The Parental Experience of Having an Infant in the Newborn Intensive Care Unit

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ABSTRACT

The purpose of this systematic review was to explore and describe the experience of parents with an infant in the newborn intensive care unit (NICU). A literature search covering the period 1998–2008 was conducted. Fourteen articles reporting qualitative studies describing parental experiences and meeting the inclusion criteria were evaluated and themes were identified. Findings revealed that parents with an infant in the NICU experience depression, anxiety, stress, and loss of control, and they vacillate between feelings of inclusion and exclusion related to the provision of health care to their neonate. Nursing interventions that promote positive psychosocial outcomes are needed to decrease parental feelings of stress, anxiety, and loss of control. Interventions need to focus on family-centered and developmentally supportive care.

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The capacity of parents to form enduring bonds with their infant is among the fundamental features of human experience. Bonding is considered the central developmental force across the lifespan (Feldman, Weller, Leckman, Kuint, & Edelman, 1999). Women develop attachment to their baby during pregnancy, which continues and develops more fully after the child is born (Wigert, Johansson, Berg, & Hellstrom, 2006).

Mothers of infants who require special care begin their experience of parenthood in the unfamiliar and intimidating environment of the newborn intensive care unit (NICU), which may result in delayed maternal attachment (Heermann, Wilson, & Wilhelm, 2005; Shin & White-Traut, 2007). Feldman et al. (1999) found that the physical condition of the infants and the mothers' personality traits contributed independently to maternal attachment. These findings suggest that newborns who are born ill and are separated from their mothers, as well as mothers who are highly anxious or depressed, are at the highest risk for disturbances in the development of maternal newborn attachment.

Upon the admission of an infant to the NICU, parents are confronted with the critical-care environment and all its associated demands. Early separation of the infant from parents increases strain on the infant-parent relationship, especially during lengthy stays in the NICU, because parents need to be able to see, hold, and touch their newborn

in order to facilitate early attachment and bonding (Feldman et al., 1999; Hall, 2005a, 2005b; Söderström, Benzein, & Saveman, 2003).

Parents of infants admitted to the NICU are believed to experience high levels of distress, including increased anxiety, depression, and trauma symptoms, as compared to parents of healthy infants. Such experiences of distress are also thought to be related to an infant's prematurity and the NICU environment, as well as isolation, physical and emotional, from their baby (Carter, Mulder, Bartram, & Darlow, 2005; Gale, Franck, Kools, & Lynch, 2004; Moon & Koo, 1999). According to Shin (2004), mothers experience feelings of ambivalence, shame, guilt, and failure that are related to social prejudice. Mothers think that their infant in NICU will have complications in growth and development, and that they are responsible for giving birth to an unhealthy infant.

The mothers of premature infants experience frustration when they are admitted to the mother/baby unit. They remain in proximity with mothers who have given birth to full-term healthy babies while their own premature infants are in the NICU, which may even be located on another floor or another city (Broedsgaard & Wagner, 2005).

The most commonly reported parents' responses to alteration of the parenting role are the inability to protect the infant from pain and provide appropriate pain management, anxiety, helplessness, loss of control, fear, uncertainty, and worries about the premature infant's outcomes (Callery, 2002; Gale et al., 2004). These findings indicate that the inability to perform a normal parenting role is the predominant source of distress.

In contrast, Conner and Nelson (1999) described factors that contribute to parents' satisfaction in the NICU, which include assurance, caring communication, the provision of consistent information, education, environmental follow-up care, appropriate pain management, and parental participation and proximity, as well as emotional, physical, and spiritual support. It is important for health-care professionals to understand the parental experience when infants are admitted to the NICU, in order to meet parents' needs and concerns and enhance their satisfaction, which will promote more appropriate attachment and bonding.

PURPOSE

The purpose of this systematic review was to explore and describe parents' experience when their infant is admitted to the NICU. This information will help nurses to develop interventions that promote family-centered care and developmentally supportive care.

SEARCH METHOD

A qualitative literature search covering the period 1998–2008 was conducted using MEDLINE, CINAHL, Ebscohost, Hinari, Blackwell Synergy, Science Direct, OVID, and Highwire Stanford databases. Terms used in the search included "parents and NICU," "preterm infants and NICU," "mothers' experience and NICU," "mothers' stories and preterm infants," "mothering preterm infants," "mothering experience," and "qualitative studies." The search strategy used free text searching. Inclusion criteria were qualitative studies of parents' experiences in the NICU published in English. Sixty articles were identified, 14 of which met the inclusion criteria and corresponded with the purpose of this review. These studies are summarized in the Table.

DATA ANALYSIS

Studies of parental experiences of having their infants in the NICU were evaluated, integrating similar categories into broader categories. All categories were then compared, and common themes were generated.

FINDINGS

The findings were described from the parents' perspectives. Analysis revealed certain themes describing parents' experience in the NICU. The overarching themes were (a) feelings of stress, strain, separation, depression, despair, disappointment, ambivalence, and lack of control over the situation and (b) vacillation between hope and hopelessness (Arockiasamy, Holsti, & Albersheim, 2008; Hall, 2005a, 2005b; Heermann et al., 2005; Jackson, Ternestedt, & Schollin, 2003; Salonen, 1998).

Noyes (1999) found that mothers experience feelings of shock and a sense of crisis during the admission of their infant to the NICU. Salonen (1998) described maternal perceptions of disappointment, loneliness, insecurity, and frustration. Because newborn infants are kept away from their mother and left alone, mothers feel disappointed and insecure after the intense experience of giving birth. Mothers also expressed feeling insecure and experienced a loss of trust in their health-care provider.

Studies show that when the mothers were involved in giving care, they shifted from a passive to an active role, moving from mere parenting to

TABLE
Qualitative Studies Reviewed

Author(s) and Year	Design	Participants	Data Collection	Key Findings
Salonen (1998)	Phenomenological	9 mothers	Interviews	The new mother experiences caring communication in sharing her life situation with the midwives.
Noyes (1999)	Grounded theory	10 mothers	Interviews	Initial shock/crisis and impact of child's appearance.
Fenwick, Barclay, & Schmied (2001)	Descriptive Qualitative	28 mothers 20 nurses	Interviews	Positive mother-nurse relationship facilitates sharing on a ''deeper'' level and increases mother's confidence, sense of control, and feelings of connection to her infant.
Nystrom & Axelsson (2002)	Phenomenological	8 mothers	Interviews	Themes: Being an outsider; feelings of despair, powerlessness, disappointment, and lack of control reflected in emotional instability, threat, guilt, and insecurity. The theme of caring included trust, love, anxiety, relief, and closeness.
Callery (2002)	Qualitative	31 mothers	Interviews	Themes: Feelings of alienation, despair, and grief; feel they were ''not being a mother''; felt supervised by the nursery staff and required permission to touch and care for their infant; feelings of distance and detachment.
Cronin (2003)	Descriptive Qualitative	3 mothers	Focus groups	Themes: Depression, loneliness, frustration and letting go, need for personal/ professional support.
Butler & Galvin (2003)	Grounded theory	8 parents	Interviews Focus groups	Themes: Parents and health-care team communicate well; parents are facilitated to integrate into the unit and do not feel a burden.
Rubarth (2003)	Phenomenological	11 nurses	Interviews Focus groups	Themes: Dealing with life/death issues, blessing of life, losing the dream. Nurses expressed a feeling of helplessness and frustration while providing care to the diseased newborn.
Hurst (2004)	Case study	1 mother	Interviews	Facilitation of families, access to their babies, interpretation, information and emotional support, and parental education.
Gale, Franck, Kools, & Lynch (2004)	Qualitative	12 parents	Interviews Focus groups	Themes: Infant pain as source of parental distress and barriers to parental role attainment.
Hall (2005a)	Phenomenological	13 parents	Interviews	Themes: Being in alien world, feeling like a spectator, being vigilant, and oscillating between hope and hopelessness.
Hall (2005b)	Phenomenological	13 parents	Interviews	Themes: Experiences of joy and despair. Nurses viewed as the sole agent, ignorant nurse, distressed nurse, worried looking nurse, the eminent nurse, or the surrogate nurse.
Heermann, Wilson, & Wilhelm (2005)	Phenomenological	15 mothers	Interviews	Themes: Moving from ''their baby'' to ''my baby,'' passive to active caregiving.
Broedsgaard & Wagner (2005)	Grounded theory	37 parents	Interviews	Mothers emphasized frustration about separation from their premature infant and lack of knowledge.

engaged parenting and from exclusion to participation in their infant's care. In addition, when parents' integration into the unit was facilitated, they felt safer, gained control over the situation, were involved in rapport-developing, were more confident, and felt more connected to their infant (Broedsgaard & Wagner, 2005; Butler & Galvin, 2003; Fenwick, Barclay, & Schmied, 2001; Heermann et al., 2005; Söderström et al., 2003).

Other studies revealed that at the beginning, mothers felt like an outsider, alienated with a sense of unreality regarding being a parent, despairing, powerless, homeless, lonely, depressed, guilty, anxious, and insecure. The mothers explained the need to have closeness and proximity and belonging to their infant. When these needs were met, the mothers became more responsible, confident, and familiar with their fragile infant (Cronin, 2003; Hall, 2005a, 2005b; Jackson et al., 2003; Nystrom & Axelsson, 2002; Wigert et al., 2006). The major theme and source of parental stress in the NICU was infants' pain; relief of infant pain was related to reduction of parental distress (Gale et al., 2004). Moreover, the mothers experienced grief and anxiety because their newborn might not survive (Feldman et al., 1999).

Having an infant in the NICU was an overwhelming experience associated with negative feelings. These included role strain, distress, and emotional pain (specifically, when parents were excluded from taking care of the infant and excluded from parental-infant proximity or closeness), and a sense of alienation. On the other hand, when parents were involved in infant care, were allowed proximity, communicated clearly and openly, and formed rapport with the nurses, they became more satisfied and confident in their parenting roles.

DISCUSSION

The aim of this systematic review was to describe parents' experience when their infant was admitted to the NICU. Admission of the infant to the NICU places parents and other family members in a stressful situation where they must cope with the NICU environment and its associated demands. Charchuk and Simpson (2005) found that the parents of an infant admitted to the NICU face challenges including access to information, disclosure about the diagnosis, and treatment and prognosis of their newborn, as well as a lack of control over the care of their newborn. Similarly, Feldman et al. (1999) found that newborns who were born ill, admitted to the NICU, and separated from their mothers were at the highest risk for disturbed attachment with their mothers and indicated that parents experience a grief and concern because their newborn might not survive.

Nystrom and Axelsson (2002) explored mothers' experiences of being separated from their newborn when their newborn was admitted to the NICU. The first theme was the mothers' experience of the situation as being an outsider, which was reflected in their feelings of despair, powerlessness, homelessness, and disappointment.

The second theme was the mothers' lack of control due to emotional instability, threat, guilt, and insecurity. Parents' positive experience was reflected in the theme of caring in which the mothers experienced love, relief, closeness, and appropriate explanations. Although Jackson et al. (2003) indicated the parents experienced a state of alienation, ambivalence, and a sense of unreality, mothers experienced more responsibility and control when they participated in the care of their infant. Fathers were more confident in leaving the care to healthcare providers and attempted to balance family life and work. The parents' experience of responsibility and concern is reflected in their narratives; for example, ''Now, I'm responsible for the babies and I have feelings about being a [parent]'' (p. 123).

Hall (2005a, 2005b) found that being a parent of a newborn in the NICU resembled being in another world, alien from what the parents knew and experienced. The parents wanted more closeness; they felt insecure, attentive, and vigilant, oscillating between hope and hopelessness. According to Hall, the parents were in shock, scared, worried, unhappy, and suffering. They expressed the deep need to be at the bedside to follow what happened to their sick infant.

Conversely, a feeling of inclusion or participation was identified when the mothers had open communications and dialogue with NICU staff, were cared for as unique persons with unique needs, and expressed positive maternal feelings (Wigert et al., 2006).

The following theme described the maternal experience: focus on the NICU environment and ownership—from ''their baby'' to ''my baby.'' The mothers moved from passive to active parenting, and they moved from silence to advocacy. The overall experience was shown as a developmental process, as the parents moved from outsiders to engaged parents. The researchers claimed that ''as mothers become engaged parents, they were ready for parenting, with a need of family–focused care'' (Heermann et al., 2005, p. 177).

Parental distress was reflected in themes related to the parents' perspectives on their infant's pain in the NICU; parents described their feelings of sadness, helplessness, disappointment, fear, frustration, and anger. Secondly, parental stress was decreased by staff support, involvement of parents in providing care to their infant, and having clear information and open communication with nurses and other health professionals (Gale et al., 2004). Conner and Nelson (1999) found that parents need caring, communication, consistent information, education, follow up, adequate pain management, participation in the infant's care, and proximity to and support with their fragile infant. Phillips and Tooley (2005) documented that mothers who did not see or touch or have proximity to their babies often felt distressed. According to Hall (2005a, 2005b), because the process of parenting is a protecting and loving phenomenon, parents should participate in the care of their sick, fragile infant in the NICU. This enhances parental knowledge and decreases stress, which promotes more effective parenting. Nurses need to be supportive, helpful, kind, and informative in dealing with parents in the NICU.

Hurst (2004) stressed the need for parents to have access to their baby, interpretation by certified interpreters to overcome language barriers, information, emotional support, and preparation for discharge planning and teaching. Hurst (2004) and Hall (2005a, 2005b) recommend incorporating family-centered care into the NICU to support the parenting roles of family.

Implementing a hospital-based intervention for parents of preterm infants in the NICU alleviates stress, anxiety, and depression and provides social support, which enhances the parental role. Browne and Talmi (2005) documented that implementing family-based interventions for parents whose infant is in the NICU will enhance parental knowledge and sensitivity and decrease stress, which promotes effective parenting roles. These findings appear to be in accordance with those of Broedsgaard and Wagner (2005) and Dokken and Ahmann (2006), who demonstrated an intervention that increased parental support, met parental needs, increased parental feelings of well being, and increased parents' ability to provide care for their infant.

Salonen (1998) documented the need of new parents to share their feelings. It may be helpful to have women share their birth experiences, especially if there are "missing pieces" or feelings of inadequacy or disappointment (Callister, 2004). Women having a preterm infant and an infant in the NICU may view their birth experience as traumatic, and they need to discuss their feelings with a caring nurse (Beck, 2004). Fenwick et al. (2001) proposed the use of "chatting" as a clinical tool, where nurses assist parents to gain confidence and become connected with their infant. These verbal exchanges between nurses and parents influence parents' confidence, sense of control, and feelings of connection to their infant. Moreover, the nurses' ability to effectively engage parents in effective information exchange is dependent on the type of language used by nurses that expresses a sense of caring and support and conveys interest in parents (Fenwick et al., 2001).

In summary, the findings showed that parents of infants admitted to the NICU experience stress, depression, anxiety, and feelings of powerlessness, hopelessness, and alienation within the environment of the NICU. These situations are often overwhelming and catastrophic. The need for family- and developmentally-centered care has been identified. Furthermore, as understanding of the parents' experience of having an infant admitted to the NICU increases, nurses will be better prepared to meet parental needs and alleviate parental suffering. Providing holistic, family-centered, developmentally supportive care and open communication with parents in this stressful experience is essential.

LIMITATIONS

Many of the studies were conducted with White, middle-class families. There is a need to consider the cultural influences on parental experience of having an infant admitted to the NICU. Transcultural studies are needed to identify similarities and differences in the parental experience, such as the study conducted by Hurst (2004) with Mexican American mothers with infants in the NICU. There is also a need to study fathers' and mothers' experiences separately, to locate their unique ways of responding. There is a need to utilize a grounded theory approach in order to understand the process parents go through during the time their infant is in the NICU. Families and health-care professionals need to work together to promote the health and well-being of vulnerable newborns and enrich the family perspective.

NURSING IMPLICATIONS

The findings highlight the feelings mothers have when their newborn infant is admitted to the NICU: distress, anxiety, depression, shock, being scared and worried, unhappiness, suffering, and feelings

of powerlessness, hopelessness, and being out of control due to emotional instability, guilt, and insecurity. Nurses in the NICU must develop interventions and strategies that minimize the stress parents experience and support their feelings in dealing with this stressful situation. Family-centered and developmentally-supportive care is essential. The use of chatting may enhance parents' sense of self-efficacy in parenting their fragile infant. The principle of family-centered care in dealing with parents and infants in the NICU can be achieved by viewing parents as partners in the care, as well as helping them to establish a supportive and loving relationship with their fragile infant. Such interventions will assist families and professionals to work together in the best interest of the child and the family.

Nurses play a vital role in helping parents throughout the stressful, challenging experience of the NICU by developing therapeutic relationships, providing emotional support, providing parents with accurate, clear information, involving parents in providing care for their infant, and accessing certified interpreters for non-English-speaking parents to enable them to ask questions and get the information they need. These approaches enable parents to feel more supported, more involved, confident, and more effective as parents of their vulnerable newborn.

Because the experience of parents in the NICU occurs during an emotionally intense period fraught with anxiety, stress, depression, and feelings of hopelessness, interventions may include a NICU orientation for expectant parents with a high risk of giving birth to a premature infant or a compromised newborn. Supporting and facilitating their parenting role will help decrease their stress, strain, anxiety, and depression. Nurses are encouraged to help parents talk about the challenging and stressful experience of the NICU and to facilitate parents having more time and proximity with their infant. There is a need for further research to understand and describe the parents' experience of family-centered care and developmentally supportive care after nursing intervention programs have been implemented with parents whose infant is admitted to the NICU.

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