



Mothering a Preterm Infant Receiving NIDCAP Care in a Level III Newborn Intensive Care Unit¹

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Purpose: The purpose of the study is to describe the unique meaning and significance of the essential elements of mothering a preterm infant receiving Newborn Individualized Developmental Care and Assessment Program (NIDCAP) care in a level III NICU. The overall aim was to promote an increased understanding among healthcare practitioners of the experience of this group of women.

Design and Methods: The authors utilized an existential–phenomenologic method to investigate the experience of 7 mothers of a preterm infant 30 weeks gestation or less at birth.

Results: Analysis of interview transcripts revealed one overarching theme, parenting with permission, and three essential themes with nine underlying subthemes: choosing to participate (subthemes: managing, settling in, making friends), dealing with people (subthemes: meeting needs, facing judgment, and recognizing not everyone is 'on board,' and coming to feel like a mother (subthemes: overcoming fear, gaining understanding, and feeling empowered).

Conclusions/Practice Implications: Mothers universally praised NIDCAP for the education and support it provided them. However findings also suggest that great sensitivity and patience is required by professionals to assist mothers to overcome their fear, gain confidence, and participate in NIDCAP without feeling judged. In addition private rooms were found to hold great significance for mothers and should be maintained for the entire hospitalization whenever possible. Finally, ongoing NIDCAP education/support for staff and regular team meetings to discuss and problem-solve concerns are suggested. This might address inconsistent adherence to the NIDCAP care plan by some nurses, which is the greatest source of maternal conflict and frustration.

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The current rate of preterm birth in the U.S. is 9.57%, accounting for over 380,000 births annually (Hamilton et al., 2015). Many of these infants require specialized care in the newborn intensive care (NICU), care which has traditionally necessitated prolonged separation of infants from their parents. Fortunately, recent trends in the care of preterm infants based on the synactive theory of development Als

(1982, 1986) have contributed to the provision of more family-friendly, individualized, and developmentally-focused care.

The synactive theory of development (Als, 1982, 1986) was derived from several decades of animal-based research, which increased our understanding of the sequential development of sensory, cognitive and motor function in the fetus (Lickliter, 2011; Pitcher, Schneider, Drysdale, Ridding, & Owens, 2011). This theory proposes that the preterm infant, by virtue of being born early, necessarily continues to experience ongoing subsystem (autonomic, motor, state-organizational, attentional/interactive and self-regulatory) integration and differentiation

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after birth, while in continuous interaction with the extra-uterine environment (Als, 1982, 1986).

Developmental care (DC) is a trend in the management of care for the preterm infant consistent with the tenants of the synactive theory of development (Als, 1982, 1986), and rooted in the same basic scientific underpinning. It involves use of specific environmental modifications and approaches to care designed to minimize stress on the premature infant and promote continued subsystem development. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (Als et al., 1986/2000; NIDCAP Federation International, 2010/2012) represents one approach to implementing DC in the NICU environment, which extends beyond the application of general DC principles. NIDCAP requires a core group of trained professionals to make frequent, formal observations of infant behavior. These observations are then used as the basis of an individualized, family-centered and goal-oriented plan to support an infant's continued developmental progress.

The primary purpose of this study was to use an existential-phenomenological methodological approach to describe the unique meaning and significance of the essential elements of mothering a preterm infant 30 weeks and younger receiving NIDCAP care in a level III NICU. The broader aim was to promote an increased understanding among healthcare practitioners of the experience of this group of women.

Literature Review

Developmental Care

As summarized by Browne (2011) "developmentally supportive" care has evolved with the goal of improving neurodevelopmental outcomes of high-risk newborns. This approach generally emphasizes decreasing stress in the NICU environment, focusing caregiving on the individual developing infant, and allowing parents to become central in the care of their own children. Lubbe, van der Walt, and Klopfer (2012) conducted a critical review of 16 research studies judged to be of high methodological quality according to the *John Hopkins Evidence Appraisal Instruments* (Newhouse, Dearholt, Poe, Pugh, & White, 2007). The review identified the following 'key elements' essential to developmental care: requirements for NICU design (such as individual care bays), individualized care (based on gestational age and infant adaptive capacity), a family-centered care philosophy (focus on parental skill development), positioning (such as containment and nesting), handling techniques (transition support), management of the external environment (reduction of light and sound), management of pain (such as use of non-nutritive sucking and sucrose), feeding methods (nonnutritive sucking and attention to feeding maturation), and knowledge of preterm infant development (p. 254–257). Other elements frequently incorporated into DC are kangaroo care, clustering caregiving around periods of uninterrupted sleep, and massage

(Bowden, Greenberg, & Donaldson, 2000). Some NICU's that have incorporated a general DC approach also use NIDCAP as a further means of operationalizing the tenants of the synactive theory of development (Als, 1982, 1986).

NIDCAP Description

As explained by Als (1982, 1986) the premature infant's relative level of differentiation and ability to modulate behavior are what make each infant unique at any one period of development and point in time. Because the level of infant subsystem development is "observable" through various behaviors Als developed two methods for documenting an infant's relative level of organization or disorganization. This may be done through use of either a systematic behavioral observation, referred to as a *NIDCAP Observation*, or a more formal observation through use of the *Assessment of Preterm Infants' Behavior (APIB)* evaluation tool (Als, Lester, Tronick, & Brazelton, 1982; Als et al., 1986/2000; NIDCAP Federation International 2010/2012).

The behavioral observations central to NIDCAP were developed from Al's initial work (Als et al., 1982) and subsequent pilot study (Als et al., 1986). NIDCAP trained practitioners can use these tools to systematically evaluate the premature infant's strengths and developmental efforts at regular intervals (Als et al., 1986). Based on this ongoing evaluation, the NIDCAP team develops an individualized, developmentally appropriate plan for the care of each infant (Als et al., 1986/2000; NIDCAP Federation International, 2010/2012). This plan provides an opportunity for supporting the infant's development through suggestions for structuring the environment, organizing medical and nursing interventions, nurturing parental care opportunities, and coordinating the care provided by special service providers (Als et al., 1986/2000; NIDCAP Federation International, 2010/2012).

DC and NIDCAP Outcomes

Many studies over the last several decades have investigated the effectiveness of DC and NIDCAP interventions on various outcomes. Because this body of work is large and often contradictory multiple scholars have conducted meta-analyses in an attempt to provide an overall sense of the level of supporting evidence.

In an early meta-analysis Symington and Pinelli (2002) reviewed 31 studies from 1966–2000 and concluded that DC interventions (including NIDCAP) had the positive short term effects of decreasing the need for respiratory support, the incidence of moderate to severe lung disease, and decreasing length of stay and hospitalization cost. In a second later meta-analysis of 36 studies from 1999 to 2005, however, the same authors concluded that DC (including NIDCAP) increases length of stay, and is of limited benefit in decreasing the incidence of moderate to severe lung disease, decreasing the incidence of necrotizing enterocolitis or improving family outcomes (Symington & Pinelli, 2009).

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