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Birthing and Parenting a Premature Infant in a Cultural Context

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Abstract

The purpose of this longitudinal qualitative descriptive study was to explore American Indian (AI) mothers' perceptions of parenting their premature infants over their first year of life in the context of their culture, including the birth and hospitalization experience. A convenience sample of 17 AI mothers and their premature infants were recruited from either a neonatal intensive care unit (NICU) or pediatric clinic in the southeast. Semistructured interviews were conducted at two time points. Through content analytic methods, three broad categories were revealed: descriptions of having a premature infant in the NICU, descriptions of parenting a premature infant, and the influence of Lumbee culture on parenting a premature infant. Certain aspects of AI culture appear to be important in having a premature infant in the NICU and in parenting a premature infant. We recommend that healthcare providers deliver culturally appropriate care that fully supports AI mothers and their premature infants.

Keywords

Aboriginal people, North America; content analysis; infants; longitudinal studies; parenting, families; pediatric nursing

In North Carolina, approximately one of every seven infants born to American Indian mothers between 2009 to 2011 was premature, compared with one of every nine infants born to non-Hispanic White mothers (National Center for Health Statistics, 2010). Despite the high rates of prematurity in American Indians (Hamilton, Martin, & Ventura, 2010), little is known about these mothers' responses to the birth and hospitalization of their premature infants and how these responses impact their parenting experiences over time. Although mothers' experiences of having a premature infant in the NICU (Holditch-Davis & Miles, 2000; Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002; Miles, Funk, & Kasper, 1991, 1992) and parenting after discharge (M. S. Miles & Holditch-Davis, 1995; M. S. Miles, Holditch-Davis, & Shepherd, 1998) have been studied, nearly all of the studies have

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focused on the experiences of White and African American mothers. Therefore, the purpose of this study was to explore Lumbee (largest American Indian tribe east of the Mississippi River) mothers' perceptions of parenting their premature infants over their first year of life in the context of their culture, including the birth and hospitalization of their premature infant.

Giving birth to a premature infant who is hospitalized in a neonatal intensive care unit (NICU) often causes distress for mothers (Franck, Cox, Allen, & Winter, 2005; Holditch-Davis & Miles, 2000; Meyer et al., 1995; Singer et al., 1999). Certain aspects of the NICU experience can heighten maternal distress, such as the mother's inability to protect the infant from pain and to comfort the infant through treatments for various complications related to prematurity (Miles et al., 2002; Miles et al., 1991; Wereszczak, Miles, & Holditch-Davis, 1997). Distress also has been associated with the appearance and size of the premature infant; alterations in expected parenting roles, including extended periods of separation and reduced opportunities to hold or interact with the infant (Dudek-Shriber, 2004; Holditch-Davis & Miles, 2000; Miles et al., 1991; Wereszczak et al., 1997); and characteristics of the NICU environment – the sights and sounds of the unit, the equipment, and relationships with healthcare providers and nursing staff (Affonso et al., 1992; Miles et al., 2002; Miles et al., 1991). Furthermore, maternal guilt over their failure to carry the infant to term; uncertainty about the infant's medical condition; and feelings of disappointment, sadness, helplessness, and worry about infant survival and health have all been reported to increase maternal distress (Brandon et al., 2011; Holditch-Davis & Miles, 2000; Miles et al., 2002; Shin & White-Traut, 2007; Trause & Kramer, 1983; Wereszczak et al., 1997). This stress often continues after hospital discharge when the mothers must assume responsibility for caring for their premature infants (Bakewell-Sachs & Gennaro, 2004; Brandon et al., 2011; Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Kersting et al., 2004; Olshtain-Mann & Auslander, 2008). Feelings of extreme protectiveness, persistent fears about infant illness and death, and concern about the child's physical health and development have been found to extend into later infancy and childhood (Holditch-Davis et al., 2003; Miles & Holditch-Davis, 1995; Miles et al., 1998; Miles, Holditch-Davis, Thoyre, & Beeber, 2005).

Maternal responses to the birth and hospitalization of a premature infant have been found to vary by race, with minority mothers experiencing more hospital-related distress than White mothers (Beckman & Pokorni, 1988; Miles et al., 2002). Miles and colleagues (2002) also found that maternal education influenced responses to having a premature infant in the NICU, as mothers with low education expressed more worry about their infants than mothers with high education. Given the potential influence of race and education on maternal responses to prematurity, it is possible that American Indian mothers' responses to prematurity could be affected by their socioeconomic backgrounds because demographically these mothers have high rates of female-headed households, have low education, and live in poverty with access to limited resources (State Center for Health Statistics, 2010).

Parenting of premature infants has also been found to vary by race. In a recent comparison study, American Indian mother-premature infant interactions were found to differ from African American mother-premature infant interactions (Brooks, Holditch-Davis, & Landerman, 2013). American Indian mothers looked more, gestured more, and served as the

primary caregiver more often than African American mothers (Brooks et al., 2013). Although ethnic differences in parenting likely exist between American Indian tribal groups, there are an insufficient number of articles reporting on American Indian parenting to determine the natures of these differences.

Most findings with parents of full-term infants suggest that American Indian parenting is characterized by shared parenting (MacPhee, Fritz, & Miller-Heyl, 1996; Nichols, 2004; Red Horse, 1997; Rogoff, 2003; Staples & Mirande, 1980). In several studies, American Indian mothers primarily provided care, but extended family members, including aunts, uncles, and grandparents, were actively involved in parenting and served as mentors or role models for the infants (DuBray & Sanders, 1999; Eni & Rowe, 2011; Glover, 2001; Mutchler, Baker, & Lee, 2007; Nichols, 2004; Red Horse, 1980, 1997; Rogoff, 2003). Nichols (2004) reported that Cherokee mothers formed a coalition of family members to help them provide culturally appropriate care for their infants.

Disciplinary practices by American Indian parents have been reported as socialization using permissive methods (Nichols, 2004; Red Horse, 1997), including modeling of appropriate behavior, using non-verbal signals or disapproving words, avoiding the child, or requiring the child to give restitution for wrongful actions (DuBray & Sanders, 1999; Glover, 2001; Red Horse, 1997; Seideman, Jacobson, Primeaux, Burns, & Weatherby, 1996). Some American Indian parents avoided spanking because it is thought to promote shyness and a lack of confidence in children (MacPhee et al., 1996). Cherokee mothers' disciplinary practices involved the restructuring of their infants' behaviors, such as the use of redirection; whereas Hupa parents preferred reasoning with their children to physical punishment (Bachtold, 1982).

Other areas explored in American Indian parenting include spirituality and infant development. Among the Cherokee, mothers reported that living spiritually and integrating the child into Cherokee culture were important (Nichols, 2004). Infant development was also a central concern for Cherokee mothers, as they were constantly working to prevent and correct perceived developmental delays (Nichols, 2004). Although American Indian parenting of full-term infants has been explored, few studies have described American Indian parenting of premature infants over time.

Certain aspects of Lumbee culture might influence parenting by Lumbee mothers of premature infants. According to Chavis (1998), Lumbee culture is deeply rooted in kinship and the practice of religion or spirituality. Kinship is probably the most important traditional element defining and sustaining Lumbee culture. Over time, the Lumbee have managed to keep their kin affiliations a priority. Extended family and kin relationships continues to remain strong (Knick, 2000) and is emphasized through routine interactions (i.e., daily) with extended family. Often living in close physical proximity, Lumbees' frequent contact and interaction with extended family creates a network of sharing and an emotional support base on which they can rely (Glover, 2001). Although development of the maternal role and the mother-infant relationship is impacted by the competing demands of the NICU environment and intensive healthcare needs of the premature infant, the close-knit community base and

involvement of extended family in Lumbee culture helps foster mothers' development and enhance their roles in caring for their premature infant (Brooks & Docherty, 2008).

Like kinship, religion and spirituality have long been a focus of Lumbee culture. The church serves as a symbolic symbol and significant force in the lives of Lumbees (Dial & Eliades, 1996; Mattis, 2005). Frequent participation in church services and functions (e.g., youth and elder programs, Bible study programs, and community outreach) promotes the maintenance of religiosity. According to Knick (2000), the Lumbee focus on spirituality, the relationship with the divine and with others, rather than on the practice of conventional religion (Mattis, 2005). Both oral and written documentation of the importance of religion in Lumbee culture suggests that spirituality and religiosity operate interdependently within this group (Mattis, 2005).

The paucity of empirical evidence suggests that additional research on the responses of Lumbee mothers to parenting their premature infants is needed. Bronfenbrenner's ecological model was selected as a conceptual framework to explore Lumbee mothers' responses to the birth and hospitalization of their premature infant and describe their parenting experiences in a cultural context (Bronfenbrenner, 1989). The ecological model is comprised of a hierarchy of nested structures, referred to as the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1989). Within each system are factors that can influence parenting, including ethnicity (micro level), extended family (meso level), and cultural background (macro level). Apart from these multilevel and interrelated factors, socioeconomic status and maternal education also have been found to impact parenting practices and beliefs. Examining mothers' responses and perceptions of parenting from an ecological approach emphasizes the study of relationships among the physical and social settings in which infants and their mothers are mutually involved (Rogoff, 2003). However, one limitation of this theory is the classification of culture as a distal construct occurring in the macro level, the furthest from the mother and infant (Hill, 2006). Given that certain aspects of parenting can result from more proximal influences of culture, such as the role of extended family in American Indian parenting, there is a need to understanding cultural influences stemming from daily encounters within the social environment.

Method

A longitudinal, descriptive, qualitative design (Sandelowski, 2000) was used to explore the birth, hospitalization, and parenting experiences of Lumbee mothers' of premature infants over the first year of life.

Sample

Convenience sampling methods were used to recruit mothers and infants who met the inclusion criteria of being at least 15 years of age and having a premature infant of less than 37 weeks gestation at birth who was hospitalized in a NICU. Infants diagnosed with congenital neurological problems (such as Down Syndrome, congenital hydrocephalus, or microcephaly) or neonatal abstinence syndrome, had hospitalizations lasting longer than 1 month post term, or were removed from the custody of the biological mother were excluded. Participants were enrolled during or immediately following the infant's hospitalization.

The sample for this analysis included 17 Lumbee mothers and their premature infants who were recruited from one of four sites: two medical centers and two pediatric clinics located in southeastern North Carolina. Maternal age ranged from 17 to 42 years (*M* = 26.4, *SD* = 7.6). Approximately 77% of the mothers received public assistance at one or more times during the study. Mothers averaged 13.4 years of education (*SD* = 2.6) and two previous births (*SD* = 1.6). Fifty-three percent of the births occurred via cesarean section. The infants (12 boys and 5 girls) birth weights ranged from 664 grams to 2775 grams (*M* = 1766.3, *SD* = 693.4). The gestational age at birth for infants ranged from 24.4 weeks to 36.5 weeks (*M* = 32, *SD* = 3.8). Infants received mechanical ventilation an average of 7 days (*SD* = 15.2) with a range from 0 to 50 days.

Procedures

The tribe and institutional review boards for the university and two participating medical centers approved this study. Mothers were approached for study participation when their infants were considered medically stable. Mothers provided informed consent and permission to digitally-record the interviews during study enrollment. All interviews were taped and conducted in the mothers' homes by the principal investigator (i.e., member of the Lumbee Tribe). Mothers were compensated ($10 gift card) at enrollment and each follow-up visit. The infant was given a small gift at each visit.

Semistructured interviews, using open-ended questions, were used to explore the birth, hospitalization, and parenting experiences of Lumbee mothers. The purpose of these interviews was to examine mothers' responses to the birth and hospitalization of their premature infants and their experiences of parenting their premature infants within a cultural context. Semistructured interviewing, a combination of structured and unstructured questions, was chosen to allow the participant to have some control over the amount and depth of responses and to ensure that areas of interest to the principal investigator were explored (Fontana & Frey, 2005).

The primary focus of the 3-month interview was to explore the mother's perceived experience of the birth and hospitalization of her premature infant (e.g., Tell me about being a mother of a premature baby in the NICU). Probes were used to elicit details of the mother's story and her experience of having a premature infant in the NICU (e.g., When were you able to hold your baby?). Three months adjusted age occurs after the transition home and the establishment of a daily routine. The primary focus of the 12-month interview was to continue to explore the experience of parenting a premature infant and to search for patterns of parenting that developed since the first interview (e.g., How do you think the experience with your baby's premature birth and hospitalization influence you now as a parent?). Probes were used to capture mothers' specific descriptions of parenting since discharge from the NICU (e.g., How do you care for your baby when he/she gets sick?). Questions encouraging the mother to explore possible cultural aspects of parenting and her understanding of how culture influenced her parenting (e.g., Are there any special ceremonies that you and your baby participate in?) were threaded throughout both interviews. Twelve months adjusted age was an important time to explore mothers' perceptions of parenting because major changes have occurred in infant development. A

total of 33 interviews were conducted with data saturation being reached, which included 17 interviews at 3 months and 16 interviews at 12 months. The 3-month and 12-month interviews, averaging 42 minutes and 26 minutes in length respectively, were digitally-recorded, and transcribed verbatim. The recordings were erased following verification of the transcripts. Field notes were written following the interviews to record relevant contextual information.

Data Analysis

The principle investigator primarily analyzed the data. Coding validity and reliability checking were completed with the second and third author. Analysis began with the completion of the first interview and proceeded in tandem with data collection to further explore areas found to be important to the participants in subsequent interviews. Throughout the analysis the research questions were compared against the data obtained from the interviews to establish the suitability of the questions and to determine whether any data was missing. This ongoing analysis provided the principal investigator with the opportunity to refine interviewing skills and the interview guides.

Data from the semistructured interviews were analyzed using an inductive content analytic approach. Content analysis is a method of interpreting the data using a systematic process of coding and identifying global themes and topics within the interviews (Hsieh & Shannon, 2005). Each narrative was initially read in depth to gain an understanding of the mother's story and the context of her experience. Field notes were reviewed for additional information that was not apparent in the digitally-recorded interview. The data from the narrative interviews were coded line by line. The validity and meaning of the initial set of codes was checked by the second and third authors who have extensive experience in content analysis. Transcripts were coded until no new codes were generated (~25 interviews) and then a further 8 interviews confirmed code book saturation. Patterns and trends in the coded interviews were then grouped into categories and overarching themes. During subsequent analysis meetings, all authors discussed the core themes. Alternative explanations of the findings were proposed and discussed by all authors to avoid potential preconceived notions from becoming dominant in the analyses. Data samples from the interview transcripts are presented to illustrate core themes. Interpretation of the findings included an understanding of the configurations and patterns identified by inspection of the themes and regularities, as well as contrasts, paradoxes, and irregularities in the data (Coffey & Atkinson, 1996).

Four specific strategies were employed to establish trustworthiness based on criteria established by Guba & Lincoln (1994): triangulation, prolonged engagement, reflexivity, and the use of an audit trail. Triangulation, the process of using various data collection methods to form conclusions (Casey & Murphy, 2009), was employed through the use of data from the interviews, observation, and field notes recorded throughout the study. The longitudinal design of the study allowed for prolonged engagement between the researcher and mothers, promoted a trusting and respectful relationship and resulted in richer and more detailed responses (Cope, 2014). Prolonged engagement was promoted through planning adequate time for data collection and multiple interactions with the mothers to obtain a

deeper understanding of parenting a premature infant. To minimize researcher bias, reflexivity, described as the awareness of one's values, background, and previous experience (Cope, 2014), was practiced through reflection and discussion with the second and third authors (Mantzoukas, 2005). Study materials, including interview transcripts and field notes, were used throughout the research process to establish an audit trail for the purposes of documenting important decisions and assumptions (Cope, 2014).

Results

Descriptions of mothers' responses to the birth and hospitalization of the premature infant and parenting experiences occurred in three broad categories: Lumbee mothers' descriptions of having a premature infant in the NICU, Lumbee mothers' descriptions of parenting a premature infant, and the influence of Lumbee culture on parenting a premature infant. At 3 months, Lumbee mothers' stories focused on the premature birth and NICU experience and parenting a premature infant. At 12 months, Lumbee mothers' stories focused less on the premature birth and NICU experience and more on parenting a premature infant over the first year of life. Categories, themes, and subthemes are listed in Table 1.

Lumbee Mothers' Descriptions of Having a Premature Infant in the NICU

The themes in the first category included Lumbee mothers' descriptions of their premature birth experience and their experience of having a premature infant in the NICU. Subthemes included the relationship with the NICU providers and maternal role alteration.

Premature Birth and the NICU Experience—Lumbee mothers could vividly recall their premature birth experience in the 3-month interview. When discussing the arrival of their premature infants, many mothers felt unprepared for their birth, "I wasn't ready for him to come yet." Another mother described the frustration associated with not having time to prepare for her infant's arrival, "I didn't have her nursery ready and I just hadn't done all my nesting stuff that I needed to do so when we came home I felt like I was behind, I was preparing for her and that was aggravating to me, and I couldn't get out and go like I wanted to, and that was annoying because I felt like I hadn't done what I needed to do to have everything ready for her." Although many mothers discussed some aspects of the premature birth experience at 12 months, their descriptions were shorter in length and less detailed.

For some mothers, having a premature infant meant dealing with the uncertainty of the infant's medical condition, which resulted in distress, "I couldn't keep my composure when I went in there to see them [the triplets] in that state [medically unstable] because I didn't know from one minute to the next what was going to actually happen to them." Some mothers also worried or questioned their infant's survival, "I actually thought that he would die. I didn't think that he would make it out." Another mother contemplated the death of her infant and how she would cope with his death after forming an attachment to him. "I would sit there and wonder how was I going to make it leaving that hospital without him."

Guilt about their failure to carry the infant to term was frequently mentioned at 3 months. "I just felt like I did something wrong for her to have to come out that early. Maybe, I wasn't doing something right." This was followed by the mothers' conscious search for the cause of

their infant's premature birth, "I know my placenta detached and the doctors said it either comes from falling or being on drugs or something, and I didn't fall and I'm not on drugs. I just don't know how it could have happened, but if I ever do have another one I would be more cautious of my stomach and taking care of him." The guilt and search persisted for some mothers through 12 months, "I felt like it was my fault that he was premature. And I was wondering why he was premature or what happened, what did I do to make me have him so early." This mother went on to describe that she had attributed the premature birth of her infant to her becoming overheated while sunbathing.

Most of the mothers commented on some aspect of their premature infant's appearance at 3 and 12 months. Some mothers experienced sadness and grief about the appearance of their infant. One mother described her initial reaction as "sad, because he was so small. It was pitiful." Another mother viewed the infant as unattractive in appearance, "He looked like a baby kangaroo because he was so little and he was red, I couldn't hear him cry, he wouldn't open his eyes up, he was just laying there." In the 12-month interviews, mothers focused on how much the infant had grown in size and how others could no longer tell the infants were born premature based on their appearance.

Relationships with Providers—The mothers had both positive and negative experiences with NICU providers. In some instances there was a lack of consistent communication between providers and mothers about the infant's medical care plan. One mother was upset about the lack of information she received about her infant's medical treatment, "What really disturbed me was when I went back the next evening, from my room, down to see them and Joe was intubated, no one told me. And even though I was in the hospital, I feel someone should have called me and told me that he had a setback, and that he was intubated."

There were variations in the type of support mothers received from members of the healthcare team. One mother described being treated negatively by a nurse when she wanted to be involved in the infant's care, "She asked me whether I wanted to change Joe's diaper, it was the first time I would have done it and I was like 'yeah.' Well he had soiled his diaper, and he was intubated and I didn't know – I didn't want to move him too much and she snapped at me like 'you're just going to mess up everything and you need to move him down.' She just said it in a more rude tone than that. I was already very emotional, and that really bothered me and it made me not want to go back when they [the triplets] were there." The same mother also described a positive experience with another nurse, "There was actually another NICU nurse who had twins and she would try to give me advice because she had twins and she kind of knew what I was going to be up against… [some nurses] had very positive things to say, the ones that had children, you could tell the nurses that had children versus the ones that didn't have any."

In a few instances, mothers were offended by the healthcare providers' failure to acknowledge or correctly identify their ethnic background. One mother described being mistakenly viewed as Black and how it affected the care she received while her infant was in the NICU. "I was talking about breastfeeding and then one of the people in the hospital gave me a book for African Americans breastfeeding…African American moms. And I felt

offended by that because I'm not Black. I think they really thought I was Black, not really knowing Lumbee."

Maternal Role Alteration—Some mothers described not feeling like a mother during their infant's NICU hospitalization. In response to being asked did she feel like a mom, one mother answered "No, not really because I wasn't able to be with him like a mother should. It didn't sink in until he came home." Some mothers were fearful of caring for their premature infant after hospital discharge, "I was scared when I brought him home if something would happen because they let him come home at four pounds and something. I had never seen a baby at home that small, it was different."

The development of the maternal role was negatively affected by hospital experiences and regulations. For example, mothers' time with their infants was reduced by visiting hours, "We weren't able to be at his bedside because they were changing shift." This mother did not agree with or understand why these regulations were in place. Visiting was important to mothers. Many of the mothers were required to travel great distances to be with their premature infants. Although mothers visited with their premature infants during their hospital stay, they were disappointed about not always being able to be with their child, "Having to go up there every day and knowing you're not able to be with him every minute…just different things about it made me feel bad." Moreover, mothers were separated from their premature infants for reasons related to medical complications and hospital policies. Mothers experienced disappointment about not being able to hold their premature infants, "we were finally going to hold her, but because she contracted MRSA she had to be on the ventilator. We couldn't hold her with the tube going down her throat. So, we had to wait to hold her."

Lumbee Mothers' Descriptions of Parenting a Premature Infant

The second category was characterized by Lumbee mothers' descriptions of parenting a premature infant over the first year of life, which included themes related to their infant's health and development and their own posttraumatic stress symptoms.

Infant Health and Development—Although most mothers reported that their infants had no serious health problems at 3 and 12 months adjusted age, only "some problems with runny nose," others reported their infants had a number of health problems during the first year, including acid reflux, colds, pneumonia, streptococcal pharyngitis, and ear infections. Some mothers felt that their infant was vulnerable to illness due to prematurity, "I can take him to the doctor's office, and if sick kids are there he automatically gets what they've got." Mothers also reported that their infants experienced problems in recovering from illness, "He's had that cold now for 2 months. If he gets a cold or something like that, not only because of being a baby but also because of being premature, it's real hard for him to get rid of it. It stays with him for a while."

Of the infants with prematurity-related health problems, some experienced improvements in health over the first year, "She doesn't get tired out like she used to." However, a number of infants continued to experience health problems from prematurity, including being monitored for vision problems related to retinopathy of prematurity and optic nerve

hypoplasia, gastrointestinal problems related to necrotizing entercolitis, and respiratory problems related to bronchopulmonary dysplasia. A few mothers of infants requiring ongoing medical care described the challenges associated with frequenting the doctor, “You have to constantly take her back and forth to the doctor because she’s needing something different than what you can give her so it’s a lot more you have to do for her.”

In addition to the health problems, mothers also expressed worries about potential developmental delays. As one mother stated, “He goes to the babysitters with a baby whose 2 weeks older than him and she’s able to lay on her stomach and pick up things now. She can hold her head up real good and he can’t. I just feel he’s going to be behind with all his skills.” This mother would engage with her infant in activities to prevent perceived developmental delays, “I try and help him grasp things, like with the book.”

Lumbee mothers described balancing everyday needs with medical needs related to prematurity. Although they desired to view and treat their premature infants the same as full-term siblings, the premature infants required special care, “It’s about the same as Sarah [first child], things can be complicated at times. Chris [premature infant] is a little bit more special than Sarah was. You’ve got to be more careful with him and he has a lot more doctor’s appointments and he gets sick easy. He has been sicker than Sarah was when she was little. I guess his immune system is weak.”

Posttraumatic Stress Symptoms—Some mothers experienced post-traumatic stress symptoms following their infant’s hospital discharge, which included reliving the birth and hospitalization of their infant. At 3 months, Lumbee mothers frequently thought about their infant’s hospitalization in the NICU. “I find myself thinking back to the NICU about every day even still, some part of that environment comes back to my mind every day.” For one mother, thoughts of the NICU experience were triggered by the infant’s current illness. “Now I think about him being sick a lot here lately when he *has* been sick, I had flashbacks from him being in [the NICU].” At 12 months, some mothers continued to relive the birth and hospitalization of their infant, “every day, I think about it because at that time it was stressful, a lot of stuff was going on when he was born.”

The Influence of Lumbee Culture on Parenting a Premature Infant

The third category was characterized by factors that influence parenting a premature infant in the Lumbee culture. Themes included multigenerational infant care, balancing traditional and non-traditional medicine, and pride in the Lumbee heritage.

Multigenerational Infant Care—The majority of Lumbee mothers utilized multigenerational infant care while maintaining their maternal role. “Mama’s took off days of work when I had surgery to take care of him…to make sure he’s been taken care of the way he should.” Grandparents, aunts, and uncles were often involved in providing routine infant care, such as bathing and feeding, however, mothers maintained sole responsibility for the infant. The same mother stated, “I just don’t want them to try and take my responsibility. I like doing it on my own too. Just to know that they’re there and care for him is fine with me. And, helping out when they can or when I need them yeah, that’s fine but all mothers want their child to know who’s their mom. So that’s me. I want him to know I’m his mom.”

Having a supportive family structure provided mothers with security that their infants would be cared for and fostered the development of relationships between the infants and their extended relatives.

Balancing Traditional and Non-traditional Medicine—Lumbee mothers described balancing traditional and non-traditional medicine when providing healthcare to their infant. Mothers would offer over-the-counter medications, seek medical treatment, or use home remedies based on the nature of the problem. One mother provided examples of the different healthcare she provided when her child was ill, “If it’s a fever I give her Tylenol and then the next 4 hours I’ll alternate it with the Motrin.” When the same child developed oral thrush, the mother took “him to [her] aunt’s house and she [the aunt] took a piece of fatback and washed off the salt and rubbed it all around his mouth and that next day that thrush was gone.” Like Cherokee mothers described by Nichols (2004), Lumbee mothers of premature infants provided healthcare using both the perspectives of their Lumbee culture and the mainstream culture.

Pride in the Lumbee Heritage—Most Lumbee mothers spoke proudly of their heritage, “When I say ‘our Lumbee heritage’ I associate that with the pride of being Native American and the stories that grandma told how it was when she was growing up, that you don’t take things for granted, that you have to work, get an education,” and felt that it was their responsibility to pass on the Lumbee heritage to their infants, “Being a Lumbee mother, there are just certain things you try to instill in them [the children] to protect your heritage.” Some Lumbee mothers described their plans to immerse the child into Lumbee culture through powwows, while others described the need to inculcate their children about their racial identity through “Teaching our children that they’re equal no matter where you come from, there’s no certain race that’s better than any other.” The cultural significance of federal recognition was identified as an important aspect of the Lumbee heritage, “I want them to be involved with whatever programs that are going on especially federal recognition [the process of getting the Lumbee American Indian tribe recognized by the United States federal government].” Some Lumbee mothers felt obligated to teach the importance of education to their children, “You just have to instill that in them that you have to work hard and get an education if you’re going to succeed in life.”

Cultural beliefs and practices, which include religiosity and spirituality, appear to be related to how Lumbee mothers define their relationships with their infants. One mother described a spiritual relationship with her infant, “I think being Lumbee is more than just the color of our skin, I think it’s more spiritual, maybe that’s the difference in other races that there’s a spirituality about Lumbee, the closeness you have with your child.” The same mother also stated that instilling Christian values are important because it “all works together to build our community and our society as a whole. It’s like there’s a fine line with the powwows and how other tribes believe like with the creation, we believe that God created the heaven and earth and Adam and Eve, and I want them to feel that sense of pride as being Native American but still instill our Christian values in them [the children] so that they’re not confused about things.”

Discussion

The premature birth and NICU experience of Lumbee mothers was salient at 3 months, however, for some mothers this experience continued to be salient at 12 months as certain aspects of their experiences were often recalled. Parenting a premature infant also appeared to be more salient at 3 months than 12 months; however, a number of mothers' parenting experiences continued to be impacted by their infant's premature birth. Posttraumatic stress symptoms, feelings of protectiveness, fears of infant sickness and death, and concern about the child's physical health and development persisted throughout the first year of life for Lumbee mothers and have been reported for mothers of other ethnic backgrounds (Holditch-Davis et al., 2003; Miles & Holditch-Davis, 1995; Miles et al., 1998, 2005). Additionally, mothers' parenting experiences were largely influenced by Lumbee culture throughout the first year of life.

Similarities were found between Lumbee mothers' perceptions of the birth and hospitalization of their premature infants and the perceptions of mothers of other ethnicities. Both Lumbee mothers and other mothers reported experiencing distress during their infant's hospitalization related to their inability to provide protection and comfort (Miles et al., 1991, 2002; Wereszczak et al., 1997). The majority of Lumbee mothers discussed their infant's size and appearance in the NICU, which is consistent with other studies reporting that certain infant characteristics related to prematurity result in maternal distress (Miles et al., 2002). Similar to other mothers, Lumbee mothers experienced guilt over their failure to carry their infant to term; uncertainty about the infant's medical condition; and feelings of sadness and worry about their infant's survival and health (Holditch-Davis & Miles, 2000; Miles et al., 2002; Shin & White-Traut, 2007; Trause & Kramer, 1983; Wereszczak et al., 1997). Additional NICU experiences of Lumbee mothers showing similarities to those of other mothers of premature infants included distress related to extended periods of separation, reduced opportunities to hold or interact with the infant, and characteristics of the NICU environment (Dudek-Shriber, 2004; Holditch-Davis & Miles, 2000; Miles et al., 1991; Wereszczak et al., 1997). Lumbee mothers reported both positive and negative experiences with healthcare providers and nursing staff, which is similar to findings reported in other studies (Affonso et al., 1992; Miles et al., 1991, 2002).

Consistent with other mothers of premature infants, Lumbee mothers' feelings of protectiveness, fears of infant sickness and death, and concern about the child's physical health and development persisted throughout the first year of life (Holditch-Davis et al., 2003; Miles & Holditch-Davis, 1995, 1998, 2005). In our study, Lumbee mothers' health and developmental concerns were illustrated in their attempts to identify perceived developmental delays related to prematurity. Similar findings have been reported for Cherokee mothers of full-term infants (Nichols, 2004) and for other mothers of premature infants (Miles et al., 1998; Nichols, 2004). Although the majority of Lumbee mothers' efforts to identify developmental delays were based on infant behaviors related to prematurity, Cherokee mothers' perceptions and parenting behaviors were not based on prematurity-related delays because their infants were born full-term. This suggests that the apparent similarities in certain parenting practices between ethnic groups result from characteristics of American Indian parenting and might not be entirely based on prematurity.

Although Lumbee mothers had similar perceptions about the birth and hospitalization of their premature infants as other mothers, they also had unique perceptions. The finding that Lumbee mothers utilized multigenerational infant care while maintaining the maternal role is comparable to practices of other American Indians in which extended family members take an active, yet supportive, role in caring for infants and children (MacPhee et al., 1996; Nichols, 2004; Red Horse, 1997; Rogoff, 2003; Staples & Mirande, 1980). In their interviews, Lumbee mothers elaborated on their primary caregiving role and the role of other family members who often assisted them with their caregiving when needed. These findings are also consistent with Lumbee culture, which emphasizes involvement of extended family and cultivation of kin relationships (Chavis, 1998; Knick, 2000). Living in close physical proximity allows Lumbee mothers frequent contact and interaction with extended family members that results in a parenting network on which they rely (Glover, 2001), much like the coalition formed by Cherokee mothers (Nichols, 2004). The parenting network that exists within the Lumbee culture could enhance infants' social development because it provides support and security in relationships with kin.

Certain aspects of parenting by Lumbee mothers of premature infants are consistent with their cultural values, such as the practice and sharing of religion, living spiritually, and attending social events with their children (Chavis, 1998). These findings are also similar to the parenting practices of Cherokee mothers who felt that living spiritually and integrating the child into Cherokee culture were important aspects of the care they provided (Nichols, 2004). The spiritual relationship between the mother and infant described by Lumbee mothers possibly result from the emphasis that Lumbee place on the relationship with God and with others, including their children (Knick, 2000). These aspects of Lumbee parenting practices are important for the continuation of values and traditions associated with Lumbee heritage.

One important and distinct finding was that Lumbee mothers wanted to be recognized by their healthcare providers as American Indian rather than being mistakenly identified as belonging to a different ethnic group. In one case, the provider's failure to recognize the mother's cultural background was offensive to the mother and led to her rejection of the health information provided on breastfeeding. This subtle yet important finding emphasizes the need to recognize diversity in culture and how distinct characteristics of a particular culture can facilitate or impede the receipt of care that healthcare personnel provide to mothers and their premature infants. Moreover, future studies exploring the delivery of culturally appropriate health education materials to ethnically diverse mothers and its impact on patient knowledge and health behaviors are warranted.

The current study was limited to a convenience sample of American Indian mothers and their premature infants from one tribe located in the southeastern United States. Inclusion criteria included mothers' self-identification as American Indian. Although all mothers in this study identified with the Lumbee ethnicity, differences could exist in the degree to which mothers identified with their culture, as expressed in their parenting beliefs and practices. There is also the potential for individual distinctions between mothers who self-selected to participate and mothers who chose not to participate in this study. Finally, ethnic matching between the interviewer and the mothers could have created an environment in

which mothers felt comfortable in sharing their birth stories and parenting experiences. In contrast, this type of matching could have led the mothers to make certain assumptions about the interviewer's cultural knowledge, thereby decreasing their likeliness to provide in-depth descriptions about their parenting beliefs and behaviors as they related to Lumbee culture.

Bronfenbrenner's ecological model appears to be a useful framework for examining Lumbee mothers' responses to the birth and hospitalization of their premature infants and their parenting experiences (Bronfenbrenner, 1989). Findings from this study highlight the direct impact of the mother's environment on parenting experiences, particularly the physical and social settings in which premature infants and their mothers are mutually involved (Rogoff, 2003). Factors occurring with the microsystem (ethnicity), mesosystem (extended family network), and macrosystem (cultural background) appeared to exert influences on Lumbee mothers' responses to having a premature infant in the NICU and in caring for their infants. Future qualitative studies focused on other factors occurring within the ecological systems that affect the birth and hospitalization experience of American Indian mothers are merited.

Recognizing that Lumbee mothers' experiences of having a premature infant in the NICU are similar to those of other mothers is important, yet some of their parenting experiences differ as a result of their distinctive culture. Neonatal nurses are in a unique position to provide mothers with resources and support during their infant's hospitalization and arrange for services following discharge if necessary to minimize the effects of separation and posttraumatic stress symptoms. Nurses can also serve as a liaison by consistently communicating with the mother in a caring way about the infant's health status and care delivery plan (Guillaume et al., 2013). Furthermore, providing mothers with opportunities to be involved in their premature infant's care will facilitate the development of the maternal role and empower them to take an active role in their infant's care. Based on findings from this study, healthcare providers need to take cultural factors into account when providing medical care by identifying and acknowledging these mothers' ethnic background rather than ignoring or incorrectly classifying their background. Being sensitive and respectful of cultural practices (e.g., involvement of extended family in infant care and use of non-traditional medication) in parenting is an essential component in the successful coordination of infant care and could enhance child health and development of premature infants from ethically diverse backgrounds.

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Table 1

Lumbee Mothers' Perceptions of Parenting their Premature Infants over their First Year of Life, Including their Responses to the Birth and Hospitalization

Categories	Themes	Subthemes
Lumbee Mothers' Descriptions of Having a Premature Infant in the Neonatal Intensive Care Unit (NICU)	Premature Birth and NICU Experience	Relationships with Providers
		Maternal Role Alteration
Lumbee Mothers' Descriptions of Parenting a Premature Infant	Infant Health and Development	
	Posttraumatic Stress Symptoms	
The Influence of Lumbee Culture on Parenting a Premature Infant	Multigenerational Infant Care	
	Balancing Traditional and Non-traditional Medicine	
	Pride in the Lumbee Heritage	