to create an environment that promotes a process of negotiation that occurs over time. This is a crucial concept. The question keeps reappearing: At what point in time does decision-making occur? An important consideration may be that rather than being an event which occurs at a point in time, health care decision-making may be a process which occurs over time. Since the Primary Care CNS provides a service which is continuous, accessible, and comprehensive, it makes sense that he/she would develop an expertise in a process which occurs over time.

Creating this environment and implementing a focus-design group would more clearly operationalize the advocacy role of the CNS. Briefly, the advocacy role guides the CNS to determine where the patient perceives himself currently to be, where the patient desires himself to be in the future, to help explain what options medical and nursing practice have to offer, and support the patient in choosing a stated option or designing his own. Again, the 15 minute office visit does not lend itself to operationalizing the advocacy role. The heart of the advocacy role lies in promoting an <u>interactive</u> process of negotiation and exchange of information. Not only what does the provider have to say but what values, ideas, concerns, suggestions does the patient bring to the process. The choice emerges from the mutual exchange of information negotiated at the level of shared decision-making that is dictated by the patient not the provider.

This is one of the major deficits in the Ludann Educational Process. The information flows one way, from provider to patient. There is not an exchange of information. The Ludann Educational Process is not an interactive process which promotes the mutual exchange of information between provider an patient that results in a negotiated decision. Ludann's perception that they have designed a patient-centered process which promotes decision-making is inaccurate. What the Ludann Educational Process does do, however, is provide accurate information describing what the surgery and the surgeon can and cannot do, clarifies patients' expectations regarding the outcomes of surgery, and describes the role patients play in rehabilitation and recovery. Recommendations to Ludann would include promoting itself as a non-interactive, one-time event which seeks to give information to the patient rather than promoting itself as patient-centered decision-making process.

The Primary Care CNS could collaborate with the neurosurgical CNS through sharing the assessment and description of the patient's preferred decision-making style. The neurosurgical CNS could use this information to design strategies which promote the patient's active participation in the recovery process and ownership of clinical outcomes. Implicit in this process is designing mutually agreed upon strategies that fit with the patient's life style and culture. The neurologic CNS would report to the Primary Care CNS what decisions and actions the patient had chosen and the Primary Car CNS could continue managing the patient, supporting decisions already made and promoting actions required for restoration and maintenance.

Implications for Future Research

The main implications from this study exist in regards to research. A study does not end with its analysis, rather, it is part of an ongoing research process which defines and refines concepts. The first implication for research is the further testing of the reliability and validity of the tool. Further reliability measures would include more tests for stability, such as test-retest methods over time. Also testing for equivalence through the use of alternate form questionnaires. Further validity measures would include more stringent content validity measures, such as review of items by a number of experts, and further detailed review of the literature. Also, construct validity needs to be extablished through the comparison of the tool to other instruments that test for similar constructs.

A second implication for research would be replicating the study with a population that clearly had a health care decision to make as the action outcome of the conceptual framework. The use of this population, where the action is now hypothesized to have been to <u>have</u> the surgery not <u>decide</u> whether to have the surgery casts, the positive outcomes of the intervention under something of a question. Another possibility is to use the same population but rephrase the research question. For example, a future researcher could ask if there is any change in the perception of active involvement in the experience of lumbar surgery and recovery after exposure to the Ludann Educational Process? Another possibility would be the use of the same population and focus the question on describing outcomes such as perception of ownership of recovery process after exposure to the Ludann Educational intervention.

A third implication for research would be to replicate the study using a higher subject number in order to increase the heterogeneity of the sample and the ability to generalize the results. This data sample was small (n=16). A larger sample would certainly add more credibility to the findings of increased positive attitudes regarding a majority of the subscales.

A fourth implication for research is further tool refinement. The instrument had 24 items using a six point Likert scale. Future tool refinement would be to rearrange the order of the scale having the options read mildly agree/disagree, agree/disagree, and strongly agree/disagree. As the tool currently reads the choices go from agree/disagree to mildly agree/disagree to strongly agree/disagree with "mildly" carrying more weight than "agree/disagree".

Other tool refinement would include a revision of specific questions which were poorly worded or inappropriate to the situation such as question # 10, "I want to be more involved about deciding whether to have surgery". Again, this decision may have already been made and the inclusion of this question is probably confusing.

The wording of question #11, "I realize I was initially unclear about the treatment I'd receive", is awkward making it difficult to know if agree/disagree means yes or no. Another problem question is "I now have new physical symptoms". Though the sentence structure is clear, including this item under the subscale accountability is confusing. The relationship should be more clear or the question should be eliminated. In addition, there should be more questions developed to measure the subscale of accountability. The current tool has only two questions and one of those is suspect.

The fifth implication for research involves the investigation of other variables which may effect subjects' perceptions of actively participating in health care decision-making. Such variables might include locus of control or more specifically desire for participation. This study attempted to explore the variable of desire for participation, however, the success was questionable. This area is important and deserves increased research and development. It was not within the scope of this study to include a measurement of locus of control and the discussion would benefit from its consideration as a variable in any further research related to decision-making.

Other variables to consider would be the interaction between patient and health care provider. What effect does the interchange between two people have on one person's perception of having been actively involved in making a decision? Is there an important effect that an affective response has to play in making health care decisions?

Although this study addressed and attempted to answer one question, it has raised many others. The primary care Clinical Nurse Specialist who is a leader and a role model for nursing must be involved in the challenge of research. Adding to the literature regarding the process of patient decision-making in health care is increasingly more important as we move into the 21st century. This study has provided direction for future research on the variables which may effect a patient's perception of active participation in health care decision-making.

A summary of the implications for research are as follows;

1) Further reliability and validity testing of the instrument,

2) Replication of the study using a population that has an actual health care decision to make,

3) Replication of the study with a larger sample,

4) Further tool refinement, and

5) Investigation of other variables which may effect patient perception of active participation in decision-making.

Contributions of the Study

This study provides initial data on a small sample of patients with back pain and their perception of increased active participation in decision-making of whether to have lumbar surgery or not after exposure to the Ludann Educational Process. Though the literature is rich with discussion of decision-making in health care there is no literature that describes this specific intervention. Data suggests a mostly positive increase in the perception of active participation after exposure to this intervention.

This study also contributes to the discussion of the relationship between role clarification , realistic expectations, and the perception of involvement in health care. These areas deserve more research and development. This study contributes initial work on developing a tool to measure perceived active participation in health care decision-making.

Decision-making in health care is increasing in its importance. This study provides initial information and methodology to begin to study strategies designed by practicing clinicians that claim to promote increased active participation in health care decision making. The most significant contribution of this study to advanced nursing practice in primary care lies in the development of the new research question: when did the decision to have back surgery occur? The new hypothesis is the decision-making occurred in primary care. Hopefully this study will contribute the ideas and the impetus for future research in this area.

Summary

In Chapter VI a summary of the study and findings was presented as well as interpretations of the results . The study results were critiqued in light of the conceptual model of the study. Recommendations for nursing practice and future research were illustrated. Finally, contributions of the study were described. Although this study is completed, the potential for further research and tool development for the assessment of the perceptions of active participation in health care decision-making has just begun. The advanced practice nurse must continue to research workable interventions that promote increased active participation in decision-making for all areas of health care.

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Appendix A

The Instrument

LETTER TO POTENTIAL PARTICIPANTS

Dear Potential Participant,

I am a graduate student in the College of Nursing at Michigan State University. My studies include the completion of my master's thesis, which is the study of your perception of actively participating in the decision to have lumbar surgery. Your perceptions will be measured before and after your exposure to the Ludann Educational Program.

I have developed a questionnaire to assess your perception of having actively participated in this decision. Men and women who meet the criteria will be asked to complete a written questionnaire <u>before</u> and <u>after</u> going through the educational program.

Your help and assistance is appreciated. As a nurse, I am interested in providing quality care to people and the community. Research, such as this, will hopefully provide information for increasing active participation on health care decision-making for all patients.

Sincerely,

Patricia Bement R.N., B.A.

LETTER OF EXPLANATION AND CONSENT INFORMATION

This study is a Michigan State University graduate student thesis. It is designed to obtain information about taking part in the decision to have lumbar surgery. Information from this study may be used to develop research plans for further testing regarding health care decision-making. Participation in this study requires completion of a short questionnaire before going through the educational program and a second short questionnaire after attending the educational program. The amount of time needed to complete each questionnaire is about 15 minutes.

If you wish to participate, open the envelope and follow the directions for completing the questionnaires. When you have completed the yellow questionnaire, seal the test in the attached addressed, stamped envelope. You have the option of mailing it yourself or placing it in the box in the office when it will be mailed to the principal investigator. KEEP THE BLUE QUESTIONNAIRE. After attending the educational program, fill out the blue questionnaire and mail it directly to the principal investigator in the second attached, addressed, stamped envelope.

Your participation is voluntary; you may refuse to participate, or stop your participation at any time. Your participation in this study will not change or effect your treatment. There are no known risks of harm either physically, psychologically, socially or economically for filling out the questionnaire.

The benefit of your participation is that it will provide information which would be used to further investigate health care decision-making.

Your responses to the questionnaire will strictly confidential. Answers to the question will be shared with the principal investigator, Patricia Bement R.N. and her thesis committee only for purposes of this study. No names will be used and subjects will remain anonymous in all reports of the research findings.

If you do not wish to participate, please replace the questionnaire in the envelope and give the envelope to the office nurse. Because all questionnaires are mailed directly to the principal investigator and no names appear anywhere on the questionnaire, you are guaranteed confidentiality.

If you have any questions or concerns about this study, please contact the principal investigator for assistance.

Patricia Bement R.N.
2350 Blaine SE
Grand Rapids, MI 49507
Phone 247-4852 (8:00 pm to 11:00 pm)

Thank you for your time and participation in this research project.

Pat Bement

— —

If you would like a report of the research findings, whether you complete both questionnaires or not, please write your address only at the bottom of this paper. Keep the top part of this letter, but mail this portion with your questionnaire. Results of this study will be addressed to:

Potential Participant
ID # ______________

Address ______________________________

City ______________________ State __________ Zip ____________

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRES

1. Open the envelope.

2. Please read the Letter of Explanation and Consent Information.

3. You will find two questionnaires; a yellow one and a blue one. There are two addressed, stamped envelopes.

4. Please fill out the yellow questionnaire. (Optional: cut off the bottom of the Letter of Explanation if you wish to receive a report of the results and fill in your address).

5. Seal the yellow questionnaire and the optional slip cut off the bottom of the Letter of Explanation in the first stamped, addressed envelope.

---

6. Keep the blue questionnaire and the enveloped attached to it in a <u>place where you can easily find it again</u>.

7. After attending the Ludann Educational Program, fill out the blue questionnaire. Seal the questionnaire in the addressed, stamped envelope and mail it to the principal investigator.

Thank you for participating in this study.

Pat Bement

Date: ______________ **ID #** ________________

Demographics

1. Age (check one) Under 20 ☐ 20-30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐ Over 60 ☐

2. Sex (check one) M ☐ F ☐

3. Education completed (check box of highest level that applies)
   a) Elementary School .... ☐
   b) High School .... ☐
   c) Junior College .... ☐
   d) College .... ☐
   e) Graduate Studies .... ☐

4. Occupation (write in)_______________________

5. Employment status: (check all that apply)
   a) Employed full time .... ☐
   b) Unemployed .... ☐
   c) Homemaker .... ☐
   d) Employed part time ... ☐
   e) Seeking Employment ..... ☐
   f) Retired .... ☐
   g) Disabled .... ☐

6. Have you ever had medical treatment for back pain before? Yes ☐ No ☐
   If "yes" what treatment was used? ___________________________________

7. My back pain limits me from the following daily activities: (please check all that apply)
   a) working .... ☐
   b) inside household care .... ☐
   c) personal care .... ☐
   d) driving a car .... ☐
   e) outside household care .... ☐
   f) walking .... ☐
   g) sitting .... ☐
   h) athletics .... ☐
   i) sleeping .... ☐
   j) sexual relations .... ☐

8. If you have lost work, how much:
   a) 0 days .... ☐
   b) 1-7 days .... ☐
   c) 8-14 days .... ☐
   d) 15-21 days .... ☐
   e) 22-28 days .... ☐
   f) 29-35 days .... ☐
   g) other (please specify) _____________

9. Have you had surgery for **<u>this</u>** back problem before? Yes ☐ No ☐
   If "yes" did Dr. Grin do your surgery before? Yes ☐ No ☐

10. how long have you been treated for this episode of back pain? (check one)
    a.) 0-2 weeks .... ☐
    b) 2-3 weeks .... ☐
    c) 4-5 weeks .... ☐
    d) 6-7 weeks .... ☐
    e) 8-9 weeks .... ☐
    f) 10-11 weeks .... ☐
    g) 12-13 weeks .... ☐
    h) 14-16 weeks .... ☐
    i) Other (please specify) _____________

11. Which treatments have you been following for this episode of back pain? (Check all that apply)
    a) non-narcotic pain medication . ☐
    b) anti-inflammatory medication. ☐
    c) bed rest .... ☐
    d) traction .... ☐
    e) Other (please specify) _____________

12. Are you **<u>currently</u>** under a doctor's care for any condition below? (check all that apply)
    a) high blood pressure .... ☐
    b) heart disease .... ☐
    c) breathing problems .... ☐
       (emphysema, COPD, asthma)
    d) diabetes (high blood sugar) .... ☐
    e) depression .... ☐
    f) schizophrenia .... ☐
    g) other (please specify__________

13. Please check any of the following medications you are on.
    a) high blood pressure .... ☐
    b) heart pills .... ☐
    c) water pills .... ☐
    d) breathing pills .... ☐
    e) mood altering drugs .... ☐
       name ____________________
    f) anti-depressant drugs .... ☐
       name ____________________
    g) other (please specify__________

14. Do you have or are you applying for workmen's compensation? (check one) Yes ☐ No ☐

Yellow Questionnaire **Date:** ___________ **ID#** ___________

Please check one response for each question

	strongly disagree	mildly disagree	disagree	agree	mildly agree	strongly agree
Since my referral for back pain I feel...						
1. That I am unable to influence the treatment I received.	☐	☐	☐	☐	☐	☐
2. That I am in control of the situation	☐	☐	☐	☐	☐	☐
3. That I am just told what to do.	☐	☐	☐	☐	☐	☐
4. That I can get all of my questions answered.	☐	☐	☐	☐	☐	☐
5. That I am allowed to play an active role in my health care.	☐	☐	☐	☐	☐	☐
6. That the health care providers are sensitive to my feelings and opinions	☐	☐	☐	☐	☐	☐
Since I began this referral for back pain, I also felt;						
7. Very much "on top" of the situation	☐	☐	☐	☐	☐	☐
8. At a loss to know what to expect	☐	☐	☐	☐	☐	☐
9. I know what the treatment will do for me.	☐	☐	☐	☐	☐	☐
As I experience my back pain I...						
10. Want to be more involved about deciding whether to have surgery	☐	☐	☐	☐	☐	☐
11. Realize I was initially unclear about the treatment I'd receive	☐	☐	☐	☐	☐	☐
12. Am dissatisfied with progress of my treatment.	☐	☐	☐	☐	☐	☐
13. Felt my problem is incorrectly managed.	☐	☐	☐	☐	☐	☐
As the result of my medical treatments I...						
14. Now have new physical symptoms.	☐	☐	☐	☐	☐	☐
At times, some of my health care providers...						
15. Do not tell me the truth about changes in my health.	☐	☐	☐	☐	☐	☐
16. Do not thoroughly explained my health status to me.	☐	☐	☐	☐	☐	☐
As a result of meeting with my health care providers...						
17. I clearly understood my part in making the decision to have surgery.	☐	☐	☐	☐	☐	☐
18. I clearly understood what the surgery can and cannot do.	☐	☐	☐	☐	☐	☐
19. I clearly understood what the surgeon's job is.	☐	☐	☐	☐	☐	☐
20. I am not clear about my part in the recovery process.	☐	☐	☐	☐	☐	☐
21. I have an important part to play in my recovery	☐	☐	☐	☐	☐	☐
22. The surgeon was responsible for my decision.	☐	☐	☐	☐	☐	☐
23. I am responsible for making my own decision about surgery	☐	☐	☐	☐	☐	☐
24. I feel I did not play a part in deciding to have surgery	☐	☐	☐	☐	☐	☐

Blue Questionnaire **Date:** ________ **ID#** ________

Please check one response for each question

Since I completed the Ludann Educational Program I feel...	strongly disagree	mildly disagree	disagree	agree	mildly agree	strongly agree
1. That I was unable to influence the treatment I received.	☐	☐	☐	☐	☐	☐
2. That I was in control of the situation.	☐	☐	☐	☐	☐	☐
3. That I was just told what to do	☐	☐	☐	☐	☐	☐
4. That I got all of my questions answered.	☐	☐	☐	☐	☐	☐
5. That I was allowed to play an active role in my health care	☐	☐	☐	☐	☐	☐
6. That the health care providers were sensitive to my feelings and opinions	☐	☐	☐	☐	☐	☐
7. Very much "on top" of the situation.	☐	☐	☐	☐	☐	☐
8. At a loss to know what to expect	☐	☐	☐	☐	☐	☐
9. I know what the treatment will do for me.	☐	☐	☐	☐	☐	☐
10. Wanted to be more involved about deciding whether to have surgery	☐	☐	☐	☐	☐	☐
11. I had been initially unclear about the treatment I'd receive	☐	☐	☐	☐	☐	☐
12. Dissatisfied with progress of my treatment.	☐	☐	☐	☐	☐	☐
13. My problem is incorrectly managed.	☐	☐	☐	☐	☐	☐
14. I now have new physical symptoms	☐	☐	☐	☐	☐	☐
15. My health care providers did not tell me the truth about changes in my health.	☐	☐	☐	☐	☐	☐
16. My health care providers did not thoroughly explain my health status to me.	☐	☐	☐	☐	☐	☐
17. I clearly understood my part in making the decision to have surgery.	☐	☐	☐	☐	☐	☐
18. I clearly understood what the surgery can and cannot do.	☐	☐	☐	☐	☐	☐
19. I clearly understood what the surgeon's job is.	☐	☐	☐	☐	☐	☐
20. I am not clear about my part in the recovery process.	☐	☐	☐	☐	☐	☐
21. I have an important part to play in my recovery	☐	☐	☐	☐	☐	☐
22. The surgeon was responsible for my decision.	☐	☐	☐	☐	☐	☐
23. I am responsible for making my own decision about surgery	☐	☐	☐	☐	☐	☐
24. I did not play a part in deciding to have surgery	☐	☐	☐	☐	☐	☐

Appendix B

Ludann Educational Process Lumbar Laminectomy Teaching Video Transcription

Ludann

[illegible]

Ludann Education Services
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THE LUDANN NEUROSURGERY PATIENT EDUCATION SERIES

LUMBAR LAMINECTOMY

by
Oliver D. W. Grin, M.D., F.A.C.S.
Dorothy L. Bouwman, R.N., M.S.N.

Mission: To Facilitate Placing the Patient at The Center of the Health Care Process

TEACHING VIDEO TRANSCRIPTION

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All illustrations in Ludann Teaching Videos are based on actual instruments and correct anatomy, and have been deliberately simplified or otherwise adapated to enhance patient understanding.

LUMBAR LAMINECTOMY
Teaching Video - Transcription

Roles:

DB = Dorothy L. Bouwman, RN, MSN
OG = Oliver D. W. Grin, M.D., F.A.C.S.
L = Linda, Neurosurgical Patient
D = Dave, Patient's Husband

Setting: Conference Table with Model of Lumbar Spine and Ludann Patient Education Series book(s) on Conference Table

INTRODUCTION BY DR. GRIN

The purpose of the Ludann Patient Education Video is to share with you, the patient, information about your health problem and the proposed surgery. This video, along with the Ludann patient education books and specific information from your surgeon, will form the basis of your patient education.

Patient education is vitally important so that you can give a knowledgeable, informed consent. Patient education also allows you to collaborate with the health care team and to become an active participant in the medical care process.

Ludann Education Services
Ludann

"WE SHARE THE CARE"

Teaching Conference

DB: What Dr. Grin has asked me to do is help you to understand the problem that he has explained to you. And, as you understand, hopefully, that the problem that you have is a ruptured disc. I understand that your leg pain is on the left and the nerve that is compressed is the left L5 nerve root. What we sort of hope to do in this conference is by taking the model and our teaching books and whatever, is explain to you exactly what it is you have, what we really need to do, and what he needs to do at the time of surgery, and, hopefully, if there are any questions from you that you may have from this kind of process.

L: O.k.

DB: What I did is I brought the lumbar model along so that you can visually see exactly what it is that you have and what it is that needs to be done. This is the lumbar spine. You have a spine that comes all the way down from the brain that we have just now segmented as to be the lower part of the spine, and to localize then, the symptoms that you are having based on this. You have the vertebral bodies, and those are the big bones that you see here. And between every body and vertebra, you have a disc. The disc really acts as a cushion between the vertebrae. And sort of in the process of living, you just bounce down a little bit on the disc, but it does really separate the bones clearly, as you can see.

L: Yes.

DB: Now the disc is a sort of fibrous kind of structure and has a really tough--tough outer ring with a softer inside. When we are young, that inside fo the disc is very similar to semi-formed jello. So it is a really nice cushion and, as kids, you can bounce around and go on all sorts of gyrations and whatever, and that has a lot of give to that. But as you get a little bit older, and obviously you have sustained a fair amount of wear and tear, that material in the disc becomes just a little stiffer. And, in the process of becoming stiffer, it is a little more prone to injury. And, as I can understand from the record, the problem you've had is eight weeks--is that correct? And your leg pain has persisted.

L: Yes, it has.

DB: And do you have an apparent injury, or anything that happened to you at that time?

L: There is nothing specific.

DB: That's difficult sometimes to figure out why suddenly, all of a sudden, you can just have this problem develop. But when we look at that, and over the process of time, you have had a lot of wear and tear. And the discs that separate the fourth and the fifth lumbar vertebrae--and at this very junction you can see on the spine--obviously, it takes more wear and tear than one that woul be found higher up.

L: Yes.

DB: And so the tough outer ring that you have is a casing to hold the material that is on the inside and through some injuries--we might not necessarily in your case know exactly what that is--but in some injuries, you have got a thinning in that casing. And then what happens is the part of the inside of the disc has ruptured. And in the rupturing out, it comes through this casing. And as you can see on here, that this is all very finely structured. So as the nerve exits, it exits through a really small little opening in that vertebral body, and there is not any room for anything else except just that nerve to exit. And when that disc ruptures, it hits against the nerve which then creates your leg pain.

L: O.K.

DB: Now you never know exactly, with this kind of thing, how much of the disc is out. But I can understand from the diagnostic studies that you have had run before, prior to the preparation for surgery, that this piece of disc that you have has broken off. So I think that you will recall that Dr. Grin referred to that as a "fragment of disc." And that means that this big, ruptured part--right here--the big part on the model that we've colored red--that has broken off. And in the process of breaking off, it lay sideways and you can see, obviously, the structure that compresses the nerve.

L: Yes.

DB: It is now the nerve for you that is causing all your symptoms, not necessarily the ruptured disc, per se. If the rupture were out here, probably not touching any kind of nerve, you might not know, not as dramatically as you do. But as it ruptures out--and it ruptured out on the left--it hit this left L5 nerve that runs down your let. The role of this nerve, as you well know because, obviously from all the pain you are having, comes down the backside or the side of your leg to the top of your foot, and it controls the movement of your foot.

L: Yes.

DB: And when you walk, obviously, the ability to lift up your foot is controlled by this nerve. So when you are tripping over your toes like that, we then begin to refer to that as a "partial foot drop." That is because this nerve itself is an electrical component as in concept only, not in actuality. But it is a bare wire that runs through here. What you have is this ruptured part is compressing that nerve and enough to stimulate it to cause the pain, but also it is diminishing the impulse through that nerve so that your foot is not able to be lifted up. So the key thing that we're worried about, and obviously that you are worried about, is ongoing pressure that you have on this nerve to the point where you have diminished function.

L: Yes.

DB: So, when surgery is considered as an option, it is a part of--you've tried to get better, as I understand. You've tried various conservative measures.

L: Yes.

DB: Then what happened, then, is that you have to take the pressure off the nerve. You can't reconstruct the disc, you can't put this back in--or whatever--but you have to take the pressure off so that the nerve can heal. Now when you do that, you come from the back .

L: Yes.

DB: And the little book that we handed to you before will show very clearly that the structure of the spine is such that the vertebral bodies are these big bones here. Closest to the front. So right here is the abdomen. Then, behind the discs and the vertebrae, are the elements of the nerves. And they come down in this main cable here, all the way down from the spinal cord and end up in a bundle, still bound in a bundle, and wherever there is a disc, the nerve exists left and right. All the way down. Very segmental.

L: Yes.

DB: So, when you were examined and the diagnostic studies were ordered, it became very specific by the pain you described and the studies, which nerve is compressed. Because when you go in to correct this situation, you go in in a very segmental way, coming down through a little bit of bone back here called the "lamina", and that is what gives the name to the surgery--"LAMIN - ECTOMY". "Ectomy" meaning "removal of" and "lamina" is this little bit of bone, and the lumbar is this part of the spine.

L: Yes.

DB: So, he has to come--the surgeon comes in and comes in very specifically--to the level that is causing the trouble. So when we refer to you as "left side, left L5", then the surgery is done specifically on that level. Any questions about that?

L: I just have one question. You say you can't--how do you actually repair that--take the pressure off that nerve?

DB: O.k. You come from the back and you take down a little bit of this bone and he finds where the nerve exits. You can see that it exits through this little bit of bone right here. And when the nerve exits, he'll be able to see this underneath the tracking of this piece of disc. And the goal of the surgery is to take the piece of disc off the nerve.

L: O.k.

DB: So, when you come in very carefully, and obviously, it is very obvious on how delicate this all is by all the little fine structures because of all the nerves that are involved, you come in and you take out this piece of disc, taking the pressure off the nerve. So the goal of the surgery is not to give you a new disc, not to fuse the spine or anything like that--the goal is to take the pressure off that nerve, first of all to try and diminish the pain you're having, but the primary thing is to allow an environment for the nerve to heal.

L: Yes.

DB: Because as long as that ongoing pressure is on the nerve, the foot is going to be weak, you're going to have numbness in the leg, and the longer you leave that pressure on, the harder it is for that nerve, obviously, to heal. So when you get to the point that surgery becomes the option, then those things have been weighed.

L: O.k.

DB: Now, when you take the pressure off the nerve--this right here on the model--will show the entire pressure on the nerve is from the ruptured disc. And what happens is sometimes, as we get older--I think that as you get older, you have some wear and tear on the disc before. So, we have what that disc may be called "degenerative." And in the process of that, because there has been a lot of wear and tear in this area, you have some rough edges on the bone--just because you have had a lot of bounce like that. You get some rough edges on this bone and those rough edges on the bone and the angle, are called "spurs."

L: O.k.

DB: So what we may find at the time of surgery, is that even though we have this big chunk of disc that has broken off as a fragment and lying sideways on the nerve, is this area may also have some spurring. That is sort of a normal aging process. In the process of opening up that opening, where the nerve comes out--and I'd have to draw it a lot bigger--and I'll draw it here--is the fact that this is the little opening where the nerve comes out of the bundle of nerves. It comes through like this.

L: Yes.

DB: It has to come through there without any pressure. It has to come through, let's say, right through the middle. And what you have on that left L5 nerve here, is that as the nerve is trying to exit like this, you have a big chunk of disc jammed in there with the nerve root. So the nerve may be pushed to the side or jammed up against the disc. But you also may have, at some of these edges where the nerve is, some rough edges of bone. And those rough edges of bone at that time will be very carefully drilled off so that that opening, then, will be re-established.

L: O.k.

DB: But the key things that you want to know, and the questions that you may specifically ask of Dr. Grin when he comes back, is the fact about the nerve afterward. A lot of work is being done by this nerve. And obviously, your concern is how comfortable will that leg be and how rapidly will the movement of the foot be re-established.

L: Yes.

DB: The important thing to know is that at the time of surgery, we can only take the pressure off the nerve. We can't make the nerve heal. The nerve has to heal on its own. So that will be a component of how long you have had the pressure, how bruised the nerve is, how inflammed it is, how well the body heals, and all sorts of things. Some people wake up from surgery, never feel that sciatica again, and think, "Oh boy--this is great!" Other people after surgery may have a lot of ache in the leg. Your foot weakness may persist. You may need some period of rehab and so to build that up.

L: Yes.

DB: Because what we have done at the time of surgery is just to take the pressure off. And it is very similar--you know, kind of a funny example, but it helps if you use examples--is the fact that if you take your finger and you shut it in the door. You jam the door on your finger. What surgery does in this instance is opens the door. Time is what heals the finger. So if you think about that and the healing of the nerve, is that at the time of surgery the pressure is taken off the nerve. But the healing of the nerve itself is going to be a component of time. And, obviously, your participation in your rehab and building of your strength and whatever, because part of what's causing the problem with the nerve is pressure, as you can see right here. But also, part of it is your injury from the pressure. So the only thing we can do at the time of surgery is to take the pressure off the nerve and allow for the nerve to heal. Is that clear?

L: Yes.

DB: And sometimes, what you may have after surgery is the sheath, or the covering of the nerve has been violated and bruised, and irritated and whatever. You may notice some numbness, and numbness is kind of a funny, "just about going to sleep" kind of feeling. You will feel that sometimes in that same nerve distribution. And really, those feelings are really quite normal, because it is the nerve and if you can conceptualize that and think about that--is the nerve bruised and in the process of healing.

D: How long will it take to heal? I know you mentioned depending on how healthy and physical you are, but in her condition is it a week or two weeks?

DB: Right. Sometimes it can be longer. Certainly, because she has what we call "a neurologic deficit", that means she does have some weakness in the nerve. And if you think of the nerve, it is electrical. It is an electrical impulse. And what is happening is she is not getting enough charge all the way out to the nerve to elevate the foot. Her foot is floppy. And so what happens, then, is what depends on the nerve healing as to recoating its insulation. If insulation has been worn off, in essence, it means it has to recoat that. It depends on how long you've had the pressure on and how much bruising is in the nerve as to when it will heal. And we really don't know that. Now, Linda is in good health and she doesn't have any other health problems, and she is physically fit and whatever. So, really, it could be at any time--she could wake up from surgery and feel dramatically better, with some return of strength in the foot. Or, it could be a process, and that's where we don't know.

L: The process meaning physical therapy?

DB: Physical therapy, exercise, walking, staying fit and working on it. Recovery is a component of actively pursuing it. You can't kind of sit back and wait to recover. Your body will heal, but you really have to pursue recovery. And that is working on your foot, doing your exercises for that--and whatever. But I think for those of of us taking care of you, the key thing to remember is the fact that the nerve has been injured, we can do nothing only other than take the pressure off, and we can't encourage that nerve to heal faster other than the whole example of opening the door on the finger. You know, as long as you've got the door closed on your finger, the finger is not going to heal. But as long as you open the door and free the finger, then that has the ability to heal.

D: What would have caused this? I mean, could it happen to me?

DB: Right. It can happen to anyone. You have a lot of discs. You have discs higher than this and, obviously, as you are very active and carry some extra weight sometimes on the spine, and you have a lot of wear and tear, the disc is a cushion and it thins and wears out and becomes stiffer. The inside, when we're young, is like I said earlier--semi-formed jello. And what happens as you get older--and one of the components of aging is the fact that we dry out a little bit--our hair, our skin and whatever--well, also our discs. And as the disc dries out a little bit, it becomes stiffer. And in the process of becoming stiffer, it is a little more rigid and more prone to injury.

D: O.k.

DB: You could wake up tomorrow, turn over, get your socks out of the door or whatever, and feel it. And many times you feel it as first you felt it--as back pain. Then as the back pain subsides a little bit, you get this irritating leg pain. The leg pain is really telling you that the nerve is involved.

L: Yes.

DB: I think the key thing that you need to think about as you learn about the problem that you have, and the questions that you have, will be the risks. And with anything that is done to you, it is important that you look at the area where you are going to be working. And in this surgical approach, obviously, it becomes fairly obvious on what structures he is going to be working on. So he's going to be working on the left L5 nerve root that is already bruised. So you have the possible--exists--that after working on this and an already bruised nerve, that the weakness in your foot could be greater. Because it is already marginal function as it is now.

L: Yes.

DB: And when he starts to work on it, bringing instruments in, taking the pressure off, it can be at that area where there is weakness. So one of the risks of this kind of surgery is to this specific nerve. Also, as you can see, the whole bundle comes down from the spinal cord. From inside of that bundle of nerves are all these little nerve roots that have to get out, because they are all wrapped up together in a tight bundle. We call that bundle the "cauda equina" or "the horse's tail." And all those little nerve roots are in there. And sometimes the disc can be jammed right in up against that cauda equina and other nerve roots can be injured, because they are in that bundle, from gently working in that area. That would give you some other kinds of weakness or paralysis. Bowel and bladder is below that. So the nerves down here that come off are the nerves to the bowel and bladder. So they're in the bundle, exactly where he's working.

L: Would you know at that point if there would be further risk to the other parts of my body?

DB: Well, lower than this, obviously, the risk is different. For as you're working here, both on individual nerve roots and on the bundle of nerve roots, the nerve roots that are in that bundle could be injured. They could be involved. It doesn't have to necessarily mean some kind of mal-happening, it's just that everything is quite compressed in there. And by working near nerves that are extremely fragile, they could have failure of function. And the failure of function below that will be the movement of the feet and the bowel and bladder. And then risk exists for some kind of bleeding and some abnormal bleeding--you do have to take down bone and go down this area through the skin, a little bit of fat, and whatever--so bleeding or hemorrhage is a risk.

L. O.k.

DB: And in any kind of healing where a wound is made, you have the risk of infection. Those are your primary risks for this kind of surgery, even though the risks are very small. And I think you can be very comfortable talking about those risks with Dr. Grin. You know, like, it's sort of like our risks of driving a car. We know that when we get behind the wheel of a car and you go to the stop sign, someone could run a stop sign. Someone could run into you. Somene could jump out in front of you. Those are inherent risks.

L: Yes.

DB: And the risks of this kind of procedure are exactly where he's working. O.k.?

D: Do we have choices? Do we have choices--if we don't do this, can it be--is there other alternatives of not going through this type of surgery?

DB: Right. And I think those are some of the things that you discussed, as I understand, earlier with Dr. Grin. And he has outlined the options for you. I think what brought you to this point, as I understand clearly from your record and from speaking with him, is the fact of your neurologic deficit. You've given this a full try, the diagnostic studies show that you have this free fragment of piece of disc sitting on the nerve--your chances of that going away are, obviously, extremely slim. And, as your pain has persisted and your foot weakness has persisted, then it becomes really imperative that you take that pressure off the nerve. There is no other way you can take that pressure off, short of surgery.

L: Yes.

DB: And certainly, if you hope to have a good rehab and get that strength back in your foot and not end up with a lot of chronic leg pain, then probably, at this point, you know, I think--as he discussed with you--it's the time to proceed.

L: Just how long would I be in the hospital?

DB: Well, it depends somewhat on exactly how the surgery goes, what he finds, and whatever, and that is quite individualized. But usually we're talking a couple of days. That really depends a great deal on you and how active you are and how you get out of bed and how much you are able to do, and whatever. But we will encourage you to get up and around and be active as much as possible and we'll start rehab on the foot as soon as possible.

L: O.k.

DB: I think also, just to back-track just a little bit where we were talking about risks, and I think we're talking about a general anesthesia, in most instances, and so we're talking about risks of that--or general health risks of surgery. The surgery is, obviously--it's invasive and there are inherent risks to surgery. I think our goal in teaching this kind of process is that you are well aware of where the work is going to be done, what needs to be done, so obviously understanding that nerves are involved. And that is quite apparent.

L. O.k.

DB: We havel also prepared this little book for you and it will take you through a process, the actual surgery, how the incisions are made, and how that is done--in sort of a generalized way. Obviously, each person's problem is a little bit different. You know, so we'll talk to you in here ~~about risks and a~~ little bit about hospital recovery and home recovery.

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L: O.k.

DB: It serves as a little manual for you so that, at your leisure, if you forget and and wonder "what she said" or whatever, you can refer back to that.

L: Just one more question. I'd like to know, if all goes well, when do you perceive me going back to work?

DB: What type of work do you do?

L: I'm an accountant.

DB: Oh, I think you can go back to work when you're comfortable. The major thing will be how well can you sit and if you have to sit for a period of time, can you get up and walk around--how free is your employer to let you kind of come and go, and if you get really fatigued--and sometimes after general anesthesia you do get fatigued and just can't take very much, sometimes just going back. So really, it will depend a great deal on just how well you do. It doesn't have to be long at all.

L: O.k.

DB: We'd like you to not do any heavy lifting or vigorous activities or sports for a little while. But otherwise, your general activities--you can get back when you're comfortable.

D: You know, we are very active in sports. This situation here--is it going to come back? Can it happen again?

DB: Yes. Everyone can have, you know--just like Linda is having her first disc rupture, she can have her second. I don't know if you've had one . . .

D: No.

DB: . . . but if you haven't, then you can have your first. So, there are other discs that can rupture. The fact that you are having the surgery is not making that disc more prone to rupture. The fact that you had a ruptured disc makes that an abnormal disc. So your disc right now is abnormal. And by taking that pressure off, there is no way that we can make the disc normal. So the disc will be abnormal.

L: Yes.

DB: The key then, for you, is to stay as fit as possible, in good health, and obviously watch your body mechanics so that you don't put undue wear on that disc itself. Oh, here's Dr. Grin now.

Dr. Grin enters and sits at the head of the table . . .

OG: Hi, Linda! Hi, Dave!

D: Hi, Dr. Grin.

OG: Nice seeing you again. Now that you have had a chance to review some of the basic things about the laminectomy with Dottie, do you have any questions for me?

L: I have a couple of things. One is, a friend of mine had this specific problem and she had a fusion. Can you explain why I'm not having a fusion, or if I should have one?

OG: Well, Linda, there is a basic difference of opinion among some surgeons who feel that a fusion is part of disc surgery. In general, most of us who do this kind of work don't feel, unless there is an instability problem, that a fusion is necessary. So that in your particular case, the key is to take the pressure off the nerve root by removing the ruptured disc and, if there is any bony pressure on the nerve, to take that pressure off. So without there being instability, you really do not need to have a fusion, in my opinion, and in the opinion of most surgeons across the country.

L: O.k. How big will the incision be?

OG: Well, the incision will probably be about, oh, a little over an inch. I don't have a fetish, personally, about how big or small the incision is--we try to make it no bigger than it has to be. We do use magnification and use an operating microscope, so we really don't need a very big incision, but I would say it would be anywhere from one to two inches.

L: Is this microsurgery, or . . .?

OG: Yes, this is what we call microsurgery in which we use magnification. I, personally, like to use the operating microscope and smaller instruments, but those are tools more than a different way of doing the surgery. They are tools that help us to do the same basic procedure that neurosurgeons do.

L: Dottie explained that in that area that you will be working on, often there are spurs that will need to be taken care of as you went in. Do you foresee other problems that I might be facing in that area?

OG: Not really, your tests look fine for the other areas and, you know, remember that we talked about spurs and discs, and the principle is getting the pressure off the nerve root. So, if that means taking out the disc that it is pressing on, or the disc plus the nerve that the bone spur is pressing on, or just in some situations only a bone spur is pressing on it. But again, the principle is to take the pressure--or what we say to "decompress" the nerve root.

L: Fine. I think that pretty much answers the questions that I had and so if you can just tell me, generally speaking, will I lead a happy, healthy normal life again?

OG: Right. Remember that once you have a ruptured disc or back problem, we can't ever make the back normal again. We don't have the latitude that the plumber has that when he takes out an old pipe and puts in a brand new pipe. We're creating the right environment for your body to heal. That disc will always be abnormal. That doesn't man that you can't live a full or normal life. It does mean that the success of the operation will be, in part, my skill and in part what the limits of medical care can do.

L: O.K.

OG: In other words, it's what the surgical procedure can accomplish and also what is the ability of your body to do the healing, and your--let's say--psychological strength to pursue a recoveryg. I think that if you take care of your body, to exercise, proper eating and certainly don't abuse it with chemical habits and those sorts of things, that you can expect to make a full recovery and do all the things that you normally want to. And, for most of us, there are certain precautions that we should take for our back--whether we've had a back problem or not. That is, proper body mechanics, proper lifting, and general common sense when it comes to using the back.

L: Yes. Would you foresee another rupture in the future, because I've had one and I'm prone to this, or is it isolated?

OG: Well, the fact that you've had it occur once is, you know, probably increases the likelihood of it happening again more than, say, someone who hasn't had it. Again, there are things that can go wrong with our bodies at any time, whether it is our back or our heart, or whatever. So, in thinking about this, I would plan on getting better, plan on an excellent recovery, and while there is a little increase incidence of that coming back, do not focus on that. Expect that if it comes, it is like any other health problem and will be dealt with at that time.

L. Yes. That pretty much answers my questions. I'm interested about how long I would be in the hospital and Dottie answered all of those questions. And physical therapy--how often and for how long did you say?

OG: We tailor make that to individual patients. We, of course, work on the bones and disc and the spine--the muscles and that are things that you can work on directly, through therapy or exercises. Some people like to go to the therapist, some people have a good exercise program at home, and so everybody has to have their own individual program. Being active in sports, as you are, I think that we would have you work with a therapist at least to know the proper exercises, and then you could be on a good home exercise program and fitness program--which you have probably been doing all along.

L: Post-op care at home--is there something I should be doing? Is there anything Dave and I can do to help increase my stamina?

OG: Again, I think just general principles of, you know, fitness, really, particularly aerobics. And again, starting off slowly. Think of yourself as an athlete. In fact, you are an athlete and play racquetball. And an athlete goes back after a period and works with a trainer, and gradually works back into his full activities. The same principles hold true for we who are--I use the term of "recreational athletes".

L: Yes.

OG: Nonetheless, the principle is still the same.

DB: Is there anything more that you would like to ask him, about the risks or anything we talked about?

L: The worst possible scenario here is that my foot would not get any better--in fact, it could get worse, as far as strength is concerned, and I understand that. In your experience, is that something that would happen generally, or you know, if we were talking about percentages, what are the percentages for someone to have this?

OG: First of all, the foot strength coming back is a function of us taking the pressure off the nerve and then your body healing. We can't really predict the healing ability of your nerve. I think that given your general status and health, and the fact that this has not been present for a particularly long period of time--and your attitude and so forth--then I think the expectancy would be that the foot would come back. But that is something that we, really, cannot determine exactly.

L: O.k.

OG: In terms of general risks, I like to say it is like me driving home tonight. We can really imagine anything could happen--in fact, us not surviving getting home. And the same possibility could happen during surgery. That is very, very unlikely. It is about less of a risk than me driving home tonight. When you say what is possible in terms of risks, you know, we can imagine any kind of terrible things that could happen--including death.

L: Yes.

OG: Again, it's not very likely and is much less than me driving home this evening in my car.

L: O.k.

D: We talked about how long in the hospital--how long is the actual surgery?

OG: Oh, roughly, I suppose we would say the actual operating time is roughly about an hour. You will be in the operating room longer than that, because of the anesthesia preparation and induction of anesthesia, and so forth. We don't make a fetish of how long it takes--we just try to do the job, but I would say as a rough estimate--an hour.

L: Then I'm allowed to get out of bed and walk around the next day, the same day, or . . .

OG: We'll allow you to get out of bed, you know, tomorrow, the same day of the surgery--and, you know, at first with help in case you felt a little light headed. But we believe that the healing goes on better as soon as you can get going and we encourage you to be active.

L: O.k.

OG: So you're comfortable then, in proceeding with the operation?

L: Yes, I am.

OG: It is important now, Linda, that we have discussed the problem and the risks and the things that could happen. I think, now, we focus on the solution. We have been talking about the problem and how we can know what to do about it. I think, mentally, it is important for you now to concentrate on getting better.

L: Yes.

OG: You know, athletes like to use imaging and winning--at whatever event they are playing. I think we'd like you to start thinking about recovery, visualizing yourself as well and returning to your normal activities. I think that is important to your recovery and now that we have discussed the problem, we want to get on to the solution.

L: Yes.

End of Video

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Appendix C

Quantitative Analysis of Subscales

Quantitative Analysis of Subgroups (n=16)

Concept	Question	Before	After	t-test
IA Desire to participate	10. Want to be more involved about deciding whether to have surgery.	*agree* Mean 1 ... 4.56 SD 1 .... 1.26	*disagree* Mean 2 ... 3.25 SD 2 .... 1.06	t = 26.87**
	22. The surgeon was responsible for my decision.	*disagree* Mean 1 ... 4.12 SD 1 .... 1.40	*disagree* Mean 2 ... 4.12 SD 2 .... 1.20	t = 0.00
	23. I am responsible for making my own decision about surgery.	*agree* Mean 1 ... 4.25 SD 1 .... 1.39	*agree* Mean 2 ... 4.31 SD 2 .... 1.44	t = 1.79
IB Participation is possible	1. That I am unable to influence the treatment I received.	*agree* Mean 1 ... 3.31 SD 1 .... 1.35	*disagree* Mean 2 ... 4.81 SD 2 .... 1.10	t = 25.80**
	3. That I am just told what to do.	*disagree* Mean 1 ... 4.25 SD 1 .... 1.23	*disagree* Mean 2 ... 5.06 SD 2 .... 0.92	t = 22.08**
	4. That I can get all of my questions answered.	*agree* Mean 1 ... 4.31 SD 1 .... 1.49	*agree* Mean 2 ... 4.75 SD 2 .... 0.85	t = 8.54**
	5. That I am allowed to play an active role in my health care.	*agree* Mean 1 ... 4.25 SD 1 .... 1.48	*agree* Mean 2 ... 4.56 SD 2 .... 0.72	t = 6.16**
IC Participation has occurred	2. That I am in control of the situation.	*agree* Mean 1 ... 4.18 SD 1 .... 1.68	*agree* Mean 2 ... 4.62 SD 2 .... 1.02	t = 10.11**
	7. Very much "on top" of the situation.	*disagree* Mean 1 ... 3.75 SD 1 .... 1.29	*agree* Mean 2 ... 4.25 SD 2 .... 1.00	t = 11.54**
	24. I feel I did not play a part in deciding to have surgery	*disagree* Mean 1 ... 4.75 SD 1 .... 1.18	*disagree* Mean 2 ... 5.12 SD 2 .... 1.14	t = 12.40**
II Expectation	8. At a loss to know what to expect	*disagree* Mean 1 ... 4.06 SD 1 .... 1.23	*disagree* Mean 2 ... 4.31 SD 2 .... 1.35	t = 3.68**
	9. I know what the treatment will do for me.	*disagree* Mean 1 ... 3.93 SD 1 .... 1.18	*agree* Mean 2 ... 4.87 SD 2 .... 0.95	t = 21.16**
	12. Am dissatisfied with progress of my treatment.	*agree* Mean 1 ... 3.87 SD 1 .... 1.45	*disagree* Mean 2 ... 4.43 SD 2 .... 1.15	t = 7.91**
	13. Felt my problem is incorrectly managed.	*disagree* Mean 1 ... 4.37 SD 1 .... 1.40	*disagree* Mean 2 ... 4.68 SD 2 .... 1.1	t = 13.84**
	18. I clearly understood what the surgery can and cannot do.	*disagree* Mean 1 ... 3.87 SD 1 .... 1.50	*agree* Mean 2 ... 4.87 SD 2 .... 1.20	t = 14.90**

** = p < .01

Concept	Question	Before	After	t-test
III Role clarification	17. I clearly understood my part in making the decision to have surgery.	*agree* Mean 1 ... 4.06 SD 1 .... 1.52	*agree* Mean 2 ... 4.68 SD 2 .... 0.94	t = 14.52**
	19. I clearly understood what the surgeon's job is.	*disagree* Mean 1 ... 3.93 SD 1 .... 1.65	*agree* Mean 2 ... 5.06 SD 2 .... 0.92	t = 18.91**
	20. I am not clear about my part in the recovery process.	*disagree* Mean 1 ... 4.12 SD 1 .... 1.20	*disagree* Mean 2 ... 4.50 SD 2 .... 1.26	t = 7.10**
IV Accountability	14. Now have new physical symptoms.	*disagree* Mean 1 ... 4.68 SD 1 .... 0.94	*disagree* Mean 2 ... 4.75 SD 2 .... 1.00	t = 1.67
	21. I have an important part to play in my recovery.	*agree* Mean 1 ... 4.18 SD 1 .... 1.60	*agree* Mean 2 ... 5.18 SD 2 .... 0.98	t = 14.05**
V Shared information	6. That the health care providers are sensitive to my feelings and opinions.	*agree* Mean 1 ... 4.25 SD 1 .... 1.00	*agree* Mean 2 ... 4.31 SD 2 .... 0.60	t = 1.67
	11. Realize I was initially unclear about the treatment I'd receive.	*disagree* Mean 1 ... 3.43 SD 1 .... 1.31	*disagree* Mean 2 ... 3.25 SD 2 .... 1.23	t = 3.51**
	15. Do not tell me the truth about changes in my health.	*disagree* Mean 1 ... 4.93 SD 1 .... 0.85	*disagree* Mean 2 ... 5.06 SD 2 .... 0.85	t = 6.66**
	16. Do not thoroughly explained my health status to me.	*disagree* Mean 1 ... 4.00 SD 1 .... 1.31	*disagree* Mean 2 ... 4.93 SD 2 .... 0.85	t = 19.38**

** = p < .01

Appendix D

Human Subjects Approval

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

March 29, 1993

TO: Ms. Patricia Bement
2350 Blaine, SE
Grand Rapids, MI 49507

RE: IRB #: 93-121
TITLE: IS THERE A CHANGE IN THE PERCEPTION OF ACTIVE PARTICIPATION IN DECISION-MAKING TO HAVE LUMBAR SURGERY OR NOT AFTER EXPOSURE TO THE LUDANN EDUCATIONAL PROCESS
REVISION REQUESTED: N/A
CATEGORY: 1-C
APPROVAL DATE: 03/29/1993

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

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must seek updated certification. Request for renewed approval must be accompanied by all four of the following mandatory assurances.

1. The human subjects protocol is the same as in previous studies.
2. There have been no ill effects suffered by the subjects due to their participation in the study.
3. There have been no complaints by the subjects or their representatives related to their participation in the study.
4. There has not been a change in the research environment nor new information which would indicate greater risk to human subjects than that assumed when the protocol was initially reviewed and approved.

There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. Investigators must notify UCRIHS promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

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

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Barbara Given

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