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## Integration of Premature Infants into Family Life

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# Integration of Premature Infants into Family Life

## **Cover Page Footnote**

Thank you to Dr. Rosalie Mainous for lending her guidance, input, and expertise to this project. Thank you also to Dr. Belcastro and Dayton Children's Medical Center for being supportive and welcoming of this undergraduate program and permitting this research to occur. -Karen Herzing Wright State University BSN Nursing Student

### Integration of Premature Infants into Family Life

Infant prematurity has been a prevalent problem for countries all around the world, but particularly in developing nations. Surprisingly, even in the United States (US) in 2010, 517,400 infants were born prematurely, at 37 weeks or earlier. This is a prematurity birth rate of 12% of total births and is far higher than the rates of Europe, Canada, Australia or Japan. The study 'Born Too Soon: The Global Action Report on Preterm Birth' that was released in May 2012 ranked the US 131st out of 184 countries, between the Congo and Nigeria, and tied with Somalia and Thailand. This report was compiled with the help of the World Health Organization (WHO) and the Partnership for Maternal, Newborn and Child Health, a non-profit education and advocacy group (Retrieved from [http://www.who.int/pmnch/media/news/2012/preterm\\_birth\\_report/en/index3.htm](http://www.who.int/pmnch/media/news/2012/preterm_birth_report/en/index3.htm) on July 9, 2012.) According to the March of Dimes, Ohio's rate of premature births for 2009 was 12.3%; down from a high of 13.6% in 2006 but still not at the goal rate of 9.6%. Ohio ranks 30<sup>th</sup> out of 52 states and territories (National Center for Health Statistics, 2009) for preterm birth.

Amidst an escalation of premature infant survival, accompanying developmental delays of prematurity have also increased. Premature infants do not provide easily interpreted behavioral cues which create frustration and stress in parents. In turn, this disrupted pattern of communication could possibly further compromise the infant's care. The parents of a premature infant need guidance and educational support as they attempt these initial infant-parent interactions (Bozzette, 2007; Woodwell, 2002).

Further, the amount of time, energy, and financial resources required to take care of a premature infant at home strains the attachment between mother and child. One British study, Spencer (2006), found a correlation between rates of abuse and prematurity regardless of socioeconomic status or maternal age. The study can't explain the findings, but postulates that perhaps premature infants may have characteristics that could provoke hostility in caregivers. Characteristics such as inconsolable crying, more intensive direct care needs, and increased time-consuming and expensive medical interactions all add to parental stress. Lowdermilk, Perry & Cashion (2010) also report that the incidence of physical and emotional abuse is increased in preterm infants or those with high risk conditions when they are separated from their parents. In order to prevent such negative outcomes, Neonatal Intensive Care Units (NICUs) have implemented steps to promote parental bonding with their babies.

In 2009, the Montgomery County Health Department (MCHD) in Ohio reported from 2006-2008, 12.4% of the total number of births in Montgomery County were babies born before 37 weeks gestation or an average of 894 premature babies a year for that period (MCHD Vital Statistics, 2009). Effective

nursing interventions are essential to the promotion of healthy families for this population of the Dayton area.

**Purpose of study:** The purpose of this study is: 1) to analyze family interactions in the present day for families whose babies were preterm and 2) to determine where possible knowledge deficits existed for the parents on how to take care of these babies after they leave the hospital with the hope of informing future parents.

**Research questions:** What are current parent-child interactions for those children that attend the Developmental Assessment Clinic (DAC) and were born prior to 38 weeks gestational age? What are the top three knowledge deficits identified concerning premature infant care?

## Method

**Inclusion/Exclusion Criteria:** The infants/families included in the study delivered a premature infant at less than 38 weeks and are a patient at the Developmental Assessment Clinic at Dayton Children’s Medical Center. This convenience sampling of patients was drawn from those parent-infant dyads attending the clinic held twice a month by Miami Valley Hospital neonatologists and facilitated by Dayton Children’s Medical Center in Dayton, Ohio.

**Study Design:** This was primarily a descriptive non-experimental qualitative study. Initially, an investigator prepared data collection form was filled out to be used in demographic analysis. A 20-minute interview was conducted with each family to evaluate parent-child interactions and collect background information on the mother and her pregnancy. Incorporated in this interview were questions assessing the families’ knowledge deficit, if any, on how to take care of their premature baby and effectively interpret their child’s developmental cues.

**Procedure:** Parents were contacted in person, as they attended the DAC and asked to participate in this study. The occupational therapist informed the patient of a researcher being in the office and asked their permission to have the investigator speak with them. First, demographic data was collected in an investigator prepared instrument. The Baccalaureate nursing student researcher collected data present day about the parents’ and babies’ past experiences through qualitative interviews that were semi-structured and open ended. The quality of parent-child interactions was assessed following interviews with the parents and through observation between parent and child. These interviews were conducted on the hospital premises while babies were attending the clinic. The verbal interview was recorded with a small digital recorder and transcribed into a Microsoft Word document. The document and recording were reviewed 5-10 times each for accuracy. Data were downloaded into a computer and checked for consistency. Tapes were erased following each download. Computer data were encrypted.

**Human Subject Concerns:** Institutional Review Board approval was obtained from Wright State University and Dayton Children's Medical Center through an expedited review process due to the minimal risk involved in this research to the families and infants. Verbal and written consent were procured from the participants in order to have access to medical records for any retrospective data. The verbal interview was recorded with a small digital recorder and transcribed into a Microsoft Word document. The document and recording were reviewed 5-10 times each for accuracy. Encrypted electronic files are being stored in the computer file server, which is password protected as well, at Miami Valley Hospital in the Clinical Research department and patient confidentiality has been maintained. Hard copies of the consent and demographic forms are stored in a locked filing cabinet at the College of Nursing and Health. The student nurse researcher and Dr. Mainous both have CITI certification for Responsible Conduct of Research for Social and Behavioral as well as for Human Subjects. Quality of data gathering was checked for internal consistencies, exactness, and completeness with the assistance of Dr. Mainous.

**Measures:** Interviews were the primary instruments to collect data. Additionally, an investigator-prepared demographic data collection form was completed by the parent or legal guardian. The interview was conducted with each family using significantly modified questions from the *Working Model of the Child Interview* (WMCI), (Zeanah, Benoit & Barton, 1995). The questions evaluated parent-child interactions and obtained background information on the mother and her pregnancy. Also, incorporated in this interview were questions assessing the families' knowledge deficit, if any, on how to take care of their premature baby and effectively interpret their child's developmental cues. The WMCI has demonstrated predictive validity of attachment classifications in a number of studies (Zeanah, 2007; Benoit, Parker et al., 1997; Benoit, Zeanah et al., 1997; Zeanah, Benoit, Hirshberg, Barton & Regan, 1994). This measure has inter-rater reliability of 96%, kappa = .94 (Huth-Bocks et al, 2004).

**Analysis:** Since this study was primarily qualitative, analysis of qualitative themes was undertaken. Interviews were analyzed through the application of Colaizzi's (1978) seven-steps of phenomenological analysis or line-by-line analysis (looking for words and sentences in the text that have meaning). From this analysis, themes were derived and supported by subjects' quotes. Demographic data were collected and compiled to reflect maternal risk factors, APGARs, birth weights, and diagnoses of prematurity.

### Results

Ten families were interviewed with 2 African-American, 1 mixed race, and 7 Caucasian infants. The mothers consisted of 2 African-American women and 8 Caucasian women. Three of the family couples were married and seven were either single or living with their partner. All but one mother had a high

school education. The three married couples were the only ones with college degrees. Maternal ages ranged from 16 to 35 with risk factors including: 3 pre-eclamptic patients, 1 diabetic patient, 2 smokers, and 3 women with previous miscarriages.

The infants’ weights ranged from 665 grams to 1760 grams. Four were born between 23-28 weeks, and the remaining six between 29 and 34 weeks. The infants’ length of stay in the NICU ranged from 3 weeks to 5 months. The infants experienced very similar symptoms of prematurity, almost all having immature retinas, anemia, hyperbilirubinemia, respiratory distress of some kind, and apnea. One infant born at 24 weeks had 5 blood transfusions. One infant born at 30 weeks with severe umbilical cord deterioration had a cerebellar infarct, enlarged liver, and kidney dysfunction. Seven babies had cranial ultrasounds that were normal with no sign of intraventricular bleeding. Two infants didn’t have an ultrasound performed. One preterm had signs of a resolved cerebellar infarct on his ultrasound (see Table 2 for all demographic data).

The depth and revealing nature of the interviews collected was surprising. Parents, for the most part, readily related their journeys with their premature infants. Five main themes were uncovered: 1) Parental uncertainty in infant survival and family roles 2) Lack of self-care/depression, 3) Suppression of emotions for sake of family/baby, 4) Hyper-vigilance over condition of baby, and 5) Guilt and distress related to lack of connection with infant. More detail is given in Table 1.

Table 1. *Overarching Themes and Sub-Themes from Parental Interviews*

Overarching Theme	Sub-Themes
Parental uncertainty	1) Survival of infant 2) Family roles
Lack of self-care/depression	1) Not eating 2) Depressed 3) Not sleeping
Suppression of emotions	1) Unresolved grief 2) Missing baby’s firsts-suppressing regret
Hyper-vigilance	1) Anxiety about infant health and safety 2) Constantly checking baby’s breathing 3) Monitors a second pair of eyes but also a hindrance
Guilt over lack of connection with infant	1) Working and traveling stress 2) Skin 2 skin helped but also made it harder 3) Mom developed a rash every time she left the hospital

In talking to many parents, frustration arose not only from having a sick infant but the stress of having dueling emotions and feelings and even some family role confusion. Parents expressed the uncertainty of whether their baby will live: *“In disbelief- ‘do you call and make arrangements?’- you just don’t know what to think-seeing him that small”* (Mom’s eyes tear up.)

One mother who had twins and lost one of the babies, *“you watch one baby and suffer and die then you watch him (gesturing to infant in room) and worry (she starts to cry)...but he was strong...”*.

One woman aptly described the feeling of almost being a parent but not quite:

*“Many people would say, ‘how does it feel to be a mommy’ but you don’t know-you don’t feel like a mom and that the God’s honest truth-you don’t feel like you’re a mom”*.

Lack of self-care was exhibited through moms not eating or sleeping right and feeling depressed. A 16-year old mom answered what it was like having her baby in the NICU, *“Very stressful, I was very depressed. Very, very depressed...because I couldn’t be with him- I just wanted him home.”* Another mom would only eat if she was at the hospital with her infant and she said, *“I couldn’t really sleep at night.”*

In contrast, one mom safeguarded her rest and downtime:

*“ I just made sure that...I got my rest because I think a lot of people don’t understand that and they’re like ‘I don’t know how you could ever leave or why you wouldn’t stay up there’ but you’re emotionally drained and you’re physically drained and you don’t know how to deal with stuff...We did take one weekend and we went to a race-we both watch NASCAR...like I wouldn’t stay gone but it was nice to get away-not that I wasn’t calling every hour on the hour checking up on him-but it was nice to step out of that box for a minute.”*

### **Suppression of emotions for sake of family/baby**

A few mothers felt that they needed to keep *“it together”* so as not to cause distress to the baby, compromising the heart rate or vital functions. Therefore, this unresolved grief was stifled with a visceral need for an outlet. One mom recounts, *“I had held it in so long that emotion because I was worried that any kind of upsetting or pressure down there would break my water- so I held in those emotions-“*. This same mom did find an outlet for expression of her grief, *“A lot of times leaving the hospital I’d hold myself together ...and when I was in my car every time I hit the interstate it would just hit me and I just sob- I would sob the whole way home....”*.

Another mother shared reluctance at having this baby but then how emotionally she responded to his birth: *“like I said I didn’t really want any more kids but after I had him well- it’s like he’s here. I broke down in the hospital, “Ms. S. you’re going to have to leave” (a NICU nurse said). ‘No, I’m not leaving my baby’ Every time he heard me cry- he’d jump. So they told me I had to leave the NICU until I calmed down.”*

A young mother who came often to visit her infant in the NICU was asked how her experience in the NICU was. She recounted that *“they were nice and stuff”* but then how she had missed her baby’s first bottle: *“..one day I went in there and there’s a bottle on the counter I said, ‘he’s eating out of a bottle already?’ They (NICU nurses) were like “Yeah, I wasn’t gonna tell you” the nurse responded “I wasn’t going to tell you- I was going to wait until your nurse came in and she was going to tell you...”*

This mother claimed she was happy about her infant taking the bottle but the manner of her comment reflected a regret that she hadn’t been there for it and the nurses had. She seemed to be suppressing that regret in order to protect that nurse/patient relationship. Neonatal nurses are crucial to the survival of an infant but can also present tension for the mom who is trying to *“do for my baby,”* as this mom put it.

#### **Hyper-vigilance at the hospital and once infant transitioned home**

Parents also experience a high level of alertness both in and out of the hospital where they constantly feel “on-call.” Maintaining this level of pressure around the clock, takes its toll physically and emotionally on the parent. One mom captures the high level of apprehension while the baby was still in the NICU: *“It was a roller coaster ride-you just dreaded if the phone rang, that was just a big thing for me-‘Do I answer it?’”*

After leaving the hospital, coming home proved even more taxing for another mom: *“It was nerve-wracking ...she was hooked up to all the monitors there...once we brought her home we didn’t have that comfort (the monitors)- it was scary..We were constantly checking if she was still breathing.”* However, parents also recognized heart monitors as a safeguard, another pair of eyes: *“it was always a comfort to know that if something was happening the monitors would go off but once we brought her home we didn’t have that comfort...it was very scary,”* again this same technology also added stress: *“It was crazy at first because he went home with a heart monitor ...kind of hectic getting used to all the equipment and maneuvering him throughout the house..”*

On the other hand, not everyone felt being at home was stressful, *“I think I relaxed more when we got home and did fine. Because when we got him out on a Saturday he weighed 4 lbs. 12 oz., and then we went to the doctor that Monday- he was up to 5 lbs. 2 oz. and then I was just like ‘we’re good.”*



Another family felt that all the time spent in the NICU made the move home less difficult: *“fairly smooth transition...because we had spent so much time in the NICU that we were comfortable with her. The nurses all told us, ‘You’ve been here every day...so you have a much better understanding of your child’...so I think that was definitely beneficial.”*

### **Guilt and Distress when not connecting with the infant**

This mother conveys again a duality that exists of trying to be there for your baby yet not emotionally connecting: *“I was in the hospital a week and there were many times I just cried- I felt like I was such a horrible person because I didn’t have that connection. There was no- I mean you could go in there and sit all day long if you wanted to but you go there and all I could was look at him and it almost made it worse. Because you just couldn’t grab your baby up and hold him...it was very hard.”*

A surprising finding occurred when asking parents about whether nursing interventions, specifically skin to skin, were helpful. Most expressed the following sentiment: *“I would do some skin to skin- when I’d call to check on him after I left- it would seem like he was doing better. I really, really do believe that made a difference.”* However, a few claimed such interventions then made leaving their baby harder. The father of one preemie describes:

*“the more you’d do these things and feed him the bottle and seeing him getting big and seeing that he’s not red no more and see who he look like and take the CPAP off of his face...and giving him a bath..it made it harder for me to leave him there. I’d rather-I’d want to see him but I don’t want to hold him and do all them type of things—see I’m about to cry just thinking about it...”*

The above astute dad recognized in a lay person’s terms that he wanted to distance himself from the baby to avoid the emotional pain of separation. Perhaps it’s a matter of control; separation on one’s own terms rather than imposed by circumstances. Another mom relates similar reactions:

*“...so we’d hold him for about an hour a piece (she and the father) and when it was time to leave- it was doing it all over again—it was redoing the first time I had to leave the hospital to come home by myself- I just wouldn’t wish that on anybody.”*

A few of the mothers were dealing with going to work out of necessity and still having their baby in the NICU, *“I had to go back to work because I’m the sole bread winner and if I don’t go to work I don’t have insurance that’s a lot of pressure when I need insurance when he’s in the NICU-so that was overwhelming.”* This same mother imparted a lack of connection, *“I wanted to be connected but at the same time he wasn’t home with me.”* One mother’s stress at

being separated from her baby was even physically manifested through a rash she'd develop when she'd leave him at the hospital.

### **Discussion**

In addressing the research questions, parent/infant interactions were observed as well as answers analyzed from the interviews. For the most part, these dyads and triads appeared to be very healthy. The parents and children definitely had strong attachments in the present. Parents talked about separation anxiety that the infants experienced when the parents leave. Almost all mentioned how the baby knows and reacts negatively when the mom is gone. They also seemed very invested in their child's development in recounting their journeys. Even the woman who expressed regret at not feeling more of a connection in the beginning, verbally expressed she felt that connection now. Most of the families that were seen had babies whose chronological age was between 5-12 months old, so it seems they had already worked through many issues at this point.

In regards to the top three knowledge deficits, parents seemed very well-educated by the NICU nurses and staff at Miami Valley Hospital. However, one couple relayed that they kept bringing their babies to church, as soon as they got them home at 38 weeks, and they hardly ever missed a time. This set of twins experienced monthly ear infections and frequent upper respiratory infections. Some educational reinforcement seemed needed to let the parents know to restrict their preemies exposure to others in order to avoid illnesses. A few parents also realized that they needed more information on what physical exercises to do with their babies once they got home to help develop muscle tone and help with developmental growth.

**Limitations:** Time restraints of trying to collect data in one summer produced a very small sample of ten subjects and therefore limited the quality of the results. However, the data captured yielded a surprising intensity through some very forthcoming self-expression by the parents. Many of the same themes were reiterated confirming that saturation was met. Another limitation was presented by our inability to gain access to MVH's NICU because of IRB procedural issues. The MVH NICU is where parents are initially learning about their preemie and experiencing a medical crisis with their child. This could be valuable in assessing how they are processing the information when the experience is fresh in their minds and they are facing immediate challenges.

The venue of data collection may have posed an issue. Those parents that are already coming to the clinic may not be representative of those families having problems with their preemie. Those parents who are coming to the follow-up clinic are already invested in their child and are being proactive in their child's care. Those that need the education, in all likelihood, aren't prioritizing their child's care and following up with the medical community. Therefore, the

possibility exists that the target audience, those lacking education, weren't reached.

Another question to ask was this small population varied enough? Did it capture a gamut of family backgrounds? For the small data sample, it was surprisingly varied. High school educated, blue-collar families, college-educated white-collar families, maternal ages from 16-45, races of Caucasian and African-American, even urban and rural families were included.

These results seem fairly applicable to other cultures and populations in that the crisis of a sick child produces universal emotions and feelings. Parental reactions are consistently similar, however, the manner of how these emotions are expressed may be different. One interesting research question to explore for the future would be how to prevent readmissions?

**Clinical Implications:** 1) Nine out of ten mothers interviewed desired another mom of a preemie to talk to while they are going through this traumatic experience. One woman even called it a "Hopeline" saying "not to talk to doctors or anybody else but to talk to other parents who have gone through it." 2) A neonatal nurse in the community following up with these families could educate to help prevent other premature births and help those families who have already had premature infants. Help me Grow is a program that exists to provide developmental checks and was said to be helpful but some people got lost in the paperwork. Out of the 10 families: 2 knew about the program but didn't participate; 6 did participate to some extent and then 2 wanted to but never got called back or connected with the organization. 3) The families would benefit from a grief or PTSD counselor regularly rotating through the NICU to help some of these families cope with feelings of frustration, fear and intense emotions as they are experiencing this acute level of stress.

In summary, the history of care for the premature infant has had a metamorphosis over the last several decades where care is determined not based on what's convenient for the hospital but what serves the needs of both the infant and the family. This study has added to the existing body of knowledge on the parental experience involved with having a premature infant. Such knowledge helps nurses define the relevant priorities for this patient population where not just the infant is the patient but the family as well. Family-centered care is essential for successful health outcomes in Dayton and where the profession of nursing continues to excel as necessary health advocates for the community.

**Table 2. Maternal and Infant Characteristics**

<b>Maternal Age (in years)</b>	<b>&lt; 20</b>	<b>20-29</b>	<b>30-39</b>	<b>≥40</b>
N=10	1	5	3	1
<b>Infant Gender</b>	M=9		F=1	
<b>Birth weight in grams</b>	<b>&lt; 800</b>	<b>801-999</b>	<b>1000-1199</b>	<b>≥1200</b>
	2	4	3	1
<b>Gestational Age at Birth</b>	Mean= 29 weeks	Medium= 29 weeks	Range= 23-34 weeks	
<b>Diagnoses During Stay*</b>	RDS AOP PDA Hyperbilirubinemia Apnea, Sepsis, IVH, Osteopenia, Immature Retina			
<b>Current Chronological Age</b>	Mean= 10.6 mths	Medium= 11 mths	Range= 5.5-17 mths	
<b>Length of Stay in NICU</b>	Mean= 10 weeks	Range= 3-20 weeks		
<b>Hospital Readmissions for Infant</b>	N= (total)  18	Range=  1-7 readmits	Mean=  2 readmits	
<b>Readmission Diagnostic Category</b>	Pulmonary  Viral- Influenza		Surgical Conditions- hernia/ Cysts found in throat	

\* RDS= Respiratory Distress Syndrome AOP= Anemia of Prematurity  
IVH= Intraventricular hemorrhage PDA= Patent Ductus Arteriosus

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