



Prolonged Distress of Parents After Early Preterm Birth

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ABSTRACT

Objective: To examine how parents describe the distress of early preterm birth in the months and years after the infant's hospital discharge.

Design: Discourse analysis of in-depth interviews and photo elicitation.

Setting: Homes or cafés in the Pacific Northwest United States.

Participants: Parents of premature infants born between 24 and 30 weeks gestation ($N = 10$) who experienced significant distress in and out of the hospital. Parents participated in the study when their children were between 15 months and 8 years old.

Methods: Participants described dealing with prematurity, emotional distress, and parenting in individual interviews and returned for second interviews in which they further described their distress using photographs. Data were analyzed using discourse analysis.

Results: Parents described preterm birth, hospitalization, and the aftermath as ongoing traumatic events. Discourses of distress included the *Perfect Child*, the *Good Mother*, and the *Good Father*. Parents used these discourses to reconcile the loss of an idealized birth and parenting after the birth of a premature child. *Isolation* and *Medicalized Parenting* were used to explain how parents struggled to interact within their social networks and to parent under challenging circumstances.

Conclusion: Participants described their trauma and distress in ways not captured by psychiatric diagnoses such as depression and anxiety. Findings may help nurses be aware of the negative effects of preterm birth and respond to parents' emotional needs.

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Preterm birth is one of the most common and significant complications of pregnancy. Although the preterm birth rate in the United States has decreased in recent years to 11.39% (Martin, Hamilton, Osterman, Curtin, & Mathews, 2015), it continues to be higher than in most developed countries. Nearly half of all infants admitted to the NICU are born preterm (March of Dimes, 2011). Very-low-birth-weight infants (<1,500 g) and infants born at less than 32 weeks gestation are the most likely to have a prolonged hospitalization (Bender et al., 2013). The experience of premature birth can have a profound effect on the transition to parenthood and a family's well-being during early childhood (Treyvaud, 2014), and separation can make it difficult for parents to bond with the fragile infant. Further, parents can be overcome with anxiety about the infant's health while grieving the loss of a normal pregnancy and birth. Once concerns about survival have passed, parents may worry

about their child's physical and cognitive development. Neonatal nurses care for newborns using increasingly complex technologies and treatments, which leaves less time to address the psychological health of parents.

Numerous researchers described the traumatic experiences of parents during the NICU hospitalization using qualitative methods (Lasiuk, Comeau, & Newburn-Cook, 2013; Schenk & Kelley, 2010; Watson, 2011) and measured high rates of anxiety, depression, and posttraumatic stress symptoms (Alkozei, McMahon, & Lahav, 2014; Lefkowitz, Baxt, & Evans, 2010). Researchers who examined parents' long-term psychological health after prematurity focused on the prevalence of and risk factors for symptoms of depression in mothers and fathers (Vigod, Villegas, Dennis, & Ross, 2010). A few researchers examined parents' psychological health, family function, and child developmental

outcomes up to 7 years after preterm birth (Huhtala et al., 2014; Treyvaud, Lee, Doyle, & Anderson, 2014). However, by using a quantitative approach, they did not explain how parents make sense of their experiences of prematurity and distress in the years after the infant comes home from the hospital. We investigated the distress of 10 parents long after their preterm infants had left the hospital to understand their perspectives on the long-term effect of preterm birth. We added photo-elicitation methods to qualitative interviews to facilitate deep inquiry into complex emotional and traumatic experiences.

Literature Review

The distress of parents, as measured by screening tests for depression, anxiety, or post-traumatic stress, was initially elevated while their infants were in the NICU but declined in the first year after hospital discharge. In a subset of parents, the symptoms continued for years after the preterm birth (Holditch-Davis et al., 2009). The risk factors for mothers for continuing depression 2 years after preterm birth included demographic characteristics (unmarried, lower education level, lower income, or teenage), infant health (worry about infant health, illness severity, or infant rehospitalization), and social factors (stress in the maternal role or decreased family support; Miles, Holditch-Davis, Schwartz, & Scher, 2007; Poehlmann, Schwichtenberg, Bolt, & Dilworth-Bart, 2009). Increased number and severity of risk factors were correlated with persistent depression symptoms. Similarly, mothers' posttraumatic stress symptoms were significantly elevated through 14 months after preterm birth compared with those of mothers who gave birth at term (Kersting et al., 2004). Fathers were also at risk for depression, and in one study, 13% of fathers had elevated depression scores 2 years after the preterm birth (Huhtala et al., 2011). In most qualitative studies, researchers examined the experience of parents during the NICU hospitalization. In a study 1 year after preterm birth, the long-term emotional responses of mothers to preterm birth included guilt, defensiveness, and loss of control (Garel, Dardennes, & Blondel, 2007).

The distress of parents may also affect the relationship between them and the child born preterm into the preschool years. A woman's depression after preterm birth has been correlated with negative perception of her child's social abilities (Silverstein, Feinberg, Young, & Sauder, 2010) and behavioral and emotional problems in the child

Little is known about parents' distress after the early preterm infant comes home from the hospital, when parent-child interactions are crucial for child development.

(Huhtala et al., 2012). Depression and parenting stress in both parents at 2 years was associated with child behavioral problems at age 3 years (Huhtala et al., 2012). As far out as 7 years after preterm birth, comparisons with families who had infants born at term showed increased stress, anxiety, and poorer family functioning (Treyvaud, Lee, Doyle, & Anderson, 2014).

A potential explanation for the connection between parents' distress and poor childhood social, behavioral, and emotional development is the parents' perception of child vulnerability. The technology-rich NICU environment establishes the preterm infant's vulnerability from the first moments, and the identity as a vulnerable child may be reinforced after hospital discharge by the need for follow-up surveillance at high-risk child development clinics. In a meta-analysis of studies on parent perception of child vulnerability after preterm birth, Tallandini, Morsan, Gronchi, and Macagno (2015) found a correlation between a mother's psychological status and parents' perception of child vulnerability. This highlighted the importance of parents' perceptions of child outcomes, but little is known about their perception of prematurity and distress in the long term. In this study we began to address this gap in the literature by asking parents about their long-term distress without restricting them to a psychological framework. The distress of parents is modified, in part, by societal norms for emotional and psychological responses to the challenges of preterm birth. Underneath these responses are beliefs that shape how parents understand their roles and experiences. These beliefs, or internalized discourses, can influence how parents think, talk, and act after preterm birth. The purpose of this study was to understand how discourses of distress affect the psychological and social responses of parents at least 6 months after preterm birth.

Methods

We used two complementary data collection methods: interviews and photo elicitation. Interviews are a standard approach to collect data on the phenomenon of interest. However, critical social theorists acknowledge that there is a power

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