

Development and Psychometric Evaluation of Patients' Perception of Feeling Known by Their Nurses (PPFKN) Scale

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# Boston College

William F. Connell School of Nursing

# DEVELOPMENT AND PSYCHOMETRIC EVALUATION OF PATIENTS'

# PERCEPTIONS OF FEELING KNOWN BY THEIR NURSES SCALE (PPFKN Scale)

a dissertation

by

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submitted in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

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Development and Psychometric Evaluation of Patients' Perception of Feeling Known by their Nurses (PPFKN) Scale submitted by Jacqueline G. Somerville RN, PhD. Dissertation Advisor, Dorothy Jones, RN, EdD, FAAN

## ABSTRACT

The importance of the nurse-patient relationship to the overall well-being of the person has been explored extensively by nurses. What is largely missing from this knowledge developed to date is the patient's perspective. The purpose of this study was to develop a reliable and valid measure of patients' perceptions of feeling known by their nurses during an acute, surgical, hospital admission. The development of the PPFKN Scale was guided by Newman's theoretical framework of Health as Expanding Consciousness (1994) and data from a qualitative descriptive study conducted in 2003 (Somerville). The current investigation focused on the development and psychometric testing of the PPFKN Scale. The four themes that emerged from the earlier qualitative study were used to guide the development of the 85-item scale. This scale was exposed to a panel of nurse experts to establish inter-rater agreement and content validity, item understandability and readability. The revised scale was piloted with five participants who had experienced an inpatient, surgical admission to determine content validity, item readability and understandability.

The revised 77-item scale was then administered to 327 surgical inpatients across seven general care units at a large academic urban medical center. A sample size of 296 completed surveys was analyzed. A four-component solution was devised using Principal Components Analysis with Varimax rotation. This four-component solution accounted for 63.3% variance, with a total scale Cronbach's alpha coefficient of 0.99. A component loading cut-off was set at 0.3 and items not loading at this value on the expected component were dropped. This process resulted in a reliable and valid 48 item PPFKN Scale with four components and a total scale Cronbach's alpha coefficient of 0.98.

# TABLE OF CONTENTS:

Abstract
CHAPTER I1
Introduction1
Background4
Nursing Knowledge Development5
Conceptual Framework
Purpose
Research Questions
Significance10
Assumptions11
Limitations12
Summary12
CHAPTER 214
Review of the Literature14
Introduction14
Patterns of Knowing14
Knowing the Patient: A Moral Imperative16
Importance of Knowing the Person
Nature of Person
The Context of Knowing: The Nurse-Patient Relation
The Impact of Knowing on Quality and Safety23
The Impact of Knowing on Clinical Decision-Making

ii The Impact of Knowing on Individualized Intervention27
Knowing the Patient and Empowerment
Knowing: A Form of Caring
The Power of Knowing: Health as Expanding Consciousness
The Cost of Knowing
Summary
CHAPTER 3
Qualitative Descriptive Study
Pilot Study: Patients Feeling Known by Their Nurses
Sample
Study Procedure
Data Analysis
Study Findings
Experienced Being Recognized as a Unique Human Being
Felt Safe40
Experienced a Meaningful, Personal Connection41
Felt Empowered by Their Nurses to Participate in Their Care
Summary43
Chapter 444
Developing the PPFKN Scale based upon the qualitative findings44
Introduction
Instrument Development

iii Item Development45
Expert Nurse Panel Review45
Expert Participant Review46
Human Rights Protection
Methodology
Setting and Sample
Study Procedure
Data Management
Summary51
Chapter 5
Evaluation of the PPFKN Scale
Introduction
Preliminary Analysis and Cleaning of the Data
Psychometric Evaluation of the PPFKN Scale
Initial Reliability Estimates
Principal Components Analysis (PCA)
Summary
Chapter 661
Introduction61
Discussion61
Findings
Limitations

Implications for Nursing Education	iv 62
Implications for Nursing Education	
Implications for Nursing Practice	63
Implications for Nursing Research	65
Implications for Nursing Theory	66
Implications for Social Policy	66
Summary	67
REFERENCES	69
APPENDICES	
Appendix A: Pilot Interview Guide	78
Appendix B: PPFKN Scale:Version 1	81
Appendix C: Expert Nurse Content Validity Guide	86
Appendix D: PPKNS :Version 2	89
Appendix E: Expert Participants Transcripts	98
Appendix F: PPFKN Scale: Version 3	105
Appendix G: Content Validity by Participant Experts	113
Appendix H Cover Letter	114
Appendix I University IRB Approval	115
Appendix J: Hospital IRB Approval	118
Appendix K: Nurse Script	120
Appendix L: Demographic Date	121
Appendix M: Formatted Version PPFKN Scale Used for the Study	122

Table 1: Demographics	49
Table 2: PCA Loadings for the PPFKN Scale Component 1	56
Table 3: PCA Loadings for the PPFKN Scale Component 2	. 57
Table 4: PCA Loadings for the PPFKN Scale Component 3	58
Table 5:PCA Loadings for the PPFKN Scale Component 4	59

List of Figures	
Figure 1: Scree Plot	

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#### CHAPTER ONE

#### INTRODUCTION

Today's health care environment is dynamic, changing and fast-paced. New technology, more effective medical treatments and improved surgical interventions have contributed to a redesign in patient care delivery and decreased length in hospital stay. The impact of these changes has contributed to improved patient outcomes while increasing the consumption of nursing care during hospitalization. They have also led to increased utilization of treatments and advanced technology in the last days of life, where such interventions may or may not be truly desired by patients. During hospitalization, patients are confronted with many challenges and choices while trying to make sense of their health experience and its implications for their lives in the future. Nurses play an important role in helping patients conceptualize their preferences for treatment and achieve their goals by humanizing the health care experience and by paying attention to the particulars of the patient's situation. Patients' recognition of nursing's role during hospitalization and recovery may contribute to patient satisfaction with care and may influence their response to treatment and healing after discharge.

Measurement of patients' perceptions of feeling known by their nurses using a reliable and valid instrument can provide new insights into patients' experiences within the current health care environment, subsequently facilitating nurses' abilities to design interventions that enhance the health care experience and address obstacles to effective health care. Nursing care is delivered within the context of the health care system and societal influences, and there is growing concern regarding the effect of this context on nurses' ability to practice nursing and influence the patients' health and well-being. Many have argued that the nursing profession has responsibilities to engage in socio-political activity on behalf of its population of concern.

1

However, in order to participate in effective socio-political activities that preserve the essence of the discipline and advance nursing goals, it is essential to understand the impact of the environment on the nurse-patient relationship. Nurse researchers can use the data obtained from patients about their perception of feeling known by their nurses to enhance and advance the relationship between the patient and the nurse who is responsible for the patient's care. Additionally, information about both the impact of this relationship and the current health care/institutional environment on the patient's recovery and healing can be gained from this sort of instrument, either directly or indirectly.

To date, significant work exploring the impact of the nurse-patient relationship on healing and recovery has been carried out (Picard & Jones, 2005) along with measures of patients' perceptions of the quality of nursing care (Radwin et al, 2003; Schmidt, 2003; Suhonen et al, 2000), but there is no instrument that measures patients' perceptions of their hospitalization for surgery and their experience of feeling known by their nurses. Hospitalization is a crucial time for patients to trust that the nurse has their best interest in mind. Thus, it is essential to develop a measure that focuses on this important aspect, the patient experience, as well as the experience of being recognized as a unique human being, who feels safe and experiences a meaningful, personal connection to their nurse that facilitates and empowers the patient to participate in their care. As described by Jones (2007) and others (Newman, 2008; Willis, Grace & Roy, 2008), the phenomenon of feeling known is grounded in a philosophical perspective of knowledge as process, a reflective, relational process in which knowledge emerges or unfolds from the genuine, dynamic partnership of the patient and his/her nurse. The nurse comes to know the patient's story through dialogue. The nurse "seeks to embody a mutual process, guiding the person through a journey of self-discovery, meaning, choice and actions to promote the human experience" (Jones,

2007, p. 167). Knowledge as problem-solving in an acute hospitalization maybe complementary to but cannot be a substitute for knowledge as process in nursing.

Health as transformation is the intent of the relationship (Newman, 2008). Perception of quality of nursing care is grounded in a philosophical perspective of knowledge as problem solving in which "definition of person is achieved through an organized, systematic approach... Using reasoning, analysis and synthesis, a problem is identified, nursing outcomes are designed and interventions are selected to resolve the problem, improve function and optimize health" (Jones, 2007, p. 165). Many quality-of-care instruments focus on a population with a specific disease process and an episode of care. Illness is viewed as a series of problems to be acknowledged and solved rather than a manifestation of health to be explored with curiosity as presumed by Newman (1994). This study is grounded in the philosophical perspective of knowledge as process.

Therefore, the purpose of this dissertation was to develop and evaluate the psychometric properties of a scale designed to measure patients' perceptions and processes of feeling known by their nurses. A qualitative descriptive study of patient's perceptions of feeling known by their nurses previously conducted by this researcher (2003) revealed four themes. When patients felt known by their nurses they experienced being recognized as a unique human being, felt safe, experienced a meaningful personal connection with their nurses and felt empowered by their nurses to participate in their care. Guided by the themes that emerged and Newman's theory of "Health as Expanding Consciousness" (1994), this dissertation focused on instrument development and psychometric testing of the PPFKN Scale.

#### BACKGROUND

Over the years, nurses have placed great value on knowing the patient and coming to understand the meaning an event has within the context of the patient's life experiences. This value is consistent with the goals of nursing, directed towards promoting health, alleviating suffering (Nightingale, 1859) and putting the person in a position to promote healing (Henderson, 1991). The degree to which these goals can be realized depends upon explorations by nurse researchers into patients as individuals and their experiences within an environment that shapes their lives. Nurses have hypothesized that knowledge embedded in knowing the person transforms the human experience of health (Swanson, 1991; Jenny and Logan, 1992; Newman, 1994).

Within the current health care environment, nursing care often focuses on task-driven activities with little time for nurses to respond fully to the experiences of patients and families. Nurse-patient interactions are often viewed by patients as superficial and task-related (Hewison, 1995). Practice-driven demands and related activities imposed by society, regulators and insurers often take the nurse away from providing patient-centric care in order to respond to activities that are externally driven. Timely access to services that emphasize safety and decreasing adverse events has become a proxy for nursing excellence, and this is a problem. Caring is an ethical imperative in nursing practice and involves the interplay of knowledge, skills and engaged interaction. Without caring intention and the ability to know the patient as person and not as a diagnosis, care is experienced as technical, cold, uncaring and impersonal.

This dominant approach to care is often conceived as the action of "doing for" which was identified by Swanson as one of the five nursing actions in her "Theory of Caring" (1991) and is defined as doing for others what they would do for themselves if possible. This goal of doing for

the patient has been viewed by many as the central focus of nursing care. It is, however, an inadequate approach for meeting the patient's real needs. The four other caring activities defined by Swanson (1991), knowing the patient as an individual, being with the patient, enabling the patient and maintaining belief that the patient can meet his or her goals, tend not to be as heavily stressed in the contemporary institutional environments where many nurses practice. The patient experience within an environment that focuses on chronic or episodic illness, and on "doing" task-driven behaviors, compromises the full impact that nursing can have in advancing health for persons, families and communities. Focusing on the disease, rather than the whole person and their response to the health experience, encourages patients to become passive recipients rather than empowered participants in their care and this has been postulated as getting in the way of a the person achieving health and healing (Jones, 2007). Fragmentation of care, lack of continuity, limited focus on understanding the patient's story, combined with less time for provider interaction with the patients for whom they care, all contribute to patients' sense of feeling "unknown," shifting their focus and energies from healing toward the need to advocate for the optimization of their care (Whittemore, 2000).

#### Nursing knowledge development

Knowledge development in nursing, including scholarly research-based studies, have attempted to delineate essential processes needed for the nurse to "know" the patient in his or her care (Newman, 2008). However, what is not well understood is the patient's perspective on being cared for by the nurse. Nursing knowledge focusing on patients' perceptions of this process has been conceptual. Research efforts have used qualitative methodologies that focus on expert nurses' perceptions and actions in the acute care setting, linking the phenomenon of nurses knowing the patients to skilled clinical judgment, advocacy and individualized nursing interventions (Horvath et. al., 1990; Jenny & Logan, 1992; Minick & Harvey, 2003; Radwin, 2002; Tanner et. al. 1993). To date, no instrument has been developed to sharpen the focus on patients' perceptions of feeling known by their nurse providers grounded in Newman's (1994) framework of "Health as Expanding Consciousness" and the power of the nurse-patient relationship. This gap in nursing knowledge development represents an opportunity for further research and could be seen as an ethical responsibility because without the patient perspective nurses can't fulfill their professional goals. The patient's perspective of nursing care is essential to enriching understanding of the unique, human experience of patients and the role of nurses in promoting health. The process is transformative and can impact patient health and healing (Capasso, 2005; Rosa, 2005). Therefore, the purpose of this study was to develop and test the psychometric properties of an instrument that measures patients' perceptions of feeling known by their nurse.

#### CONCEPTUAL FRAMEWORK

The author's interest in pursuing this line of inquiry stems from personal and professional experiences that, along with knowledge gained from contemporary literature, have exposed the power of the nurse-patient relationship in facilitating patients' well-being. The relationship between the nurse and the patient enhances the human experience for both the nurse and the patient (Newman, 2008). When the patient's experience is central to the nurse's focus, the nurse is better able to facilitate patient care and is more likely to feel that he or she is meeting their professional goals. This value is best captured in Newman's theoretical conceptualization of "Health as Expanding Consciousness" (HEC, 1994), which provides a framework to guide and build knowledge grounded in mutual partnership, intentional relationship, meaning and patient response to being known by the nurse within that relationship. Newman's theoretical perspective

on nursing, HEC, emerged from the conceptual framework of Martha Rogers (1970) and gives witness to the dynamic, intentional, reciprocal, nurse-patient relationship as a vehicle to gain caring insight into the pattern of the whole person. Newman's thinking about relationship resonated with Roger's conceptualization of the human experience expressed in the "Science of Unitary Human Beings" (1990). Rogers spoke to the irreducible and indivisible nature of individuals and the integrality of people and their environment, a pan-dimensional universe of open systems where change is continuous and innovative.

Bentov (1978) introduced Newman to the theory of life as a process of expanding consciousness. Consciousness as defined by Bentov is the informational capacity of the system reflected in the quality of the interaction of the system with the environment. According to Newman (2008), the nurse intentionally creates a shared partnership with the patient that helps both move to a shared consciousness, connection and increased awareness. For Newman, this caring relationship is the focus of nursing (Picard & Jones, 2005).

HEC is grounded in the belief that health is not the absence of disease but rather a manifestation of the whole person. Disease and illness are part of health, expressed in a life pattern unique to each person. "From the moment we are conceived to the moment we die, in spite of changes that accompany aging, we manifest a pattern that identifies us as a particular person" (Newman, 1994, p.71). The nurse interacts with the patient and the environment to promote healing of the whole and facilitate health.

Life, for Newman, is the continual process of movement toward higher levels of consciousness. The evolution of consciousness is the process of health. Pattern reflects how individuals interact with their environment, evolves over time and is shaped by the individual's

history and experiences. Humans are open systems in constant interaction with their environment and each other. According to Newman,

The new paradigm of health, essential to nursing, embraces a unitary pattern of changing relationships. It is developmental. The task is not to try to change another person's pattern but to recognize it as information that depicts the whole and relate to it as it unfolds (1994, pg. 13).

Conceptualization of self as a center of consciousness, within an overall pattern of expanding consciousness, allows the person to begin to recognize their life as part of a much larger whole and to find the meaning in being human. Nursing, in mutual partnership with persons, families and communities, is essential to this process of human engagement and selfrecognition which promotes movement toward higher levels of increased awareness and expanded consciousness.

Through pattern recognition, the nurse comes to know the patient and assists him/her in making choices and realizing opportunities that he/she may not have recognized in the past. The patient experiences new options and possibilities and takes action to make them a reality. Within this authentic nurse-patient relationship, mutual sharing occurs, and the nurse and the patient are forever changed. This intentional presence of the nurse in interaction with persons helps to create opportunity for the human story to unfold and for mutual knowing of the nurse and patient to occur within the partnership. When the nurse and patient engage in this intentional process of interaction, a person-centered connection is created. "The professional responsibility of nursing practice includes establishing a primary relationship with the client for the purpose of identifying health care needs and facilitating the client's action potential and decision-making ability" (Newman, 1994, p.125).

In summary, the elements of the theory of HEC include the nurse coming together with clients at critical points in their lives and participating with them in the process of expanding consciousness, a rhythmicity and timing in their relationship, the nurse letting go of the need to direct the relationship, pattern identification and personal transformation of both the nurse and the patient. This framework acknowledges the concept of knowing the person and adds self-knowing, connecting, personal discovery, choice and action. Using this framework as a guide, the PPFKN Scale provided a context to develop, test and refine an instrument that captured these goals.

#### PURPOSE

The purpose of this study was two-fold: 1) to develop an instrument to measure patients' perceptions of feeling known by their nurses (PPFKN) during an acute surgical hospitalization and 2) to conduct psychometric evaluation of the PPFKN Scale. The importance of the nurse-patient relationship to the overall well-being of the person has been explored extensively by nurses. Missing from this knowledge base is the patient's perspective.

#### **RESEARCH QUESTIONS**

There were three questions that guided this investigator. Question 1 asked, how contentvalid is the PPFKN Scale in measuring the stated construct?

Question 2a asked, how internally consistent is the PPFKN Scale in measuring the stated construct?

Question 2b was concerned with: To what extent can the four themes (feeling recognized as a unique human being, feeling safe, feeling a meaningful, personal connection and feeling empowered to participate in care) be demonstrated through principal components analysis?

Question 3 asked, how internally consistent are the resulting component subscales derived from the principal components analysis?

#### SIGNIFICANCE

"No other discipline is developing knowledge related to how the quality of relationship facilitates health" (Smith, 1999, p.19). Research to date provides evidence that nurses value knowing their patients (Horvath et al, 1990; Radwin, 1996). Creating data that supports the development of a practice environment facilitative of nurses' knowing their patients has the potential to promote health, enhance prevention and contribute to nursing knowledge development and ultimately the interests of the patient. Development of a reliable and valid instrument that can be used to uncover the impact of the nurse-patient relationship on the patients' perceptions of health will allow nurses to gain insight into patients' understanding of being known by their nurses and ultimately how this experience impacts their care and related outcomes. This knowledge will help evaluate the effectiveness of interventions in the practice environment that are aimed at preserving the integrity of the nurse-patient relationship and also highlight obstacles that exist to patients feeling they are "known" by their nurses. Data obtained utilizing the PPFKN Scale creates an opportunity for nurse researchers to explore the nurse-patient relationship and the influence of organizational outcomes and environmental factors that contribute or diminish patients' perceptions of feeling known by their nurses.

In this era where "evidence"-based practice is valued by many, the nurse-patient relationship is placed at risk because this perspective sometimes neglects the individual's particular needs. To preserve the integrity of this relationship, nurses must create care environments where the patient is the focus of nursing care and in fact this is an ethical responsibility as noted in the American Nurses Association Code of Ethics (2001). The ability to measure the patient's perspective creates a new lens through which to explore this phenomenon's relationship to patient safety and satisfaction, nursing efficacy and satisfaction and other measures

of organizational success. Having available nurse-sensitive indicators that are responsive to these variables can enhance evidence-driven nursing care while preserving the nurse-patient relationship. Using a psychometrically sound version of the PPFKN Scale, future studies of new care delivery models that enhance knowing the patient from the mutual perspective of the nurse and the patient can be designed and enacted. . In addition, using an instrument like this enables the development of new methods of patient assessment for nurses in acute care settings. Such methods would focus on understanding what interventions, intentions and actions are necessary in order for the patient to feel known and the evaluation of their effectiveness in meeting individual patient goals. The instrument can be used to inform the development of outcome studies exploring the relationship between feeling "known" and organizational and patient outcomes. The development of studies designed to assess the impact of interventions targeted toward increasing nurses' abilities to know their patients will also be facilitated by data gained from the PPFKN Scale. Lastly, grounded in Newman's (1994) theory of "Health as Expanding Consciousness", this instrument represents the first known attempt to develop a quantitative measure of the impact of the nurse-patient relationship and knowing the person using Newman's conceptualization of health and environment. This has the potential to measure at a broader scale the impact of what has been to date studied in a case study method at an individual patient level.

#### ASSUMPTIONS OF THE STUDY

The study was grounded in the assumptions that some patients do:1) experience being known by their nurses during hospitalization;2) respond honestly on the PPFKN Scale; and

3) reflect upon and estimate care giving by their nurses during an

11

acute hospitalization prior to responding to the items on the instrument.

#### LIMITATIONS

The experience of surgical patients in an academic urban medical center may or may not be reflective of the experience of patients treated by other specialties or in other settings. In addition, this is a new tool and has not been tested to date.

#### SUMMARY

The two-fold purpose of this study was to develop and psychometrically evaluate an instrument to measure patients' perceptions of feeling known by their nurses during an acute hospitalization. The study was grounded in a qualitative study that isolated four themes (Somerville, 2003) which guided item development for the PPFKN Scale. When patients reported feeling known by their nurses, they experienced being recognized as a unique human being, felt safe, experienced a meaningful, personal connection with the nurse and felt empowered by the nurse to participate in their care. Believing that the focus of nursing is captured in the relationship with person as a whole, the challenge nurses face is the development of methods that capture the holistic nature of personhood, while accessing the human experience unique to each person. Data from this qualitative study supported work by Margaret Newman and HEC. This framework provided a lens to guide the generation of questions for the PPFKN Scale and embodied themes that emerged from initial qualitative analysis.

To advance the state of the science, instruments that emerge from nursing knowledge to study new phenomena of concern to the discipline can be effective in capturing the nurse and patient relationship in acute care settings. Once the psychometric properties of the PPFKN Scale developed with one population are established, the scale can be used across settings, specialties and other populations to determine stability and generalizability. Future outcome studies will explore the relationship between being known from the nurse and the patient perspective and nurse, organizational and patient outcomes. Intervention studies will be designed to assess the impact of interventions targeted toward increasing nurses' abilities to know their patients. The scale may also be utilized to assess the impact of the sociopolitical environment on nursing practice to monitor the potential for further deterioration of the nurse-patient relationship.

#### CHAPTER TWO

#### **REVIEW OF THE LITERATURE**

## Introduction

Nurses have an ethical imperative as defined in the American Nurses Association Code of Ethics (2001) to advance the "good" on behalf of each patient, ensuring that the individual's needs are met. This requires understanding what the good is for each patient. As a discipline, nursing has long been concerned with the human experience of health and its meaning to each patient (Newman, 1994). In listening to the voices of patients, nurses begin to understand the uniqueness of each person, their values and beliefs and utilize this knowledge to guide changes that impact the patients' nursing care during a health care experience.

Over the years, a growing body of knowledge has emerged that focuses on the value of "knowing" the patient from the nurse's perspective. Swanson (1991) described a theory of caring that involves five caring processes, including knowing, being with, doing for, enabling and maintaining belief. Knowing the patient has emerged as central to nurses' caring practice, defined by Swanson (1991) as "striving to understand an event as it has meaning in the life of the other" (p.162).

### Patterns of knowing in nursing

Carper (1978) identified four fundamental patterns of knowing in nursing which include empirical, personal, moral and aesthetic ways of knowing. All are important for good nursing care, but without understanding who the patient is, nurses can not meet the patient's needs. This knowing is dependent upon the nurse-patient relationship which is advanced through aesthetic and personal knowing. Aesthetic ways of knowing in nursing include "the knowing of a unique particular rather than an exemplary class" (Carper, 1978, p. 18). The process of coming to know the unique nature of each person is the essence of the nurse-patient relationship. Empathy empowers the nurse to be with the other to gain insight into the unique perspective of another human being as they experience living. Over time, the knowledge gained through this process creates an increased awareness of each person's responses to health and illness. Within partnership and action, the nurse responds to individual choices and behaviors of the person. Aesthetic knowledge is created by engaging, interpreting and envisioning, and each encounter is expressed in action taken to increase awareness and transform the person.

Personal knowledge, a way of nurses' knowing, is gained through the reciprocal nursepatient relationship. "The focus of the discipline of nursing is a relational activity in regard to the client's health. In this process, one cannot separate the observer from the observed..." (Newman, 2008, p.18). This relational process requires knowledge of one's own stereotypes, expectations and beliefs and a commitment to patient self-determination and the dynamic process of "becoming" in others.

To be in touch with the other person and the environment, the task is to be in touch with oneself, to sense into one's own pattern ... The more we can sense into ourselves, to trust the information that is there, the clearer we will be in expressing our own truth and in knowing other persons" (Newman, 1994, p.106).

This personal knowledge empowers the nurse to experience the reality and uniqueness of their patients at a moment in time. " It is concerned with the kind of knowing that promotes wholeness and integrity in the personal encounter, the achievement of engagement rather than detachment; and it denies manipulative, impersonal orientation" (Carper, 1978, p. 20).

Personal knowledge is created through encountering, focusing and realizing. It is expressed as authentic and disclosed self. This knowledge is assessed through response, reflection and congruity of word and action. Accessing this personal way of knowing has led to concepts such as therapeutic use of self and the ability to create personalized and holistic approaches to caring for patients and their families. Through experiential learning and reflection, the nurse begins to intuit and draw upon the collective wisdom gained through personal encounters, and is able to anticipate individual patient and family responses and patterns across populations that capture responses to emerging issues. The nurse prepares to be an open window, invites the rhythm of the other, draws upon the science of the discipline, synthesizes differences and similarities and only after all of the above occurs, sometimes in a nano-second, arrives at a conception of the situation that may have meaning across many situations. "The goal of nursing is not to make people well, or to prevent their getting sick, but to assist them using the power within as they evolve toward higher levels of consciousness" (Newman, 2008, p.5).

There are many challenges to this knowing process. It requires intentionality on the part of the nurse and an ability to engage even what may be perceived as the most difficult patient. Differences in academic preparation of nurses, their philosophy and values and the impact of the practice environment on the nurse's ability to be reflective, all pose challenges to the creation of a healing partnership between the patient and the nurse. Nurses are obligated by their assertions about the purpose of the discipline to understand and confront these challenges at the individual patient and sociopolitical levels.

#### Knowing the patient: A moral imperative for nurses

There is a certain way of being that is my way. I am called upon to live my life in this way, and not in imitation of anyone else's. But this gives importance to being true to myself. If I am not, I miss the point of my life. I miss what being human is for me...Being true to myself means being true to my own originality and that is something that only I can articulate and discover. In articulating it, I am also defining myself. I am realizing a potentiality that is properly my own...This is the background that gives moral force to the culture of authenticity... (Taylor, 1991, p. 29).

Taylor speaks to the essence of what makes homo sapiens human. For Taylor, humans are more than complex physiologic systems that support a physical presence in this world. The individuality that each person brings to and leaves as their mark on this world reflects the unique talents and gifts of each person. Each human is endowed with talents and the ability to make conscious choices that impact human existence. It is this uniqueness of the individual and their ability to make choices that characterizes the authentic human being. Nursing as a discipline embraces this ideal as a moral imperative and works to ensure that this essence of each human being is present within the nurse-patient relationship and is cherished. As each person is given knowledge and support, they are able to come to choices and actions consistent with their life goals. Lack of time, heavy workloads and an inability to articulate the patient's perspective on the impact of the nurse-patient relationship, all impact nurses' ability to support this moral imperative. The patient perspective is essential to changing the current health care environment and creating a unifying force for nurse researchers, educators and leaders to advance a reflective culture supportive of nursing values.

The American Nurses Association Code of Ethics with Interpretive Statements (2001) calls nurses to value the uniqueness of each human being while setting aside personal bias. The nurse-patient relationship creates an environment that transcends bias as nurses experience

each person as a human, not as a group stereotype. In so doing, nurses experience, bear witness to and honor the inherent worth of each human being as person.

#### Importance of knowing the person

The works of various nurse philosophers and researchers support the idea that it is crucial to know the person in order to provide good care. Research by Benner, Tanner and Chesla (1996) found that nurses come to clinical situations with values that affect what they attend to. The common "goods" such as comfort, compassion and individualized care are based on nurses' knowledge of the patient, and emerged across expert nurse exemplars. Nurses as moral agents based clinical reasoning on a fundamental sense of what is right and good, informed by generalized knowledge and the particulars of the person and their situation.

Unless nurses understand their moral responsibility to know the patient within the patient's world view and value this knowledge as essential for care to be optimized, nurses run the risk of having this knowledge viewed as "fluff... These different types of knowing the person and the context of that knowing are a matter of the kind of world we want to have and the kind of people we want to be" (Liaschenko, 1997, p.37).

The consequences of not "knowing" the patient include the depersonalization of patients and negative effects on clinical judgment, decision-making and the nurse-patient relationship, which is the

"moral foundation of nursing...Nurses end up providing care based on typical cases, not individual persons...safe passage has become an indicator of quality as opposed to holistic care and excellence in practice. Knowing the body becomes the proxy and necessity of safe practice; knowing the person is relegated to a luxury" (Whittemore, 2000, p.77). The practice of nursing is broader than merely a physical safeguarding of the patient.

The dissonance between what nurses are called to be and their ability to assert their responsibilities within the current health care environment has been described as moral distress (Jameton, 1993). This problem arises when "there is an inconsistency between one's beliefs and one's actions" (Hardingham, 2004, p.128). Moral residue is carried by the nurse when she recognizes the times that she faced moral distress, and compromised her beliefs or allowed them to be compromised by others.

#### Nature of person

The focus on the body and its parts at the expense of holistic health care is the remnant of a Cartesian world view. Sixteenth century philosopher Rene Descartes, the father of dualism, uttered the famous quote, which has been translated in English as, "I think, therefore I am." He proposed that the mind and body are dichotomous, made up of matter and spirit, resulting in a person with two natures. The separation of mind and body, and the further focus on parts underpins the traditional view of today's health care. The current goal of health care focuses on keeping parts functioning well and "fixing" them when they are broken. The focus is not on health promotion but rather on responding to the signs of disease or dysfunction with a goal of isolating the cause and treating the problem. This approach, both mechanistic and reductionistic, consumes the majority of our resources with in the current health care delivery systems.

Contrary to Cartesian perspectives of human nature, Martha Rogers (1964) proposed that persons are irreducible wholes manifested by "energy fields" that are open systems, in constant interaction with their environment, in a mutual process that is dynamic and changing. To search for causality is without meaning from a Rogerian perspective. The physical body is only one of the manifestations of the energy field that is unique to each person. From a Rogerian perspective, nurses engage in a dynamic relationship with the patient, helping them know the patient as person, that is more than just a body, rather an integration of body, mind and spirit.

## The Context of Knowing: the nurse-patient relationship

While Rogers and others were intent on highlighting the importance of viewing people holistically, others such as Peplau (1952) focused nursing's attention on the nurse-patient relationship. Peplau was the first nurse theorist to place the nurse-patient relationship at the core of nursing. The "Interpersonal Relationship Theory" (Peplau, 1952) described the essential qualities of a therapeutic nurse-patient relationship as presence, congruency, respect, self-esteem, value clarification, empathy, forgiveness, hope, trust, empowerment, patientcentered objectives and goals, insight, openness, self-disclosure, self-exploration and unconditional positive regard. This perspective called for a change in nurse focus from patient pathology to a therapeutic connection between the patient and the nurse. The nurse-patient relationship was seen as necessary to appropriately carry out the nursing process. When the patient presented with a felt need, the nurse-patient relationship was seen as the medium for change and problem resolution. According to Reed (2004), "Peplau fostered a scholarly interest in nursing practice and the nurse-patient relationship that continues to grow today" (p.485).

The "American Nurses Social Policy Statement" (2003), American nursing's contract with society, is informed by the work of such scholars and speaks explicitly to holistic care for patients by nurses. It acknowledges that the nurse-patient relationship is the vehicle by which health is contextually defined. This relationship "involves privileged intimacy, physical and interpersonal" (p. 44). From patient and family perspectives the attributes of "good" nursing care includes the nurse's knowledge of patient as person, acknowledgement of the patient's individuality and based on this knowledge, provision of individualized nursing care (Attree, 2001).

One of the many things that can potentially hinder the development of the nurse-patient relationship is the nurse's lack of self-reflection on and understanding of personal biases. In a recent report by the Institute of Medicine (2002), *Unequal treatment: Confronting racial and ethnic disparities,* it was noted that provider stereotyping and prejudice impact the experience of care and patient outcomes. The nurse-patient relationship is a vehicle to transcend bias and experience the uniqueness and value of each human being. The basis of this relationship is nurses' belief that each person has inherent worth and through the nurse-patient relationship the nurse experiences, honors and bears witness to the patient's worth.

Not all nurses choose to invest in self and others to facilitate this knowing process. "...Envisioning and realizing humanization and meaning are much harder emotional work...it goes beyond superficiality or just trying to 'fix' a problem and hurriedly move on" (Willis, Grace & Roy, 2008, p 39). Ramos (1992) reviewed 67 critical incidents concerning nurses' perceptions of nurse-patient relationships. Three levels of relationships emerged from analysis of this data. The first or instrumental level is focused on task completion. The second level, nurse-controlled or protective, notes that while nurses profess a desire to understand the patient's values and experience, nursing care is driven by the nurse's values and opinions. In level three, the nurse moves beyond the instrumental and nurse-controlled levels to create a truly mutual partnership and plan of care guided by the nurse-patient interaction and shared understanding.

An even greater challenge than achieving shared understanding among patients and nurses with common cultural backgrounds may be faced by culturally diverse patients in terms of nurses knowing and valuing their individual differences. Cioffi (2006) drew a purposive sample of eight registered nurses and patients from diverse backgrounds to conduct a qualitative study which explored nurses' and patients' experience within the nurse-patient relationship in a acute care hospital. Patients and nurses were found to focus on differences rather than common ground, creating challenges in establishing mutual, engaged relationships. Both patients and nurses were guarded about the risk of being misunderstood and as a result limited their communication. The outcome suggested that care was experienced by patients as task-oriented versus individualized.

When the nurse enters the nurse-patient relationship truly open to the experience of the patient, regardless of diversity of background, beliefs and values, healing occurs. Patterson and Zderad (1976) described the focus of nursing as the human experience of health and illness as defined within the context of an individual's life experience and personhood. Despite the disease and diagnosis focus of the health care system, the authors contended that the work of nursing is to create an environment that promotes healing by honoring the unique worth and values of each human being.

The ability of the nurse to understand the meaning of the event within the context of the individual's life enhances the possibility of well-being. Rogers (1964) conceptualized the unitary nature of person and viewed health and illness as expressions of one rhythmic life process. Newman (2008) built upon Roger's conceptualization, postulating that each individual has a unique pattern and rhythm to their life, and the life process is toward higher levels of consciousness. Through purposeful interaction between the patient and the nurse, there is an increased understanding of the people, events, history and experiences that are meaningful in shaping that individual's life. As a result of this mutual and reciprocal process, the nurse and patient are recognized as unique human beings as they enter into a partnership. The nurse attends to the person as a whole which Newman (2008) states is the phenomenon of nursing practice.

Patients enter the health care system with prior history and experiences that have contributed to making them the unique human beings that they are and are continuing to become. Patients enter the hospital expecting and wanting to be treated for their health problems. They also desire to be known as unique human beings, not simply as diagnoses (Schmidt, 2003). Patients described feeling known as present when nurses communicated an awareness of them as a person with a unique identity and with specific needs. (Berg & Hansson, 2000).

#### Knowing the Patient: Quality and Safety

Within the demands of a complex health care system, the importance of patients' individuality seems to be ignored. Even the discipline of medicine is taking seriously the problem of impersonal care and its attendant problems. This makes the timing truly ripe for nursing to press the issue. In the Institute of Medicine report (2000) *To Err is Human*, findings suggest that tens of thousands of Americans die and hundreds of thousands of Americans suffer each year as a result of medical errors. In the Institute's second report, *Crossing the Quality Chasm* (2001), the committee proposed six aims for improving quality of care.

One of these aims focuses on the need to provide patient-centered care. Patient-centered care is defined as "care that is respectful of and responsive to individual patient preferences, needs and values and ensures that patient values guide all clinical decisions" (p. 6). The report affirms the belief that informed patients and families who are welcomed as knowledgeable partners and participants in their care are safer patients. The ability to comfortably raise concerns and advocate for their needs is an essential safety net in the human and fallible health care system.

Hess (2005) noted that one common factor in many medical errors was clinicians who reported that they did not know their patients. Beyea (2006) contested that the challenges of current hospital experiences are that they can often become so specialized that the clinicians' focus inevitably is on the task at hand at the expense of understanding the person in context. Encounters with patients are often focused on attention to a body part or treatment of symptoms rather than the pursuit of knowledge about the patient as person within the context of the hospital event. The role of the nurse is to "establish a relationship with the patient, serve as the patient advocate when they cannot act for themselves and to convey important information ... during handoffs to other caregivers" (Beyea, 2006, p.823).

Knowing the patient has also been identified by expert nurses as essential for detecting and responding to subtle changes in patient condition. Minick and Harvey (2003) studied medical-surgical nurses' decision-making utilizing an interpretive, phenomenologic approach. Clinical managers were asked to identify nurses they believed were skilled in the early recognition of patient problems. Group interviews were conducted with 14 medical–surgical nurses, and content was analyzed for emergent themes. Nurses identified the strategies linked to knowing the patient directly and through the family as enabling early recognition of emerging patient problems. The ability to respond to changes in the patient was enabled by the nurse's previous contact with the patient and the family's knowledge of the patient's typical behavior.

The perception of feeling safe is also an important factor in the patient's human experience of health care. Patients described the importance of believing that their nurses recognized, acknowledged and acted upon their concerns and of having trust that their nurses would look out for their well-being (Schmidt, 2003). Patients felt safe when they perceived that their nurses knew what was going on with them (O'Brien, Fothergill-Bourbonnais, 2004). Safety, though, is a minimum criterion necessary for quality nursing care. Lynn, McMillen and Sidani (2007) utilized a grounded theory approach to interview 24 patients, asking them to describe "quality nursing care". Similar themes arose from the group's data analysis. Patients identified several aspects of the nursing process as being associated with quality nursing care including the nurse's ability to be with the patient, demonstrating patience, providing understandable information to the patient and family, being responsive to patient needs and the nurse's ability to understand the uniqueness of the patient within the context of their life within and outside of the clinical setting.

#### The Impact of Knowing on Clinical Decision-making

The phenomenon of "knowing" the patient" has continued to be described in the literature since the 1980s. It is viewed by many as integral to skilled clinical decision-making. After reviewing critical incidents of expert nursing practice, Benner (1984) identified seven domains of nursing practice that were critical to the development of expert practice. One domain, the teaching-coaching function of the nurse, incorporates several competencies, including eliciting and understanding patients' interpretation of their illness and assisting patients to integrate implications of the illness into their lifestyle.

In 1993, Tanner, Benner, Chesla and Gordon built upon this research by conducting group interviews with 130 critical care nurses regarding the phenomenon of "knowing the patient". A subset of 48 of these nurses were observed in their practice setting as they were caring for patients. Study findings described how nurses differentiated between problem engagement, nurse partnership and involvement with patients and families. Nurses believed that advancing the patient's health and well-being involved the interchange of all of these skill sets. When the nurse connected with the patient, they were able to respond to what was salient in the situation. Nurses described that this connection or "knowing" the patient was essential to their clinical decision-making process. Nurses used the phrase "knowing my patient" when they described their sense of the patient as a unique human being, when they were able to grasp the meaning the current situation held for that person, when they recognized patterns in the individual patient's responses and when they created the possibility of individualized care and advocacy. Nurses articulated that "knowing" the patient required active engagement and involvement and that engagement needed to be motivated by a value for a therapeutic nurse-patient relationship, which they viewed as the context within which excellence in nursing care emerged.

Clinical decision-making was also the focus of other studies. Jenks (1993) completed a qualitative, descriptive field study investigating practicing nurses' perceptions of clinical decision-making. Informants described knowing as more than knowing about a patient's medical history or clinical status. Knowing involved an interpersonal relationship that provided insight into values and motivators of patients, and nurses described this as essential to sound clinical judgment and intervention.

Other studies used more particular clinical situations to investigate the impact of knowing the patient on clinical decision making. A qualitative study examined expert nursing practice during the ventilator weaning process (Jenny & Logan, 1992). Nurses described a cognitive and relational process that assisted them in determining salient aspects of each unique patient situation. This process was reported to be both situational and reciprocal. Creating a sense of trust between the nurse and the patient further enhanced the knowing process. "Knowing" the patient was perceived by nurses as increasing the nurse's sense of control and authority to make decisions and take action.

26

Ellefsen and Kim (2005) used a qualitative, descriptive design to study the nature of nurse clinical engagement and actions in an acute care setting while working with six registered nurse participants. Data were collected via participant observation, in-depth interviews during three full shifts for each nurse, and by reviewing nursing documentation. Nurse involvement was found to be related to the process of knowing the patient, which involved collecting subjective data from patients and families, the nurse's direct observations and how often the nurse accessed objective knowledge. Caring for the patient involved a dialectic process among these three data sources, which constantly expanded and informed the nurse's ability to know their patient.

Using a broader perspective based on a review of nearly 200 studies exploring the clinical judgment of nurses, Tanner (2006) found that sound clinical judgments depended on the nurse's knowing the patient's typical pattern of responses as well as knowing the patient as a person. Skilled clinical judgment required nurse involvement with the patient and created the possibility for advocacy and clinical learning.

In the U. K., Macleod (1994) conducted a phenomenological study of ward nursing practice and identified 'noticing' 'understanding' and 'acting' as three distinct processes within the knowing practice. Through involvement with the patient, the nurses noticed patient cues, understood their meaning within the context of the patient's world view and responded guided by this knowledge.

#### The Impact of Knowing the Patient on Individualized Intervention

Other studies explored the impact of knowing the patient on individualized intervention. During an expert nurse practice discussion group in the late 1980s (Horvath, Secatore & Reilly, 1990) which explored exemplars of critical incidents, nurses described "knowing" the patient or unique knowledge of the patient as a person as leading to individualized plans of care that nurses perceived positively influenced patient outcomes. "Knowing" was defined as "learning about and understanding a patient's response to his or her illness" (p. 264). Use of the concept was not restricted to long-term relationships or to patients who were conscious.

Radwin (1994) explored the impact of nurse-driven value for knowing the patient and its relationship to both sound judgment and tailored nursing actions. Radwin used a grounded theory method to study nurses' clinical decision making. Field notes, in-depth interviews and documents were analyzed. A core process related to sound clinical decision making, "knowing" the patient, emerged. Intimacy and familiarity were the core properties of this process and the nurse-patient relationship was the context. According to Radwin, "knowing" the patient involved obtaining base-line information, creating a trusting relationship, ascertaining the meaning of the situation to the patient and the creation of individualized interventions. Based upon this knowledge, nurses took "purposeful action where by the nurse used understanding of the patient's experience, behaviors, feelings and/or perceptions to select individualized interventions" (Radwin, 1994, p.245).

Moreover, knowing the patient has been reported as especially important in assisting "difficult" patients. Macdonald (2005) utilized a grounded theory method to explore the management of difficult patients. Data sources included 120 hours of participant observation on a family medicine unit in a hospital in Atlantic Canada. There were 12 formal interviews with former unit patients, ten formal interviews with unit nursing staff, and numerous informal interviews with nursing staff during participant observation. Although knowing the patient was found to minimize difficult encounters, nurses described the challenges they faced in their dayto-day practice in terms of their ability to create the time to facilitate this knowing process. Jackson described a different perspective on knowing the patient (2005). In a phenomenological, descriptive study of the experience of a "good day" for newly graduated nurses, the researcher studied eight nurses on surgical wards. Several themes emerged from the study. These included the power of knowing the patient from a personal as well as clinical perspective. Participants described closeness to patients as an essential part of a "good day" and an essential part of what they enjoyed about being a nurse. Knowing the patient from the personal as well as clinical perspective enabled nurses to provide care individualized to and reflective of their patients' preference. Through this process, nurses found meaning and value in their work.

When nurses are impeded from knowing the patient, they reported that they did not enjoy their work or find it satisfying which in turn may lead to poor care or nurses leaving the profession. Speed and Luke (2004) explored British district nurses' perceptions of the impact of policy changes that led to increased workload on their practice. Four study sites were chosen to conduct an ethnographic research study utilizing a range of qualitative methods with 17 district nurses. Results suggested that nurses perceived that "the direct involvement of the district nurse in personally knowing patients has been replaced by a knowing about or knowing by proxy" (p. 930). "For the majority of nurses in this setting, when they reflected on this way of working and knowing their patients they spoke with remorse …they almost universally yearned for the old way" (p. 926). Nurses described providing generic care based on a medical diagnosis rather then individualized care based on knowledge of the uniqueness of the person, their family and community.

The direct involvement of the district nurses in personally knowing patients had been replaced by a knowing about or knowing by proxy...In place of personal knowing, a new

29

discourse of "techno-care" or empirics was replacing the old patterns of knowing, relegating personal, moral and aesthetic knowing to secondary positions. (p.930).

Nurses expressed remorse at the perceived loss in their ability to partner with their patients.

#### Knowing the Patient and Empowerment

Freire (1970) studied the liberation of oppressed groups via educational strategies. The first step toward empowerment was to know the person or population and understand that which was meaningful to them. For the author, oppression involved limiting another's freedom by imposing one's choices on another human being. "For the oppressors, 'human beings' refers only to themselves; other people are 'things'' (p. 57). Simply through the establishment of an oppressive relationship, one in which the voice of another was not heard or valued with regard to their own self determination, violence occurred. Violence was defined as knowingly imposing one's choices on others without regard for their rights, beliefs or values. The goal for humanity involved liberating both the oppressed and their oppressor who is dehumanized in their very act of dehumanizing others. Empowerment was present when all had choice. The key was that the individual freed him or herself via dialectical exchange of knowledge between two persons who had different knowledge bases.

Similarly, Newman (2008) noted that when the nurse engaged in knowing the person using pattern reflection, the nurse assisted the patient to know self, to gain insight into his or her life pattern and recognize new choices that led to an expanded level of consciousness and empowerment. The experience was often reciprocal. Nurses engaged with patients as knowledgeable partners in care and were able to provide information that helped patients make informed choices. When this occurred, the nurses then supported those choices and helped the patients to sustain change. Thus, power was equalized among parties.

Harstock (in Sprague and Hayes, 2000) identified power as commodity, power as relationship or power as capacity or capability. Empowerment theory focuses on this third type of power (Gutierrez, DeLois and GlenMaye, 1995), not the value of expert nurse knowledge as commodity or nurse power over their patient. Rather, the basic tenets of empowerment theory are grounded in fostering non-hierarchical relationships and a recognition of the patient as expert. The nurse is not the expert in regard to patient self-determination, the individual is. In order to support patient empowerment, nurses inform patients and families regarding all options, answer questions openly and support self-directed liberation versus nurse-imposed regulation. Nurses exert their power to support the self-determination of others. Doane and Varcoe (2005) described nursing as relational inquiry. Expert knowledge does not lie within the nurse but rather when the nurse adopts a stance of inquiry, expert knowledge emerged from the relational process of knowing. Thus, empowerment is not about imposing one's values on another or helping patients and their families make the "right decision," which is a paternalistic approach. The paternalistic approach runs counter to the goal of nursing to partner with the patient regarding their health and limits the self-determination of those that nurses propose to 'serve.' "... Empowerment can not be offered or enacted on by anyone other than the client herself" (Bay-Cheng, Stewart, Lewis & Malley, 2006, p.77).

Rogers (1970) described power as knowing participation in change. According to Rogers, there are no boundaries to the experience of human knowing and change. Ultimate freedom and power exist in realizing one's potential in the becoming process. Four dimensions of power as knowing participation include awareness, choices, feeling free to act on intentions and orchestrating desired changes. Power is not for others to give and does not involve liberating others based on the values we determine. The goal of nursing is to create an environment of care

to enhance the inherent power and freedom that exist within each person to learn, grow and change.

Building on this Rogerian perspective, Barrett's theory of "Power as Knowing Participation in Change" (1989) views power as awareness of what one is choosing to do, feeling free to do it and doing it intentionally. This theory guided the development of the Power as Knowing Participation in Change Tool (PKPCT) which has been used as a patient outcome measure in many nursing intervention studies (Caroselli & Barrett, 1998).

#### Knowing: a form of caring

As stated previously, Peplau (1952) described an essential quality of a therapeutic nursepatient relationship as unconditional, positive regard. This attribute manifests itself in the nursepatient relationship through caring attitudes and behaviors on the part of the nurse toward the patient. Swanson (1993) defines nursing as informed caring for the well being of others. Caring is a way for nurses to relate to patients. It is a concept grounded in the belief that the innate value of persons and the knowledge of that person's reality is gained through the therapeutic nurse-patient relationship. Caring, manifested through five caring processes, includes knowing or striving to understand the human experience of the patient.

Boynkin and Schoenhofer (1993) theorized that, within the context of the nurse-patient relationship, the nurse approaches each patient with the intention of knowing the other as a caring person. The fundamental premise of this perspective affirms that all persons are caring by nature and that caring can exist in the individual as a reality or potential. Nurses extend a direct invitation to the patient, asking them to share what matters most to them in the situation in order to understand the unique meaning of the experience as a human being. In participating in this moment, the patient feels known as a person of value, and this is an important facet of their journey toward health and well-being.

Watson's (1999) beliefs embedded in the "Science of Caring", holds caring as a central concept to nursing. Within this framework, nurses engage in ten carative factors or the "caritas processes" to create a platform for human connection through which genuine care is experienced by the patient within this experience. Caring responses are directed by knowledge of each person and acceptance of who they are in the moment as well as who they may become. A caring consciousness on behalf of the nurse is the vehicle through which knowing occurs. *The Power of Knowing Grounded in "Health as Expanding Consciousness" (HEC)* 

Nursing practice, as long professed by Peplau (1959), is also a process of knowledge development. Transforming practice knowledge into nursing knowledge through insight gained through the intentional nurse-patient relationship has been guided for many by Newman's (2008) theory of HEC as praxis. Barron (2001), guided by Newman's theory as praxis, engaged 22 adults with advanced cancer in pattern recognition as they described what was important to them in their lives. Barron described the power and transformation of the relational process guided by HEC as even more meaningful than pattern identification. Through relationship, the participants become known and recognized in their humanness, and in finding the meaning in their current experience of health within the context of their lives, were restored to a new level of well-being and healing.

Picard (2005) used Newman's methodology to explore meaning for mid-life women through pattern identification. The process involved both participant dialogue and a group creative movement experience. A piece of reflective art was then created by the researcher to reflect the unique pattern manifested by each of the 17 participants as experienced in relationship with the nurse. The art was shared with each participant and their feedback revealed personal knowing and a knowing by other. The approach provided participants with an opportunity to reflect on their lives in ways that were most meaningful and unique to their personhood.

Neill (Picard & Jones, 2005) engaged four women with multiple sclerosis and three women with rheumatoid arthritis in a two-year partnership. During the experience, these women related their life stories, focusing on people and events that were most meaningful to them. Each participant was provided a draft life pattern and discussed the information. In addition, the women shared photographs they had taken as part of a reflective process. Study participants and the researcher described the experience as a transformative process that lead to expanded consciousness and a new sense of self-awareness.

Dexheimer Pharris (2002) engaged communities in the process of pattern recognition. Partnership with a caring nurse was found to be particularly meaningful for individuals, families and communities, helping them to gain insight into the past and present and, by defining that which was meaningful in their lives, created unique potential and opportunities for the future.

This evidence suggests that, through intentional and purposeful presence in the nursepatient relationship, the nurse comes to know about the experience and its meaning for individuals and communities, developing a care environment that fosters renewal and healing for both the nurse and the patient.

#### The Cost of Knowing

While the literature supports knowing the patient as an important concept for good nursing care, some have noted that within the context of the current health care environment it is not without its pitfalls. Liaschenko (1997) explored reservations about "knowing" the patient and the potential for intrusiveness and increased complexity of nurses' practice.

...If the nurse takes into account only those needs that are immediately present through case and patient (clinical) knowledge, the possibility for appropriate actions are limited,

thereby making the responses straightforward and prescriptive. On the other hand, when the nurse perceives these (patient) needs against the background of the person's life and values, the ends at which the nurse's actions should be aimed are not always so clear (p. 36).

#### SUMMARY

As reflected in the above review, most of the evidence to date regarding the phenomenon of knowing the patient has been approached qualitatively and largely focuses on acute, inpatient care and the experience of the expert nurse. This initial step has been a necessary one and has led to greater understanding of the value and process of this phenomenon, "knowing the person," from the nurse perspective and less frequently from the patient perspective. Extant evidence has been used to describe that the knowing process involves feeling recognized as a unique human being, a sense of well-being, feeling safe and advocated for by the nurse, a sense of personal connection and finally a sense of empowerment to participate in their care (Somerville, 2003). To advance the state of nursing science on this topic, instruments that measure the presence of this phenomenon must be developed based on the current evidence. Grounding this work in Newman's (1994) theory of HEC engages both the nurse and patient perspective on being known within the acute care setting. Once measures have been found to have sound psychometric properties, they can be tested across settings and specialties to determine usability.

#### CHAPTER THREE

# A QUALITATIVE DESCRIPTIVE PILOT STUDY: UNDERSTANDING THE PHENOMENA Introduction

Dramatically decreased length of stay for surgical inpatients, coupled with a largely parttime nursing workforce, have the potential to impact nurse continuity. These factors also have the potential to diminish the effect of the nurse-patient relationship on patients' need to feel known by the nurses and the human experience of nursing care as perceived by the patient.

#### Pilot Study: Patients Feeling Known by Their Nurses

The purpose of this study was to explore surgical inpatients' experience of feeling known by their nurses within the context of the current health care environment in the United States. A qualitative, descriptive design was used to achieve this goal. According to DeVellis (2003), initial understanding of human phenomena which researchers attempt to measure often derives from a theoretical perspective which can be further informed by insight gained through dialogue in their natural setting with persons experiencing the phenomena. Analysis of this dialogue, using qualitative methodologies, aids in understanding the abstract relationships that exist among the hypothetical constructs and can guide subscale or component and item development. Such knowledge of the specific phenomena of concern aids in the development of reliable and valid scales.

#### Sample

A convenience sample consisted of 17 participants admitted to a surgical service on one of six surgical general care units at an academic medical center. Patients between the ages of 18 and 95 who met inclusion criteria were part of the study sample. Interpreter services were available to interview those patients who did not speak English and to transcribe the interviews in English.

Only those patients who were unable to verbalize (aphasic, ventilator) were excluded from the study.

#### Study Procedure

Participants engaged in a single, semi-structured interview on the unit. An interview guide which included a series of open-ended questions was used to guide the interview (Appendix A). Questions centered on the patient's perceptions of their current hospitalization overall, the experience of being cared for by nurses, perceptions of feeling known by nurses and the patient's sense of empowerment manifested by participation in their care. Questions were developed by the nurse researcher based upon a review of the extant literature. A panel of nursing experts was used to establish content validity and to insure that questions reflected the study aims.

After internal review board approval for the study was obtained, the researcher met with the staff on each of the six units to explain the study aims and enlist their support in identifying potential participants. The inclusion (e.g., patients admitted to a surgical service between the ages of 18 and 95) and exclusion criteria (e.g., patients who were unable to verbalize) were reviewed and staff were asked to approach any and all patients who met these criteria. A nurse with first-hand knowledge of the patient approached participants, explaining briefly the study aim and procedure and asked if the patient would be willing to speak with the researcher. If the patient accepted this invitation, the unit nurse contacted the researcher. The researcher introduced herself to the patient and reviewed study procedures with the patient. After informed consent was obtained, which reviewed potential risks and benefits, one single, semi-structured interview was tape- recorded with each participant.

Each interview lasted 20 to 60 minutes with a mean time of 35 minutes. The variation in time reflected participants' willingness to explore and discuss the topics. Although the researcher

utilized the interview guide, branching questions such as "can you tell me more" or "can you expand a little on that answer" were frequently used to elicit more data and gain greater clarity. *Data Analysis* 

Interviews were transcribed verbatim by the researcher. The researcher listened to, transcribed and read each interview, and the researcher dwelt with the data to ensure familiarity. Significant statements were extracted from these transcripts and became the raw data for analysis. Duplicate statements were eliminated, and meanings were formulated from the significant statements. These meanings were arrived at by reading, rereading and reflecting upon the significant statements in the transcripts to get the meaning of the client's statement in the original context. The aggregate of formulated meanings was organized into clusters of themes held in common by participants (Creswell, 1998; Downe & Womboldt, 1992). Interviews continued until no new themes emerged. Four major themes emerged from the data. Descriptions of these themes and selected quotes supporting the data were reviewed by experts, with 100% agreement reached.

#### Study Findings

The 17 participants in the study ranged from 34 to 84 years of age with a mean age of 57 years. There were seven females and ten males who were enrolled in the study over a two-month period. All had experienced a prior hospitalization and spoke English. Fifteen participants self-identified as White, one as Asian and one as Latino. Eight participants had undergone a surgical intervention for cancer, five had undergone a surgical intervention for a benign problem, one patient had sustained trauma and four participants were being observed and medically managed. From the analysis, four themes emerged. When patients described "feeling known" by their nurses, they experienced being recognized as a unique human being, felt safe, experienced a

meaningful, personal connection with their nurses and felt empowered by nurses to participate in their care.

#### Experienced Being Recognized as a Unique Human Being

"Recognized as a Unique Human Being" was defined as the patient's experience of nurses who through purposeful interaction, gained insight into the person, events, history and experiences that were meaningful in shaping that individual's life. This knowledge of the uniqueness of each person was reflected in the provision of care that was respectful of patient preferences and values. Within the sample, patients most frequently identified "their" nurse as "knowing" them best. They described being seen as a unique person, not just a number or diagnosis and that this recognition of unique personhood influenced how they experienced their nursing care. When patients experienced a feeling of being known, they described their care as being individualized, with interventions tailored to respond to their unique needs.

According to DS, "If the nurse asks questions like 'where are you from?', it initiates conversation so they know you a little bit more as a person and not just as a transplant patient with cancer. There is more to my life than being a patient." FB stated, "The nurse understands my need to get up and move. She knows I want to get home to my children." MM shared, "They treat me like a person, not like a patient. Nobody wants to be a number or a person without a name. They break it down to an individual, not a statistic, not a number." Lastly SS noted, "The nurses treat me with respect, like an individual. You know everyone has their own peculiarity but that is humanity."

#### Felt Safe

"Felt Safe" was defined by patients as having confidence in their nurses' intentions and abilities to advocate for their well-being, to act upon their concerns and to ensure that their needs were communicated effectively to all providers so that vital information was not lost. A consistent theme was the importance of having a voice and being heard. Most patients felt well prepared for the technical aspects of their hospitalization but not for the sense of isolation and the experience of depending upon others who may or may not choose to hear their concerns. Patients described the anonymity of residents and interns as they moved in and out of their rooms, often without introduction or a visible identification badge. A lack of "feeling known" by their nurses gave patients the perception of being viewed as a task or diagnosis which led to a feeling of anxiety and fear that something "wrong" might occur. All participants expressed a vulnerability around hospitalization. They felt a lack of control over the environment and the importance of being able to access caregivers who were emotionally available and communicated an interest in their wellbeing. New encounters with providers and changes in usual routine were perceived by patients as threats to being known, a time of possible miscommunication and increased anxiety and uncertainty.

Participants assumed that communication occurred among caregivers and across settings but very few witnessed it first-hand. Fear regarding miscommunication or lack of communication increased uncertainty and led to increased anxiety at times of transition. Participants felt the burden of telling their story once again to ensure that their unique care needs were known and to ensure their safety. Reference to a familiar provider, to unique knowledge of the participants' life or responses or to their plan of care by new caregivers were valued by all participants.

Participant KB said, "Another time a nurse came in to give me some morphine and she was just about to put the needle in and I remembered that I thought that I had a reaction to this once before. She immediately stopped and it turns out I was given a lot of it in the recovery room so we knew it was ok. The fact is that she listened and was willing to stop and check." Participant SA shared, "It is really helpful when nurses and doctors referred back to the previous person providing care for me, saying 'Sue just told me that you had a bad night.' I would have felt more comfortable if my morning nurse said 'I spoke to Dr. S and he said...' I would have felt like the dots were being connected." Similarly, LT noted, "The other day the nurse overheard that I was going home. Hey, I know I am not ready. So she talked to them and they gave me another day. Now I am ready. The nurse listened and things happened." Lastly, BS stated, "When I first got to the emergency room, and I had a dressing on over my drain that was stitched very tightly. I asked the physician to please cut the dressing off, please do not pull the dressing off and she pulls the dressing off with the stitches in my leg and pulls the drain out. She really didn't listen." (BS) *Experienced a Meaningful, Personal Connection with Their Nurses* 

"Personal Connection" was defined as a shared consciousness and mutual partnership between the patient and their nurses. Participants found nurses willing to share of themselves, thus changing the dynamics of the relationship from one of dependency to one of mutuality. This transformative experience led patients to feel that nurses did not simply provide care but actually cared about the person. The engagement of the nurse in the caring experience increased patient comfort and enabled the nurse to provide support when needed. Patients experienced a sense of mutual presence and sharing by the nurse.

According to MM, "She goes the extra mile. She does that little extra that makes me feel she really cares. She picked up on things without my telling her, like my anxiety." DL said, "Susie lives in Swampscott and I come from Lynn. So there was a connection. My wife and I know where she lives. She just had a daughter and we just had a grand daughter. It was great." Participant OP stated, "All the nurses have been so good to me that I feel they truly care about my recovery." Lastly PP provided this insight. "Most of them are very proactive, very compassionate and really seem to care about what you are going through."

#### Felt Empowered by Their Nurses to Participate in Their Care

"Empowered to Participate in Their Care" was defined as patients' experience of nurses who valued patients as knowledgeable partners in care and who provided information that helped patients make informed choices. Nurses assisted the patient in gaining insight into their life pattern and to recognize new choices and opportunities in their lives. "Being known" helped patients experience a sense of partnership that empowered them to be an active participant in shaping their care.

Participant MM noted, "She knew when to encourage me, when to wait, was willing to negotiate and that is important to me. With a little bit of relationship, there is more safety to say 'can we wait' or 'what do you think, cause I can't make a decision right now." Another participant SS said, "I ask them to give me some sleep and they do. At midnight they check my pulse, I take my sleeping pill and they promise to leave me alone for four hours. I take more medicine at 4am and I sleep for another four hours. They pass that on to the next nurse. Everybody knows." Similarly, DD stated, "In fact there were some things that went on the last time that I was in that I wanted to make sure I got again so I reminded people, like the patch for motions sickness. I reminded her and I got it. I don't know if I would have got it anyway but I felt like I can ask for things and I get them." Lastly, MM identified the following. "When I knew I had to get up and walk, they gave me choices about when and how much."

42

#### Summary

The results of this qualitative study were consistent with the themes found in the literature that addressed the phenomena of knowing the patient. From both the patient and the nurse perspective, this process was created from a mutual partnership which is grounded in the nursepatient relationship and transforms the experience of health care for both the patient and the nurse.

The four themes that emerged from this qualitative study reflected both positive and negative perceptions. Patients perceived that the nurse had been the most knowledgeable about their unique needs and wishes. This reflection supported the disciplinary focus of nurses but also the element of time. When nurses were able to spend more time with the patient across shifts as well as the continuum of care, patients' comfort increased. Feeling unique or "known" created a sense of safety for the patient and decreased fears that something might go wrong. Participants in this study sensed concern for their well-being and the ability of nurses to anticipate their responses and needs. The goal of nursing is to foster partnership, increase patient comfort and create an environment of care that promotes healing. Patients' perception of feeling known by their nurses appeared to facilitate this process.

#### CHAPTER FOUR

# DEVELOPING THE PPFKN SCALE BASED UPON THE QUALITATIVE FINDINGS

#### Introduction

The purpose of this study was to develop and evaluate the psychometric properties of the Patients' Perceptions of Feeling Known by their Nurses Scale (PPFKN Scale) during an acute, surgical, inpatient admission. This chapter discusses the research methodology including setting, sample, instrument development, data collection and management, and protection of human rights.

#### INSTRUMENT DEVELOPMENT

Based upon qualitative descriptive study findings of patients' perceptions of feeling known by their nurses, four sub-constructs emerged and reflected the multi-dimensionality of the construct. These included: "Experienced Being Recognized as a Unique Human Being", "Felt Safe", "Experienced a Personal, Meaningful Connection with Their Nurses" and "Felt Empowered by Their Nurses to Participate in Their Care".

The first construct, "Experienced Being Recognized as a Unique Human Being", was defined as the patients' experience of nurses, who through purposeful interaction, gained insight into the people, events, history and experiences that were meaningful in shaping that individual. This knowledge of the uniqueness of each person was reflected in the provision of care that was respectful of patient preferences and values. The second construct, "Felt Safe", was defined as patients having confidence in their nurses' intentions and abilities to advocate for their wellbeing, to act upon their concerns and to ensure that their needs were communicated effectively to all providers so that vital information was not lost. The third construct, "Experienced a Meaningful, Personal Connection with Their Nurses", was defined as a shared consciousness and mutual partnership between the patient and their nurses. Nurses were willing to share of themselves, changing the dynamics of the relationship from one of dependency to one of mutuality. This transformative experience led to a sense that nurses did not simply provide care to but actually cared about the person. The final construct, "Felt Empowered by Their Nurses to Participate in Their Care", was defined as experiencing nurses who valued patients as knowledgeable partners in care and who provided information that helped patients make informed choices.

#### *Item Development*

Initially, 85 items were written as closed-ended, declarative statements, with each sub-scale ranging from 20 to 23 items (Appendix B). Items were tailored to measure each domain. The declarative statement items were placed on a four-point Likert scale reflecting agreement or disagreement, with 1=strongly disagree, 2=disagree, 3=agree and 4=strongly agree. Using the Fry Readability Formula (Fowler,1995), items and the cover letter were written at an eighth grade level.

#### Expert Nurse Panel Review

A panel of 11 nurse experts reviewed the items for content relevance, understandability and readability, assigning answers on an evaluative continuum from one through ten, with higher scores indicating a greater degree of relevance, understandability and readability (Appendix C). The experts were master's prepared Clinical Nurse Specialists practicing at an urban academic medical center who served on a Clinical Nurse Specialist Research Task Force. "Relevance" was defined as how closely the item matches or reflects the component's operational definition. "Understandability" was defined as the ability to grasp the meaning of what you read when you read it. "Readability" was defined as the ease with which the item can be read. Experts were asked to comment on any scores between zero and five. After analysis of the results, the experts were reconvened to edit items. One-hundred percent consensus was reached on rewording, eliminating or adding items, guiding adaptation of the survey with the exception of two items ("On this unit, I feel close to my nurses" and "On this unit, I feel a connection with my nurses"). The group was split regarding the terms "close" and "connection", wondering if patients would interpret these terms in the context of a professional, therapeutic relationship versus an intimate, personal relationship. Both items were retained for the field test with patients. Eighty-seven items remained after this critique (Appendix D).

#### Expert Participant Review

Once modified, a pretest of the PPFKN Scale Version 2 was conducted with a sample of five participants who had experienced a surgical admission within the past five years. They were asked to complete the scale. Once completed, participants were interviewed individually by the nurse researcher and asked:

- To what extent, if any, did you have difficulty reading the item as worded? If it was difficult to read, do you have suggestions on how to word the item differently?
- To what extent, if any, did you find the item difficult to understand? If difficult, why? Do you have suggestions on how to word the item differently?
- To what extent, if any, did you having difficulty answering the question or feeling you had the information you needed to answer the question based on your experience? If difficult, why? Do you have any suggestions on how to word the item differently?"

Responses were recorded, transcribed, and analyzed by the researcher (Appendix E). The results were used to guide further instrument refinement (Appendix F).

In general, participants provided feedback noting that many items required greater specificity. They believed questions should be worded to include "my nurses make me feel...,"versus declarative statements about nurses. Participants reported they had no way of "knowing" what their nurses thought or did outside of the room. Participants relied on their own perceptions or feelings. Participants did not view nurses as planning or providing options about their care. They viewed this as a physician role. Nurses delivered the care once the plan was determined. Although the term "story" was meaningful to nurses, participants revealed that the term was not understood from their perspective. In addition, items that addressed patients' feelings needed clarification in terms of specifying physical or emotional feelings. Finally, items that related to feeling safe were alarming to participants who did not perceive the nurse needing to keep them safe or free from harm.

This rich feedback resulted in the revision of the scale including the deletion of ten items and the rewording of several items. The resulting 77-item scale was next given to the five experts determine content validity. Content validity is "the determination of the content representativeness of the items of an instrument in a two-stage process"(Lynn, 1986, p. 382). During the developmental stage, domains are identified, items are generated and the instrument is formed. During the quantification stage, using a minimum of five experts, a content validity index (CVI) was established for each item and the instrument as a whole. In order to be retained, four or more participants had to rate the item on a four point scale as "relevant but needs minor revision" or "very relevant and succinct". Once items were reviewed, the proportion of total items judged content-valid reflected the CVI for the entire instrument. Participants were asked to rate on a four- point Likert scale the relevance of each of the items in each subscale in relation to the operational definition (1=not relevant, 2=unable to assess relevance without item revision, 3=relevant buts needs minor alteration, 4=very relevant and succinct) (Appendix G). The item content-validity index for each item was 100 as was the scale content-validity index (Stromberg & Olsen, 2004). The final 77-item PPFKN scale was formatted (Appendix M).

#### HUMAN RIGHTS PROTECTION

Institutional Review Board (IRB) approval was obtained from both the hospital and Boston College. A cover letter (Appendix H) outlined the purpose of the study and the risks and benefits of participation. Completion of the survey indicated the participant's consent for participation in the study. Each instrument was coded with a number, and no patient identifiers such as name or medical record number appeared on any of the forms. Appendices I and J contain copies of the letters of approval from both the hospital and university IRBs.

#### METHODOLOGY

#### Setting and Sample

The PPFKN Scale was administered on seven surgical units at a large urban academic medical center in the northeast United States to patients on their day of discharge from a surgical service. Inclusion criteria reflect all surgical patients between the ages of 18 and 95 years who were able to read English and consent to participation in the study. The researcher recruited 327 participants. The typical participant was 55.4 years (SD 3.4 yrs.), Caucasian, female and married or living with a partner. The typical participant reported an education of 15 years (SD 3.4 yrs) which corresponds to some college or technical training. Length of stay in the hospital was 5.5 days (SD 7.3 days), and care was limited to only one unit and no previous care on that unit prior to this hospitalization. (Table 1)

## Table 1

# Participant Demographics N= 296

Characteristics	5	f	%	М	SD	MDN
Race	White not Hispanic	258	88.0			
	Black not Hispanic	14	4.8			
	Hispanic	12	4.1			
	Asian or Pacific Islande	er 2	0.7			
	Other	8	2.7			
Gender	Male	126	42.6			
	Female	169	57.1			
Marital Status	Single	56	19.0			
	Divorced	26	9.0			
	Widowed	30	10.0			
	Married/ Partner	176	60.0			
	Separated	7	2.4			
Cared for	On 1 unit	210	71.0			
	On more than 1 unit	86	29.0			
	Not on that unit before	238	80.4			
	On that unit before	58	19.6			
Age Range 19-94 years					55	17.1
Education Range 5-23 years				15	3.4	
Days Hospitali	zed Range 1-90				5	7.3

Sample size was guided by Tinsley and Tinsley (1987), who suggested a ratio of five to ten participants per item up to 300, and when the sample is as large as 300, the ratio can be relaxed. Knapp and Brown (1995) suggested a ratio of as low as three participants per item or a total sample of 100-200 participants which they believed was adequate for most purposes. *Study Procedure* 

The investigator attended multiple staff meetings with unit nurses and sent an e-mail to staff nurses on the seven surgical units describing the study aims and procedures. Information including a cover letter, coded instrument, a large envelope to seal the survey, a small sheet of paper to write their address should they like to receive the results of the study and a small envelope to seal the address separate from the survey were brought to the unit by study staff each day. The study staff consisted of the Principal Investigator and seven graduate nursing students who had completed CITI training and were approved by the IRB to collect data. Each study staff was oriented and observed by the Principal Investigator performing recruitment, one consent and data collection cycle.

On the day of discharge, the nurse caring for the patient explained the purpose of the study to the patient (Appendix K) and, if the patient was interested, asked the study staff to speak with the patient. Study staff reviewed the cover letter with the potential participant which outlined the purpose, risks and benefits of participation and how participants could reach the Principal Investigator (PI) if they had questions or wanted to share any comment. Staff stressed the importance of responding to every item if the survey was to be included in the study. Once participants agreed to complete the survey and did so, they were asked to again review the survey to ensure every item was answered. Study staff then reviewed the survey to ensure items had been completed prior to sealing the completed survey in the envelope in front of the participant. If the participants requested study results, they were asked to provide their address on a sheet of paper which was sealed in a separate envelope. A demographics sheet was included in the survey, containing a request to provide age, ethnicity, gender, length of time in the hospital, length of time on the unit, whether they had been previously cared for on that unit, and, if so how many times in total (Appendix L)

#### Data Management

Each survey was sealed in an envelope in front of the patient. There were no patient identifiers on the envelope or the coded instrument. A separate sheet of blank paper and envelope were provided for participants to list their names and addresses or e-mail addresses should they wish to receive a copy of the findings. The study staff took the envelopes and placed them in a locked box in the PI's office each day. After data entry, surveys were stored in the PI's locked office in a secured cabinet.

#### Summary

The purpose of this study, utilizing a mixed methods design, was to develop and psychometrically evaluate the Patients' Perceptions of Feeling Known by their Nurses Scale (PPFKN Scale) during an acute surgical inpatient admission. This chapter reviewed the research methodology including setting, sample, instrument development, data collection and management, and protection of human rights.

#### **CHAPTER 5**

#### EVALUATION OF THE PPFKN SCALE: FINDINGS

#### Introduction

The purpose of this study was to develop an instrument to measure patients' perceptions of feeling known by their nurses during an inpatient surgical admission and to conduct a psychometric evaluation of the instrument.

#### Preliminary Analysis and Cleaning of the Data

Data were entered into SPSS, version 15.0 database. Once entered, the data were validated by review of every fifth survey by the research assistants. Several errors were identified, and the PI went back to the original data and made corrections. A total of 327 completed surveys were entered into the database. Descriptive statistics were computed on all study variables and examined for marked skewness, systematic missing data and outliers. The mean score on the instrument was 265 with scores ranging from 88-308. There were 31 participants who were dropped from the analysis for missing data related to item response. When examining the missing data, the range of missed items was from 1-63. Since missing data occurred in a sequence of almost total pages, the researcher deduced that the smoothness of the paper made it difficult to turn the pages. The final sample size was 296 surveys with no missing item responses. *Psychometric Evaluation of the PPFKN Scale* 

Psychometric evaluation of the PPFKN Scale included: a) internal consistency reliability of the total scale using Cronbach's alpha and examination of the item-total correlations; b) principal components analysis (PCA) with iterations, Varimax rotation and Kaiser normalization; and c) internal consistency reliability using Cronbach's alpha coefficients of the resulting components. Reliability is an essential characteristic of any instrument and a prerequisite for validity

(Waltz, Strickland and Lenz, 1991). Cronbach's alpha coefficient of 0.70 was the minimal criterion for reliability.

#### Initial Reliability Estimates

Item-total correlations were computed for the 77-item PPFKN Scale. All but one item met the minimum total criterion item-total correlation level of 0.30 recommended for inclusion in the scale (Nunnally, 1978; Nunnally & Bernstein, 1994). This item was retained to see if it performed better in the PCA. The standardized Cronbach's alpha coefficient for the now 77- item scale was .99. An examination of the inter-item correlation matrix showed many items with an inter-item correlation of >0.7, indicating some redundancy (Stromborg and Olson, 2004). All items were retained for PCA. Corrected item-total correlations ranged from .44 to .85 with the exception of the one outlier at .22.

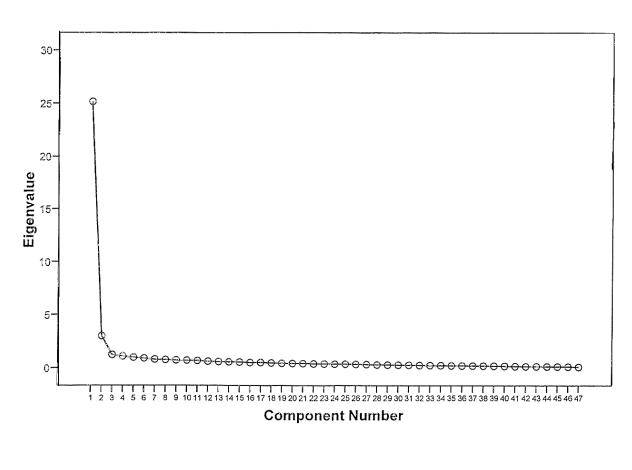
#### Principal Components Analysis (PCA)

"Principal components analysis" is a statistical technique applied to a single set of variables to discover which variables in the set form coherent subsets that are relatively independent of one another (Tabachnick and Fidell, 2007). It is a useful approach to assess construct validity when a measure is designed to assess various dimensions of a phenomenon of concern (Waltz, Strickland and Lenz, 1991).

The PPFKN Scale for the 296 participant responses with no missing data were next subjected to PCA with iterations, Varimax rotation and Kaiser normalization. Unrotated factors with eigen values > 1.0 resulted in an 8-component solution accounting for 69.1 percent of the variance. The Scree plot was more parsimonious and was suggestive of a three or four component solution (Figure1). A second principal-components analysis using Varimax rotation and Kaiser normalization for a four-component solution consistent with the theoretical underpinnings

### Prinipal Components Analysis (PCA)

Figure 1.



Scree Plot

of the scale was next undertaken, accounting for 63.3% of the variance. The component loading cutoff was .30. If an item failed to load on the expected component or did not make sense where it significantly loaded, the item was dropped. A total of 29 items was dropped at this time, resulting in a 48-item scale with a Cronbach's alpha coefficient of .98.

Component 1, labeled "Experienced a Meaningful, Personal Connection with Their Nurses", was composed of 17 items, all of which were designed to measure that component and had a Cronbach's alpha coefficient of .96.

Component 2, labeled "Felt Safe", consisted of 8 items, all of which were designed to measure that component and had a Cronbach's alpha coefficient of .90.

Component 3, labeled "Experienced Being Recognized as a Unique Human Being", had 15 items, all of which were designed to measure that component and had a Cronbach's alpha coefficient of .93.

Component 4, labeled "Felt Empowered by Their Nurses to Participate in Their Care", consisted of eight items, five of which were designed to measure that component. The other three items side-loaded on Component 4 and conceptually fit with the other items in this component. Component Four had a Cronbach's alpha coefficient of .92. The Cronbach's alpha coefficient for the 48-item scale was .98 (See Tables 2-5).

### Table 2

# PCA Loadings for Varimax-Rotated Factor Matrix for Component 1 of PPFKN Scale

N=296

Component 1: Experienced a Meaningful Personal Connection	Variance	34.4%
(Cronbach's Alpha = .96)		
Item	Compo	nent Loading
My nurses were personable.		.64
My nurses were easy to talk to.		.82
I could talk with my nurses.		.68
I had a good relationship with my nurses		.78
My nurses made me feel that I was important to them.		.71
When my nurses cared for me they made me feel like I was their only patient.		.44
My nurses made me feel that they cared about me as a person.		.73
My nurses took the time to ask me about my feelings.		.35
My nurses made me feel special.		.60
My nurses were kind.		.76
My nurses asked about my comfort.		.62
My nurses gave me individual attention.		.78
I experienced a meaningful connection with my nurses.		.56
My nurses made me feel that my well-being was important to them.		.69
My nurses responded to my needs even before I asked.		.45
My nurses cared about me.		.76
My nurses were friendly to me.		.85

### Table 3

# PCA Loadings for Varimax-Rotated Factor Matrix for Component 2 of PPFKN Scale

N=296

Component 2: Experienced Being Recognized as a Unique Human Being	Variance 17.4 %	
(Cronbach's Alpha =.93)		
Item	Component Loading	
My nurses made me feel that they cared for me not only as a patient but also as a person.	.34	
My nurses were attentive to my needs.	.34	
My nurses gave me personal attention.	.36	
My nurses listened to my concerns.	.34	
My nurses treated me as a unique human being.	.49	
My nurses made my family and visitors feel welcome.	.47	
My nurses knocked or spoke before opening the door or curtain.	.39	
My nurses made me feel they knew me better than my doctors knew me.	.41	
My nurses asked how being in the hospital impacted my life.	.85	
My nurses asked me to talk about my experience in the hospital.	.80	
My nurses asked me my goals for my hospital stay.	.79	
My nurses asked how being in the hospital affected my family.	.78	
My nurses asked about my life outside of the hospital.	.65	
My nurses asked me what name I like to be called.	.61	
My nurses asked about what is important to me while I am in the hospital.	.59	

Table 4 PCA Loadings for Varimax-Rotated Factor Matrix for Component 3 PPFKN Scale N= 296

Component 3: Felt Safe	8.1 % Variance

(Cronbach's Alpha = .90)

Item	Component Loading
My nurses knew about me before coming into my room.	.57
My nurses made me feel confident that my needs would be met.	.48
I felt confident that my nurses talked with each other about my care.	.49
I felt confident that my nurses talked with my doctors about my care.	.38
My nurses took care of my needs when I asked.	.44
My nurses responded quickly when I needed help.	.47
My nurses made me feel reassured.	.40
My kept nurses me informed about each day's schedule and care.	.45

Component 4: Felt Empowered to Participate in Care Variance	3.5 % Variance	
(Cronbach's A	s Alpha = .92)	
Item	Component Loading	
I did not feel rushed by my nurses.	.35	
My nurses kept me informed.	.33	
My nurses made sure that I knew what to do when I leave the hospital.	.35	
My nurses helped me to understand the information given to me by doctors and specialists.	.40	
My nurses encouraged me to follow my plan of care in order for me to leave the hospital.	.42	
My nurses made sure that I understood what was happening with my care.	.36	
My nurses explained what they were doing when they cared for me.	.39	
My nurses make me feel that they were glad to know me.	.30	

## Summary

This chapter reported the results of data analysis and addressed the research questions. .

Participants included 296 surgical inpatients.

Research question one: How content-valid is the PPFKN Scale in measuring the state construct?

The five expert participants rated a content validity index (CVI) of the original 77 items at 100%.

Research question two: How internally consistent is the PPFKN Scale in measuring the stated construct? To what extent can the four components be demonstrated through Principal Components Analysis (PCA)?

Cronbach's alpha coefficient for the 77 item scale was .99. A confirmatory principal components analysis using Varimax rotation and Kaiser normalization for a four-component solution consistent with the theoretical underpinnings of the scale accounted for 63.3% of the variance. The component loading cut-off was 3.0. If an item did not load on the expected component or did not make sense where it significantly loaded, the item was dropped. A total of 29 items was dropped at this time, resulting in a 48-item scale.

Research question three: How internally consistent are the resulting components?

Component 1, "experienced a meaningful, personal connection with their nurses", comprised of 17 items, all of which were designed to measure that component, had a Cronbach's alpha coefficient of .96. "Felt safe" comprised of eight items, all of which were designed to measure that component and had a Cronbach's alpha coefficient of .90. "Experienced being recognized as a unique human being", comprised of 15 items, all of which were designed to measure that component, had a Cronbach's alpha coefficient of .93. "Felt empowered by their nurses to participate in their care", comprised of eight items, five of which were designed to measure that component, had a Cronbach's alpha coefficient of .92. Cronbach's alpha coefficient for the 48 item scale was .98.

#### CHAPTER SIX

# DISCUSSION AND IMPLICATIONS

### Introduction

This chapter presents a brief overview of the study and addresses its findings. Limitations and implications for nursing education, practice, theory, knowledge development, research and policy will be discussed.

### Discussion

The purpose of this mixed methods study was to develop a reliable and valid measure of patients' perceptions of feeling known by their nurses while being cared for during an acute, surgical, inpatient admission. The overall development of the PPFKN Scale was guided by Newman's theoretical framework of "Health as Expanding Consciousness" (1994) and the results of a qualitative descriptive study of patients regarding their perceptions of feeling known by their nurses. Newman believes that through pattern recognition, nurses come to know the patient and assist them in realizing opportunities they may have not recognized in the past. The qualitative, descriptive study of surgical inpatients' perceptions of feeling known by their nurses (Somerville, 2003) revealed that when patients felt known by their nurses, patients experienced being recognized as a unique human being, felt safe, experienced a meaningful, personal connection with their nurses and felt empowered by their nurses to participate in their care. The development and psychometric testing of the PPFKN Scale was guided by HEC and the four themes that emerged from the qualitative study. The PPFKN Scale is the 85 item scale that resulted. The scale was exposed to a panel of nurse experts for content validity, item understandability and readability. Consensus was validated using this process. The revised scale was also exposed to five participants who had experienced an inpatient, surgical admission for

content validity, item readability and understandability. A 77-item scale was derived from content validation and administered to 327 participants from surgical inpatient settings across seven general care units at a large academic urban medical center.

### Findings

The results yielded 296 completed surveys without missing item data for analysis. A fourcomponent solution was devised and accounted for 63.3% of the variance, with a Cronbach's alpha of .99. Utilizing a component loading cut-off of 0.3, the scale was reduced to 48 items. Each of the four subscales retained from 17-8 items with a range of Cronbach's alpha coefficient from .84 to .97. The total scale Cronbach's alpha coefficient was .98.

There are many implications to be drawn for nursing from this study. The literature and qualitative pilot study results provide some essential information about what patients find essential to good nursing care. These insights about patients' experiences are validated by the PPFKN Scale and use of the scale will bring further information related to the context of care. In addition findings will provide support for nurses in advocating for changes in the current care delivery system. The scale is a reliable and valid method for analyzing the issues of patients feeling known or not, and therefore these scores have implications related to nursing practice.

Data analysis and study related findings supported the themes identified in the qualitative, descriptive study as well as the themes that emerged from the review of the extant literature. As a discipline, nursing has long been concerned with the human experience and health and the unique responses of each human being. Carper (1978) described aesthetic ways of knowing as "the knowing of a unique particular rather than an exemplary class" (p. 18). Population-based nursing care must be informed by nurses' knowledge of the unique human being whom nurses have the privilege to serve. This concern can be tempered by personal ways of knowing in nursing (Carper,

1978). Personal ways of knowing in nursing challenge the nurse to understand the patient experience beyond expected patient responses and stereotypes. The nurse-patient relationship is informed through active engagement between the nurse and the patient, rather than impersonal, task-driven detachment. When the nurse is willing to extend him or herself to the patient, care is informed by the experience of the patient. Personal knowing resists paternalism and embraces the wholeness and integrity of the other. The nurse-patient relationship becomes a vehicle to transcend bias and bear witness to the patient's unique worth. According to Newman (2008), "For the discipline, the emphasis on relationship means that knowledge development focuses on process as content. The essence of the process is in being fully present in the transformation of ourselves and others as we search for meaning in the lives of persons who have come to critical junctures in their lives" (p.51). Excellence in nursing care presupposes nurses' knowledge of their patient as person and the PPFKN Scale creates the opportunity to measure the presence or absence of this phenomenon.

#### Limitations

Study limitations were identified as follows. The typical participant was white, well educated, married or living with a partner and had been admitted to a surgical service with a mean length of stay of approximately between five and six days. Further research is needed to determine if similar psychometrics emerge with other more diverse participant samples..

### Implications for Nursing Education

When educating new nurses, we must not forget the importance of knowing the patient. Liaschenko (1997) explored reservations about "knowing" the patient and the potential for intrusiveness and increased complexity of nurses' practice. ...If the nurse takes into account only those needs that are immediately present through case and patient (clinical) knowledge, the possibility for appropriate actions are limited, thereby making the responses straightforward. On the other hand when the nurse perceives these (patient) needs against the background of the person's life and values, the end at which the nurse's actions should be aimed are not always so clear (p. 36).

Early in all educational programs, disciplinary knowledge must be integrated into educational and mentoring strategies. Introduction to nursing philosophy and the essence of nursing, the nurse-patient relationship, are essential to advancing the discipline. Knowing the patient as person, nurse presence and accessing the patient experience are all strategies required in the current environment to enact the nurse-patient partnership. As stated repeatedly, this is complicated by a practice environment that often challenges this knowledge. It is essential to explore with students the skills and coping strategies required to preserve "knowing" their patients and to live with such tension in a society and health care system that values quick fixes and "evidence-based" and case-based solutions and clinical decisions. Nurse educators can help influence new practitioners to value unique knowledge of their patient as a type of "evidence" that is as important to be considered when designing nursing interventions as the results of randomized clinical trials.

#### Implications for nursing practice

In terms of nursing practice, the ability to measure patients' perceptions of feeling known by their nurses using a reliable and valid instrument, will provide new insights into patients' experiences within the current health care environment. This knowledge will support nurses in fostering opportunities for choices and actions that can help transform the care experience for the nurse and patient. In this era that values patient-centric care, the nurse-patient relationship can be promoted.

To preserve the integrity of this relationship, nurses must design care based on patient data and create care environments where the patient is the central focus within the nursing care delivery model. The ability to measure the patient's perspective of the nurse-patient relationship enhances the ability to explore this phenomenon's relationship to such variables as patient safety, patient satisfaction, nursing efficacy and nurse satisfaction, creating a new lens to evaluate organizational success. Guided by this new knowledge, care delivery models that enhance knowing the patient from the mutual perspective of the nurse and the patient can be developed and evaluated. New methods of patient assessment for nurses in acute care settings that focus on knowing the patient could be established and evaluated for their effectiveness. One approach to be considered would be to utilize Newman's process of pattern recognition as part of the initial patient assessment and to assess the impact of this approach on care and patients' perceptions of feeling known.

#### Implications for Nursing Research

Future studies can be designed to explore the generalizability of the scale and its theoretical underpinnings across a variety of populations. Nurse researchers can study the effect of the nurse-patient relationship on recovery, satisfaction and healing. Such knowledge can be used to create an opportunity for nurse scientists to explore the nurse-patient relationship and the influence of organizational changes/challenges and environmental factors that either contribute or detract from patients' perceptions of feeling known by their nurses. In addition, the scale can lead to creation of a comparable version of the instrument for nurses to evaluate the nurse-patient relationship in a more measurable way.

65

### Implications for Theory

Grounded in Newman's (1994) theory of "Health as Expanding Consciousness", this instrument represents the first known attempt to develop a quantitative measure guided by Newman's conceptualization of health and environment. Utilizing mid-range theoretical concepts, the qualitative study validated the conceptual constructs and the instrument allows nurses to measure the theoretical concepts in the practice environment. The findings add to existing knowledge as well as add new knowledge with the ability to test and evaluate the constructs. *Implications for Policy* 

The Institute of Medicine's six aims for improving quality of care (2001) addressed the relationship between safety and clinical decisions guided by unique knowledge of the patient as person. This includes understanding patient preferences, needs and values. Focusing on a body part, providing treatment or relieving symptoms without understanding the patient as person within the context of their life, is reductionistic and often results in the patient feeling unsafe, devalued and dehumanized. It often leads to creation of a "plan" that the patient, for a host of reasons, can not "live" with. The health care system does not view this as its failure but rather labels the patient or family as "non-compliant". Nurses are compelled to welcome patients as partners in designing their care and utilize the nurse-patient relationship to support the patient in realizing their capacity and potential. Based on the literature review and tool development and testing, it can be argued that pattern recognition and ensuring choice, action and personal transformation are the ultimate form of patient empowerment.

Nursing care is delivered within the context of the health care system and society. There is growing concern regarding the effect of this environment on nurses' ability to practice nursing and influence patient care outcomes that reflect the focus of the discipline. In order to participate in sociopolitical activities to advance and preserve the essence of the discipline, it is essential to understand the impact of the environment on the nurse-patient relationship. Nurse researchers can use data obtained from the PPFKN Scale to further explore the relationship between the patient and their nurse and the impact of this relationship and the current environment on recovery and healing.

#### Summary

The PPFKN Scale needs to be tested across settings and populations to determine its generalizability. "No other discipline is developing knowledge related to how the quality of relationship facilitates health" (Smith, 1999, p.19). Research to date provides evidence that nurses value knowing their patients (Horvath et al ,1990; Radwin, 1996). Creating data that supports the development of a practice environment supportive to nurses' knowing their patients has the potential to promote health, enhance prevention and contribute to nursing knowledge development. Development of a reliable and valid instrument used to uncover the impact of the nurse-patient relationship on the patients' perceptions of health will allow nurses to gain insight into patients' understanding of being known by their nurses and ultimately how this experience impacts their care and related outcomes. Data obtained utilizing the PPFKN Scale creates an opportunity for nurse researchers to explore the nurse-patient relationship and the influence of organizational outcomes and environmental factors that contribute to or diminish patients' perceptions of feeling known by their nurses.

In this era that values "evidence"-based practice, the nurse-patient relationship is placed at risk. To preserve the integrity of this relationship, nurses must create care environments where the patient is the focus of nursing care. The ability to measure the patient's perspective and explore the phenomenon's relationship, as related to patient safety and patient satisfaction, nursing efficacy and satisfaction, will create a new lens that can be used to evaluate organizational success. Having available nurse-sensitive indicators that are responsive to these variables can enhance evidence-driven nursing care. Guided by this instrument, future studies can focus on development, implementation and evaluation of new care delivery models that enhance knowing the patient from the mutual perspective of the nurse and the patient. In addition, development of new methods of patient assessment for nurses in acute care settings that focus on knowing the patient could be established and evaluated for their effectiveness. Outcome studies will explore the relationship between the presence of this phenomenon from the nurse and the patient perspective and nurse, organizational and patient outcomes. Intervention studies will be designed to assess the impact of interventions targeted toward increasing nurses' abilities to know their patients. Lastly, grounded in Newman's (1994) theory of "Health as Expanding Consciousness", this instrument represents the first known attempt to develop a quantitative measure of the impact of the nurse-patient relationship and knowing the person using Newman's conceptualization of health and environment.

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# Appendix A

# PILOT, QUALITATIVE STUDY INTERVIEW GUIDE

Guidelines for the Patient: In order to help us understand your current hospitalization better, I would like to ask you a series of questions that will help inform the team about the care you received during your stay at the MGH. This information will not identify you in any way and will be analyzed and reported as group data. You are free to terminate your participation in this study without any compromise to your care. We appreciate your assistance.

1. Demographic Information:002

- Age\_\_\_\_\_
- Sex \_\_\_\_\_
- Race \_\_\_\_\_
- Medical Diagnosis \_\_\_\_\_\_
- Nursing Diagnosis/Patient Problems \_\_\_\_\_\_
- Unit on which care is given \_\_\_\_\_\_

# Questions

- 1. Have you been a patient staying overnight in the hospital before?
- 2. Yes\_\_\_\_\_NO\_\_\_\_\_
- 3. If yes, when? \_\_\_\_\_
- 4. Was it at this hospital? Yes\_\_\_\_\_NO\_\_\_\_\_
- 5. Was it on this unit? Yes\_\_\_\_\_NO\_\_\_\_\_

\_\_\_\_\_

6. Why were you hospitalized at that time?

7. Is your current hospitalization what you thought it would be like?

Yes\_\_\_\_\_ NO\_\_\_\_ If no describe.

In general, can you tell me what it has been like to be cared for on this unit? \_\_\_\_.

\_\_\_\_\_

	Can you tell me about the people who cared for you (e.g. nurse, therapist etc)
	What was it like when you were cared for by the nurse? The doctor?
1.	Other? (As named by the patient)
2	Who do you feel knows you best?
3	Why do you think that this is so?
5	How does it feel to be known? Does this influence the care you receive? How so?
6	Do you feel that you have been able to participate in decisions about your care? Yes
17.	Describe when and How?

	you feel safe? Yes ff who are skillful? Knowl		Is the care provided by
	you feel the MDs/ nurses NO n you give an example?		oout your hospitalization? Yes
 22. Are	e you encouraged to ask qu	uestions? Yes	NONO
	e your questions answered e you encouraged to call if		
26. Do 27. Ye	e your calls responded to p you feel the team commu s NO n you give an example?	nicates with each other ab	NO out your hospitalization?
	you feel that there is a teany and can you give an example	<b>e</b>	sNO

# Appendix B

### PPFKN Scale Items: Version One (85 items)

# **Experienced being recognized as a unique human being** (21 items)

During this hospital stay:

1 ) My beliefs and values were known by my nurses.

- 2) I felt understood as a person by my nurses.
- 3) I believe that my nurses had unique knowledge about me as person.
- 4) My nurses knew what this hospitalization experience meant to me.
- 5) My nurses understood how this hospitalization will impact my life.
- 6) My nurses planned my care in a way that met my needs.
- 7 ) My nurses knew me best.
- 8) My nurses anticipated my responses to my illness and hospitalization.
- 9) My nurses knew my likes and dislikes.
- 10) My nurses knew my family and other individuals that are important to me.
- 11) My nursing care was guided by my nurses' knowledge of my preferences.
- 12) I felt my nurses accepted me as an individual.
- 13) My nurses accepted my values and beliefs.
- 14) My nurses accepted me for who I am.
- 15) My nurses did not pass judgment about my preferences.
- 16) My nurses treated me with respect.
- 17) My nurses were interested in my life outside of the hospital.
- 18) My nurses made me feel that they valued me as a whole person.

Appendix B (continued)

Recognized as a unique human being (continued) During this hospital stay: 19) My nurses made every effort to understand the things that were really important to

me while I was in the hospital.

20) My beliefs and values were respected by my nurses.

21) My nurses took the time to listen to my story.

Felt safe (23 items)

22) I did not feel the need to tell each nurse my story the first time I met them.

23) I felt safe when my nurses cared for me.

24) I felt confident that my nurses would get me what I needed.

25) My nurses communicated with each other about my care in a way that nothing got missed.

26) I always knew the name of the nurse who was taking care of me.

27) My nurses responded quickly when I needed help.

28) My nurses communicated about my care with my team so that nothing got missed.

29) Important information about my care was passed on from the nurse taking care of

me to the next nurse who cared for me.

30) My nurses made sure that I understood what was happening during my hospital

stay.

31) My nurses knew what I needed to get well and return home.

32) I trusted that my nurses would look out for my well being.

33) My nurses made me feel that everything would be ok.

34) My nurses checked on me frequently.

35) My nurses really knew what they were doing.

Appendix B (continued) Felt Safe (continued)

- 36) My nurses watched over me.
- 37) My nurses watched out for me.
- 38) My nurses took my concerns seriously.
- 39) When I met my nurses for the first time they already knew my story.
- 40) I did not fear for my safety.
- 41) My nurses protected me from danger.
- 42) My nurses always responded to my concerns.
- 43) My nurses listened to my concerns.
- 44) My nurses were very knowledgeable about my care.

### **Experienced a Meaningful Personal Connection** (20 items)

- 45) I felt close to my nurses.
- 46) My nurses asked me to talk about how I felt.
- 47) My nurses asked me to tell my story.
- 48) My nurses took the time to listen to me.
- 49) My nurses were interested in knowing how I was feeling.
- 50) My nurses made me feel that I was important to them.
- 51) My nurses made me feel like I was their only patient.
- 52) My nurses were concerned about me.
- 53) My nurses wanted to hear what I was thinking.
- 54) My nurses made me feel that they really cared about me as a person.
- 55) My nurses knew when I was upset before I even told them.
- 56) My nurses made me feel special.

Appendix B (continued) Personal Connection (continued)

- 57) I was able to confide in my nurses.
- 58) My nurses were available to me when I was frightened.
- 59) My nurses gave me individual attention.
- 60) My nurses talked with me about their lives.
- 61) My nurses and I shared our thoughts freely.
- 62) My nurses made me feel that my well being was important to them.
- 63) My nurses made me feel that they have benefited from knowing me.
- 64) My nurses were able to share information honestly with me.

## Felt Empowered to Participate in Care (21 items)

- 65) My opinions mattered to my nurses.
- 66) My nurses sought out my opinions.
- 67) My nurses made sure that I had the information that I needed to make decisions

about my care.

68) My nurse stopped what they were doing and addressed my concerns when they were raised.

- 69) My nurses made me feel in control about decisions related to my care.
- 70) I was comfortable sharing my preferences with my nurses.
- 71) My nurses helped me to understand the impact of my choices on my life.
- 72) My nurses made sure that I was always in control of my choices.
- 73) My nurses spoke to me directly.
- 74) My nurses explained things in a way that was easy to understand.
- 75) My nurses helped me understand the information given to me by doctors and

Appendix B (continued) Felt Empowered (continued)

specialists before I made choices.

76) My nurses made me feel supported in the decisions I made about my care.

77) My nurses respected the decisions that I made.

78) I was supported by my nurses when I needed to make a decision about my care.

79) I felt comfortable asking my nurses questions about my care.

80) When I asked my nurses a question, it was never too much trouble for them to take

the time to explain.

81) My nurses made sure that I was provided all options or choices before I made a

decision about my care.

82) My nurses encouraged me to take as much control over my care as I wished.

83) My nurses made sure that I had the necessary skills and knowledge to care for

myself at home.

84) My nurses made sure that I had a say in what happened to me.

85) I never felt rushed by my nurses to make a decision.

Appendix C

#### Nurse Expert Content Validity Guide

Dear Reviewers:

The purpose of this instrument is to measure patients' perceptions of feeling known by their nurses. Feeling known is defined as a multi-dimensional perception which is measured using four components: a sense of being recognized as a unique person, feeling safe, feeling a personal connection with nurses and feeling empowered to participate in their care.

#### **Operational Definitions:**

**Recognized as a unique human being:** defined as the patient's experience of nurses who, through purposeful interaction, gain insight into the people, events, history and experiences that are meaningful in shaping that individual. This knowledge of the uniqueness of each person is reflected in the provision of care that is respectful of patient preferences and values.

**Feeling safe:** defined as patients having confidence in their nurses' intentions and abilities to advocate for their well being, to act upon their concerns and to ensure that their needs are communicated effectively to all providers so that vital information is not lost.

**Personal Connection:** defined as a shared consciousness and mutual partnership between the patient and their nurses. Nurses are willing to share of themselves, changing the dynamics of the relationship from one of dependency to one of mutuality. This transformative experience leads to a sense that nurses do not simply provide care to but actually care about the person.

**Empowered to participate in their care:** defined as nurses valuing patients as knowledgeable partners in care and providing information that helps patients make informed

choices. Nurses assist the patient to gain insight into their life pattern and recognize new choices and opportunities in their lives.

**Instructions:** Please evaluate items developed for each of the four components in relation to their relevance to the operational definition, their understandability and their readability. Please circle the response that reflects your judgment and provide suggestions for improving any of the items in the comment section.

### **Operational definitions of ratings:**

1)**Relevance** is defined as how closely the item matches or reflects the component's operational definition

Relevancy 0=not relevant ; 10= highly relevant

2)**Understandability** is defined as the ability to grasp the meaning of what you read when you read it.

Understandability 0= Difficult to Understandable; 10= Easy to Understand

3)**Readability** is defined as the ease with which the item can be read

Readability 0=Difficult to Read; 10= Easy to Read

### **Example:**

**Theme 1: Recognized as a unique human being**: defined as the patient's experience of nurses who through purposeful interaction, gain insight into the people, events, history and experiences that are meaningful in shaping that individual. This knowledge of the uniqueness of each person is reflected in the care that the nurses provide.

1) During this hospital stay my beliefs and values were known by my nurses.

Relevancy to the construct of being recognized as a unique human being							
01	2	3	4	5	6	7	8910
Not relevant							Highly Relevant
Understandabili	ty						
01	2	3	4	5	6	7	8910
Difficult to unde	erstand						Easy to Understand
Readability							
01	2	3	4	5	6	7	8910
Difficult to read	l						Easy to Read
Comments:							

### Appendix D: PPFKN Scale Version Two (after nurse expert panel comments)

#### *Experienced being recognized as a unique human being*

During this hospital stay:

1) My nurses knew what was important to me. Strongly Agree Strongly disagree Disagree Agree 2) My nurses understood me as a person. Strongly disagree Disagree Strongly Agree Agree 3) My nurses knew me as a unique person. Strongly disagree Disagree Agree Strongly Agree 4) My nurses knew what being in the hospital meant to me. Strongly disagree Disagree Strongly Agree Agree 5) My nurses understood how being in the hospital will impact my life. Strongly disagree Disagree Strongly Agree Agree 6) My nurses planned my care in a way that met my needs. Strongly disagree Disagree Agree Strongly Agree 7) My nurses knew me better than my doctors. Strongly disagree Disagree Agree Strongly Agree 8) My nurses were able to predict how I would react to my illness and hospital stay. Strongly disagree Disagree Agree Strongly Agree 9) My nurses knew my likes and dislikes. Strongly disagree Disagree Agree Strongly Agree 10) My nurses knew my family and other people who are important to me. Strongly disagree Disagree Agree Strongly Agree

11) My nursing care was guided by what my nurses knew about me.

Strongly disagree	Disagree	Agree	Strongly Agree			
12) My nurses accepted me as an individual.						
Strongly disagree	Disagree	Agree	Strongly Agree			
13) My nurses knew n	ny beliefs.					
Strongly disagree	Disagree	Agree	Strongly Agree			
14) My nurses accepte	d me for who I am.					
Strongly disagree	Disagree	Agree	Strongly Agree			
15) My nurses treated	me with respect.					
Strongly disagree	Disagree	Agree	Strongly Agree			
16) My nurses wanted to understand what my life is like outside of the hospital.						
Strongly disagree	Disagree	Agree	Strongly Agree			
17) My nurses made me feel that I was more than my disease.						
Strongly disagree	Disagree	Agree	Strongly Agree			
18) My nurses made every effort to understand the things that were important to me while I was						
in the hospital.						
19) My nurses took the time to listen to my story.						
Strongly disagree	Disagree	Agree	Strongly Agree			
Felt safe						
1) My nurses knew my story before meeting me.						
Strongly disagree	Disagree	Agree	Strongly Agree			
2) My nurses made me feel safe.						
Strongly disagree	Disagree	Agree	Strongly Agree			

3) My nurses made me feel confident that I would get what I needed.

Strongly disagree	Disagree	Agree	Strongly Agree			
4) My nurses got me what I needed when I needed it.						
Strongly disagree	Disagree	Agree	Strongly Agree			
5) My nurses commun	nicated with each other abo	out my care in a way	that nothing got missed.			
Strongly disagree	Disagree	Agree	Strongly Agree			
6) I always knew the r	name of the nurse who was	s taking care of me.				
Strongly disagree	Disagree	Agree	Strongly Agree			
7) My nurses responded quickly when I needed help.						
Strongly disagree	Disagree	Agree	Strongly Agree			
8) My nurses communicated about my care with my doctors so that nothing got missed.						
Strongly disagree	Disagree	Agree	Strongly Agree			
9) My nurses made sure that I understood what was happening during my hospital stay.						
Strongly disagree	Disagree	Agree	Strongly Agree			
10) My nurses knew what I needed to feel better while I was in the hospital.						
Strongly disagree	Disagree	Agree	Strongly Agree			
11) My nurses looked out for me.						
Strongly disagree	Disagree	Agree	Strongly Agree			
12) My nurses knew what I needed to leave the hospital.						
Strongly disagree	Disagree	Agree	Strongly Agree			
13) My nurses helped me feel prepared for when I needed to leave the unit for a test or care.						
Strongly disagree	Disagree	Agree	Strongly Agree			

14) My nurses made me feel that everything would be ok.

Strongly disagree	Disagree	Agree	Strongly Agree				
15) My nurses checked	15) My nurses checked on me frequently.						
Strongly disagree	Disagree	Agree	Strongly Agree				
16) My nurses knew w	hat they were doing.						
Strongly disagree	Disagree	Agree	Strongly Agree				
17) My nurses watche	d over me.						
Strongly disagree	Disagree	Agree	Strongly Agree				
18) My nurses watche	d out for me.						
Strongly disagree	Disagree	Agree	Strongly Agree				
19) My nurses took m	y concerns seriously.						
Strongly disagree	Disagree	Agree	Strongly Agree				
20) When I met nurses for the first time, they already knew my story.							
Strongly disagree	Disagree	Agree	Strongly Agree				
21) My nurses made me feel safe.							
Strongly disagree	Disagree	Agree	Strongly Agree				
22) My nurses protected me from harm.							
Strongly disagree	Disagree	Agree	Strongly Agree				
23) My nurses responded to my concerns.							
Strongly disagree	Disagree	Agree	Strongly Agree				
24) My nurses listened to my concerns.							
Strongly disagree	Disagree	Agree	Strongly Agree				

Strongly disagree Disagree Strongly Agree Agree *Experienced a meaningful personal connection* 1) I felt close to my nurses. Strongly disagree Disagree Agree Strongly Agree 2) My nurses asked me to talk about how I felt. Strongly disagree Strongly Agree Disagree Agree 3) My nurses asked me to tell my story. Strongly disagree Disagree Agree Strongly Agree 4) My nurses took the time to listen to me. Agree Strongly disagree Disagree Strongly Agree 5) My nurses wanted to know how I felt. Strongly disagree Strongly Agree Disagree Agree 6) My nurses made me feel that I was important. Strongly disagree Disagree Agree Strongly Agree 7) When my nurses cared for me, they made me feel like I was their only patient. Strongly disagree Disagree Agree Strongly Agree 8) My nurses cared about me. Strongly disagree Disagree Agree Strongly Agree 9) My nurses wanted to hear what I was thinking. Strongly disagree Disagree Agree Strongly Agree 10) My nurses made me feel that they cared about me as a person. Strongly disagree Disagree Agree Strongly Agree

25) My nurses were knowledgeable about my care.

11) My nurses could tell when I was upset.

Strongly disagree	Disagree	Agree	Strongly Agree			
12) My nurses made me feel special.						
Strongly disagree	Disagree	Agree	Strongly Agree			
13) I was able to confi	de in my nurses.					
Strongly disagree	Disagree	Agree	Strongly Agree			
14) My nurses were th	ere when I was frightened	l.				
Strongly disagree	Disagree	Agree	Strongly Agree			
15) My nurses gave m	e individual attention.					
Strongly disagree	Disagree	Agree	Strongly Agree			
16) My nurses shared stories about their lives with me.						
Strongly disagree	Disagree	Agree	Strongly Agree			
17) My nurses and I shared our thoughts and opinions.						
Strongly disagree	Disagree	Agree	Strongly Agree			
18) My nurses made me feel that my well being was important to them.						
Strongly disagree	Disagree	Agree	Strongly Agree			
19) My nurses made me feel that they were happy to know me.						
Strongly disagree	Disagree	Agree	Strongly Agree			
20) My nurses were willing to share information honestly with me.						
Strongly disagree	Disagree	Agree	Strongly Agree			
21) I felt a connection with my nurses.						
Strongly disagree	Disagree	Agree	Strongly Agree			

# Felt empowered to participate in care.

1) My opinions mattered to my nurses.							
Strongly disagree	Disagree	Agree	Strongly Agree				
2) My nurses asked m	2) My nurses asked my opinions.						
Strongly disagree	Disagree	Agree	Strongly Agree				
3) My nurses made sur	re that I had the information	on I needed to make	decisions about my care.				
Strongly disagree	Disagree	Agree	Strongly Agree				
4) My nurses take the	time to address my concer	ms.					
Strongly disagree	Disagree	Agree	Strongly Agree				
5) My nurses made me feel in control over decisions about my care.							
Strongly disagree	Disagree	Agree	Strongly Agree				
6) I was comfortable sharing my choices with my nurses.							
Strongly disagree	Disagree	Agree	Strongly Agree				
7) My nurses helped me to understand the impact of my choices on my life.							
Strongly disagree	Disagree	Agree	Strongly Agree				
8) My nurses made sure that I was in control of my choices.							
Strongly disagree	Disagree	Agree	Strongly Agree				
9) My nurses spoke directly to me.							
Strongly disagree	Disagree	Agree	Strongly Agree				
10) My nurses were easy to understand.							
Strongly disagree	Disagree	Agree	Strongly Agree				

11) My nurses helped me understand the information given to me by doctors and specialists about choices I needed to make.

Strongly disagree	Disagree	Agree	Strongly Agree		
12) My nurses made me feel supported in the decisions I made about my care.					
Strongly disagree	Disagree	Agree	Strongly Agree		
13) My nurses respect	ed the decisions that I mad	le.			
Strongly disagree	Disagree	Agree	Strongly Agree		
14) I was supported b	y my nurses when I neede	d to make decisions	about my care.		
Strongly disagree	Disagree	Agree	Strongly Agree		
15) I felt comfortable	asking my nurses question	ns about my care.			
Strongly disagree	Disagree	Agree	Strongly Agree		
16) Whenever I asked my nurses a question, they took the time to explain.					
Strongly disagree	Disagree	Agree	Strongly Agree		
17) My nurses made sure that I was provided with options or choices before I made a decision					
about my care.					
Strongly disagree	Disagree	Agree	Strongly Agree		
18) My nurses encouraged me to take as much control over my care as I wished.					
Strongly disagree	Disagree	Agree	Strongly Agree		
19) My nurses made sure that I could take care of myself when I go home.					
Strongly disagree	Disagree	Agree	Strongly Agree		
20) My nurses made sure that I had a say in what happened to me.					
Strongly disagree	Disagree		Strongly Agree		

21) I didn't feel rushed by my nurses to make a decision.

Strongly disagree	Disagree	Agree	Strongly Agree
~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~			~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

22) My nurses accepted my decisions without passing judgment.

Strongly disagree	Disagree	Agree	Strongly Agree
0, 0	$\mathcal{U}$	U	0,0

#### Appendix E

#### **Expert Patient Transcripts**

#### Participant One

#1 "Not easy to answer. A little tricky. There were things I wanted to say but didn't because I thought I would offend the nurse. There was a big difference between what the first nurse and what the second nurse did for me. Not all nurses are the same. Maybe if I had shared my opinions I could answer this question easily. It was the way she entered the room, the way she said 'Hi', that made me feel like I just better do what she said and keep quiet."

#4 "Yes and No. Not easy to understand. Do nurses know my reasons for being there in the hospital?

#8 "I don't understand and would eliminate"

#16 "Not clear. 'On this unit my nurses want to understand what my life was like before I came #22 "What story-define more. What brought me here, my life before, what I think my life will be after, how it will effect my future?"

#26 "Not easy to read-would change to 'On this unit my nurses communicate with each other about my care."

#46 "Not clear-How I feel physically or emotionally/ mentally? Should be two separate questions."

#69 "Not easy to read-would change to 'On this unit my nurses make me feel that I have control over decisions about my care.'"

#71 "Not easy to read-'On this unit my nurses help me to understand how the choices I make about my health can impact my life."

#76 "Not clear-reword. 'On this unit my nurses support the decisions that I make about my

care.""

#81 "Not clear. 'On this unit my nurses make sure that I have the information I need to make decisions about my care.'"

Participant 2

Began with general comments that she felt some items needed a "not applicable" choice as she

reflected on her own experience.

#2 Difficult to understand- what does "understand me" mean-that they we spoke the same language

so they knew what I wanted?

#4 Difficult to answer based on personal experience-No one cared.

#5 Difficult to answer based on personal experience –did not feel it applied to her.

#6 Again physician role vs. nurse role based on personal experience.

#9 Difficult to understand. My likes and dislikes about what?

#13 Difficult to understand. My beliefs about what?

#21 Difficult to understand. What does "my story" mean? Why I am in the hospital?

#22 Difficult to understand –what does "my story" mean? Suggested instead "why I am in the hospital."

#23 Difficult to answer based on experience-Why would I need a nurse to make me feel safe?

#13 Difficult to answer. May not apply to all patients. I never left the unit.

#39 Difficult to understand. What does "my story" mean? What brought me to the hospital?

#41 Difficut to understand. Harm from what?

#45. Difficult to answer. Felt "feeling close" implied intimacy. Suggested instead "I trust my nurses."

#46 Difficult to understand-How I feel physically, emotionally?

#47 Difficult to understand term "story" –again recommend inserting "why I came to the hospital."

#67 Difficult to answer. Didn't experience this as a nurse's role, only a physician's role

Participant 3

#1 Difficult to understand-What is important to me in terms of what? Getting home? Getting my meds on time?

#3 Difficult to read. A unique individual? They just don't have the time.

#4 Difficult to understand. How it impacts my life?

#5 Worded better than 13.

#6 Difficult to answer. First, do they offer options or ask how I would like to be cared for vs. responding to my requests. Received very routinized vs. individualized care.

#8 Difficult to understand. Predict? How would they do that? First, do they want to know how I am feeling about my illness and hospital stay? Then do they use this information to help them anticipate what I need? e.g. Pain med before PT?

#9 Likes and dislikes about what?

#11Difficult to understand. Understand what approaches make me feel better?

#12 Difficult to answer. How would I know if they accept me? Make me feel accepted? Make me feel they see me as a unique individual?

#13 Difficult to understand-What beliefs-values? Religious?

#17. Worded awkwardly. On this unit my nurse make me feel that they see more to me than my illness or procedure. –just a tiny part of who I am and my life. –see me as more than just a patient-as a person.

#21 ? Story

#22 Difficult to understand-What does "story" mean? Do they talk with me? Do they get it from the biased perspective of the medical record?

#23 Difficult to understand. Safe from what? Why wouldn't I be safe in a hospital?

#24 Difficult to understand. "Make me feel confident" in what way? How would I know?

#27. Difficult to answer based on my experience. I would take out "quickly" because based on the urgency they often needed to prioritize multiple calls.

#33 Difficult to answer. False sense of promise in some situations.

#34 Difficult to interpret. "Check me regularly"-come back to follow up after medications or a

treatment are given? After I have been sitting up for a while?

#37 Evoked concern. What is it they have to "look out for"? Over-protective sense.

#38 Over-protective-does this really mean they "monitored me and my care well?"

#39 ?Story?

#40 Again why? Should I worry?

#45 Nurses were in and out. It was the second level down that I felt closer to.

#46 Difficult to understand. How I feel physically? Emotionally? The nurses' interactions with me

were very superficial.

#47 Difficult to understand. What story? There is also a balance of overkill and repeating the same thing multiple times.

#48 Difficult to answer based on my experience. There was no focused attention on listening. It was while they were doing other things.

#49 Difficult to understand. Physically? Emotionally?

#50 Difficult to understand. "Important" is vague and why would I need the nurse to make me

feel important? They were pleasant, but focused on tasks. They were pleasant though. More the MD role. When he came in the room, he would sit in the chair and talk, go over things.

#53 Thinking about what? My hospitalization?

#54Difficult to understand. How would I know this? "Care" that I get the treatment that I needphysical, emotional? "Care" about me as a person? First –do I feel like they see me as a person or are interested in anything more than the tasks and monitoring. Care about or see me not just a patient, but as a person.

#56 Difficult to understand. What does "special" mean?

#57 Why would I need to?

#58 I did not rely on the nurses for this-I reached out to others.

#65 Difficult to understand. My opinions about what? How I want to be treated or cared for?

#66 Difficult to understand. My opinions about what? Involved in decisions about my care?

#67 Difficult to answer based on my experience. This is the physician's role. I never saw the MD and RN in the room at the same time.

#68 Difficult to answer –yes, if I raised concerns-but they did not actively seek them out.

#69 This is the physician's role.

#70 Difficult to read. Changed from being about nurses to whether I am comfortable. Nurses should be seeking about my care preference related to hygiene, comfort, sleep etc and using these to guide or coordinate my day and care.

#72 MD role.

#76 the MD's role.

#77 Difficult to answer. How would I know that they respect my decisions?#78 MD role.

#81 MD role.

#82 MD role.

#84 How would I know?

Participant 4

#1 Difficult to answer-How would I know if they want to know? Change to "they ask..." Also be clearer about what is important to me-when? During my hospital stay?

#2 Difficult to answer-again, how would I know? Change to "make me feel that they..."

#4 Difficult to understand-How being in the hospital affects my life and family?

#5 Again change to ask

#6 Difficult to understand. I think of doctors planning my care. Would change to "care for me..."

#7 Difficult to answer – again, how would I know. Change to "make me feel".

#9 Again how would I know-Change to "ask about my life outside of the hospital."

#13 Too vague-listen to my concerns?

#25 Again would change to "make me feel"...I don't know what "nothing gets missed means". – talk with each other about my care?

#28 Same issue -how would I know-change to "make me feel" and again about my care.

#29 Make me feel.....

#30 Difficult to understand. "keeps me informed about each day's schedule and care?#35 Make me feel...

#44 Make me feel. "Knowledgeable" too big a word. "Make me feel that they are experts in..."

#53 Difficult to understand-do they take the time to ask me to talk abut my feelings?

#13 How would I know-change to "ask."

#15 To whom? Me?

#19 Difficult to understand the word "sense"? How would I know? "Respond to my needs even before I ask?"

#75 Too wordy-would stop at "and specialists".

#### Participant 5

Overall themes the same How would I know what nurses want or think? Change to "ask".

#23 Difficult to understand "at ease"-would change to "comfortable."

#24 Difficult to understand? "Confident that my needs will be met?"

#27 Difficult to understand"help." Would change to "when I need them."

#30 "What is going on with me", in the hospital, in the world? Too vague. Would change to "what is happening with my care."

#33 Again -how would I know. "Make me feel reassured?" Things aren't always going to be ok.

## Appendix F

# **PPFKN Scale Version 3 After Expert Patient Feedback**

## Experienced being recognized as a unique human being

During this hospital stay:

1) My nurses asked about what is important to me while I am in the hospital.				
Strongly Disagree	Disagree	Agree	Strongly Agree	
2) My nurses made me	e feel that they cared for m	e as a patient and a p	berson.	
Strongly Disagree	Disagree	Agree	Strongly Agree	
3) My nurses asked ho	w being in the hospital aff	fected my family.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
4) My nurses asked ho	w being in the hospital im	pacted my life.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
5) My nurses cared for	me in a way that met my	needs.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
	Disagree feel that they knew me be	C		
	C	C		
<ul><li>6) My nurses made me</li><li>Strongly Disagree</li></ul>	feel that they knew me be	etter than my doctors Agree	sknew me.	
<ul><li>6) My nurses made me</li><li>Strongly Disagree</li></ul>	feel that they knew me be Disagree	etter than my doctors Agree	sknew me.	
<ul><li>6) My nurses made me</li><li>Strongly Disagree</li><li>7) My nurses made my</li><li>Strongly Disagree</li></ul>	e feel that they knew me be Disagree 7 family and visitors feel w	etter than my doctors Agree velcome. Agree	knew me. Strongly Agree	
<ul><li>6) My nurses made me</li><li>Strongly Disagree</li><li>7) My nurses made my</li><li>Strongly Disagree</li></ul>	e feel that they knew me be Disagree family and visitors feel w Disagree	etter than my doctors Agree velcome. Agree	knew me. Strongly Agree	
<ul> <li>6) My nurses made me</li> <li>Strongly Disagree</li> <li>7) My nurses made my</li> <li>Strongly Disagree</li> <li>8) My nurses treated m</li> </ul>	e feel that they knew me be Disagree family and visitors feel w Disagree he as a unique human being Disagree	etter than my doctors Agree velcome. Agree g.	sknew me. Strongly Agree Strongly Agree	

10) My nurses gave me personal attention.

Strongly Disagree	Disagree	Agree	Strongly Agree
11) My nurses treated r	ne with respect.		
Strongly Disagree	Disagree	Agree	Strongly Agree
12) My nurses asked at	pout my life outside of the	hospital.	
Strongly Disagree	Disagree	Agree	Strongly Agree
13) My nurses listened	to my concerns.		
Strongly Disagree	Disagree	Agree	Strongly Agree
14) My nurses asked m	e to talk about my experie	ence in the hospital.	
Strongly Disagree	Disagree	Agree	Strongly Agree
15) My nurses asked at	pout my goals for my hosp	oital stay.	
Strongly Disagree	Disagree	Agree	Strongly Agree
16) My nurses asked m	e what I liked to be called	l.	
Strongly Disagree	Disagree	Agree	Strongly Agree
17) My nurses knocked	l or spoke before opening	the door or the curta	in.
Strongly Disagree	Disagree	Agree	Strongly Agree
Felt safe			
1) My nurses knew abo	out me before coming into	my room.	
Strongly Disagree	Disagree	Agree	Strongly Agree
2) My nurses made me	feel comfortable.		
Strongly Disagree	Disagree	Agree	Strongly Agree
3) My nurses made me	feel confident that my nee	eds would be met.	
Strongly Disagree	Disagree	Agree	Strongly Agree

4) My nurses took care of my needs when I asked.

Strongly Disagree	Disagree	Agree	Strongly Agree	
5) My nurses made me feel confident that they talked with each other about my care.				
Strongly Disagree	Disagree	Agree	Strongly Agree	
6) I always knew the	name of the nurse who wa	s taking care of me.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
7) My nurses responde	ed quickly when I needed t	hem.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
8) My nurses made me	e feel confident that they ta	alked with my doctor	rs about my care.	
Strongly Disagree	Disagree	Agree	Strongly Agree	
9) My nurses made sur	re that I understood what w	was happening with 1	ny care.	
Strongly Disagree	Disagree	Agree	Strongly Agree	
10) My nurses made me feel that they were competent and professional.				
Strongly Disagree	Disagree	Agree	Strongly Agree	
11) My nurses make m	ne feel reassured.			
Strongly Disagree	Disagree	Agree	Strongly Agree	
12) My nurses kept me	e informed about each day	's schedule and care		
Strongly Disagree	Disagree	Agree	Strongly Agree	
13) My nurses checked	d on me frequently.			
Strongly Disagree	Disagree	Agree	Strongly Agree	
14) My nurses made m	ne feel that they knew what	t they were doing wl	nen they cared for me.	
Strongly Disagree	Disagree	Agree	Strongly Agree	

15) My nurses explained what they were doing when they cared for me.

Strongly Disagree	Disagree	Agree	Strongly Agree		
16) My nurses made me feel confident that they would take good care of me.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
17) My nurses made me feel that they took my concerns seriously.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
18) When I met nurses	for the first time, they alre	eady knew why I wa	s in the hospital.		
Strongly Disagree	Disagree	Agree	Strongly Agree		
19) My nurses made su	re that I was comfortable.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
20) My nurses respond	ed to my concerns.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
21) My nurses made me feel that they were experts in my care.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
22) My nurses introduced themselves when they came into the room.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
Experienced a meaning	gful personal connection				
1) My nurses were personable.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
2) My nurses were easy	y to talk to.				
Strongly Disagree	Disagree	Agree	Strongly Agree		

3) My nurses find things we share in common to talk about.

Strongly Disagree	Disagree	Agree	Strongly Agree		
4) I could talk with my	nurses.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
5) I had a good relatio	nship with my nurses.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
6) My nurses made me	feel that I was important	to them.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
7) When my nurses can	red for me, they made me	feel like I was their o	only patient.		
Strongly Disagree	Disagree	Agree	Strongly Agree		
8) My nurses cared about me.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
9) My nurses made me	feel that they cared about	me as a person.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
10) My nurses took the	e time to ask me about my	feelings.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
11) My nurses made m	e feel special.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
12) My nurses were kind.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
13) My nurses asked a	bout my comfort.				
Strongly Disagree	Disagree	Agree	Strongly Agree		

14) My nurses gave me individual attention.

Strongly Disagree	Disagree	Agree	Strongly Agree	
15) My nurses were fri	endly to me.			
Strongly Disagree	Disagree	Agree	Strongly Agree	
16) My nurses made m	e feel that my well-being	was important to the	m.	
Strongly Disagree	Disagree	Agree	Strongly Agree	
17) My nurses made m	e feel that they were glad	to know me.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
18) I experienced a me	aningful connection with	my nurses.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
19) My nurses respond	ed to my needs before I ev	ven ask.		
Strongly Disagree	Disagree	Agree	Strongly Agree	
Felt empowered to par	ticipate in care			
1) My nurses made me	feel that my opinions abo	out my care really ma	ttered.	
Strongly Disagree	Disagree		~ 1	
2) My nurses asked for my thoughts about my care.				
2) My nurses asked for		Agree .re.	Strongly Agree	
<ol> <li>My nurses asked for</li> <li>Strongly Disagree</li> </ol>		C	Strongly Agree	
Strongly Disagree	my thoughts about my ca	re. Agree		
Strongly Disagree	my thoughts about my ca Disagree	re. Agree		
Strongly Disagree 3) My nurses made sur Strongly Disagree	my thoughts about my ca Disagree e that I was informed about	Agree ut my care. Agree	Strongly Agree	

5) My nurses encouraged me to actively participate in my care.

Strongly Disagree	Disagree	Agree	Strongly Agree		
6) I was comfortable sharing my concerns with my nurses.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
7) My nurses made sure that I had a say in my care.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
8) My nurses spoke din	rectly to me, not over me o	or about me.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
9) My nurses told me t	hings in a way that were e	asy to understand.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
10) My nurses helped me to understand the information given to me by doctors and specialists.					
Strongly Disagree	Disagree	Agree	Strongly Agree		
11) My nurses made su	are that I had input into m	y care.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
12) I felt comfortable a	asking my nurses question	s.			
Strongly Disagree	Disagree	Agree	Strongly Agree		
13) Whenever I asked	my nurses a question, they	took the time to and	swer.		
Strongly Disagree	Disagree	Agree	Strongly Agree		
14) My nurses kept me	e informed.				
Strongly Disagree	Disagree	Agree	Strongly Agree		
15) My nurses encoura	nged me to follow my plan	of care in order for	me to leave the hospital.		
Strongly Disagree	Disagree	Agree	Strongly Agree		

16) My nurses made sure that I knew what to do when I leave the hospital.

Strongly Disagree	Disagree	Agree	Strongly Agree
17) My nurses made sur	re that I had a say in what	happened to me.	
Strongly Disagree	Disagree	Agree	Strongly Agree
8) I didn't feel rushed by my nurses.			
Strongly Disagree	Disagree	Agree	Strongly Agree
19) My nurses asked ho	My nurses made sure that I had a say in what happened to me. ongly Disagree Disagree Agree Strongly Agree I didn't feel rushed by my nurses. ongly Disagree Disagree Agree Strongly Agree My nurses asked how I felt about my care.		
Strongly Disagree	Disagree	Agree	Strongly Agree

Thank you for completing this survey. Please place it in the envelope provided, seal it and give it to your nurse. If you would like to receive results of the research, please write your name and address or e-mail address on the piece of paper provided, seal it in the smaller envelope and give it to your nurse.

#### Appendix G

#### **Content Validity by Patient Experts**

Please read the operational definition and rate each item as to its relevance. How closely does the item match or reflect what is stated in the operational definition?

**Recognized as a unique human being:** defined as the patient's experience of nurses, who through purposeful interaction, gain insight into the people, events, history and experiences that are meaningful in shaping that individual. This knowledge of the uniqueness of each person is reflected in the provision of care that is respectful of patient preferences and values.

Example:

Recognized as a unique human being

During this hospital stay:

1)My nurses asked what was important to me during my hospital stay.

1=not relevant2=unable to assess relevance without item revision3 = relevant but needs minor alteration4=very relevant and succinct.

#### Appendix H

#### **Cover Letter**

Dear Potential Participant:

My name is Jackie Somerville, RN, PhDc and I am a doctoral candidate at Boston

College William F. Connell School of Nursing. My research is focused on developing an

instrument to measure how well you think your nurses knew you during your hospital stay.

I will be testing the instrument to make sure it is a reliable and valid measure of that experience.

There are no right or wrong answers.

Your responses should honestly reflect your personal experience and how well you felt known by

your nurses. The following apply to your study participation.

- Completion of the survey is voluntary and anonymous.
- Your return of a completed survey indicates your consent for participation.
- Your name will not appear anywhere on the survey.
- Each survey will be assigned a unique number that will not identify you.
- The survey will take about ten minutes to complete.
- Taking the survey may make you feel tired. If this happens, you can have a family member help you complete the survey.
- If you choose not to complete the survey, there will be no impact on your care.
- Your responses will provide needed information for nurses to help care for patients in the future.

When you complete the survey, please seal it in the large envelope provided and place the survey

in the secure lock box as you leave the unit. I will pick up the envelopes at the end of each day.

#### After completing the survey, please take a minute to be sure that each statement has a

#### circled response.

We sincerely thank you for considering participation in this study. If you have any questions, your nurse can page me or you can email me at jsomerville@partners.org.

Jackie Somerville, RN, PhDc Doctoral Candidate Professor: Dorothy A. Jones, RN, EdD, FAAN Chair, Dissertation Committee Appendices I and J University and hospital IRB approvals



#### BOSTON COLLEGE Institutional Review Board Office for Human Research Participant Protection Waul House, 2<sup>nd</sup> Floor Phone: (617) 552-4778, fax: (617) 552-0948

Protocol IRB: 07.137.01E

TO: Jacqueline Somerville

FROM: Institutional Review Board - Office for Human Research Participant Protection

DATE: October 5, 2007

RE: Patients' Perceptions of Feeling Known by Their Nurses

#### Notice of Evaluation- [EXEMPT 45 CFR 46.101(b) (2)]

The Office for Human Research Participant Protection (OHRPP) has evaluated the project named above. According to the information provided, you intend to develop and evaluate an instrument to measure patients' perceptions of feeling known by their nurses during an acute surgical hospitalization. This is a minimal risk study.

This study has been granted an exemption from Boston College IRB review in accordance with 45 CFR 46.101 (b) (2), This designation is based on the assumption that the materials that you submitted to the OHRPP contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This exemption is given with the following conditions:

- 1. You will conduct the project according to the plans and protocol you submitted;
- No further contact with the OHRPP is necessary unless you make changes to your project or adverse events or injuries to subjects occur;
- If you propose to make any changes in the project, you must submit the changes to the OHRPP for IRB review; you will not initiate any changes until they have been reviewed and approved by the IRB;
- 4. If any adverse events or injuries to subjects occur, you will report these immediately to the OHRPP.

The University appreciates your efforts to conduct research in compliance with the federal regulations that have been established to ensure the protection of human subjects in research.

Date of Exemption: October 4, 2007

Sincerely,

CRG Sta

Christina Booth Steele, MS, CIPP IRB Designee Administrative Director, Institutional Review Board

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Partners Human Research Committee Partners Human Research Office 116 Huntington Avenue, Suite 1002 Boston, MA 02116 (617) 424-4100

## Application: Notification of IRB Approval/Activation Protocol #: 2007-P-001546/1; MGH

Date: 08/28/2007

To: Jacqueline Somerville, RN, Ph.D Nursing FND 343

Clenter O Thill for F. S. Management

From: Fred Syllien Output PHS Research Management 116 Huntington Ave Suite 1002

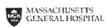
Title of Protocol: Version Date:	Patient's Perceptions of Feeling Known by Their Nurses 08/01/2007
Sponsor:	Internal Funding
IRB Review Type:	Expedited
Minimal Risk:	45 CFR46.110 and 21 CFR56.110
Expedited Category/ies:	(7) Research on individual or group characteristics or behavior, or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or QA methodologies.
IRB Approval Date:	08/20/2007
Approval Effective Date:	08/28/2007
IRB Expiration Date:	08/20/2008

This Project has been reviewed and approved by the MGH IRB, Assurance # FWA00003136. During the review of this Project, the IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

# NOTES: The following documents have been reviewed and approved by the IRB: Protocol Summary (8/1/07) and Questionnaires (1).

As Principal Investigator you are responsible for the following:

- Submission in writing of any and all changes to this project (e.g., protocol, recruitment materials, consent form, study completion, etc.) to the IRB for review and approval prior to initiation of the change(s), <u>except</u> where necessary to eliminate apparent immediate hazards to the subject(s). Changes made to eliminate apparent immediate hazards to subjects must be reported to the IRB within 24 hours.
- Submission in writing of any and all adverse event(s) that occur during the course of this project in accordance with the IRB's policy on adverse event reporting.
- 3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.
- 4. Use of only IRB approved copies of the consent form(s), questionnaire(s), letter(s), advertisement(s), etc. in your research. Do not use expired consent forms.
- Informing all physicians listed on the project of changes, adverse events, and unanticipated problems.



PARTNERS

Partners Human Research Committee Partners Human Research Office 116 Huntington Avenue, Suite 1002 Boston, MA 02116 (617) 424-4100

The IRB can and will terminate projects that are not in compliance with these requirements. Direct questions, correspondence and forms (e.g., continuing reviews, amendments, adverse events, safety reports) to Fred Syllien, (617) 424-4124.



### Staff nurse script for recruitment

We have a study being done on this unit by a nurse doctoral student at Boston College who is hoping to develop a survey that measures how patients feel known by their nurse. The survey takes about 10-15 minutes to complete. Would you be willing? The letter in this packet explains that if you choose not to participate, it will not impact your care. If you are willing, I will invite one of the study nurses to speak to you and give you more information. Appendix L

#### **Demographics sheet**

Age:

Race/Ethnic Origin: White, not Hispanic; Black, not Hispanic; Hispanic only; Asian or Pacific Islander; Filipino; American Indian/Alaskan Native; Other (specify)

Gender: Male Female

Marital Status: Single; Married/Living with Partner; Divorced; Widowed; Separated

Education: 1-23+-circle highest

Number of days in the hospital this visit\_\_\_\_\_

Were you cared for on more than one unit during this hospital stay Y N If Yes, on how many units were you cared for ?

Have you ever been cared for on this unit before this hospitalization? Yes No

If yes how many times in the past before this admission?\_\_\_\_\_

Appendix M-

# VERSION OF PPFKN Scale administered to participant

# Patients' Perceptions of Feeling Known by Their Nurses Study



Jacqueline Somerville, RN, PhDc Boston College Williams Connell School of Nursing Jsomerville@partners.org

C July 2007



Dear Potential Participant:

My name is Jackie Somerville, RN, PhDc and I am a doctoral candidate at Boston College William F. Connell School of Nursing. My research is focused on developing an instrument to measure how well you think your nurses knew you during your hospital stay.

I will be testing the instrument to make sure that it is a reliable and valid measure of that experience. There are no right or wrong answers.

Your responses should honestly reflect your personal experience and how well you felt known by your nurses. The following apply to your study participation.

- · Completion of the survey is voluntary and anonymous.
- · Your return of a completed survey indicates your consent for participation.
- · Your name will not appear anywhere on the survey.
- · Each survey will be assigned a unique number that will not identify you.
- The survey will take about ten minutes to complete.
- Taking the survey may make you feel tired. If this happens, you can have a family member help you complete the survey.
- If you choose not to complete the survey, there will be no impact on your care.
- Your responses will provide needed information for nurses to help care for patients in the future.

When you complete the survey, please seal it in the large envelope provided and place the survey in the secure lock box as you leave the unit. I will pick up the envelopes at the end of each day.

After completing the survey, please take a minute to be sure that each statement has a circled response.

We sincerely thank you for considering participation in this study. If you have any questions, your nurse can page me or you can email me at jsomerville@partners.org.

Econcline & Somund

Jackie Somerville, RN, PhDc Doctoral Candidate

Professor: Dorothy A. Jones, RN, EdD, FAAN

Professor: Dorothy A. Jönes, RN, EdD, FAAN Chair, Dissertation Committee

2				
D	irections			
Please circle the number that best ref cared for you during this hospital stay		perience w	ith those r	nurses who
Example: If you Strongly Agree with th	ne following st	atement,	circle the n	number 4
	Strongly Disagree	Disagree	Agree	Strongly Agree
During this hospital stay:				
1. I enjoyed the food.	1	2	3	4

		Strongly Disagree		Agree	Strongly Agree
	During this hospital stay:	Disagice			, igi 00
1.	My nurses asked about what is important to me while I am in the hospital.	1	2	3	4
2.	My nurses knew about me before coming into my room.	1	2	3	4
3.	My nurses were personable.	1	2	3	4
4.	My nurses made me feel that my opinions about my care really matter.	1	2	3	4
5.	My nurses made me feel that they care for me not only as a patient but also as a person.		2	3	4
6.	My nurses made me feel comfortable.	1	2	3	4
7.	My nurses were easy to talk to.	1	2	3	4
8.	My nurses asked for my thoughts about my care.	it 1	2	3	4
9.	My nurses asked how being in the hospital affected my family.	1	2	3	4
10.	My nurses made me feel confident tha my needs would be met.	t 1	2	3	4
11.	My nurses made sure that I was informed about my care.	1	2	3	4
12.	My nurses found things that we share i common to talk about.	n 1	2	3	4
13.	My nurses asked how being in the hospital impacted my life.	1	2	3	4
14.	I felt confident that my nurses talked with each other about my care.	1	2	3	4

During this hospital stay:	Strongly Disagree	Disagree	Agree	Strongly Agree
15. I could talk with my nurses.	1	2	3	4
<ol> <li>My nurses took the time to address my concerns.</li> </ol>	1	2	3	4
<ol> <li>I always knew the nurse who was takin care of me.</li> </ol>	g 1	2	3	4
18. I had a good relationship with my nurse	es. 1	2	3	4
<ol> <li>My nurses encouraged me to actively participate in my care.</li> </ol>	1	2	3	4
<ol> <li>My nurses cared for me in a way that met my needs.</li> </ol>	1	2	3	4
<ol> <li>My nurses made my family and visitors feel welcome.</li> </ol>	<b>s</b> 1	2	3	4
22. My nurses made me feel that I was important to them.	1	2	3	4
<ol> <li>I was comfortable sharing my concernative with my nurses.</li> </ol>	s 1	2	3	4
<ol> <li>My nurses made me feel that they knew me better than my doctors knew me.</li> </ol>	v 1	2	3	4
<ol> <li>I feel confident that my nurses talked with my doctors about my care.</li> </ol>	1	2	3	4
<ol> <li>When my nurses cared for me, they made me feel like I was their only patient.</li> </ol>	1	2	3	4
<ol> <li>My nurses made sure that I had a say in my care.</li> </ol>	n 1	2	3	4
<ol> <li>My nurses took care of my needs when asked.</li> </ol>	I 1	2	3	4

	Strongly Disagree	Disagree	Agree	Strongly Agree
During this hospital stay:				
29. My nurses responded quickly when I needed them.	1	2	3	4
<ol> <li>My nurses spoke directly to me, not over me or about me.</li> </ol>	1	2	3	4
<ol> <li>My nurses made sure that I understoo what was happening with my care.</li> </ol>	od 1	2	3	4
<ol> <li>My nurses made me feel that they cared about me as a person.</li> </ol>	1	2	3	4
<ol> <li>My nurses told me things in a way that was easy to understand.</li> </ol>	at 1	2	3	4
<ol> <li>My nurses treated me as a unique human being.</li> </ol>	1	2	3	4
<ol> <li>My nurses made me feel that they we competent and professional.</li> </ol>	ere 1	2	3	4
<ol> <li>My nurses took the time to ask me about my feelings.</li> </ol>	1	2	3	4
37. My nurses were attentive to my needs	s. 1	2	3	4
38. My nurses gave me personal attention	n. 1	2	3	4
39. My nurses made me feel reassured.	1	2	3	4
<ol> <li>My nurses made sure that I had input into my care.</li> </ol>	1	2	3	4
41 My nurses asked about my life outside the hospital.	e 1	2	3	4
<ol> <li>My nurses helped me understand the information given to me by doctors an specialists.</li> </ol>		2	3	4

	During this hospital stay:	Strongly Disagree	Disagree	Agree	Strongly Agree
43. N	My nurses listened to my concerns.	. 1	2	3	4
	My nurses asked me to talk about r xperience in the hospital.	ny 1	2	3	4
45. N	My nurses made me feel special.	1	2	3	4
	My nurses kept me informed about ach day's schedule and care.	1	2	3	4
47. N	My nurses were kind.	1	2	3	4
48. N	My nurses checked on me frequent	ly. 1	2	3	4
49. <b>N</b>	My nurses asked about my comfort	. 1	2	3	4
	My nurses asked about my goals for my hospital stay.	or 1	2	3	4
	My nurses asked me what name I li o be called.	ke 1	2	3	4
k	My nurses made me feel that they new what they were doing when th ared for me.	1 ley	2	3	4
	My nurses knocked or spoke before pening the door or curtain.	e 1	2	3	4
	My nurses explained what they wer oing when they cared for me.	re 1	2	3	4
55. N	My nurses treated me with respect.	1	2	3	4
56. N	ly nurses were friendly to me.	1	2	3	4
	ly nurses gave me individual ttention.	1	2	3	4
	felt comfortable asking my nurses uestions.	1	2	3	4

	During this hospital stay:	Strongly Disagree	Disagree	Agree	Strongly Agree
		1	2	2	4
59.	My nurses kept me informed.	I	2	3	4
	I felt comfortable that my nurses wou take good care of me.	ıld 1	2	3	4
	Whenever I asked my nurses a quest they took the time to answer.	stion, 1	2	3	4
	My nurses encouraged me to follow plan of care in order for me to leave hospital.		2	3	4
	My nurses made me feel that they to my concerns seriously.	ok 1	2	3	4
	l experienced a meaningful connecti with my nurses.	on 1	2	3	4
	My nurses made sure that I had a sa what happened to me.	yin 1	2	3	4
	When I met nurses for the first time, already knew why I was in the hospit		2	3	4
	My nurses made me feel that my well being was important to them.	II 1	2	3	4
	My nurses made sure that I was comfortable.	1	2	3	4
	My nurses responded to my needs e before I asked.	ven 1	2	3	4
	My nurses made me feel that they we glad to know me.	ere 1	2	3	4
	My nurses made sure that I knew wh do when I leave the hospital.	at to 1	2	3	4
72.	I did not feel rushed by my nurses.	1	2	3	4

		Strongly Disagree	Disagree	Agree	Strongly Agree
	During this hospital stay:				
73.	My nurses asked how I felt about n care.	ny 1	2	3	4
74.	My nurses introduced themselves when they came into my room.	1	2	3	4
75.	My nurses responded to my concerns.	1	2	3	4
76.	My nurses made me feel that they were experts in my care.	1	2	3	4
77.	My nurses cared about me.	1	2	3	4
	Demo	graphics			
Dir	ections: Please respond to each iter	n below.			
1.	Age:				
2.	Race/ Ethnic origin:				
	O White, not Hispanic		n or Pacific	Islander	
	<ul><li>O Black, not Hispanic</li><li>O Hispanic only</li></ul>	⊖ Filipi ⊖ Ame	no erican Indiar	n/Alaskan	Native
		<ul> <li>Other</li> </ul>	er(Spe	cifu)	
3.	Gender :		(She	(iny)	
	O Female	O Male	•		
4.	Marital Status:				
	<ul> <li>Single</li> <li>Divorced</li> <li>Widowed</li> </ul>	⊖ Marri ⊖ Sepa	ed/ Living w rated	vith Partne	er

5. Education: Circle the Highest year of school completed:
1 2 3 4 5 6 5 6 7 8 9 10 11 12 13 14 15 16 17 18 (Primary) (High School) (Post High School)
19 20 21 22 23 + (Graduate School) (Doctoral)
6. Number of days you have been in the hospital on this visit days.
7. Were you cared for on more than one unit during this hospital stay? O Yes O No If Yes, on how many units were you cared for?
8. Have you ever been cared for on this unit before this hospital stay? O Yes O No If Yes, how many times before this admission?
Please go back to see that you have answered each item, then place your completed survey in the envelope provided and drop it in the lock box on the unit. If you would like to receive a brief report of the study findings, please write your name and address or your email address on the "findings" form provided, place it in the smaller envelope and drop it in the lock box. Thank you very much for participating in this survey. jsomerville@partners.org