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# Needs Perceived by Parents of Preterm Infants: Integrating Care Into the Early Discharge Process<sup>1</sup>

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**Introduction:** The birth of a preterm infant can have a great emotional impact on the parents when the length of stay is long. Early discharge programs facilitate the transition to the home and have beneficial effects on both the parents and children. However, only a few studies have been conducted to identify the real needs of parents of preterm infants and to determine whether early discharge programs meet such needs. The main objective of this study was to identify the experiences and obstacles, during hospitalization and after discharge, of fathers and mothers of preterm infants who did or did not participate in an early discharge program.

**Method:** A qualitative study using semi-structured interviews was performed and included 23 parents of preterm infants. Thematic analysis was performed with the assistance of Atlas.ti 6.2 software.

**Results:** Two main themes were identified: the emotional experience and obstacles to care during hospitalization and the emotional experiences and obstacles at home related to the early discharge program. The results indicated that preterm birth initially has a deep emotional impact on parents.

**Discussion:** There is a remarkable lack of coordination regarding the information provided to parents on their infant's health status. Being first-time parents seems to be an important factor, although further evidence supporting this notion should be provided.

**Conclusion:** Parents considered early discharge programs to be very useful in addressing the emotional aspects of hospitalization and the acquisition of neonatal care skills. Parents claim that the coordination and the information provided should be improved.

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THE PRIMARY CAUSES of morbidity and mortality in newborns are prematurity (births before the 37th gestational week) and perinatal hypoxia-associated complications (Phelan, Martin, & Korst, 2005; Revage et al., 2008). Such increases are associated with changes in the mothers' lifestyle and the use of assisted reproductive technology, which relate to

an increase in the number of multiple pregnancies (Davidoff et al., 2006). In 2008, preterm births accounted for 8.2% of the total number of births in Spain (Zeitlin et al., 2013).

Although the survival rates for preterm infants have increased as a result of technological developments and improvements in neonatal care, prematurity remains the most frequent risk factor (Bird et al., 2010). Additionally, various outcomes are related to premature birth: a) preterm infants have higher morbidity and mortality rates (Zeitlin et al., 2013), b) a higher proportion of preterm infants are hospitalized at birth and re-hospitalized in the neonatal

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period and during their first year of life, and they have higher risks of neuro-developmental disorders, and c) the average length of stay is higher for preterm infants (Bird et al., 2010; Leone et al., 2012). In many cases, some risk factors and complications can be prevented or alleviated through specific measures and programs that address infants' clinical care and their family's care skills (Kynø et al., 2013).

Scientific evidence has shown that a protracted hospital stay may cause complications and negatively impact both the preterm infants and their parents (Benjamin & Stoll, 2006; Sadrudin, Young, Rogers, & Reilly, 2012). Parents of preterm infants may experience emotional distress, particularly with an unexpected delivery or when the newborn is critically ill (Feely, Gottlieb, & Zelkowitz, 2007). In addition, the parents may present symptoms of depression, guilt, post-traumatic stress and fatigue up to 1 year after birth (Garel, Dardennes, & Blondel, 2006). Watson (2010) identified the following three key dimensions that are expressed by fathers and mothers in the postpartum period: a) experiences of crisis, anxiety and varying emotions, b) uncertainty as to their newborns' health status and c) helplessness when feeling unable to care for their baby. Other studies have reported that mothers of preterm infants experience emotional distancing towards their newborn and blame themselves or other people (Baum, Weidberg, Osher, & Kohelet, 2012; Guerra & Ruiz de Cárdenas, 2008).

The average length of stay for preterm newborns has been shown to be high (Álvarez-Miró, Bello-Rodríguez, & Arroyo-Gili, 2008; Gutiérrez-Benjumea, Rodríguez-García, Matute-Grove, & Aguayo-Maldonado, 2000). The reason for long hospitalizations seems to be parents' lack of self-confidence about their ability to care for their newborn at home and health professionals' belief that early discharge of low birth weight infants may present complications that cannot be managed at home (Gutiérrez-Benjumea et al., 2000). A recent meta-analysis concluded that early discharge programs may have positive short and long-term motor and cognitive effects on preterm children (Spittle, Orton, Anderson, Boyd, & Doyle, 2012). Therefore, early discharge programs are gaining popularity in neonatal care units (Álvarez-Miró et al., 2008). The main purpose of these programs is to shorten the length of hospital stay to prevent the potential complications due to long hospitalization.

The studies performed on home care after an early discharge of preterm children have proven to be safe, effective and beneficial for the newborn and their parents compared with newborns with longer hospital stays (Álvarez-Miró et al., 2008; Kynø et al., 2013). Descriptive studies have been performed to analyze the experiences of parents engaged in early discharge programs, particularly the problems found at home after the program (Kynø et al., 2013; Murdoch & Franck, 2012; Sturm, 2005). However, few studies have focused on the needs and deficiencies identified by parents during the entire process, ranging from the moment of delivery to hospital discharge. It is also not known whether the parents involved in early discharge programs have similar difficulties as other parents. To our knowledge, this is one of the first studies to compare parents that

do or do not participate in an early discharge program through individual interviews. This information can be useful in adjusting and modifying interventions to the real problems as perceived by parents by identifying the potential sources of stress that can be prevented or anticipated (Sadrudin et al., 2012).

The Virgen de las Nieves University Hospital (Granada, Spain) has developed an early discharge program for preterm or low birth weight infants who are clinically stable and only need basic care. The design of these programs is similar to those of other home care programs that have been implemented in Andalusia and Spain in the last decade (Álvarez-Miró et al., 2008; Gutiérrez-Benjumea et al., 2000). These programs include specific training for parents during hospitalization (training in coping skills, child care in the areas of hygiene, feeding and vaccination, and the promotion of emotional and social/familiar support) and a follow-up program that involves neonatal nurse home visits to the preterm infant to assess their health status. The interventions at home are concluded when the child reaches a weight of 2.200 gr. (4.8502 lb). On average, the home visits lasted 1 hour and occurred once a week during the first 2 months after discharge. The follow-up visits were performed by a specialized nurse with experience in prematurity. The following inclusion criteria were required to participate in the early discharge program: a) a clinically stable preterm child (stable body temperature, feeding through mouth, breathing stabilization and absence of other diagnosis), b) a domicile located at most 20 km. away (12.427 mi) from the city of Granada, c) and parents wanting to participate in the program. If one of the criteria is not fulfilled, they participated in the standard program and were discharged from the hospital when their child reached the minimum weight (2.200 gr./ 4.8502 lb). The standard program did not include the follow-up home visits or specific training at the unit.

The main objective of this study was to identify the experiences and obstacles of fathers and mothers of preterm infants during hospitalization and after discharge, who did or did not participate in the Virgen de las Nieves hospital's early discharge program.

## Methods

### Design

The study was structured using a qualitative descriptive design (Howitt, 2013). This approach was chosen to understand the direct experience and perceptions of parents of a preterm infant.

### Participants

The sampling was intentional and based on inclusion and exclusion criteria (criterion sample) (Flick, 2007; Howitt, 2013; Patton, 1990). The following inclusion criteria were used: a) being the father or mother of a preterm infant and b) hospitalization in the neonatal care unit. An exclusion criterion was having a diagnosis other than prematurity. The homogeneity criterion was being a father or mother of a preterm infant. The heterogeneity criteria were gender, participation in the early discharge program and having an older child (Martín-Crespo & Salamanca-Castro, 2007). A total of 23 parents (7 fathers and

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