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Measurement of Parents of High-Risk Newborns: Beliefs, Attitudes, and Intentions

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**MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS**

by

MARGARET M. KURTZ

**A Thesis Submitted to the Faculty of the Graduate School
of Loyola University of Chicago in Partial Fulfillment
of the Requirements for the Degree of
Master of Science in Nursing**

December

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VITA

The author, Margaret Mary Kurtz, is the daughter of John Douglas Kurtz (deceased) and Annette (Carnivele) Kurtz. She was born March 28, 1961, in Chicago, Illinois.

Her elementary education was obtained at St. Vincent Ferrer grammar school in River Forest, Illinois. Her secondary education was completed in 1979 at Trinity High School, River Forest, Illinois.

In August, 1979, Ms. Kurtz entered Loyola University of Chicago. During her sophomore year, she spent one semester studying at the Loyola University Rome Center. In May, 1983, she received her Bachelor of Science in Nursing. Since graduation, she has worked full-time as a nurse in the neonatal intensive care unit at Loyola University of Chicago's Foster G. McGaw hospital in Maywood, Illinois. She began her part-time graduate work at Loyola University of Chicago, in 1985.

Ms. Kurtz has presented the results of this study at four research conferences. She is a member of the National Association of Neonatal Nurses, the Nurses Association of the American College of Obstetricians and Gynecologists, and the Midwest Nursing Research Society.

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CHAPTER I

INTRODUCTION

The birth of a high-risk newborn and subsequent admission of the infant to a neonatal intensive care unit (NICU) has an impact on the mother and father of the child. In anticipation of the delivery of the child, parents form certain expectations about the birth of their newborn infant. When the infant is sick and/or premature at birth, the parents are faced with the crisis of accepting a "different-than-expected" infant (Elsas, 1981). The parental response to the birth is not only influenced by the event of the infant's admission, but also by the parental beliefs, attitudes, previous experiences, and expectations about the infant's outcome. Identification of these antecedents of behavior may assist in providing appropriate interventions for these parents in crisis. Currently, intervention is based more on concern for parents, rather than on an empirical knowledge of the precursors of parental reaction.

The purpose of this study was to develop an instrument to measure parental beliefs, attitudes, and intentions. Evolution of a reliable and valid instrument may assist in describing the relationship between the phenomena associated with parental reaction to birth of a high-risk newborn. An understanding of the antecedents of parental behavior is needed to provide a basis for identifying families at risk and devising intervention programs that enhance family function and the developmental outcomes for these infants.

Problem Statement

Can a reliable and valid tool be developed to measure the beliefs, attitudes, and intentions of parents who have experienced the birth of a high-risk newborn?

Theoretical Framework

The Fishbein Theory of Reasoned Action (Fishbein & Ajzen, 1980) was used as the theoretical

framework for studying the antecedents of parental behavior. This cognitive processing model is presented below in Figure 1.

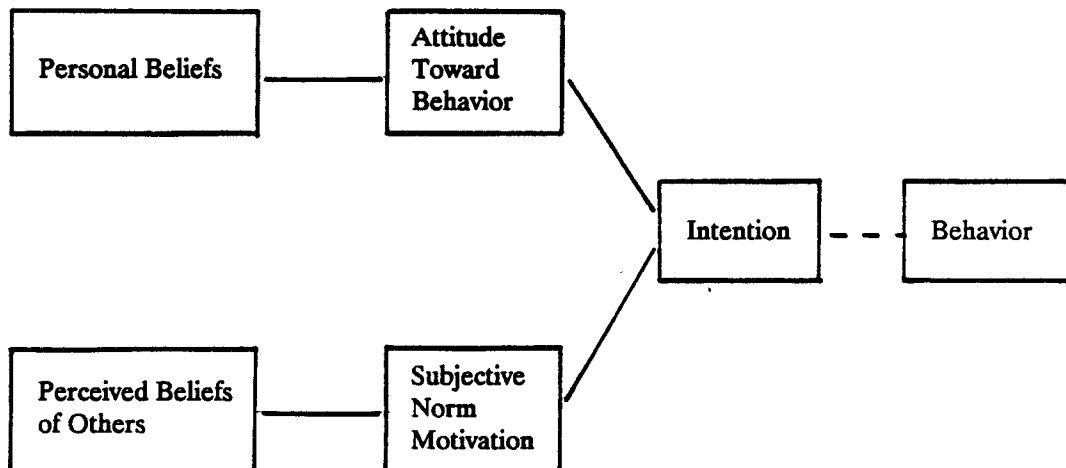


Figure 1. Theory of Reasoned Action (Fishbein & Ajzen, 1980).

The applicability of this cognitive processing model to a crisis situation, such as the birth of a high-risk neonate, has not been tested.

The model postulates that the immediate antecedent of overt behavior is the intention to perform the behavior in question. This intention can be altered by situational factors. The behavioral intention is a function of attitudes toward performing the behavior and of beliefs about what others expect to be done in the situation (Ajzen & Fishbein, 1974). The relative importance of the normative belief and the attitude toward the act is expected to vary with the kind of behavioral intention that is being predicted, with the conditions under which the behavior is to be performed, and with the individual who is to perform the behavior (Ajzen & Fishbein, 1972).

In 1963, Fishbein proposed the theory of relationships between beliefs about an object and attitudes toward that object. Other theorists (Atkinson, 1957; Rotter, 1954) had arrived at similar models to account for overt behavior.

According to one component of Fishbein's theory, the Expectancy-Value Model, attitudes are defined as the evaluative dimensions of a concept (e.g., is the concept "good" or "bad"?). The

evaluative dimension is described as "mediating evaluative responses". Beliefs are defined as the probability dimension of a concept (e.g., is the concept "probable" or "improbable"?).

Fishbein's Expectancy-Value Model may be stated as follows: (a) an individual holds many beliefs about a given object; (b) associated with each belief is an implicit evaluative response (e.g., good-bad); (c) associated with each of the attitudes is the subjective probability (e.g., 0-100%) that the attitude is associated with the object (Austin, 1981); (d) through conditioning, the evaluative responses are associated with the object; (e) the evaluative responses summate; and (f) on future occasions, the attitude object will elicit the summated evaluative response.

Beliefs are related to an individual's attitude, because beliefs about objects contain an evaluative aspect. According to the expectancy-value theorists, people learn "expectations" because "events" are perceived as either positive or negative. People learn to perform behavior they believe will result in positive outcomes (Ostrom, 1969).

Expectancy-value models are useful for determining attitudes toward situations. An information processing approach is viewed as underlying the formation of attitudes. The model can be applied to the study of parents' attitudes toward their infant's admission to the NICU. The model is expressed as follows:

$$A_e = \sum b_1 \times e_1 \quad NB = \sum b_2 \times e_2$$

In the first equation, A_e is the parent's attitude toward the event of the NICU admission, b_1 is the strength of belief about the event of the NICU admission (0-100%), and e_1 is the evaluation of the event of the NICU admission (good/+3 or bad/-3). In the second equation, NB is the parent's normative belief toward the event of the NICU admission, b_2 is the parent's perceptions of the strength of what others believe about the NICU admission, and e_2 is the parent's perception of others evaluation of the event of the NICU admission. The sigma (\sum) indicates that each separate belief multiplied by evaluation rating is summed together to produce an overall rating of the individual's attitude or normative belief.

One way of identifying parental attitudes toward the admission of an infant to the NICU is to

ask them to describe their thoughts and feelings toward the event. In Phase I of this study, parents were asked to state what they thought and felt about the admission of their infant to the NICU.

Figure 2 illustrates the use of the model.

My infant's admission to the NICU . . .	Belief strength (0%-100%)		Evaluation (-3 to +3)		$b_1 \times e_1$	$b_2 \times e_2$
	b_1	b_2	e_1	e_2		
caused me to be frightened	100%	80%	-2	-2	-2.0	-1.6
relieved me	80%	80%	-3	-3	-2.4	-2.4
made me aware I needed information	100%	10%	+3	+3	+3.0	+0.3
TOTAL ATTITUDE SCORE					-1.4	-3.7

(b_1 = belief strength of parent; b_2 = belief strength of significant other)

(e_1 = evaluation of parent; e_2 = evaluation of significant other)

Figure 2. Example of Attitude Measurement of a Sample Parent.

Assume that a parent stated "the admission of my infant to the NICU . . . caused me to be frightened; or relieved me; or made me aware I needed information". The parent was then asked to rate the beliefs on a seven point good-bad scale. For the example in Figure 2, the parent is asked, "how would you rate being frightened on a scale from +3 to -3, where -3 is very negative and +3 is very positive?" To measure the strength of the parent's belief, the parent is asked, "how sure are you from 0% (not sure at all) to 100% (very sure) that the admission of your infant to the NICU frightened you?" The parent's response is recorded in a decimal format (e.g., 80% = .80) to calculate

the strength of the parent's attitude. The parent's perceptions about the beliefs of significant others are evolved in the same manner.

The attitude and normative beliefs of parents toward the admission of their infant to the NICU is then computed by multiplying the evaluation of each belief by the strength of the belief, and then summing all the products together for a total set of responses. Products for self (attitudinal) and significant others (normative belief) components are determined independently.

Actual parental beliefs are the optimal source of statements about their attitudes and normative beliefs. However, there are a vast range of beliefs held by parents. In order to resolve this problem, qualitative methods must be used to generate event specific representative beliefs. These beliefs can then be used to construct an instrument to measure parental attitudes and normative beliefs.

Summary

Based on the Fishbein Theory of Reasoned Action (Fishbein & Ajzen, 1980), it is proposed that beliefs, attitudes, and intentions influence responses of parents to the birth of a high-risk newborn. These antecedents of behavior may be measured through the development of a reliable and valid tool. Such a tool may determine the applicability of Fishbein's theory as a means to explain phenomena associated with parental reaction to the birth of a high-risk newborn.

CHAPTER II

REVIEW OF RELATED LITERATURE

The focus of the literature review was to find other research regarding the antecedents of parental behavior in the NICU. Of specific interest were any investigations conducted on beliefs, attitudes, and intentions as precursors of behavior.

No studies have investigated the relationship between either parental beliefs or intentions, and the parental reaction to the admission of their high-risk newborn to an NICU. Tools to measure these variables have not been reported in the literature.

Studies have been conducted which focus upon the relationship between health beliefs and behavior. The health belief model has been applied to preventative health behavior (Rosenstock, 1974), and to sick role behavior (Becker, 1974). In one study, it was concluded that health beliefs interact with situational demands and constraints in relation to actions taken in the face of health threats (Kirscht, Becker & Eveland, 1976).

According to Allport, attitudes are difficult to measure, but are extremely important in the formation of intentions and subsequent actions (Miller, Wikoff, McMahon, Garret & Johnson, 1982). The Fishbein Expectancy-Value Model of Attitude was used to assess parental attitudes of pediatric patients (Austin, McBride & Davis, 1984; Tse, Perez-Woods & Opie, 1987). This established psychosocial model suggests that attitudes toward any object, (e.g., person, issue, concept, behavior, disorder) are a function of salient beliefs about the object and the implicit evaluative responses associated with those beliefs (Austin, McBride & Davis, 1984; Tse, Perez-Woods & Opie 1987).

Austin, McBride and Davis (1984) assessed the parental attitudes and adjustment to epilepsy over a four-month period on a convenience sample of 50 parents whose children were treated for epilepsy, as outpatients in a large children's hospital. The Fishbein Expectancy-Value Model of Attitude was

used to study parental attitudes. This research supports the model's usefulness in studying attitude. An open-ended format tool was used to identify salient beliefs and provided the content for the fixed-belief format tool. Structured interviews were conducted to obtain demographic information, seizure data, and two attitude scores.

Parental adjustment was measured by both a self-report instrument and an independent psychosocial assessment, made by a psychiatric social worker during a semistructured interview. A multiple regression with the two attitude scores as independent variables and the self-report parental adjustment score as the dependent variable was computed to determine the nature of the attitude-adjustment relationship. The major finding of the study was a positive attitude-adjustment relationship, which was much stronger for the mothers ($R^2 = .67, p < .001$) than for the fathers ($R^2 = .31, p = .49$) in the study.

Tse, Perez-Woods and Opie (1987) conducted a study of 50 parents selected from two pediatric intensive care units associated with tertiary care centers. The study focused on parental attitudes and beliefs toward the admission of their child to the intensive care unit. The Fishbein Expectancy-Value Model was used and data were collected through structured interviews. In order to assess salient beliefs, the parents were asked to state in their own words what they associated with, or believed to be true about the child's intensive care unit admission.

A tool was constructed during a preliminary phase of the study, based on the qualitative data. A content analysis of the data from the preliminary phase of the study assured the inclusion of salient beliefs into the fixed-belief format tool. Following pilot testing, this tool was used to collect the quantitative data. Parents were asked to indicate the strength of their beliefs (0% to 100%), and to evaluate each of the beliefs he/she stated on a seven-point, good-bad scale (-3 to +3). The attitude score for each parent was determined by summing the products of the strengths multiplied by the evaluations.

Statistically significant differences in parental attitudes were found, when t-tests were used. Parents that had previous knowledge of similar situations had higher positive attitudes than parents

with no previous knowledge ($t = 2.25$, $p = .030$). Using a one-tailed paired t-test, the fathers' attitudes were found to be more positive than the mothers' ($t = 4.20$, $p = .050$). While the fathers' attitudes ($x = -5.30$) were found to be more positive than the mothers' ($x = -8.20$), the mean attitude scores of both parents were unfavorable.

In the aforementioned studies, Fishbein's model has been used with parents of a pediatric population. In Austin, McBride and Davis' study (1984), the parents were dealing with their child's chronic illness. Acute illness was dealt with by Tse, Perez-Woods and Opie (1987), yet the parental data were collected after the discharge of the child from the intensive care unit. To date, there have been no attempts to investigate the parents of neonates soon after their admission to the NICU.

Problems of parents in the NICU have been documented. Recent literature focuses on the importance of supporting parents in the NICU (Green, 1979; Nugent & Goldsmith, 1979; Sherman, 1982; Thorton, Berry & Dal Santo, 1984). Parental grief and anxiety are recognized as symptoms of emotional stress that must be recognized (Yu, Jamieson & Astbury, 1981).

Concern for traumatized parents has stimulated intervention programs (Beaton, 1984; Crnic, Greenberg, Robinson & Ragozin, 1984; Nurcombe, Howell, Rauh, Teti, Ruoff & Brennan, 1984; Zeanah, Canger & Jones, 1984). Approaches used with parents in the NICU include crisis intervention, psychotherapy, and parental support groups.

Follow-up studies have been done to evaluate NICU graduates. These studies occurred because of concern about the development of these children and the potential effects of the hospitalization during this critical period, on the parent-child relationship (Minde, Whitelaw, Brown & Fitzhardinge, 1983; Philipp, 1983; Trause & Kramer, 1983).

Systematic investigation of parental behavior being recognized and intervened upon has yet to occur. The studies by Austin, McBride and Davis (1984) and by Tse, Perez-Woods & Opie (1987) provided a basis for the development of this research. An understanding of parental beliefs, attitudes, and intentions may facilitate a more appropriate intervention process for the parents of infants in the NICU.

CHAPTER III

METHOD

Design

This study was a replication of an investigation by Tse, Perez-Woods and Opie (1987) in a pediatric intensive care unit, with a new population. The goal of this study was to develop a reliable instrument to measure the antecedents of parental behavior, following the birth of an infant requiring admission to an NICU. A period of several months was required to obtain a sample of adequate size for achievement of this goal. The study was conducted in two phases.

Variables

The following variables were investigated in this study. Conceptual definitions are compatible with information in Webster's (1970) or as specified in the section on Theoretical Framework in Chapter I. Operational definitions are as follows.

Beliefs. Beliefs were measured in Phase I of the study by the salient beliefs ascertained from the parents during the semistructured interview. During Phase II, beliefs were the responses of the parents on the study instruments.

Attitudes. Attitudes were measured in Phase I of the study by the salient statements ascertained from the parents during the semistructured interview. During Phase II, attitudes were the sum of the parent's beliefs multiplied by belief strengths.

Intentions. Intentions were measured in Phase I of the study by the salient statements reflecting attitudes ascertained from the parents during the semistructured interview. During Phase II, intentions were the responses of the parents on the study instruments. Beliefs, attitudes, and intentions are proposed to evolve through a cognitive process over time.

Methodological Limitations

Generalizability is limited by the demographics of the study sample. Replication in other populations will be necessary.

Consent

Approval of the Loyola University Institutional Review Board was obtained. A letter explaining the study was given to parents who were potential subjects. Voluntary participation of subjects occurred following informed consent. Written consent was obtained from parents after a discussion of the purpose and relevant details of the study. The risks involved included stimulation of feelings, (e.g., pain, guilt, anxiety, etc.) that may not have been recognized by the parent at the time of the study. However, these feelings are normal in this population, and the investigator is an experienced NICU nurse who is employed on the unit from which participants were selected. In fact, parents were positive about an opportunity to express their feelings.

The benefit to subjects was negligible. The benefit to society is the development of a tool for future research. An understanding of the antecedents of parental reactions to the birth of a high-risk newborn may provide a basis for the development of more appropriate intervention programs and reduce parental stress. The risk benefit ratio is favorable.

Parents were advised that they could choose not to participate without altering the quality of care they received on the unit. They were advised they could choose to withdraw consent and refuse involvement with the study at anytime, without altering the high quality of medical or nursing care they received. No names were required on study documents, assuring anonymity. Reports of the findings are in the form of grouped data, assuring confidentiality. The Loyola University Institutional Review Board approval and a copy of the consent forms can be found in Appendix A.

Summary

This replication study involved the use of both qualitative and quantitative methods. Further description of the procedures for Phase I and Phase II will be provided in subsequent chapters.

CHAPTER IV

PHASE I

Sample

The subjects for phase I of the study were parents of newborns requiring admission to the level III NICU at a large midwestern medical center. Only parents of singleton births of ill and/or premature infants (born prior to the 37th week of gestation), which occurred in-house, were included in the sample. Each parent (mother or father) was considered as an individual subject.

Procedure

The first phase consisted of semistructured interviews with parents to obtain salient statements of belief. During this phase, a tool was also constructed. Qualitative methods were used to generate the salient beliefs of parents and to develop the tool.

The semistructured, audiotaped interview occurred 24-36 hours following the infant's admission. All interviews were conducted by the investigator within the NICU, either at the infant's bedside or in the staff lounge. A trial interview was conducted and transcribed, for the purpose of debriefing the investigator. A debriefing meeting with the thesis committee chairperson resulted in the development of an interview guide, which facilitated verbalization of the parent and consistency in responses. The discussion during the informal interview revolved around a request for the parent to describe what he/she associated with or believed to be true about the admission of his/her infant to the NICU.

Each interview was transcribed and a qualitative analysis was performed by three coders to produce a list of statements reflecting parental beliefs. The coders were the three thesis committee members, all whom are doctorally prepared. Data collection through interviewing continued until new categories of salient beliefs ceased to emerge during the qualitative analysis. The interview guide

and the transcribed interviews can be found in Appendix B.

Results

Qualitative Analysis. Emerging categories of salient beliefs were identified by the coders, as observed by the investigator. Qualitative analysis by the coders occurred during meetings of, and verbal and written communication between, the thesis committee members and the investigator. In preparation for the first content analysis meeting, each committee member reviewed the transcription of parental responses from the first interview and listed the concepts which they identified present in each response.

Copies of the transcription of the second interview were provided during the meeting, and the coders analyzed and categorized this content. Categorizing the concepts with consistency among the coders ensured reliability. Once all three coders and the investigator were comfortable with this process, copies of the other transcribed interviews were distributed, for analysis of this data. The categorization of initial interviews is provided in Table 1 on the following page.

Table 1 -- Categorization of Concepts from Initial Interviews

CATEGORY:	CONCEPTS:	CATEGORY:	CONCEPTS:
<u>Affective Responses</u>	Blame. Comfort. Confidence in others. Confusion. Doubt. Gratefulness. Grief. Hope. Relief. Trauma (psychological) / Concern.	<u>Cognitive Responses</u>	Compartmentalizing time, as a coping mechanism. Education and understanding, regarding survival, risks, etc. Taking responsibility for self-competence.
<u>Environmental Characteristics (professional / nonprofessional)</u>	Affirmation / Support. Competence of people and place. Education provided. Honesty. Reassurance.	<u>Expectations</u>	Chance / Probability. The Unknown. Time. Trajectory (including critical points and hurdles).
<u>Infant Characteristics</u>	Age of infant. Normalcy. Size of infant.	<u>Self-environment</u>	Previous experience with an NICU.
<u>Spiritual Response</u>	Faith.		

Analysis of subsequent transcribed interviews resulted in the addition of new categories and concepts. The recategorization of concepts is displayed in Table 2 on the following page.

Table 2 -- Recategorization of Concepts

CATEGORY:	CONCEPTS:	CATEGORY:	CONCEPTS:
<u>Affective Responses</u>	Amazement. Burden. Confusion. Effort. Gratefulness / Gratitude. Patience. Satisfaction.	<u>Doubt</u>	Chance / Probability. Direction of course. Fate. Lack of experience. Skepticism. The Unknown.
<u>Grief</u>	Blame. Education provided. Education and understanding. Enthusiasm. Future experience. Happiness. Lack of experience. Previous experience. Relief. Resignation. Sadness. Self-pity. Shock. Surprise. Taking responsibility for self-competence. Guilt.	<u>Support</u>	Affirmation. Comfort. Commonness of problem. Competence of people and place. Confidence in outcome. Discomfort. Faith. Honesty of people. Hope (optimism). Mutual Support. Reassurance. Shared experience.
<u>Adaptation / Getting By</u>	Comparison. Compartmentalizing time. Coping. Time. Trajectory.	<u>Health / Parameters of Normal- Abnormal</u>	Abilities. Age of infant. Appearance. Breathing. Health-Illness. Size of infant. Weight.
<u>Threat / Fear</u>	Environmental threat. Fright. Progress. Trauma (psychological). Concern. Reality. Worried.	<u>Preparedness</u>	First child. Unprepared.

Qualitative analysis of further transcribed interviews revealed few new concepts. Data collection through interviewing was considered complete after eight interviews, since new categories no longer emerged during the qualitative analysis. The next recategorization resulted in five major groups of concepts, as depicted below in Table 3.

Table 3 -- Second Recategorization

CATEGORY:	CONCEPTS:	CATEGORY	CONCEPTS:
<u>Parental Supports--self, spouse, staff to help with stress</u>	Affirmation. Comfort. Commonness of problem. Competence of people and place. Confidence in outcome. Faith. Education provided. Honesty of people. Hope (optimism). Mutual support. Previous education. Previous experience. Reassurance. Self-competence. Shared experience.	<u>Parental Affective Responses to Infant's Hospitalization</u>	Amazement. Blame. Burden. Claiming. Concern. Confusion. Discomfort. Enthusiasm. Effort / Exhausted. Gratefulness / Gratitude for competence of staff and facility. Grief. Guilt. Happiness. Patience. Petrified. Reality. Relief. Resignation. Responsibility. Sadness. Satisfaction. Self-pity. Shock. Surprise. Threat. Trauma. Understanding.

Table 3 -- Second Recategorization (cont'd.)

CATEGORY:	CONCEPTS:	CATEGORY:	CONCEPTS:
<u>Infant Characteristics / Parameters of Normal-Abnormal</u>	Abilities. Age of infant. Appearance. Breathing. Diagnosis. Health / Illness. Size of infant. Weight.	<u>Infant Outcome</u>	Chance / Probability. Direction of course. Doubt. Fate. Fear. Lack of expectations.
<u>Parental Coping Strategies</u>	Adaptation. Comparison. Compartmentalizing time. Coping. Effort. Need for education. Need for support. Prepared / Unprepared. Time. Trajectory (developmental stages).		Progress. Skepticism. The Unknown. Worried.

The five broad groups of concepts which evolved from this recategorization were: (a) perceived supports, (b) affective responses, (c) experience of the infant, (d) coping strategies, and (e) perceived outcome for the infant. These categories which emerged reflect the parents reaction to the event of the infant's admission to the NICU. The following examples from the transcribed interviews exemplify the categories that evolved.

Perceived supports: "people here know exactly what they're doing at all times; they don't pull any punches; they don't overly reassure you"; "well, you pray for the best and you hope for a great outcome"; "I happened to talk to a friend the other day who had a little boy who happened to be 3

months premature--and he said, it's a roller coaster of emotions, and that the wife better be a little bit hard or a little bit dulled to her emotions, kind of low-keyed".

Affective responses: "it's just amazing"; "so, how else can you feel--but, to be accepting of it, really; and, be thankful that at least there's a place like this"; " I was just worried--was the baby going to be big enough to have a fighting chance--that was my only fear; and, I cried a little bit; but basically, once I got here, I felt pretty at ease".

Experience of the infant: "I just know she looks pretty good"; "actually, I'm farther ahead than I thought I would be, or she would really--she's six weeks older than the doctor had thought--the doctor thought she was 24 weeks"; "the fact that he's breathing on his own and stuff is amazing to me"; "he's an albino, which is rare, but that's great"; "I think that when you know you're in a good percentile for survival and that girls have a better tendency for survival and that her weight was pretty good--that was comforting".

Coping strategies: "I just take 1 hour at a time, and just hope for the best"; "I look around here and I see smaller babies; it may not be very nice to say, but it makes you feel good in a way, to know that you've got a little more going for you than somebody else does--but, it's at somebody else's misfortune"; "I basically haven't had time, but I would like to try and at least find some people who have been through this--to see what happened to them and you know, just to get a general picture--everything is new for us, this being our first child and not knowing anybody who has experienced it".

Perceived outcome for the infant: "I know she's going to make it, I'm pretty sure of that"; "at first I was kind of skeptical, because to me I just thought it was just prolonging the chances you know, and that would come--but then after awhile, you say you know, you never know what happens unless you try to save the baby"; "I just feel so confident--I think sometimes, maybe I'm overconfident; that might be bad too--feeling too secure".

Twenty-six belief statements were generated from these categories. The list of statements are presented in Table 4 on the following page.

Table 4 -- List of Belief Statements

1. amazed me
 2. caused me to blame others for my baby's problem
 3. caused me to be burdened
 4. made me concerned
 5. made me confused
 6. made me uncomfortable
 7. exhausted me
 8. made me grateful the staff were competent
 9. made me grateful my baby was at Loyola
 10. caused me to be sad
 11. caused me to be impatient
 12. relieved me
 13. made me satisfied
 14. caused me to pity myself
 15. shocked me
 16. made me feel threatened
 17. traumatized me
 18. made me feel guilty
 19. caused me to petrified
 20. made me feel responsible
 21. made me feel I needed to learn things
 22. made me want someone to lean on
 23. caused me to feel unprepared
 24. made me confident
 25. made me hopeful
 26. made me feel incompetent
-

Three alterations in the list of belief statements were made so that there were about equal numbers of positive and negative statements. Therefore, "made me uncomfortable" was changed to "made me comfortable"; "caused me to be sad" was changed to "caused me to be happy"; and "made me feel incompetent" was changed to "made me feel competent". With these alterations, the final list was composed of eleven positive and fifteen negative statements. The list of belief statements was read by three parents in the NICU to insure understandability, prior to development of the tool.

Tool Construction. A tool was constructed based on the twenty-six beliefs generated during the qualitative phase.

The tool was composed of a number of Likert and semantic differential scales. Items to measure selected demographic variables were generated from a review of the literature, for the purpose of describing the sample population.

The first three scales were based on the twenty-six salient beliefs of parents. The first scale was a twenty-six item belief scale. For each item, the respondent was asked to evaluate the belief as if it were true for them on a seven-point (+3 to -3) good-bad scale. The second scale was a twenty-six item belief strength scale. For each item, the respondent was asked to rate the belief in terms of how true it was for them on a 0 to 100% scale. The third scale was a twenty-six item subjective norm scale. For each item, the respondent was asked to rate the belief in terms of how most significant others expect them to feel on a seven point (+3 to -3) probable to improbable scale.

A semantic differential scale, a known method of measuring attitudes, was incorporated to test for construct validity. Expectations of outcome were measured on a two-item scale, and previous experience was measured on a three-item scale. The formulated tool can be found in Appendix C.

Summary

Qualitative methods were used in Phase I. The qualitative analysis of transcribed interviews generated a list of salient belief statements of parents experiencing the birth of a high-risk newborn. The salient belief statements provided the basis for tool development, for use in measuring parents with infants requiring admission to the NICU.

CHAPTER V

PHASE II

Sample

The subjects for phase II of the study were a convenience sample of 30 parents of newborns requiring admission to the level III NICU at a large midwestern medical center. Only parents of singleton births of ill and/or premature infants (born prior to the 37th week of gestation), which occurred in-house, were included in the sample.

Procedure

The second phase consisted of pilot testing the tool generated during phase I on this convenience sample of 30 parents. A test-retest design was used to determine if parents attitudes were stable over time.

Each parent completed the tool 24-36 hours following the infant's admission to the NICU. The tool was completed in various settings, dependent on the preference and convenience of the respondent. Parents of infants that survived were asked to complete the tool for a second time, in two weeks or when the infant was discharged, whichever occurred first. The investigator was available, in person or by telephone, to assist parents with completion of the tool. It was verbally explained to the parents that they were to answer the queries of the tool in regard to their own situation.

Results

The question to be answered by this study was: Can a reliable and valid tool be developed to measure the beliefs, attitudes, and intentions of parents who have experienced the birth of a high-risk infant? Data collection occurred between January 21 and April 23, 1987.

Demographics. A total of 30 parents participated, including 13 parents who completed the tool

at both data collection intervals. The 17 parents who did not complete the tool at the second data collection point either declined participation, or had an infant that expired or was transferred out of the NICU.

The results of the analysis of demographic characteristics are displayed below in Table 5.

Table 5 -- Demographic Characteristics

VARIABLE	NUMBERS (PERCENTAGES)	VARIABLE	NUMBERS (PERCENTAGES)
<u>Parents</u>	17(56.7%) mothers 13(43.3%) fathers	<u>Marital status</u>	26(86.7%) married 4(13.3%) single
<u>Age of parents</u>	16 to 43 years; mean of 30.7 yrs	<u>Gestational Age of infants</u>	22 to 40 weeks; mean of 31.75 wks
<u>Race</u>	25(83.3%) caucasian 2(6.7%) asian 2(6.7%) black 1(3.3%) hispanic	<u>Religion</u>	18(60%) Catholic 6(20%) Protestant 5(16.7%) other/ none 1(3.3%) Jewish
<u>Insurance coverage</u>	28(93.3%) yes 1(3.3%) no 1(3.3%) no answer	<u>Time of data collection (number of hours after delivery)</u>	24 to 36 hours; mean of 32.15 hrs
<u>Education</u>	12(40%) attended college 7(23.3%) graduate education 7(23.3%) completed high school 2(6.7%) less than	<u>Employment</u>	19(63.3%) work full-time (> 35hours/wk) 4(13.3%) home- makers 4(13.3%) not employed 3(10%) work part-time (< 35hours/wk)

Table 5 -- Demographic Characteristics (cont'd)

VARIABLE	NUMBERS (PERCENTAGES)	VARIABLE	NUMBER (PERCENTAGES)
<u>Income</u>	7(23.3%) > \$50,000	<u>Number of</u>	18(60%) 1 child
	6(20%) \$40-49,000	<u>children in</u>	7(23.3%) 2 children
	6(20%) no answer	<u>family</u>	3(10%) 3 children
	4(13.3%) \$30-	<u>(including</u>	1(3.3%) 4 children
	\$39,000	<u>infant in</u>	1(3.3%) 5 children
	4(13.3%) \$15-	<u>NICU)</u>	
	\$19,000		
	3(10%) < \$10,000		

Reliability and Validity. Cronbach's alpha was used to evaluate internal consistency reliability.

The reliability of the attitude measure was .83 at time one and .61 at time two. A repeated measures analysis of variance revealed a significant difference in the stability of this measure over time at the $p = < .05$ level. A graphic representation of the attitude scores is presented below in Figure 3.

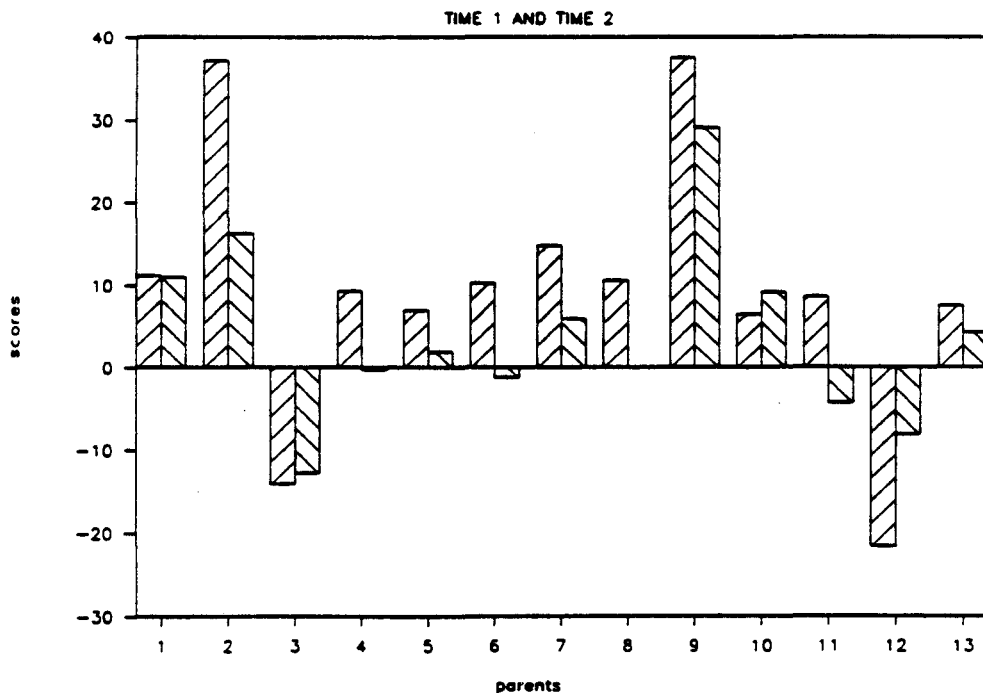


Figure 3. Comparison of Parent Attitude Scores.

This comparison of parental attitude scores is provided because of the limited size of the sample which completed the tool a second time. The comparison illustrates the variance in parental responses.

The Cronbach's alpha reliability of the normative belief measure was .79 at both time one and time two. A repeated measures analysis of variance revealed no significant difference in the stability of this measure over time. A graphic representation of the normative belief scores is presented below in Figure 4.

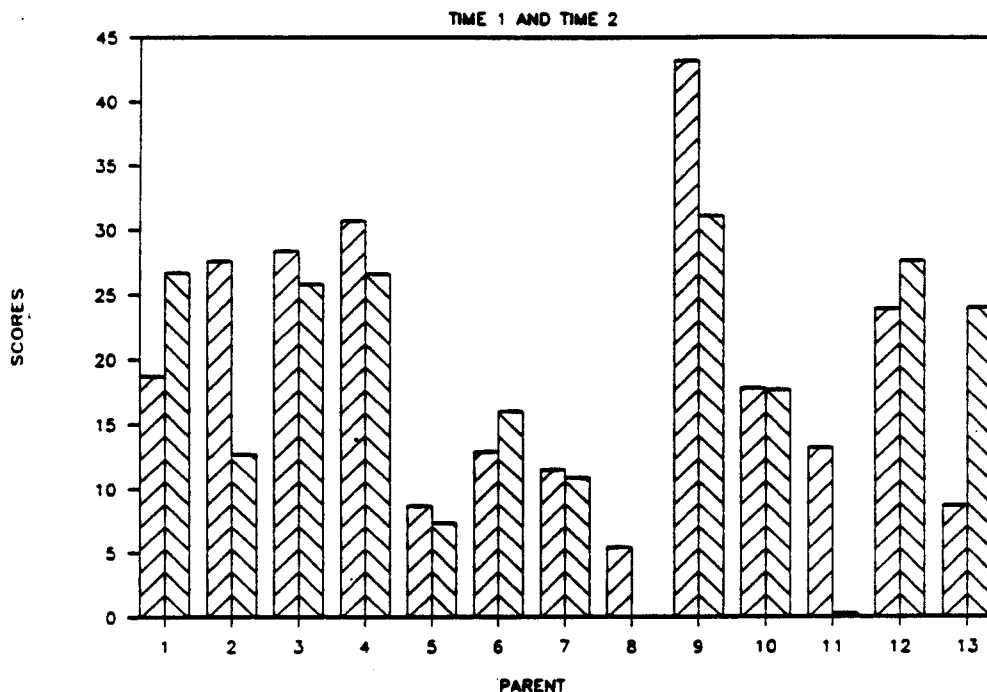


Figure 4. Comparison of Parent Normative Belief Scores.

This comparison of parent normative belief scores is provided because of the limited size of the sample which completed the tool a second time. The comparison illustrates the variance in parental responses.

Attitudes scores resulted from the sum of the parent's beliefs multiplied by belief strengths. Normative belief scores resulted from the sum of the parent's subjective norms multiplied by belief strengths. The reliability of the belief scale was .64 at time one and .84 at time two. The internal

consistency reliability of the subjective norm scale was .67 at time one and .76 at time two. The reliability of the belief strength scale was .84 at time one and .88 at time two. A repeated measures analysis of variance revealed no significant difference in the stability of these three measures over time.

The reliability of the semantic differential scale was .89 at both time one and time two. A repeated measures analysis of variance revealed no significant difference in the stability of this measure over time. A graphic representation of these scores is presented below in Figure 5.

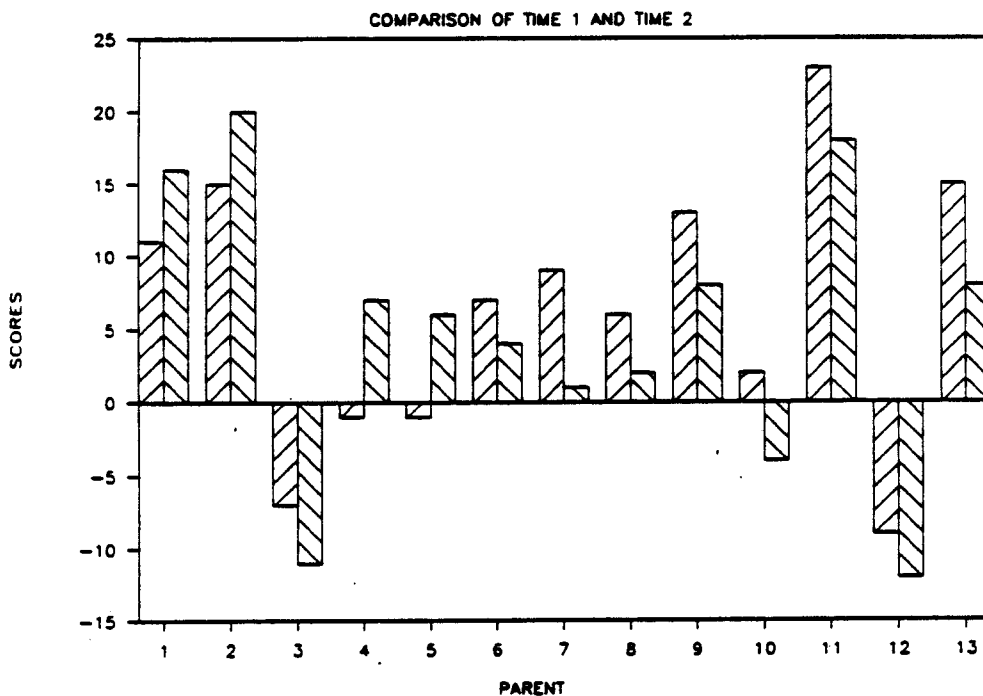


Figure 5. Comparison of Parent Semantic Differential Scores

This comparison of parent semantic differential scores is provided because of the limited size of the sample which completed the tool a second time. The comparison illustrates the variance in responses.

The coefficient alpha reliability of the expectations about outcome scale was .88 at time one and .94 at time two. A repeated measures analysis of variance revealed no significant difference in the stability of this measure over time. A graphic representation of the expectations about outcome scores is presented in Figure 6, on the following page.

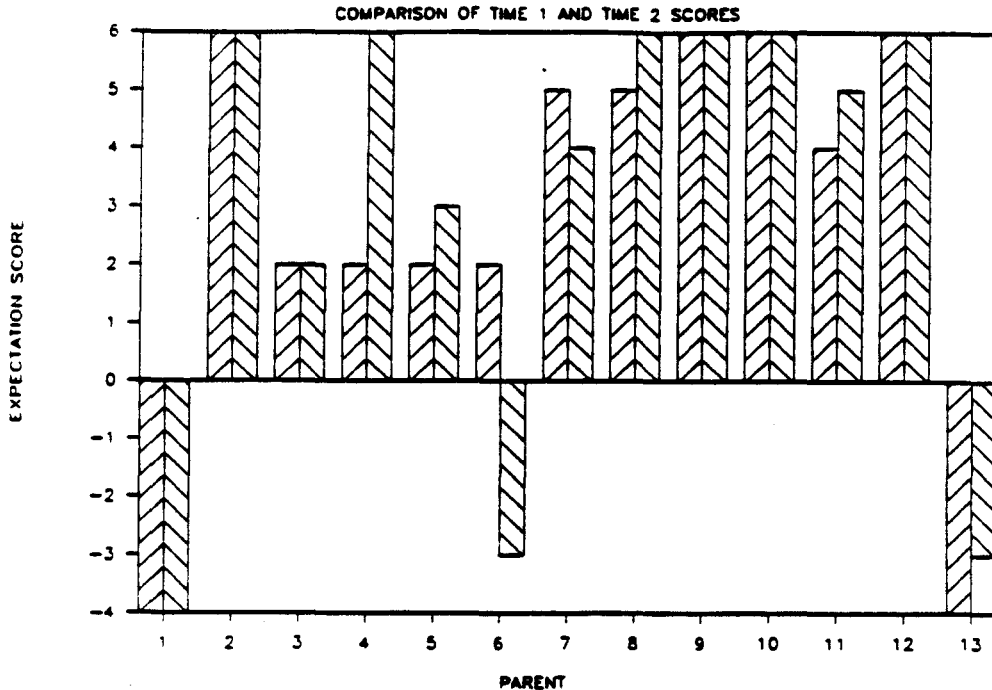


Figure 6. Comparison of Parent Expectations About Outcome Scores.

The comparison of parent expectations about outcome scores is presented because of the limited size of the sample which completed the tool a second time. The comparison illustrates the variance in responses.

The internal consistency reliability of the previous experience scale was .66. An analysis of variance was not performed since this scale was only administered during the initial data collection.

The results of the population specific measure of attitude were correlated with a known measure of attitude, the semantic differential scale, at a .51 level at time one and at a .50 level at time two. This supports construct validity for the measure of attitude.

Model Validation. The strength of relationships between model components were identified using Pearson product moment correlation coefficients significant at the $p < .05$ level. A Spearman's rho procedure was used to analyze the association of the experience scale with other model components.

The most significant relationship to note is the positive correlation between belief strength and normative beliefs at both time one (.61) and time two (.78). While a positive correlation was found

between subjective norms and expectations of outcome at time one (.39), a lack of correlation between expectations about outcome and all others measures was found at time two.

Summary

Quantitative methods were used in Phase II. The developed tool was pilot tested to determine reliability and validity.

CHAPTER VI

DISCUSSION

The results suggest that the cognitive processing model may not be an appropriate framework for describing behavior of parents immediately following the admission of their high-risk newborn to the NICU. Time is necessary for cognitive processing to occur.

The analysis of demographic characteristics described a specific population. The majority of the subjects were young, married, employed, and of the middle to upper class.

The reliability of the attitude measure was .83 at time one and .61 at time two. This difference may have occurred because the tool did not incorporate items specifically pertinent to the beliefs of parents at two weeks or the time of discharge. Generation of additional salient items related to parental beliefs at two weeks or at the time of discharge, and incorporation of these items into the tool, may be necessary to improve reliability.

The reliability of the normative belief measure was .79 at both time one and time two. This consistency probably occurred because these beliefs remained stable over this short period of time. Further investigation is necessary to determine stability of normative beliefs in this population over longer periods of time.

The reliability of the belief scale was .64 at time one and .84 at time two. This difference may have occurred because the tool administered was based upon salient beliefs obtained from parents 24 to 36 hours following admission of their infant to the NICU. The greater reliability at time two may have occurred because the parents had an opportunity for the cognitive processing to occur over the interim between tool administrations.

The reliability of the subjective norm scale was .67 at time one and .76 at time two. The improvement of the reliability of this scale over time may be reflective of a lack of dependence on

subjective norms at the initial tool administration. Perhaps the parents were not aware of their subjective norms in the period immediately following their infant's admission to the NICU.

The reliability of the belief strength scale was .84 at time one and .88 at time two. These reliabilities are highly acceptable and reflect the consistency of this scale over time.

The reliability of the semantic differential scale was .89 at both time one and time two. These reliabilities are highly acceptable and are expected for this known measure of attitude.

The reliability of the expectations about outcome scale was .88 at time one and .94 at time two. The greater reliability at time two suggests that consistency in confidence about outcome develops over time.

The reliability of the previous experience scale was .66. This reliability is marginally acceptable for the size of the sample population at time one.

The correlation between the two measurements of attitude, the generated scale and the semantic differential scale, was .51 for time one and a .50 for time two. The convergence of the two measures is interesting to note in contrast to the difference in the reliability of these measures of attitude over time.

A positive correlation between belief strength and normative beliefs was found at both time one (.61) and time two (.78). This suggests the importance of strength of belief as a determinant of normative beliefs.

A positive correlation was found between subjective norms and expectations about outcome at time one (.39), while a lack of correlation between expectations about outcome and all other measures was found at time two. Perhaps the subjective norms would have again been positively correlated if they had been generated from salient beliefs of parents at two weeks or the time of discharge.

Perhaps the model cannot be demonstrated because the time frame for this investigation was too short. Thus, it may be necessary to use another type of model because the clinical time frame available for identification of families at risk is short and similar to that used in this study.

The findings may be due to the lack of cognitive processing which occurred by 24 to 36 hours

following admission. Additional time may be needed for parents to evolve attitudes and normative beliefs that are associated with adaptive behaviors. The findings at two weeks or the time of discharge may have occurred due to the use of a tool based upon salient beliefs generated from parents at 24 to 36 hours following the admission of their infant to the NICU. Incorporation of items based upon salient beliefs of parents at two weeks or the time of discharge may be necessary, for appropriate use of this cognitive processing model.

CHAPTER VII

SUMMARY, RECOMMENDATIONS, AND CONCLUSIONS

Summary

These data provide a description of the perceptions of parents at the time of admission of their high-risk newborn to the NICU. The salient beliefs identified in the qualitative phase may be used to describe the phenomena of parental attitude and normative beliefs experienced in the period of time 24 to 36 hours following the NICU admission. It may also provide a measure of the actual experiences of parents during this period.

Recommendations

1. Further study should be done to test the usefulness of the model to measure antecedents of parental response to the birth of a high-risk newborn.
2. Validation of the study findings should occur in a larger, more diverse sample.
3. Additional qualitative investigations are needed to determine the salient beliefs of parents at two weeks following admission, or at the time of discharge.
4. These salient beliefs should be incorporated into the tool.
5. The use of models which do not require cognitive processing in order to predict response is warranted.
6. The description of the parent's salient beliefs should be validated, and considered by clinicians in formulating expectations of parents in the period immediately following the infant's admission to an NICU.

Conclusions

The usefulness of the Fishbein Theory of Reasoned Action has not been well supported by this investigation. This model may be useful for measuring antecedents of parental response to the birth

of a high-risk newborn, however this cannot be supported without further studies.

The generalizability of the results is limited to the demographics of the sample. The investigation was conducted on a relatively small sample at a large, midwestern medical center. The majority of the subjects were young, married, employed, and from the middle to upper class. Larger studies conducted on a more diverse sample throughout the country are needed to validate the findings of this investigation. These studies could then allow for generalizability of the results.

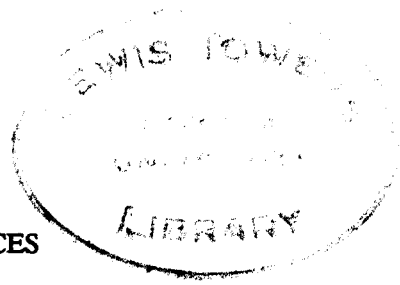
Generation of salient beliefs of parents at two weeks following admission of their high-risk newborn to the NICU, or at the time of discharge, will provide a basis for describing the perceptions and behavior of parents in this situation. Qualitative studies like that reported in Phase I and as published by Tse, Perez-Woods and Opie (1987) and by Austin, McBride and Davis (1984), are necessary for identification of the salient beliefs that provide the foundation for tools to evaluate parental attitudes.

The salient beliefs generated through qualitative study should then be incorporated into the formulated tool. Use of the salient beliefs specific to parents at two weeks following the admission of their high-risk newborn to the NICU, or at the time of discharge, may result in the development of more reliable scales for the tool. Also the strength of relationships between model components at two weeks or the time of discharge may be improved when the specific salient beliefs are incorporated into the tool.

Additional time may be needed for parents of high-risk newborns to evolve attitudes and normative beliefs that are associated with adaptive responses. Thus, perhaps further investigations on the prediction of parental response in the initial post-admission period should be based upon the use of models other than a cognitive processing model.

The qualitative analysis in Phase I of this study resulted in the description of parent's salient beliefs during the period of 24 to 36 hours following the admission of their infant to the NICU. Validation of these findings may facilitate the use of this information by clinicians dealing with

parents in this situation. An awareness of these salient beliefs can be used in formulating expectations of parents with high-risk newborns in the NICU.



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2

APPENDIX A

FORM A

LUMC INSTITUTIONAL REVIEW BOARD
APPLICATION FOR CLINICAL INVESTIGATION

1. Title: Measurement of Parents of High-Risk Newborns:
Beliefs, Attitudes, and Intentions

2. Is this part of a grant application? Yes No

a. If this is part of a grant application, indicate agency and grant number (if known), and check appropriate box:

Agency and Grant Number: _____
 New
 Continuing
 Renewal

3. Has this protocol been previously reviewed by the IRB? Yes No

If yes, please give IRB Number: _____

4. Has this protocol been submitted to any other IRB? Yes No

If yes, give name of institution, date of review, and recommendation: _____

5. This protocol is expected to make use of:

- Experimental drugs (if checked, complete Form B)
- Radioactive agents (if checked, complete Form C)
- New use for established drug (if checked, complete Form B)
- Other (psychological tests, questionnaires, etc.)
List: Interview, Questionnaire

6. Major Investigational departments:

Maternal Child Health Nursing

Investigators:

Principal Investigator: Joanne Perez-Woods

Co-Investigator(s): Margaret H. Kivitz

Consultant(s): _____

7. Patient Information:

a. Number of individuals to be studied: 30-50 Male Female Children

b. Source of subjects: Outpatients ; Inpatients ; Volunteers ; Vol Source Parents of Newborns

c. Age range of subjects: 15-45

d. Will hospitalization be required solely for participation? Yes No.

e. Will the length of hospitalization be increased solely by participation? Yes No.

If yes, how much? _____

f. Is this a randomized study? NO

g. Expected duration of study: 6-15-86 - 6-15-87

Expected duration of study on individual subject: 30 min

h. Is any compensation involved? Yes No.

If yes, how much and in what form (cash, meals, etc.)? _____

8. Location of study:

McGaw Hospital

Dental School

37

Mulcahy Outpatient Center

Nursing School

Medical School

Hines V.A.

Other (specify): _____

9. Laboratory Services:

a. Will any tests be performed which are normally included as part of a diagnostic work-up for treatment?

Yes No List: _____

b. Who or what agency will pay for the above tests or additional hospitalization?

Grant (Number: _____)

Departmental R&E

Patient

Other (Specify): _____

The undersigned accepts responsibility for assuring that all applicable HHS/FDA and IRB policies relative to the protection of the rights and welfare of the patients/subjects used in this study are adhered to.

Koume Leroy-Woods Ed.D, PA
Principal Investigator

6-5-86
Date

Margaret M. Kirby RN, BSN

This proposal has been reviewed and approved for submission to the IRB.

Katherine Wiley
Department Chairman, Et Pco

6-5-86
Date

Where consultants are listed in a project (the consultant being an individual who is not a primary or co-investigator but performs a significant role in the project), it is required that the investigator submit documentation from the consultant that he is aware of his role in the project and has agreed to carry it out.

Date received by IRB: 6-5-86

Considered at meeting of: 6-18-86



LOYOLA UNIVERSITY OF CHICAGO
INSTITUTIONAL REVIEW BOARD FOR PROTECTION
OF HUMAN SUBJECTS — MEDICAL CENTER

38

2160 South First Avenue, Maywood, Illinois 60153

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Administrative Secretary
531-4608

June 18, 1986

Margaret Kurtz, R.N., B.S.N.
School of Nursing
Loyola University Medical Center

Re: "Measurement of Parents of High-Risk Newborns: Belief, Attitudes and Intentions."
IRB# 6/86-4f.

Dear Ms. Kurtz:

At its meeting of June 18, 1986, the Institutional Review Board for Protection of Human Subjects reviewed the above-captioned protocol.

Via Expedited Review, the Board approved the low-risk nurses project.

You now have full IRB approval to proceed with your research study and have been assigned the IRB number indicated above.

The IRB suggests that the attending physicians of patients employed in your research study, be informed that their patients are on an experimental protocol.

If you should have any questions or possible future changes with regard to your project, please do not hesitate to contact me.

Yours truly,

A handwritten signature in cursive script that reads "Kenneth C. Micetich".

Kenneth C. Micetich, M.D., Acting Chairman
Institutional Review Board for Protection
of Human Subjects - Medical Center

KCM/s

cc: IRBPHS Members
IRBPHS file

**LOYOLA UNIVERSITY OF CHICAGO
MAYWOOD, ILLINOIS**

**Marcella Niehoff School of Nursing
Department of Maternal-Child Health Nursing**

INFORMED CONSENT

Subject's Name: _____

Date: _____

Project Title: **Measurement of Parents of High-Risk Newborns: Beliefs, Attitudes, and Intentions
(Phase I)**

Subject Information

Dear Parent,

You are invited to participate in a research study. The purpose of the study is to investigate the reactions of parents towards their baby's admission to the neonatal intensive care unit and describe parent's expectations about their baby's outcome. The objectives of the study are:

- 1. to find out what parents feel and think about the admission of their baby to the neonatal intensive care unit; and**
- 2. to find out if a questionnaire (research instrument) can be developed to measure how parents feel and think about their baby's admission to the intensive care unit.**

If you decide to participate in this phase of the study, you will be asked to partake in an informal interview. Your interviewer will be the investigator, who is a graduate student at Loyola University's School of Nursing, and a registered nurse in this neonatal intensive care unit. The interview will take place at this time and should last approximately 30 minutes. You will be asked to describe what you associate with or believe to be true about the admission of your baby to the intensive care unit. With your permission, the investigator will tape record the interview and transcribe it later into research notes. Your name or your baby's name will not be used in the study. The answers from your interview will be joined with answers from other parents. Your audiotaped interview will be destroyed at the completion of the research study. The interview is a way to find out how parents think and feel about the admission of their baby to the neonatal intensive care unit.

There are no risks associated with partaking in the interview. However, sometimes people feel uncomfortable answering personal questions. You may stop partaking in the interview at any time. There are no legal, social, or physical risks foreseen in partaking in the interview. Should you choose not to participate in the study, you are assured the same high quality care will remain available for you and your baby.

Your answers will remain confidential. Only members of the research team will have access to the interview tapes. The results of the study will be presented so that there is no way to identify an individual's response.

There is no direct benefit to participating in this study; however, your feelings about your experiences as a parent of a baby that has been hospitalized in the neonatal unit may help improve the care given to other parents of sick and/or premature newborns. There is no compensation for participation in the study.

If you decide to participate in the study, you are free to stop answering questions at any time without effecting the high quality of care available to you and your baby.

Please feel free to ask any questions you may have about the study. We will be glad to help you in every way possible. You may contact either Meg Kurtz, R.N., B.S.N., Graduate student, Loyola University, Niehoff School of Nursing (531-4032) or Rosanne C. Perez-Woods, R.N., Ed.D., C.P.N.A., Niehoff Chair and Professor, Loyola University, Niehoff School of Nursing (531-3101) if you have questions at any time. You will be given a copy of this form to keep.

You are being asked to make a decision about whether you want to participate. Your signature indicates that you understand the information provided above and have decided to participate in the study.

Sincerely:

Rosanne C. Perez-Woods, Ed.D., R.N., C.P.N.A.

Margaret Kurtz, B.S.N., R.N.

Consent

I have fully explained to _____ the nature and purpose of the above-described research and the risks that are involved in its performance. I have answered and will answer all questions to the best of my ability.

(Signature: Principal Investigator)

I have been fully informed of the above-described research with its possible benefits and risks. I give permission for my participation in this study. I know that Meg Kurtz and Dr. Rosanne C. Perez-Woods will be available to answer any questions I may have. If, at any time, I feel my questions have not been adequately answered, I may request to speak with a member of the Medical Center Institutional Review Board. I understand that I am free to withdraw this consent and discontinue participation in this study at any time without prejudice to my own or my baby's medical and nursing care. I have received a copy of this informed consent document.

In the event that I believe that I have suffered any physical injury as the result of participation in the research study, I may contact Dr. Robert E. Henkin, Chairman, Institutional Review Board for the Protection of Human Subjects at the Medical Center, telephone (312) 531-4608.

I agree to allow my research records to be available to other authorized physicians, nurses, and researchers for the purpose of evaluating the results of this study. I consent to the publication of any data which may result from this investigation for the purpose of advancing medical and nursing knowledge, providing my name or any other identifying information (initials, social security numbers, etc.) is not used in conjunction with such publication. All precautions to maintain confidentiality of the medical and research records will be taken. I understand, however, that the Food and Drug Administration of the United States Government is authorized to review the research records relating to this study.

Witness to signature

(Signature: parent)

Date

**LOYOLA UNIVERSITY OF CHICAGO
MAYWOOD, ILLINOIS**

**Marcella Niehoff School of Nursing
Department of Maternal-Child Health Nursing**

INFORMED CONSENT

Subject's Name: _____

Date: _____

Project Title: **Measurement of Parents of High-Risk Newborns: Beliefs, Attitudes, and Intentions
(Phase II)**

Subject Information

Dear Parent,

You are invited to participate in a research study. The purpose of the study is to investigate the reactions of parents towards their baby's admission to the neonatal intensive care unit and describe parent's expectations about their baby's outcome. The objectives of the study are:

1. to find out what parents feel and think about the admission of their baby to the neonatal intensive care unit; and
2. to find out if a questionnaire (research instrument) can be developed to measure how parents feel and think about their baby's admission to the intensive care unit.

If you decide to participate in this phase of the study, you will be asked to partake in an informal interview. Your interviewer will be the investigator, who is a graduate student at Loyola University's School of Nursing, and a registered nurse in this neonatal intensive care unit. The interview will take place at this time and should last approximately 30 minutes. You will be asked to describe what you associate with or believe to be true about the admission of your baby to the intensive care unit. With your permission, the investigator will tape record the interview and transcribe it later into research notes. Your name or your baby's name will not be used in the study. The answers from your interview will be joined with answers from other parents. Your audiotaped interview will be destroyed at the completion of the research study. The interview is a way to find out how parents think and feel about the admission of their baby to the neonatal intensive care unit.

There are no risks associated with partaking in the interview. However, sometimes people feel uncomfortable answering personal questions. You may stop partaking in the interview at any time. There are no legal, social, or physical risks foreseen in partaking in the interview. Should you choose not to participate in the study, you are assured the same high quality care will remain available for you and your baby.

Your answers will remain confidential. Only members of the research team will have access to the interview tapes. The results of the study will be presented so that there is no way to identify an individual's response.

There is no direct benefit to participating in this study; however, your feelings about your experiences as a parent of a baby that has been hospitalized in the neonatal unit may help improve the care given to other parents of sick and/or premature newborns. There is no compensation for participation in the study.

If you decide to participate in the study, you are free to stop answering questions at any time without effecting the high quality of care available to you and your baby.

Please feel free to ask any questions you may have about the study. We will be glad to help you in every way possible. You may contact either Meg Kurtz, R.N., B.S.N., Graduate student, Loyola University, Niehoff School of Nursing (531-4032) or Rosanne C. Perez-Woods, R.N., Ed.D., C.P.N.A., Niehoff Chair and Professor, Loyola University, Niehoff School of Nursing (531-3101) if you have questions at any time. You will be given a copy of this form to keep.

You are being asked to make a decision about whether you want to participate. Your signature indicates that you understand the information provided above and have decided to participate in the study.

Sincerely:

Rosanne C. Perez-Woods, Ed.D., R.N., C.P.N.A.

Margaret Kurtz, B.S.N., R.N.

Consent

I have fully explained to _____ the nature and purpose of the above-described research and the risks that are involved in its performance. I have answered and will answer all questions to the best of my ability.

(Signature: Principal Investigator)

I have been fully informed of the above-described research with its possible benefits and risks. I give permission for my participation in this study. I know that Meg Kurtz and Dr. Rosanne C. Perez-Woods will be available to answer any questions I may have. If, at any time, I feel my questions have not been adequately answered, I may request to speak with a member of the Medical Center Institutional Review Board. I understand that I am free to withdraw this consent and discontinue participation in this study at any time without prejudice to my own or my baby's medical and nursing care. I have received a copy of this informed consent document.

In the event that I believe that I have suffered any physical injury as the result of participation in the research study, I may contact Dr. Robert E. Henkin, Chairman, Institutional Review Board for the Protection of Human Subjects at the Medical Center, telephone (312) 531-4608.

I agree to allow my research records to be available to other authorized physicians, nurses, and researchers for the purpose of evaluating the results of this study. I consent to the publication of any data which may result from this investigation for the purpose of advancing medical and nursing knowledge, providing my name or any other identifying information (initials, social security numbers, etc.) is not used in conjunction with such publication. All precautions to maintain confidentiality of the medical and research records will be taken. I understand, however, that the Food and Drug Administration of the United States Government is authorized to review the research records relating to this study.

Witness to signature

(Signature: parent)

Date

APPENDIX B

**MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)**

Interview Guide

First of all, can you please tell me about (your/the mother's) labor and delivery?

When did (you/the mother) come to the hospital?

When did (you/she) go into labor?

What happened?

If you could go back to when you first heard the news that your baby would have to be admitted to this neonatal intensive care unit, what were your thoughts and feelings about it?

Now that it is a (day/day-and-a-half) later, what are your thoughts and feelings about having your baby in a neonatal intensive care unit?

If different, in what way?

Have you thought about what your baby's outcome will be?

Have you ever been through an experience like this before?

If so, what was your reaction?

Do you know any family or friends who have been through this?

If so, what was your reaction?

Is there anything else I have forgotten to ask about, that may be related?

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #1

1. it was an early labor
2. relieved
3. that this was the place to be
4. that if anybody could give him a better chance, that he could give himself, it would be here
5. and then after talking to everybody, there's just no doubt in my mind that this is where he should be
6. and if something should happen, it's absolutely nobody's fault
7. they know what they're doing here
8. there was no doubt
9. when I initially heard he had to come here, my concern was that he was so small, he doesn't have a chance
10. and then after being here a while and talking to people, that wasn't the case at all
11. people here know exactly what they're doing at all times
12. they don't pull any punches
13. they don't overly reassure you
14. but, they'll tell you, hey we had somebody else in here that was smaller than he was who just came back--he's 9-months-old and the kid's cute
15. they're reassuring as much as they can be
16. they tell you the risks, as far as they know
17. mentally it's traumatic, because you know that this baby is small and he has a long way to go
18. but, you know that this is the only place we want him to be
19. there's just no doubt about it

Transcribed Interview
Parent #1, cont'd.

20. complete confidence
21. complete trust
22. there was never any reserve
23. they know what they're doing
24. they've been here before
25. it's just amazing
26. during labor and after labor, little or no chance
27. until we found out a little bit more about the situation, after not having no experience with this at all, now after talking with the people here and hearing from some of our friends that have either known people or had preemies themselves that were his size and are now healthy, it's not impossible
28. so, his chances are good
29. it definitely helps to know people who have been through it before--it seems that the grandparents are talking to their friends and they're hearing stories; our friends are talking to their friends and telling us stories--you know, positive things which we need right now
30. I have never been in premature labor before
31. you know, you go through the mental pain of--that this isn't normal- I'm supposed to go 9 months, and it's not 9 months, and the baby's too small-and we still have that--we have that now and we probably will for a long time
32. but, you can get a lot of comfort and reassurance out of him being here in neonatal where this is what they do--they've been here before and have a high success rate, so there is comfort there

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #2

1. kind of mixed
2. you want to help the baby, and a great outcome
3. I knew I was early, the bag had broke early, and I was also a gestational diabetic, so then you think about why
4. but, then you want to make sure that he is taken care of well
5. so, that's why I decided to deliver at Loyola, just in case there were any problems with the baby--to get adequate support for the baby
6. so, I was real glad they caught it and acted quickly
7. I'm just grateful that things turned out the way they did
8. I'm just glad he's in good hands
9. my husband felt pretty much so the same way I felt--that things needed to be done--they were done quickly
10. I can't speak for him, but I'm just saying that it seemed like everything was fine--but, then we looked over to the baby and things weren't going as well as we initially thought
11. so, I'm sure that was his concern too
12. my daughter was born 6 weeks early, so we thought pretty much we were over the hurdle as far as timewise
13. but, knowing that he was timewise later, he had a better chance than she did
14. so, this is our second visit to an intensive care unit
15. she spent sometime also, but they didn't even need to intubate her-- she did real well, had a real good course there too
16. it definitely helped--I was totally freaked out last time, just with being early--and I also was preeclamptic too, so I had other complications
17. just with her being so early and having to go to the intensive care unit--just totally psychologically not prepared at all

Transcribed interview
Parent #2, cont'd.

18. it was real difficult
19. this time it's not old hat, but we've been this route--at least this way
20. like I say, he's later, so that made it a better prognosis
21. but, then we kind of thought we were over the hurdle
22. well, you pray for the best and you hope for a great outcome
23. but, we aren't too optimistic--just in case things don't turn out as planned--but, we're hoping that's what'll happen
24. I just take 1 hour at a time, and just hope for the best

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #3

1. well, I felt relieved in a way, only because I knew the other hospital was honest enough to say--hey we don't have the facilities here to do it, so we're going to take her somewhere where they do--so, it was a relief, in a way
2. at least I know she's going to get the proper care and have all the, whatever, to take care of her--monitors and stuff
3. pretty much, the shocker was there that she popped her water bag and she would have to have the baby premature, and so we expected that--but not quite everything, just for the most part
4. I feel good about it
5. it's just like I said, if she's going to get the proper and everything to take care of her--I'm not worried about her
6. I know she's going to make it, I'm pretty sure of that
7. I just know she looks pretty good
8. I look around here and I see smaller babies
9. it may not be very nice to say, but it makes you feel good in a way, to know that you've got a little more going for you than somebody else does--but, it's at somebody else's misfortune
10. I'm looking forward to having her home, especially when she starts crawling around stuff
11. I didn't expect it to happen
12. it was a big shock when she woke me up and told me she broke her water bag--I was like, oh boy
13. the way the doctor explained it, the doctor said that the baby wouldn't have much of a chance at all in the beginning
14. the obstetrician said that the odds were about 10 percent for making it--and I was upset about that
15. actually, I'm farther ahead than I thought I would be, or she would really--she's six weeks older than the doctor had thought--the doctor thought she was 24 weeks
16. so I was relieved when I heard that she was a month ahead

Transcribed Interview
Parent #3, cont'd.

17. I guess that one month makes a big difference
18. I've never been through an experience like this
19. I don't think I ever want to be in a situation like this again
20. I don't know anybody that would
21. I was surprised when I walked in here, at how many children there are in here
22. I thought maybe a couple others--but there's a lot in here
23. we really haven't talked about it, but just by seeing the way she reacts--like when I gave her the pictures, I told her don't be surprised, but she has a lot of wires on her--and she wasn't surprised, she was happy and she smiled
24. I'm sure she's worried, but she really doesn't show it that much--so, she seems ok

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #4

1. first they told us the chances of the baby--the different departments came down and talked to us and told us the reality of it--you know, a 50/50 chance-if he weighed under gm he would basically have no chance at all-but, above that about a 50/50 chance
2. then, after delivery, when they told us the baby weighed 800 grams, then they told us we have more like a 60 to-70% chance of survival
3. at first I was kind of skeptical, because to me I just thought it was just prolonging the chances you know, and that would come--but then after awhile, you say you know, you never know what happens unless you try to save the baby
4. and then after awhile, you know as the day goes on, I became more believing than skeptical about his chances of survival
5. and then right now, it's just wait and see what happens
6. but, I'm more enthusiastic about it now than in the beginning
7. I can see almost 100% turn around
8. with my wife though, when she first came up here, she was emotionally down--and then as she's been coming up here, she moreso realizes the situation and is being optimistic about everything--but, in the beginning, she was real low
9. and that didn't help me either at all
10. but now that she's more optimistic, you know it helps me to do better
11. the doctor told us all his organs are fine, but you never know in the long run
12. I thought you know, probably some deformity or something like that you know--like being blind, you know having one of his senses or something handicapped--and I wasn't too happy with it, but if that's the way it's meant to be then that's the way it's going to be
13. I was kind of frightened about it--you know not being actually a normal child, as opposed to being normal
14. I was kind of scared in that respect, and I still am alittle
15. you don't know what to expect, really

Transcribed Interview
Parent #4, cont'd.

16. and I should also say, it is also really--not being really ready for this--you know, it was really a total shock altogether
17. this is the first time for me, this is our first
18. I basically haven't had time, but I would like to try and at least find some people who have been through this--to see what happened to them and you know, just to get a general picture--everything is new for us, this being our first child and not knowing anybody who has experienced it
19. so, you know it's really different, and you don't know what to expect
20. basically, you don't really know what to do
21. you don't know if you're doing this right or wrong or anything like that--so if I knew somebody who went through the same experience, it would be helpful
22. I'm just grateful, you know
23. yesterday I was a basket-case because the whole burden was on me--having to take care of her and do everything
24. it's really been hard, with basically no relatives around and all
25. now, having some family up here, does help a lot

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #5

1. they thought that I might have an infection that would effect him, so they had to get him out of there before it would get to him
2. well they discussed it with me and explained what could happen
3. but, it was nothing like what they told me it would be, because they just didn't know for sure
4. they said, he might not breathe very well without a machine and that he'd have a bunch of tubes, which he doesn't have
5. it really didn't matter
6. I mean as long as they got the kid healthy--you know, that was all that mattered to me, right off the bat
7. it really didn't effect me, because I really didn't expect it to be an intensive care unit--just a care unit, not an intensive care unit
8. now, my feelings are no different
9. I mean as long as he's healthy, it doesn't matter to me
10. I hope he'll be healthy
11. if I was coping with it bad, you could tell
12. I think I'm coping with it quite well
13. the fact that he's breathing on his own and stuff is amazing to me

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #6

1. this is the best place for a premature baby to go
2. we definitely wanted the best care
3. I wasn't really that worried, because the doctor really explained it to us real good and made us feel safe about it
4. I knew that this was the best possible care he could get
5. the way he explained it, it made sense that this would be the best thing possible--to bring her here with the baby inside of her, instead of delivering the baby somewhere else and then bring him here, whatever
6. so, I wasn't that worried
7. and as the day went on, we just got better and better news that things were going to be ok
8. I felt real good about it
9. now, I feel great, alot better
10. I'm feeling better every minute
11. every time we see him, we feel better
12. I think everything's going to be fine
13. he's an albino, which is rare, but that's great
14. my wife feels just as good
15. we're both on top of the world, pretty much--better than we thought we'd feel even
16. we just got him sooner
17. I've never been through an experience like this before
18. we know alot of people that have babies, but no intensive care
19. it's a totally new experience for us

Transcribed Interview
Parent #6, cont'd.

20. I just feel great about everything--better than I've ever felt in my life, for sure
21. everybody at this hospital made me feel great--the doctors and everybody
22. everybody made us feel so secure about everything
23. it just keeps getting better everyday
24. I know they can handle it here
25. if he has some problems, we'd just love him just the same

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #7

1. kind of dulled, and a little bit scared
2. I was apprehensive and a little nervous
3. it was explained ahead of time what would happen
4. that was all part of the early delivery--I knew that we were going to have special treatment with intensive care
5. my reactions were scared, dulled, and apprehensive--but, happy that you have this unit because I know that she's in good hands
6. but, you just don't know--as a parent, you don't know what to expect
7. obviously, it's become a habit--I've been up here 3 times, so it's becoming familiar
8. we know that she's in good hands, and I'm comfortable with it
9. it's too bad that we can't have her downstairs, and we could have her home in 4 days--but, as good as can be
10. and probably, from what I understand, we're probably lucky that we moved to Chicago
11. I'm expecting to take her home as a normal healthy baby
12. I happened to talk to a friend the other day who had a little boy who happened to be 3 months premature--and he said, it's a roller coaster of emotions, and that the wife better be a little bit hard or a little bit dulled to her emotions, kind of low-keyed
13. and another friend had a premature baby who is not very healthy today--she had had a lot of problems
14. but, you try to be optimistic--you can't be anything other than that
15. I think that when you know that you're in a good percentile for survival and that girls have a better tendency for survival and that her weight was pretty good--that was comforting
16. obviously, you can tell that we're not prepared for the bad part yet--because we haven't had to go through that yet

Transcribed Interview
Parent #7, cont'd.

17. when you ask about being up here, I'll ask you a question--is there an alternative?--no, there isn't
18. so, how else can you feel--but, to be accepting of it, really
19. and, be thankful that at least there's a place like this
20. that's positive--they have the technology so much better now than years ago
21. maybe I'm being overly positive--maybe I shouldn't be
22. I just feel so confident--I think sometimes, maybe I'm overconfident
23. that might be bad too--feeling too secure
24. I feel very secure about it
25. I know we're going to have problems later
26. but, there's no other alternative
27. she's got the best care she can get
28. the strange thing is going to be when mom has to go home, and leaving her here--and we might not see her for even 2 days
29. we won't have the opportunity to have the normal parental bonding, except the little bit we can do in there
30. she'll probably be asking for the nurse when she can finally talk--instead of mamma--the nurse always got me what I wanted
31. we've been so positively reassured--that we couldn't go to a better place, that this is the place to be--we were conditioned
32. at 28 weeks, the chances are so good, and they're so much better here

MEASUREMENT OF PARENTS OF HIGH-RISK NEWBORNS:
BELIEFS, ATTITUDES, AND INTENTIONS
(Phase I)

Transcribed Interview

Parent #8

1. I remember them taking the baby--you know, I got a fleeting glance of her as they passed us and said this is your daughter
2. panic--when they told me she was going to be too little to be cared for at the other hospital, adequately
3. first of all, I thought the doctor was a prince for admitting that the hospital and himself just weren't equipped
4. that was very reassuring--instead of having somebody that would just go ahead and take the chance, and helicoptering the baby out afterwards
5. because alot of times, they don't know that it's that little and something's wrong
6. I was relieved that he wasn't going to risk moving the baby after the baby was born--that he wanted to take care of everything before the baby was born
7. I was just worried--was the baby going to be big enough to have a fighting chance--that was my only fear
8. and, I cried a little bit
9. but basically, once I got here, I felt pretty at ease
10. the baby came so quick--he didn't even get a chance to come up here and find out what it was all about
11. the first time we were up here was yesterday morning, after Sara was probably 6 hours old
12. but, it wasn't as nerve-racking as I would've thought
13. just the name, puts your mind at ease alot
14. so, I was scared
15. but, I wasn't petrified--because, I knew it was so much more than 20 years ago
16. at that time, I probably would have been a basket-case--but, not as much now
17. at the time of delivery, I already understood that the baby was going to have to come up here

Transcribed Interview
Parent #8, cont'd.

18. I'm going to feel alot better when I can get this stupid I.V. off my arm--because, everytime I come in, all I can do is kind of sit there and look at her and watch her breathe
19. I want to be able to hold her, hold her
20. at least, I can touch her--she's so nice and soft
21. I'd love to have her come home with me--but, that's not being realistic
22. the longer she's here, the stronger she's going to be
23. so, I've resigned myself to that fact
24. I'd rather have her come home when she's good and ready, and out of danger--and then, she's home to stay, for the next 18 years hopefully--so, she can play with her dog and 2 older brothers, who are elated
25. my brother and cousin were preemies
26. the only thing is that you'd rather go term and have a nice healthy baby--but, if you can't do it that way, then there's no place better than being in a hospital like this which has got the facilities
27. you walk in and you just feel very, very relieved
28. everybody wants a nice, healthy baby--but, God doesn't always do it that way--he does things like make them come early or give them severe problems--I'm glad mine is 32-33 weeks along
29. I'm thankful there's a place like this
30. we're making the best of it--we know how bad she could have been

APPENDIX C

**PARENT'S ATTITUDE TOWARD THE ADMISSION
OF AN INFANT TO THE NICU**

GENERAL INSTRUCTIONS

In the questionnaire you are about to fill out there are questions which make use of rating scales with seven places. You are to make a (✓) in the place that best describes your opinion. For example, if you were asked to rate, "The weather in Chicago" on such a scale:

The weather in Chicago:

bad ___: ___: ___: ___: ___: ___: ___: good
 -3 -2 -1 0 +1 +2 +3

You would first have to decide whether the weather in Chicago is good or bad. If you decide the weather is good, you would have to decide which point best describes your impression. Consider "good" as an impression that can be divided into three equal parts. If you place your (✓) mark over the blank labeled "+3", you would indicate that you thought the weather in Chicago was extremely good. If you think the weather in Chicago is slightly good, then you would place your (✓) mark on the blank labeled "+1".

A check mark (✓) over the blank labeled "0" indicates that neither word describes your impression of the weather, or that both good and bad describe your impression.

If you decide the weather in Chicago is bad, you would make a check mark (✓) over the blank closest to "bad", which you think best describes your impression. A check mark (✓) placed over the blank labeled "-1", indicates you think the weather in Chicago is slightly bad. A check mark over the blank labeled "-3", indicates you think the weather in Chicago is extremely bad.

Place your check marks in the middle of the spaces and only put one check mark for each question. Be sure you answer all the items.

Thank you.

Below are some beliefs about the admission of a baby to the neonatal intensive care unit (NICU) that parents may have. Use the scale below and rate each belief as to how it would make you feel if it were true.

Extremely -3 -2 -1 0 +1 +2 +3 Extremely
Bad Good

THE ADMISSION OF MY BABY
TO THE NICU...

How would this make
you feel if it were
true?

-3 to +3

- 1. amazed me _____
- 2. caused me to blame others for my baby's problem _____
- 3. caused me to be burdened _____
- 4. made me concerned _____
- 5. made me confused _____
- 6. made me comfortable _____
- 7. exhausted me _____
- 8. made me grateful that the staff were competent _____
- 9. made me grateful that my baby was at Loyola _____
- 10. caused me to be happy _____
- 11. caused me to be impatient _____
- 12. relieved me _____
- 13. made me satisfied _____
- 14. caused me to pity myself _____
- 15. shocked me _____
- 16. made me feel threatened _____
- 17. traumatized me _____
- 18. made me feel guilty _____
- 19. caused me to be petrified _____
- 20. made me feel responsible _____
- 21. made me feel I needed to learn things _____
- 22. made me want someone to lean on _____
- 23. caused me to feel unprepared _____
- 24. made me confident _____
- 25. made me hopeful _____
- 26. made me feel competent _____

The following questions relate to how people that you are close to (your significant others) would expect you to feel about your baby's admission to the NICU. Use the scale below:

Extremely -3 -2 -1 0 +1 +2 +3 Extremely
Improbable Probable

MOST OF MY SIGNIFICANT OTHERS WOULD EXPECT ME:

1. to be amazed _____
2. to blame others for my baby's problem _____
3. to be burdened _____
4. to be concerned _____
5. to be confused _____
6. to be comfortable _____
7. to be exhausted _____
8. to be grateful that the staff were competent _____
9. to be grateful that my baby was at Loyola _____
10. to be happy _____
11. to be impatient _____
12. to be relieved _____
13. to be satisfied _____
14. to pity myself _____
15. to be shocked _____
16. to feel threatened _____
17. to be traumatized me _____
18. to feel guilty _____
19. to be petrified _____
20. to feel responsible _____
21. to feel I needed to learn things _____
22. to want someone to lean on _____
23. to feel unprepared _____
24. to be confident _____
25. to be hopeful _____
26. to feel competent _____

This questionnaire is about your attitudes toward the admission of your baby to the NICU. Rate each question as to your attitude when your baby was admitted into the NICU. Place a check mark over only one blank for each of the word pairs. Do not omit any of the pairs.

**THE ADMISSION OF MY BABY TO THE
NICU IS...**

bad	___:	___:	___:	___:	___:	___:	___:	good
	-3	-2	-1	0	+1	+2	+3	
rewarding	___:	___:	___:	___:	___:	___:	___:	punishing
	-3	-2	-1	0	+1	+2	+3	
negative	___:	___:	___:	___:	___:	___:	___:	positive
	-3	-2	-1	0	+1	+2	+3	
pleasant	___:	___:	___:	___:	___:	___:	___:	unpleasant
	-3	-2	-1	0	+1	+2	+3	
awful	___:	___:	___:	___:	___:	___:	___:	nice
	-3	-2	-1	0	+1	+2	+3	
satisfactory	___:	___:	___:	___:	___:	___:	___:	unsatisfactory
	-3	-2	-1	0	+1	+2	+3	
fair	___:	___:	___:	___:	___:	___:	___:	unfair
	-3	-2	-1	0	+1	+2	+3	
harmful	___:	___:	___:	___:	___:	___:	___:	beneficial
	-3	-2	-1	0	+1	+2	+3	

Below are two statements about the parent's expectations of a baby's outcome when the baby is admitted to the NICU. Rate each statement as to what you really expect your baby's outcome to be. Use the scales for each statement.

When my baby was admitted to the NICU, I expected my baby to . . .

<u>not</u> recover	___:	___:	___:	___:	___:	___:	___:	recover
at all	-3	-2	-1	0	+1	+2	+3	completely

When my baby was admitted to the NICU, I was _____ that my baby would recover.

extremely	___:	___:	___:	___:	___:	___:	extremely
uncertain	-3	-2	-1	0	+1	+2	certain

Infant's Hospital # _____

SELECTED SITUATIONAL AND DEMOGRAPHIC VARIABLES FORM

Interview Schedule for Parents

- a. Parent's relationship to infant:
1. Mother ____ 2. Father ____ 3. Other ____
- b. Parent's religion:
1. Catholic ____ 2. Protestant ____ 3. Jewish ____ 4. Other/none ____
- c. Number of Children (including infant):
1. ____ 2. ____ 3. ____ 4. ____ 5. greater than 4 ____
- d. Parent's employment status prior to infant's admission:
1. Full-time homemaker ____ 3. Employed part-time (<35 hrs/wk) ____
2. Unemployed ____ 4. Employed full-time (>35 hrs/wk) ____
- e. Briefly describe what you do for work:
- f. Parent's educational level:
1. Have not completed high school ____ 5. Completed college ____
2. Completed high school ____ 6. Masters degree ____
3. Technical or trade school ____ 7. Doctoral degree ____
4. One to three years of college ____
- g. Approximate income per year (combine if married):
1. < \$10,000 ____ 5. \$30,000 - \$39,000 ____
2. \$10,000 - \$14,000 ____ 6. \$40,000 - \$49,000 ____
3. \$20,000 - \$29,000 ____ 7. > \$50,000 ____
- h. When your infant was admitted to the NICU who was most helpful in providing support?
- i. Before your infant was admitted to the NICU, did you know any information about situations like your infant's?
1. Yes ____ 2. No ____ 3. Uncertain ____
- j. If yes, how did you obtain the information?
- k. Have you ever been exposed to a situation similar to what happened to your infant?
1. Yes ____ 2. No ____ 3. Uncertain ____
- l. If yes, who did this happen to?
- m. How many years ago?
- n. What happened?
- o. What was the outcome?

- p. Have you ever been exposed to an intensive care unit before the admission of your infant?
1. Yes ___ 2. No ___ 3. Uncertain ___
- q. If yes, who was in the intensive care unit?
- r. How many years ago?
- s. What happened?
- t. What was the outcome?
- u. Type of ICU:
1. Adult ___ 2. Child ___ 3. Mixed ___
4. Neonatal ___ 5. Uncertain ___
- v. Can you think of anything else I may have missed that has influenced your attitude and expectation of your infant's admission to the NICU?

Data From Infant's Chart

- u. Parent's age: (years) ___
- v. Parent's sex: 1. F ___ 2. M ___
- w. Parent's race:
1. Caucasian ___ 2. Black ___ 3. Hispanic ___ 4. Asian ___ 5. Other ___
- x. Marital Status:
1. Single ___ 2. Married ___ 3. Separated ___ 4. Divorced ___ 5. Widowed ___
- y. Payment source for hospitalization:
1. Self ___ 4. SSI ___
2. Insurance ___ 5. BCBS ___
3. Medicaid ___ 6. Other ___
1. Infant's gestation in weeks ___
2. Infant's sex ___
3. Admitting diagnosis _____
4. Admitting Index of Severity ___
5. Age at time of data collection ___

APPROVAL SHEET

The thesis submitted by Margaret M. Kurtz has been read and approved by the following committee:

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The final copies have been examined by the chairperson of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the Committee with reference to content and form.

The thesis is therefore accepted in partial fulfillment of the requirements for the degree of Master of Science in Nursing.

Dec 10, 1987

Date

Rosanne Perez-Woods

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