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## Parents' Experiences during their Infant's Transition from Neonatal Intensive Care Unit to Home: A Qualitative Study

### Abstract

Limited literature exists which examines how parents of infants hospitalized in the Neonatal Intensive Care Unit (NICU) transition from their infant's NICU hospital stay to home. This study examines the question, "What are the experiences of parents during their infant's transition from the NICU to home? Grounded theory methods served as the paradigm to explore twelve NICU parents' experiences during their infant's transition. The basic social psychological process identified was "becoming a parent" which was based on the core problem "I'm not a parent." Analysis of data contributed to a model described by the researchers as the resultant Model of Parental Progression that describes how the parents proceeded through their experiences of their infants' transitions from the NICU to home.

### Keywords

NICU Parents, Transition, Parenthood, Qualitative Research

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## **Parents' Experiences during their Infant's Transition from Neonatal Intensive Care Unit to Home: A Qualitative Study**

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*Limited literature exists which examines how parents of infants hospitalized in the Neonatal Intensive Care Unit (NICU) transition from their infant's NICU hospital stay to home. This study examines the question, "What are the experiences of parents during their infant's transition from the NICU to home? Grounded theory methods served as the paradigm to explore twelve NICU parents' experiences during their infant's transition. The basic social psychological process identified was "becoming a parent" which was based on the core problem "I'm not a parent." Analysis of data contributed to a model described by the researchers as the resultant Model of Parental Progression that describes how the parents proceeded through their experiences of their infants' transitions from the NICU to home. Key Words: NICU Parents, Transition, Parenthood, Qualitative Research.*

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The neonatal intensive care unit (NICU) provides care for both premature and full term infants with medical complications. Parents whose infants receive care in the NICU must adjust not only to the unexpected complications of their infant's birth, but also the highly technical environment of the NICU (Rapacki, 1991). Unlike parents who have an infant without health complications, parents of infants hospitalized in the NICU must forgo their expectations of what constitutes a normal birth experience (Ahmann, 1996).

Early research indicates that parents of healthy term infants and parents of premature infants must adjust to the new restrictions on their freedom and independence, (Goldberg & Michaels, 1988; Trause & Kramer, 1983). The difference, however, between the two groups of parents (parents of infants in the NICU and parents of well infants) might be explained by the prolonged duration of the transition from hospital to home. For instance, an extended hospitalization of an infant admitted to a neonatal intensive care unit (NICU) may alter the normative process of transition to parenthood (Odom & Chandler, 1990). As one mother described her experience, "They had taken my baby away. My husband was concerned I wasn't going to be close to her. The nurse took a Polaroid picture. I felt empty. There's no baby, just me."

Early works which examined the transition experience of parents of premature infants investigated the parent's experiences after the infant's discharge from the hospital

and how the parents transitioned once home (Able-Boone & Stevens, 1994; Affleck, Tennen, Rowe, & Higgins, 1990; Kenner, 1988; Kenner & Lott, 1990). These studies employed both qualitative (Kenner, 2007; Kenner, 1988) and quantitative (Affleck et al., 1990) methods as the means for understanding the parents' experiences during their infant's hospitalization. However, the studies were conducted after the infant's discharge to home.

Erdeve et al. (2008) explored the correlation amongst maternal presence, parent participation in the NICU infant's care and the occurrence of re-hospitalization of the infant after discharge from the NICU and found increased maternal presence and parent participation correlated with lower re-hospitalization of an infant discharged from the NICU. An earlier study conducted by Browne and Talmi (2005) examined how guided educational interventions could change maternal knowledge and behaviors and reduce stress. Their study concluded that educational interventions provided for the mother prior to the infant's discharge was effective in increasing knowledge, changing maternal behaviors and decreasing maternal stress. Their finding was consistent with Fowlie and McHaffie (2004) who concluded appropriate support helps to reduce parental stress while the infant is hospitalized in the NICU. A separate study conducted by Teti, Hess, and O'Connell (2005) investigated the effect on maternal adaptation on parental perceptions of child vulnerability. They concluded that the manner in which mothers adapted to their preterm infant and the mothers' feelings of efficacy regarding competence in feeding their infants predicted whether or not the mother perceived the infant as vulnerable to illness or injury. Broedsgaard and Wagner (2005) recognized the importance of understanding the preterm infant's family's situation and investigated Danish parents' experiences on the pathway from the birth of a premature infant to the transition home. What they learned was mothers of premature infants felt they needed special care to address the new situation of a premature infant and were frustrated when placed on the same hospital units as mothers of full term infants which separated them from their infants. Furthermore, Broedsgaard and Wagner indicated the "re-establishment of the family of the premature infant should begin at the premature infants birth (p. 201)" and that nurse coordinated interventions were effective in meeting the needs of mothers of preterm infants.

Understanding the parents' experiences within the context of their infant's transition from the NICU to home is necessary for improved health outcomes for both the parent and infant (Broedsgaard & Wagner, 2005; Chick & Meleis, 1986). However, limited literature exists which examines the transition process during the infant's hospitalization (Jackson, Ternstedt, & Schollin, 2003; Shin & White-Traut, 2007). Examining the parents' experiences as they exist during transition from NICU to home is necessary to promote positive experiences for parents of NICU infants. Thus, the intent of this study was to develop a theory based on parents' perceptions that would provide a more thorough description of how the parent of an infant hospitalized in the NICU proceeded through the transition process.

Chick and Meleis (1986) described transition as a "passage from one life phase, condition, or status to another, and embracing the elements of process, time span, and perception" (p. 239). The characteristics of transition include: (a) the movement from one phase to another (b) the disruption due to the loss of an expectation (c) the perception because of individualized meaning, and (d) the response to the transition. The transition

process occurs in three phases, entry, passage, and exit. Each transition is either situational (beyond the individual's control), a result of a disturbance in the health-illness continuum, or developmental (naturally occurring). (Chick & Meleis, 1986)

Time span, an element of transition, begins with the anticipation of the transition and continues until the establishment of a new view or perception of the individual's world. For instance, an infant's admittance to and discharge from the NICU is an example of transition. What occurs during the passage, or period of time between admission and discharge is important as these experiences and the meanings attributed to them by the parent help illuminate the transition process as seen through the parent's eyes. This information is important to healthcare professionals who provide care for both the hospitalized infant and their parents. The parent's perceptions can provide direction in preparing educational materials which prepare the parent for the NICU experience, as well as the subsequent discharge of their infant home. Sneath (2009) asserts there is "a [further] need for more research into parent perceptions of their preparedness for their infant's discharge" (p. 245).

The duration of the transition is variable, but the phases are not. Individuals in transition must restructure a new reality. Schumacher and Meleis (1994) theorized that although the elements of transition are universal, the individual's perception of the transition greatly influences how each individual experiences the restructuring of his/her world. The ideal time therefore to examine the transition experiences a parent of an infant hospitalized in the NICU is not after discharge, but during passage when parents are more apt to recall the daily experiences and their preparedness for discharge home. For the purpose of this study transition began with the infant's or neonate's admittance to the NICU and ended three weeks after the infant's discharge from the NICU to the home.

## Methods

The primary research question in this study was "What were the experiences of parents during their infants' transition from the NICU to the home setting?" Because existing literature that explored parents' experiences of transition from NICU to home was limited to retrospective studies, a deeper understanding of parents' NICU transition experience *during* their infant's hospitalization was needed. Thus, a grounded theory design (Glaser & Strauss, 1967, Strauss & Corbin, 1998) was chosen since this approach is appropriate when little is known about an existing phenomenon or to gain a new perspective on a similar situation (Stern, 1980).

Several schools of thought prevail regarding grounded theory methodology (Charmaz, 2010; Glaser & Strauss, 1967; Strauss & Corbin, 1998). However, the primary author ascribes to the pragmatist view in that the parents of infants in the NICU had a story to tell and the context of the transition experience itself was the key to understanding the meaning the parent attributed to their experience. The primary author also believed the information learned from the parents' stories would be beneficial in providing services for future NICU parents. Therefore, the primary author selected Strauss and Corbin's (1998) grounded theory methodology as Strauss and Corbin believe theory evolves from the data based on the researcher's construction of theory based on the interpretation of the participant's story. An additional assertion by the primary researcher was in the absence of the context of the transition passage, the parents would

lose some of their contextual experiences to time and the richness of their true experience would be marginalized (Munhall, 2007).

The impetus for this study grew out of the primary author's experience as a staff nurse on an Intermediate Care Nursery Unit, a hospital unit for premature and full-term infants who required more intensive health care than typical full term infants or less care than those admitted to the NICU. Part of the author's responsibilities included preparing parents for their infant's discharge to home. Discharge also included making a subsequent follow-up phone call to determine how well the infant and their parents had adjusted to being home. The questions parents asked were often surprising especially when the topic was covered in depth before the infants were sent home. Therefore, the primary author undertook this study to discover what could be done differently to enhance the parent's transition from hospital to home.

### **Ethical Considerations**

Prior to gaining access to the hospitals, the study received approval from all participating hospitals and the University's Committee on the Use of Human Subjects. All participating hospitals required approval from the University's Human Subjects Committee before considering the study. In addition to approval, the hospitals required that the Director of Nursing and the NICU nurse managers received the research protocol and consent form. An in-service was also provided for the staff nurses who worked in the NICU. The hospital which employed the primary author was excluded to avoid bias and ethical considerations.

Three hospitals' NICUs (NICU-A, NICU-B, and NICU-C) were selected as sites for recruiting parents for the study. Hospital selection was based on existing hospital policy related to interviewing of parents whose infant was hospitalized. All NICUs were located within different geographical locations of a major southern metropolitan area. One NICU was a regional facility and would yield parents with different experiences. The difference between the regional and non-regional facility was the regional facility did not have a labor and delivery unit and therefore mother and infant would be in separate facilities immediately following the delivery of their premature infant. As such, mothers would have to wait until their discharge prior to visiting their infants. Also, fathers would have to visit the mother in one facility and the infant at the regional facility.

#### **Gaining Access**

The processes for gaining entry to the NICU and staff of the three facilities used in this study were similar but different. Prior to beginning the study the Director of Nursing gave approval and identified the NICU nurse manager as the contact person to access the staff. All hospitals required a copy of the University approved protocol and that monthly updates regarding enrollment of parent participants be provided to the NICU manager. The contact person oriented me to the NICU and introduced me to the staff nurses. Additionally, the nurse manager for NICU-A and NICU-B required that I do a formal staff in-service regarding the study's purpose and develop a "Nurses' Fact Sheet" so all nurses would be aware of my purpose and presence in the unit. However, the third facility (NICU-C) required that the primary investigator meet with the Director of Nursing Education first before meeting with the NICU nurse manager. The third facility did not require a formal presentation, but instead, the primary investigator placed the

“Nurses’ Fact Sheet” in the NICU-C “Communication Book”, the unit’s primary means of communication.

### **Informed Consent**

The consent form was read in its entirety for all parents who participated in the study. This measure addressed the possibility of enrolling a parent who may have had reading difficulties. Parent anonymity and confidentiality issues were discussed in the consent form. Furthermore, the parent understood participation was voluntary and they could stop participation in the study at any time without any repercussions. Once the parent consented to participate, the parent chose a pseudonym to identify them and their infant.

In addition to informed consent, process consenting was used to minimize harm to study participants. Process consenting provided “immediate renegotiation of the consent as circumstances changed or unexpected events occurred during the interview” (Kavanaugh & Ayers, 1998, p. 93). The use of process consenting provided the parents with an immediate form of therapeutic intervention and rest during the interview. Process consenting also allowed the participant to proceed with the interview at a pace that allowed topics to easily emerge. The primary author employed the following measures when parents displayed signs of emotional distress (e.g., crying, prolonged silence) during the interview:

1. Asked the participant if they were capable of continuing with the interview.
2. Took a break from the interview.
3. Stopped the interview, and resumed at a later date.
4. Referred the parent(s) to staff nurses for information or the need for social support services.

### **Recruitment**

Parents received notification of the study by means of a “Parent Notification” letter affixed to their infant’s isolette, radiant heat warmer, or crib. The “Parent Notification” letter briefly stated the intent of the study and provided background information regarding the primary author including a number at which the primary author could be reached for further information. Posting of notification letters occurred on a weekly basis. Parents who were interested after the initial phone call made arrangements to meet with the primary author during their next visit to the NICU. At the initial meeting, informed consent was obtained, and parents chose a pseudonym for themselves and their infants

Recruitment of parents occurred in a similar manner for all NICUs. However, after six months of posting parent notification letters only three parents, (one couple and one mother) were enrolled. Brainstorming with the second author led to a revision of the notification letter which informed potential participants that the primary author was a registered nurse who previously spoke with several other parents regarding their NICU experience this resulted in an increased response. Also NICU-A provided the primary



author with hospital envelopes for the posting of the parent notification letters. This measure symbolized the official support of the hospital and could account for the greater number of participants being enrolled from NICU-A.

### Sample/Participants

Twelve parents (nine mothers and three fathers) participated in the study over a 10-month period. Six of the parents were Caucasian, four were African-American, and one was Hispanic, and one Italian. The three fathers included were spouses of the mothers. The age of the parents ranged from 19 to 41 years. The parents were from diverse racial and educational backgrounds with the majority of the parents being Caucasian ( $n = 6$ ) and primary educational background was a high school diploma. Two of the parents had more than one infant in the NICU (see Table 1).

Table 1. *Parents' Demographics*

Ethnicity	NICU	Age	No. Of infants in the NICU	Marital Status	Education
Caucasian	A	41	1	married	4-yr college
Caucasian	A	42		married	4-yr college
Caucasian	A	-	2	married	4-yr college
Caucasian	A	19	1	married	high school
Italian	A	21		married	high school
Hispanic	A	28	1	married	graduate school
Caucasian	A	38	1	married	4-yr college
African-Am	B	25	1	single	some college
African-Am	B	23	3	single	high school
African-Am	C	28	1	married	high school
African-Am	C	29		married	high school
Caucasian	C	20	1	single	high school

### Data Collection

Data collection occurred through interviews and field notes over a 10-month period.

**Interviews.** The number and duration of the parents' interviews depended on the parents' willingness to talk and the length of the infants' hospitalization. The number of interviews ranged from one to nine interviews per infant family with the average interview time of 45 minutes. Two mothers participated in only one interview due to the infants' transfer to another facility or difficulty in coordinating meeting times. Each of their interviews was 30 minutes in duration. Each interview was transcribed and analyzed before the next interview enabling the primary author to explore relevant concepts in later interviews. Saturation was achieved when variation in data themes were understood and no new themes occurred.

The interview consisted of open-ended questions designed to elicit the parents' personal experiences. The interview began with the following statement: "Tell me the story of how your baby came to be in the NICU." Parents answered follow-up questions based on responses to preceding questions and prior interviews. Follow-up questions permitted further exploration of the parents' experiences during their infants' transition. Examples of follow-up questions were:

"Who else is going through this experience with you?"

"Tell me about your relationship with the NICU staff."

"How do you feel about your baby remaining in the NICU after you were discharged from the hospital?"

"What has happened to you since your baby came home from the hospital?"

**Field notes.** As previously stated, the primary author recorded field notes regarding the NICU environment including physical layout, and the parents' non-verbal behaviors during the interviews, staff interactions, and parent-infant interactions. Field notes consisted of observations of the settings in which the interviews occurred, memos regarding parents' non-verbal behaviors, nurse-parent interactions, interactions between NICU staff members, and the daily routines. Initial observations of the NICU daily routine occurred one week before the enrollment of participants. The goals for the initial observations were: (a) To establish a relationship with the staff and key nurse liaisons; and (b) To gather concrete data related to the physical layout of the unit, staffing schedules (change of the nursing staff shift), doctors' rounds, and patient care routines. These observations occurred over a five to seven day period, including weekend days. The observations occurred between the hours of 8:00 am – 8:00 pm. Further observations of the unit's activities occurred weekly during the posting of the parent notification letters, or at the end of a parent's interview. Field notes also included memos about the primary author's feelings, drawings of the NICU settings, and descriptions of observations made as the participants interacted in the NICU.

**Data analysis.** Analysis of data occurred through the use of the constant comparative method of data analysis (Strauss & Corbin, 1998). This method involved analyzing each interview and field notes for recurrent themes and codes prior to the next interview and comparing newly obtained data to codes identified from the previous

interview transcriptions. The primary author transcribed audio tapes the same day of the interview after leaving the NICU. Missed probes and unclear statements were addressed at follow-up interviews. This process generated primary codes and subcategories for both the NICU settings and the parents' experiences. Primary categories for the NICU setting addressed the physical features of the NICU and the NICU's policy regarding visitation, boarding, and the healthcare providers who provided care.

Analysis of interviews began with the enrollment of the first two parents, a mom and dad for the same infant. Initial categories generated from open coding of the parents' transcripts for the parents' experiences were emotions, events, and staff interactions. The two primary parent experience codes (emotions and events) were later subdivided into six subcategories with even further division. Subcategories generated for emotions were: concern, joy, and guilt, lack of control, emptiness, and spirituality. Subcategories generated for the category events were: premature birth, NICU Admit, health status, parenting activities, discharge, support, readmission, and death.

These categories and subcategories were then placed within an event flow diagram and time-ordered meta-matrix for each parent to discover when the parent's experiences occurred. The event flow diagram provided the authors with a better understanding of the process of each parent's experience (Miles & Huberman, 1994). Meta-matrices helped identify recurring patterns and themes across all parent experiences. Time-ordered matrices developed for each parent showed events listed chronologically and how parents, infant, staff, and hospital policy related to the emotions and events as they occurred. The time-ordered matrixes also provided the authors with an understanding of the flow and connection of events (Miles & Huberman, 1994). Through the time-ordered matrixes the primary and second author identified that each parent experienced the early or premature onset of becoming a parent to the infant hospitalized in the NICU, a feeling of incompleteness due to not being able to hold their infant, a time of greater involvement or participation in the care of their infant, and an end or completion of their infant being hospitalized in the NICU.

Thematic analysis and theory development originally led to the development of the theory of maternal absence since it appeared that the mothers were having difficulty associated with being separated from their infants. However, this preliminary theory did not explain the father's experiences. Data collection and analysis continued and it appeared the theory evolving was the theory of *parental completion*. Further theoretical sampling and discussion with the other authors resulted in the theory being appropriately labeled the *Model of Parental Progression* which was more reflective of the data and the movement of time. This progression from onset to completion occurred in four distant phases, which permitted the categorizing of emotions and events experienced by parents during the transition process. Progression of events were in the forward direction, followed the same sequence, but not the same length of time. Though different experiences occurred within each phase, overlapping did occur. The phases were Premature Parental Onset signaled by birth of the premature infant and admittance to the NICU; Parental Incompleteness characterized by not being able to bond or hold the infant; Parental Involvement began with being able to touch and hold the infant, and Parental Completion, the infant's discharge from NICU to home.

**Validity and reliability/rigor.** This study addressed validity based on Maxwell's (1996) framework of descriptive, interpretive, and theoretical validity in qualitative research. The methods used were as follows: (a) audio taped all interviews along with simultaneous note taking during the interviews, (b) transcribed all audiotapes and replayed the tapes once for accuracy, (c) read all transcripts for inconsistencies and then clarified with the audiotape, and (d) maintained handwritten field notes on the observations of the staff, the parent's interactions with their infants, and the NICU settings.

Member checks confirmed whether or not interpretations of parents' statements were accurate. Parents had the opportunity to review their transcripts at the next visit to the NICU. The final transcript was mailed to the address provided. Six of the parents responded and mailed back their corrections of their stories which consisted mainly of missing birth weights and date of births. The parents who did not respond had either moved and left no forwarding address (one parent), or simply did not respond (the remaining five). A single attempt at follow-up did not yield any response. Descriptions of the characteristics of all three NICUs were mailed to each unit manager or supervisor for verification. The only corrections made were the number of staff nurses employed and the number of NICU patient beds.

The use of peer review process helped allay possible biases interjected unknowingly by the primary author during analysis. Three doctoral candidates (one nursing and two special education candidates) familiar with qualitative data analysis coded five excerpts from five different parent participants' transcripts. Peer reviewers had no prior knowledge of existing codes, and they did not communicate with each other during the peer review process. Each peer reviewer's identified codes were then compared to other peer reviewers' codes and codes previously identified by the primary author. All peer reviewers identified the "I am not a mom" or "I am not a parent" theme.

## Results

*What were the experiences of parents during their infants' transition from the NICU to the home setting?* The experiences of the parents in this study occurred in one of four phases which describe how the parent proceeds through the transition from having an infant admitted to the NICU until the infant's discharge home.

### Phase I - Premature Parental Onset

The mothers' premature birth event signaled the onset of the NICU transition experience for both the infant and their parents. Eleven of the parents had infants delivered prematurely. These parents experienced fear, hysteria, awe, emptiness, spiritual change, and a concern about death. For instance, Mrs. B., a 38-year-old first-time mother, described the onset of her transition experience: "Even though I knew that my water bag had broken, I wasn't prepared for them to tell me [I would deliver]. I was just scared to death. I was just in tears. I asked, can't you stitch me up? It's too early. I want to go home."

The infant's or mother's health status determined whether or not the parents could hold their infants in the delivery room. Only three of the parent participants held their

infants while in delivery room. For those parents who did not hold their infants, the absence of bonding generated much concern. One mother stated, “I only got to kiss his lil’ forehead....” and began crying before she completed her sentence. Another mother who did not bond at delivery voiced concern as to whether the infant would know her. She noted, “They had taken my baby away. My husband was concerned I wasn’t going to be close to her. The nurse took a Polaroid picture. I felt empty. There’s no baby, just me” (see Table 2).

Information provided to parents by healthcare professionals during the Parental Onset phase also produced consequences such as concern for the infant’s development and death. “They [healthcare professionals] went through the whole scenario. They assured me my baby would survive. I don’t want a survival! You know you have high hopes and dreams for your child. Everybody does, I don’t want a survival baby.” While another mother’s experience caused her to wonder if her baby “was going to survive.”

## **Phase II - Parental Incompleteness**

Parental Incompleteness involved the parent’s first visit to the NICU, the parent’s inability to hold his/her infant because of the infant’s health status, the mother’s discharge home without the infant, and staff interactions. These influencing factors resulted in the majority of parents having the revelation that their infant’s survival was the result of God’s intervention. A source of concern for the majority of parents was the initial visit to the NICU. During the initial visit, parents learned that their infant’s health status would determine whether or not the parents could hold their infant. Ten of the parents who visited the NICU for the first time could not hold their infant. This experience created a hardship for most. The parents’ reflections follow:

Mrs. R. “I had headaches for two days [after the visit]. They were hooked up to so much stuff. I just couldn’t take it. So much tension, I was in pain.” Mrs. A., “I didn’t look at the monitors. I just looked at my baby. I guess they [nurses] explained it to me.” Ms. S. reflected “It was hard sitting there and not being able to hold him. [You wonder] are they [the nurses] taking care of him?”

Another difficult experience for the parents was the mother’s discharge home without the infant. It is this experience that produced the feelings of “not being a parent.” The five mothers and one father who verbalized these feelings also felt guilty and depressed. Mrs. A. stated, “I told my husband, I shouldn’t be congratulated. I didn’t feel like a mom... going home without them [twins].” Mr. H. felt similarly, “I wondered, will she blame me for leaving her [his infant daughter in the NICU]? I haven’t had a chance to be a dad yet.”

Ms. J., the one parent who had a full-term infant and subsequent rooming-in experience after the birth of her infant, did not have this experience. At Ms. J.’s discharge from the hospital, her infant accompanied her home, but was readmitted to the hospital after being home two days. Her first visit to the NICU evoked feelings of hopelessness and helplessness. She stated, “I just felt helpless. I couldn’t do anything. Hopeless and helpless, that’s what I felt. I never felt like I wasn’t a mom” (see Table 2).

## **Phase III - Parental Involvement**

Parental Involvement was the phase with the most parent-infant interaction. Characteristics of this phase consisted of the parents' increased involvement in their infant's care, setbacks in the infant's health status, and the restricted parent visitation. These influencing events produced emotions of ambivalence, nervousness, fear, joy, and lack of control.

Table 2. *Influencing Factors (Events) and Consequences (Emotions) during the Phases of Parental Progression*

Events	Emotions
<b>Phase I Premature Parental Onset</b>	
Birth experience	Fear, hysteria, awe, uncertainty, spiritual change
Health status	Concern about death
<b>Phase II Parental Incompleteness</b>	
Lack of Bonding	Emptiness
First NICU visit	Surprise, upset, reference to God
Couldn't hold infant	Sadness, upset, guilt, disappointment
Mom discharged without infant	I'm not a mom or dad, sadness
<b>Phase III Involvement</b>	
Holding infant for first time	Ambivalence, nervous, joy
NICU Visitation policy	Anger, lack of control, frustration
Parenting	Fatigue/insomnia
Health status setbacks	Devastation, concern
<b>Phase IV Completion</b>	
Rooming-in	Surprise
Discharge	Joy, surprise
Being home	I'm a parent, fatigue, immobility, change in social life

As the infant's health stabilized, parents held their infants for the first time. This was a joyous experience for most parents. Mr. L. recalled their first experience with holding their infant: "We held the baby in our arms for the first time after he had been off the ventilator. [My wife] looked up at me and said I can't see the baby. She had so many tears in her eyes." Ms. S., on the other hand, was fearful: "I thought, [what] if I were to make the wrong move, I would seriously hurt him." The more stable the infant's health status, the more parents participated in their infant's care. However, the progression was not always smooth.

Some infants had setbacks or regressions in their health status. For example, one infant had begun oral feedings, only to have those feedings stopped because of gastric problems. One parent whose infant developed a pulmonary hemorrhage recalled, "Dr. M.

called us and told us about it and said, you do realize that if this occurs again, she could die, which was [a]devastating [statement to make] to us.”

The NICU visitation policy also produced events that created emotional consequences for the parents. Two of the NICUs had restrictive visitation policies. Parents were allowed to visit with their infants only during certain hours and only if there were no other complications, such as a new admit or another infant’s sudden change in health status. This restrictive visitation policy resulted in parents’ limited interactions with their infants. For instance, Mrs. A. stated, “I just told my husband it sucked! I can’t see my babies when I want to. I had no control.”

The NICU that had a flexible visitation policy allowed parents to visit their infants at any time. Ms. Sam’s following statement summarized the parents’ feelings regarding visitation: “I’m always here, holding him, feeding him, rocking him, changing his diaper. There’s no chance of me not feeling like a mom” (see Table 2).

#### **Phase IV - Parental Completion**

Parental Completion was the final phase of the parents’ transition experience. In Phase IV, parents or mothers roomed-in with their infants, the infants were discharged from NICU to home, and parents reestablished their home routines and acquired community services for their infants. In some instances, infants were readmitted to the hospital, and unfortunately in one instance, an infant died. These events produced joy, fatigue, frustration, and fear.

For instance, those parents who experienced rooming-in felt they were not prepared to room-in. Ms. A. recalled the discharge of one of her twins: “We knew we’d bring one home before the other, but we weren’t ready. We had to go get things ready, and that’s when those emotions came in--excited, nervous, sad.” Mrs. B. objected to the lack of advance notice. She reported, “[About] 12 o’clock noon, [the nurse] said, you have to room-in tonight. And I said, No. We can’t. We are not prepared. We are not doing it [rooming-in]. It’s too hectic.” Other mothers also complained about the lack of notification regarding the actual date of their infant’s discharge. One mother was at the hair salon, and a family member was informed of her infant’s discharge.

Even Ms. J., who did not have a premature infant in the NICU, had a similar experience at discharge. She thought the actual date was a week later, and reminded the NICU staff nurse that she was supposed to room-in.

Once home with their infants, parents expressed “feeling like a mom” or “feeling like a dad.” Parents established routines for caring for their infants and their home lives, identifying when to sleep or how to make arrangements for “an evening out.” Mrs. A., the mother of twins, had mixed feelings. She stated, “I felt like I had to split my whole being in half. Like I had to be one mom here [referring to hospitalized twin] and one mom at home [referring to discharged twin]. I feel like a mom more [with discharged twin] because I’m having an everyday routine at home with her [discharged twin].

Establishing home routines also included adjusting to a home cardiac monitor that parents indicated limited their infant’s mobility. Parents described the difficulty associated with moving an infant from place to place with a cardiac monitor. Mrs. B. stated, “Just to pick him up and move into another room is more difficult. You tend not to hold him as much, unless you are just sitting down for a long period of time.”

Parents also experienced the frustration associated with not being able to locate needed medication and the fear associated with the infant's readmission. Mrs. J. experienced frustration in locating a pharmacy to fill her infant's prescription. She stated, "I couldn't get her Catapril at the drugstore [rural community]. I called back to the hospital and they couldn't help. My baby needs her medicine. I had to drive 15 miles [each way] to get her medicine (see Table 2)."

The Model of Parental Progression depicts how the parents of infants discharged from an NICU proceed through their infants' transition from the NICU to home. The core variable identified was "becoming a parent". The variable was not gender specific as both the mothers and one father identified with "becoming a parent". As illustrated in Figure 1, the four phases of transition--Premature Parental Onset, Parental Incompleteness, Parental Involvement, and Parental Completion--overlap. Within each phase, there were influencing factors or events that explained the parents' resultant consequences (emotions). The horizontal line representing emotions extends the length of all four phases with downward arrows representing the impact of the influencing events on the emotional consequences which also extends throughout the four phases and is represented by the lower horizontal line. The phase with the most parent-infant interaction, Parental Involvement, is signified by the larger size of the third overlapping circle. In moving through this experience, parents proceeded from not feeling like a parent while separated from their infants to being a parent once the infants were home (see Figure 1).

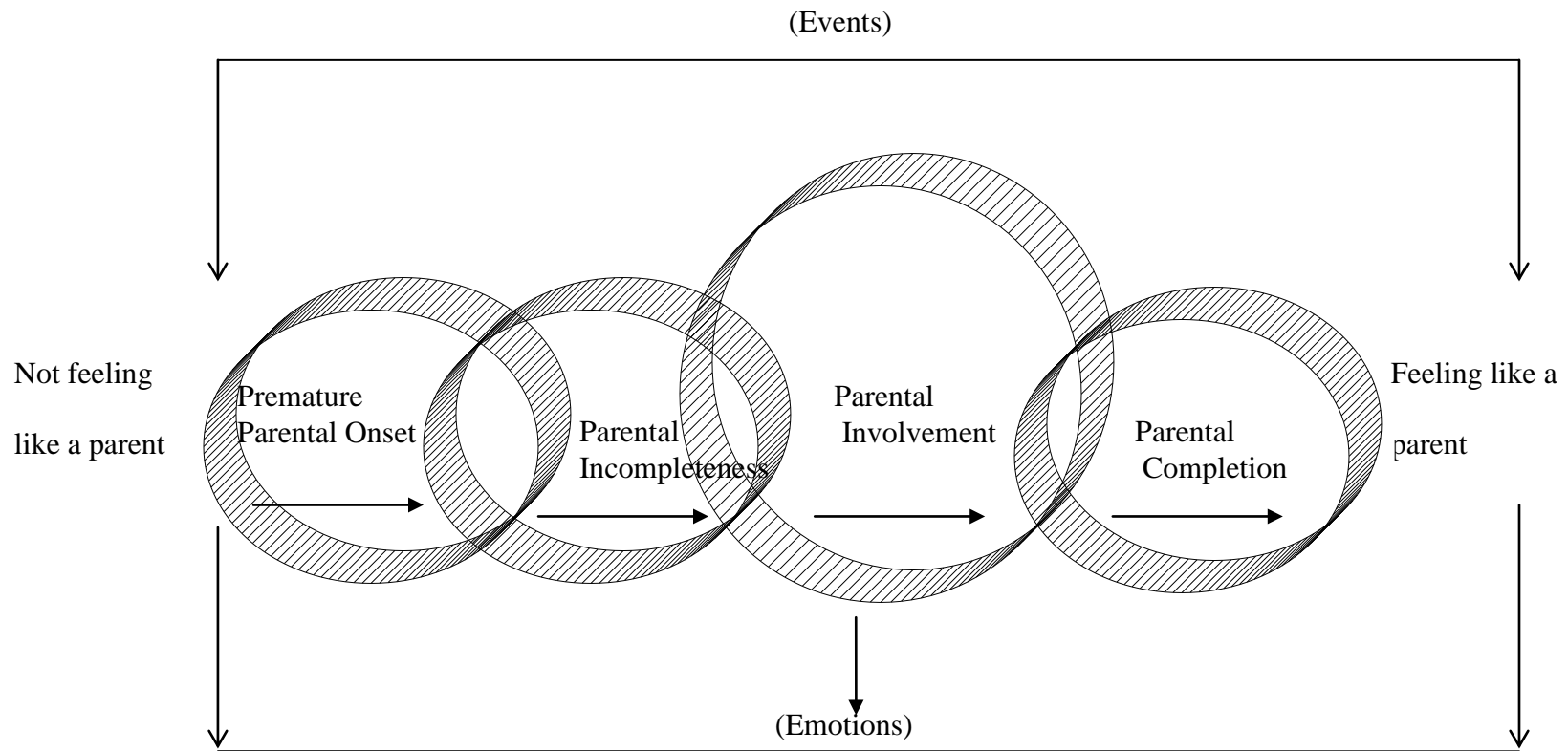
## Discussion

A limitation of this study is that the Model of Parental Progression is applicable only to the parents of infants discharged from an NICU who transition from the NICU to home. The study is also limited by the small number of participants. A third limitation was the limited number of interviews by two of the mothers and only one father consented to participate in the study. Notwithstanding the limitations of the study, the findings provide important insights into parents' experiences during their infants' transition from the NICU to home.

### Phase I - Premature Parental Onset

This study found the major events which occurred in the Premature Parental Onset Phase were the mothers' premature birth event and the ability to hold or not to hold their infants immediately after birth. Shin and White-Traut (2007) found similar findings in their study which employed "Rodgers' evolutionary method and Schwartz-Bartcott & Kim's Hybrid method" (p. 95) for their concept analysis of transition in Korean mothers of NICU infants. What Shin and White-Traut found was the unexpected outcome of pregnancy and mother-infant separation were antecedents to transition. In the context of Shin and White-Traut's study, the mothers in this study premature birth event and their ability or inability to hold their infants served as the antecedents to the parents not "feeling as though they were a parent" of the premature infant.



Figure 1. *The Model of Parental Progression's*

Four phases: Premature Parental Onset, Parental Incompleteness, Parental Involvement, and Parental Completion. Influencing factors (events) and subsequent consequences (emotions) help parents transition from not feeling like a parent to I'm a parent.

Mothers from both this study and Shin and White-Traut (2007) began to transition with their infants from the NICU to home, but the mothers in this study also transitioned from not feeling like a parent to being a parent. The unexpected premature birth is also supported by Jackson, Ternestedt and Schollin's (2003) study which described parents of infants hospitalized in NICUs experiences of parenthood during the infants' first 18 months of life.

McCubbin (1999) suggests a premature birth experience is an "off time" event. The off-time event occurs at the beginning of the transition experience and creates disorganization and confusion as the parents began to deal with the unexpected changes. Powell and Wilson (2000) found that parents described having experiences of wanting to see their babies, as the birth experience did not seem real. These assertions support this study's findings that parents began their premature birth experience "not feeling like a parent." The birth experience was not to have occurred in this manner. Parents expected to bond with their infants immediately after delivery, an expectation also supported in the literature (Brazelton & Cramer, 1990). Additionally both this study and Jackson et al. (2003) found staff interactions were a major factor for NICU parents. Jackson et al. found their parents interacted with staff for information, "the need to know", and the Kenner Transition Model (Kenner, 2007) places parents' information needs at the core of parents' experiences. Similarly, this study's findings found staff interactions were also a major influencing factor during the Premature Parental Onset phase, and staff interactions produced, for some parents, feelings of concern regarding their infant's future.

## **Phase II - Parental Incompleteness**

This study found that three main events occurred during the Parental Incompleteness phase: (a) parents' first visit to the NICU, (b) parents' inability to hold their infant for the first time, and (c) mothers' discharge home without their infants. These main influencing factors created feelings of sadness, guilt, and "not being a mom or dad." The initial visit to the NICU served as a confirmation that the parents actually did have a baby. Parents were overwhelmed by what they saw during the first visit. The infant's size was not what was expected or the amount of equipment attached was intimidating. Miles (1986) and Rapacki (1991) reported that parents were overwhelmed by the NICU environment and the appearance of their premature infants. After the mother's discharge without the infant, parents experienced "not feeling like a mom or dad." Shin and White-Traut (2007) found the mother-infant separation served as an antecedent of "transition to motherhood in the NICU" and "delayed motherhood" was a consequence of the transition experience. However, Jackson et al. (2003) held the assumption parents of infants hospitalized in the NICU were already parents in that they began their parent interviews with the request for parents to "Please tell me how you think it feels to be a parent" (p. 122).

During the phase of Parental Incompleteness, parents could not hold their infant because of the infant's fragile health. Similarly, Jackson et al. (2003) also found the mothers' experience of alienation, the mothers' discharge home and being able to hold the infant were important events during the parents' NICU experience. Furthermore, Jackson et al. also found parents in their study felt the need to participate in the infant's

care during their feelings of alienation. Alienation was not a theme identified in the current study.

### **Phase III - Parental Involvement**

Parental Involvement, the third phase, is the period of greatest activity. In this phase the primary influencing factors which produced emotional consequences were: (a) the parents holding their infant for the first time, (b) fluctuations in the severity of the infants' health, (c) increasing parental involvement in caring for their infants, and (d) the parents' lack of control over visitation to the NICU. These pivotal events signaled the parents' further transition in assuming their roles as parents. The parents' ability to hold their infant signaled not only an improvement in the premature infant's health, but the fulfilling of their expectations of the parental role. As the parents assumed a more active role in caring for their premature infant, anger and frustration occurred when visitation policies took away their ability to continue the transition to the role of a parent. Fenwick, Barclay, and Schmied (1999) reveal that even though "the presence of mothers in the [intensive care] nursery is high, nurses remain the primary caretakers [of premature infants]" (p. 53). Both Shin and White-Traut (2007) and Jackson et al. (2003) support this finding as findings from their studies also revealed the ability to hold the infant was a major turning point in the parents' NICU transition experience and signaled the beginning of increased parental participation in the infant's care. However, findings from other research also identified "mothers' need for information during their infant's stay in the neonatal unit was considerable because there had not been enough preparation to absorb the information they were presented with earlier in the process" (Broedsgaard & Wagner, 2005, p. 200), a finding not attributed to the present study.

### **Phase IV - Parental Completion**

The fourth and final phase, Parental Completion, occurred when the infant was discharged from the hospital to the home setting. The infant's discharge fulfilled the parents' expectations of bringing their infant home after birth. Parents reported that "they were now a parent." Parents were now complete parents and capable of making decisions about the daily care of their infants. Once home, parents began the work of establishing a home routine and adjusting their social lives to accommodate their infants. Available literature informs the findings of the fourth and final phase, Parental Completion, in that the adjustments that occur in this phase suggest a disconnectedness with the NICU experience and the beginning establishing home routines without the presence of NICU staff (Broedsgaard & Wagner, 2005; Shin & White-Traut, 2007; Jackson, et al., 2003; Chick & Meleis, 1986).

### **Conclusion**

The significance of this study's findings is its contribution to knowledge in the form of a conceptual model with relevance to parents' experiences during their infants' transition from the NICU to home. The study serves as a guide for nurses and healthcare professionals who assist parents of infants in the NICU to complete the transition to

parenthood. Parents progress from “not being a parent” to “being a parent.” While existing literature reports the parents’ transition as progressing from alienation to familiarity and confirms the parents’ transition is a time-dependent process that hovers around motherhood (Shin & White-Traut, 2007), available literature does not acknowledge that parents of infants hospitalized in the NICU do not feel as though they are parents to the infant.. It is important that healthcare providers understand parents’ feelings during the transition from NICU to home as the parents’ perceptions and experiences subsequently can and do influence how they interact with their infants including receptivity to participating in the care. Furthermore it is important for healthcare professionals to understand that not feeling as though one is a parent influences parent attachment and compliance with healthcare requests. Healthcare professionals also need to be aware that staff perceptions of when parents of infants admitted to the NICU achieve parenthood are dependent on the parents’ experiences. While this study explored primarily the experiences of mothers of infants hospitalized in the NICU, other members were also affected. Knowledge of the parents’ perspective will help nurses and other healthcare professionals better understand the dynamics of the parents’ interactions in neonatal intensive care unit, permitting appropriate effective discharge planning and the fostering of family centered care. Further research which addresses transition within the context of families of infants in neonatal care unit is warranted.

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