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Factors Influencing Parental Participation in Neonatal Pain Alleviation

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Purpose: Neonates are likely to experience numerous painful procedures in neonatal intensive care units (NICUs). Parents have expressed a wish to be more involved in their infants' pain alleviation. The purpose of this study was to describe parents' perceptions concerning the factors that influence parental participation in pain alleviation in an NICU.
Design and methods: The qualitative study was conducted in level II and III NICUs (7 units) of Finland's four university hospitals. Data were collected through open-ended questionnaires and analyzed using inductive content analysis.
Results: Factors that promoted parental participation consisted of five main categories: parental counseling by staff, parents' awareness of their own role, parents' motivation to participate in pain relief, family-friendly facilities and good communication. Factors hindering parental participation consisted of eight categories, including restrictive environment, lack of knowledge, everyday life requirements, underestimation of parents, the nature of the medical procedures, procedure- and pain-related emotions, deteriorated health status of the child and mother and (8) uncertainty of parenting.
Conclusions: This study revealed a number of factors that are important to take into account when improving parental involvement in neonatal pain alleviation. Especially, parental participation can be promoted by providing sufficient counseling based on the parents' needs and creating facilities that support parents' participation.
Practice implication: Parents should be engaged as partners in caregiving and decision making, and they should be given space to assume the role of parents during their child's hospitalization.

In the last decade, there has been increasing interest in parental participation in neonatal pain management (Franck, Oulton, & Bruce, 2012; Skene, Franck, Curtis, & Gerrish, 2012) and the non-pharmacological pain relieving methods that allow parents to play an active role in the management of their infants' pain (Axelin, Salanterä, & Lehtonen, 2006; Campbell-Yeo, Fernandes, & Johnston, 2011). However, there is a lack of knowledge about factors that influence parents' participation in their child's pain relief in a neonatal intensive care unit (NICU). The principles of family-centered care highlight that family and healthcare staff share responsibility for the infant's hospital care (Mikkelsen & Frederiksen, 2011), which has a positive effect on infant development and parents' well-being (Gooding et al., 2011).

Literature Review

Having an infant in the intensive care unit is a new and unexpected situation for parents, as watching the tiny infant surrounded by equipment is frightening. Parents worry about the infant's condition and emergencies, and many of them are afraid that the infant will die (Heinemann, Hellström-Westas, & Hedberg Nyqvist, 2013). Parents have stress over

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their parental role (Turan, Basbakkal, & Özbek, 2008), and some NICU parents have reported feeling that they are not truly parents before they are able to establish more physical contact with their infant. Parents need repeated information about their child's condition and about education how to participate in the care of an infant (Gooding et al., 2011). Knowledge about infants' care and involvement helps parents to find their parental role (Heinemann, Hellströmm-Westas, & Hedberg Nyqvist, 2013). Painful and stressful procedures are common in NICUs (Carbajal et al., 2008; Roofthooft, Simons, Anand, Tibboel, & van Dijk, 2014), and a significant part of procedural pain is left untreated (Carbajal et al., 2008). Parents are aware that their infant experiences pain as part of intensive care (Franck, Cox, Allen, & Winter, 2004), and this causes psychological stress for parents (Gale, Franck, Kools, & Lynch, 2004). Parents have reported that the infant experienced more pain than they expected, and most parents were worried about the effects of pain and pain treatments on their infant (Franck, Cox, Allen, & Winter, 2004). Parents and health care professionals had differing views about the care of neonatal pain (Franck, Allen, Cox, & Winter, 2005), and parents felt frustration about their inability to fulfill the parental protective role (Gale, Franck, Kools, & Lynch, 2004).

Parents have expressed their willingness for greater involvement in their infant's pain care (Franck, Allen, Cox, & Winter, 2005; Franck, Oulton, & Bruce, 2012). In the last ten years, only few studies have been published that provide information about parents' role in neonatal pain management in the context of the NICU (Franck, Oulton, & Bruce, 2012). The earliest studies revealed that parents were unprepared for infant's pain (Franck, Cox, Allen, & Winter, 2004; Gale, Franck, Kools, & Lynch, 2004). Parents had received information about infants' pain and pain management mainly verbally from nurses (Franck, Cox, Allen, & Winter, 2004), but many parents were dissatisfied with the information they received (Franck, Allen, Cox & Winter, 2005). Parents had individual information needs and preferences (Gale, Franck, Kools, & Lynch, 2004) and lack of knowledge seemed to be barrier to parental participation in pain relief (Franck, Oulton, & Bruce, 2012).

Parents see medical procedures as the major source of their infant's pain (Franck, Allen, Cox & Winter, 2005). Many parents feel the desire to be present at the time of the procedures and to participate in their infant's pain care (Axelin, Lehtonen, Pelander, & Salanterä, 2010; Skene, Franck, Curtis, & Gerrish, 2012), but the desired role in infant's pain management varies greatly (Franck, Oulton, & Bruce, 2012). A study by Axelin et al. (2010) stated that mothers have three different styles of involvement in preterm infants' pain care, which seemed to be related to maternal attachment and the level of the mother's NICU-related stress. According to the findings of Skene, Franck, Curtis, and Gerrish (2012), parental participation in comfort care develops in stages. However, parents do not always have the opportunity to play their preferred role in infant pain management. The staff attitudes and behaviors are barriers to parental participation in neonatal pain relief (Franck, Oulton, Bruce, 2012).

In summary, earlier studies have produced mostly information about parental perceptions and desires for participation in infant pain management. Parents have received information about infant pain and pain management from staff, but information has been insufficient. In addition, parents have had some confusion about their role in pain management, and they have not always been able to carry out their preferred role. However, parents should have a major role in infant care. It is important to build comprehensive understanding of the factors that influence parental participation in pain management. Therefore, the purpose of this study was to describe parents' perceptions of factors that influence their participation in pain alleviation in the NICU. The specific research questions were as follows: (a) What kind of factors promote parents' participation in their child's pain relief in a neonatal intensive care unit? (b) What kind of factors hinder parental participation in their child's pain relief in a neonatal intensive care unit?

Methods

Study Design and Participants

A qualitative design with descriptive methods based on questionnaires with open-ended questions was adopted. Participants consisted of parents whose infants were hospitalized in one of the NICUs in Finland's university hospitals (Helsinki, Kuopio, Tampere, Turku), and the questionnaires were pilot-tested in one of them (Oulu). All parents who met the following inclusion criteria were recruited: (a) being the child's mother or father; (b) having an infant hospitalized in the NICU; (c) were Finnish speaking; and (d) were willing to participate in the study.

Setting

Public service providers offer most of the healthcare in Finland. The five university hospitals share the national responsibility for specialized healthcare providing high-quality medical care throughout Finland. Level III NICU care is centralized into university hospitals, all of which are located in different areas of the country. In addition, there are special care newborn nurseries, level II NICUs. This study was conducted in four different university hospitals (Helsinki, Turku, Tampere, and Kuopio), and the participants were recruited from four level III and three level II NICUs. The most critically ill and the most preterm infants go to level III NICUs. The level II NICUs take care of less severely ill or later weeks premature infants. Also the premature infants' follow-up care after intensive care is centralized in level II NICUs.

Level III NICUs treated approximately 330–440 neonates per unit every year, and level II NICUs 490–1000 neonates. The designs of all NICUs in this study were open-bay. There were 15–21 beds in NICUs, and 3–7 infants in the same room. In the level II NICUs there were also a few single