



Original Article

Parental participation in neonatal care

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Abstract This study's purpose was to identify the principal components of the neonatal care process with respect to parents' views of parental participation, and to analyse the relationships between these variables and parents' characteristics. To accomplish this goal, a survey of a convenience sample of 141 parents was conducted, based on the EMPATHIC-N questionnaire. Principal component analysis revealed that neonatal care, with respect to the parents' views of parental participation, was characterised by two principal components: interactions with caregivers and nursing the baby. Multiple regression analysis revealed that both of the principal components were significantly related to infants' gestational week, but not to any of the parental characteristics examined. The practical implication of these results is that healthcare professionals should focus on creating conditions that facilitate parental participation in terms of interactions with caregivers and nursing the baby, and to a larger extent, the needs of infants born very premature. © 2016 Neonatal Nurses Association. Published by Elsevier Ltd. All rights reserved.

Introduction

Involving patients in healthcare processes can make a difference from a quality perspective, as

patients might be able to identify possibilities for improvements that might otherwise go unnoticed by healthcare professionals (Gustavsson, 2016). Patient involvement also helps healthcare professionals to view care from a patient's perspective. Quality of care can benefit from patient involvement in technical (what service is

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delivered) and functional (how the service is delivered) aspects of care. Hence, patients should be regarded as co-creators of healthcare processes (Bergman et al., 2011). However, patients cannot be involved in some care processes, and the challenge shifts to involving their relatives instead. In the neonatal intensive care unit (NICU), for example, patients might not be involved in the care process for obvious reasons, but their parents, in most cases, can be to some extent. Thus, the challenge for healthcare professionals in this context is to encourage parents to participate in their baby's care in the best possible way, given the circumstances (Lantz and Ottosson, 2013).

Facilitating parental participation in their baby's care in the NICU entails several challenges. First, it might be difficult from a functional perspective, as healthcare professionals typically emphasise their own significance in care processes and often under-appreciate the parents' ability to contribute to the process and influence the outcome (Gustavsson et al., 2016; Lantz and Ottosson, 2014). Parental participation in nursing and caring for their baby in the NICU apparently requires an invitation from the professionals and permission to do so independently, to some extent. In practice, however, care, including the conditions for parental participation, is often driven by the terms set by the staff, with routines focused on the medical-technical care and environment, and budgetary constraints (Wigert et al., 2008).

Second, parental participation in care processes in the NICU is necessary for attachment reasons (Gulmarães et al., 2015; Wigert et al., 2006). Both physical and emotional closeness are crucial to the physical, emotional, and social well-being of both the infant and the parent (Flacking et al., 2012). It is well known that attachment develops because of repeated interactions between an infant and its parent or constant caregiver (Steinhardt et al., 2015). Most parents have a natural urge to take care of their child, so facilitating parents' participation might have positive effects on infant brain development, parents' psychological well-being, and the parent–infant relationship.

Third, the NICU is a high-tech environment where many types of advanced equipment are used. In addition to the fact that it is a stressful environment for parents to see their baby in, introducing them to, and educating them about the different types of equipment might constitute a physical obstacle to their participation (Foster et al., 2008). Furthermore, parents might view

the necessary equipment as a mental barrier to their wish to interact visually or physically with their infants, as the baby might be covered with respiratory support equipment, monitoring sensors, and/or a phototherapy mask, for example (Lantz and Ottosson, 2013; Cervantes et al., 2011).

Facilitating parental participation might also be problematic because parents are all different individuals. What works well for some parents might not work for others. Indicators of how parental participation can be facilitated and supported in the institutional setting are valuable (Coyne, 1995). In particular, parental characteristics, such as gender, age, and previous parental experience, should be considered in this context (Hedberg-Nykvist and Engvall, 2009; Lantz, 2013a; Wigert et al., 2014). Hence, a solid knowledge of the parents' views is needed to involve them sufficiently in the care process in the NICU. The purpose of this study was to identify the principal components of the neonatal care process with respect to parents' view of parental participation and to analyse the relationship between these variables and parental characteristics.

Methods

Participants

We asked all parents of children admitted for more than 48 h to any of the five NICUs in the XXXX region of Sweden during the spring of 2013 to participate in the study at the time of discharge. Parents whose children passed away during their NICU stay were excluded from the survey. We provided the parents with oral and detailed written information about the study, and informed them that declining to participate would not affect their future interactions with the healthcare system in any way. The parents who agreed to participate received questionnaires and return envelopes. In order to ensure the anonymity of all participants, only the contact persons in the NICUs were provided information so they could match the respondents' identities to the respondent numbers, and only the second author could match the respondent numbers to the specific answers. After one reminder was sent to the parents who had agreed to participate, but had not delivered their questionnaires within three weeks, a total of 141 of the 173 (80.5%) parents returned their completed questionnaires.

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