

Experiences of Mothers of Infants with Neonatal Abstinence Syndrome in the Neonatal Intensive Care Unit

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ABSTRACT

Objective: To describe the experiences of mothers of infants with neonatal abstinence syndrome (NAS) in the neonatal intensive care unit (NICU).

Design: Qualitative description.

Setting: We recruited participants from community-based, out-patient, addiction treatment facilities in a large urban city in the southwestern region of the United States.

Participants: A convenience sample of 15 Hispanic, substance addicted mothers of infants with NAS participated.

Methods: We conducted semistructured, individual, interviews and analyzed the data using qualitative content analysis. First, we analyzed the data independently and then discussed the themes until a consensus was reached.

Results: We identified four themes: (a) understanding addiction, (b) watching the infant withdraw, (c) judging, and (d) trusting the nurses. The participants felt there was a lack of understanding concerning addiction that was particularly noted when interacting with the nurses. They shared their feelings of guilt and shame when observing their infants withdrawing. The participants felt judged by the nurses for having used illicit drugs during pregnancy. Feeling judged interfered with the participants' ability to trust the nurses.

Conclusion: These findings provide nurses with a better understanding of the experiences of mothers who have addiction problems and may lead to more customized nursing care for this high-risk population of mothers and their infants.

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Substance use during pregnancy can lead to poor neonatal outcomes by increasing the risk of prematurity, low birth weight, and neonatal abstinence syndrome (NAS) (National Institute on Drug Abuse, 2011). Infants with NAS present with symptoms of withdrawal such as extreme irritability, inconsolable crying, vomiting, diarrhea, and even seizures (Hudak & Tan, 2012). These infants frequently experience lengthy hospital stays (Patrick et al., 2012) and typically require a significant amount of nursing care (Fraser, Barnes, Biggs, & Kain, 2007; Macguire, Webb, Passmore, & Cline, 2012; Murphy-Oikonen, Brownlee, Montelpare, & Gerlach, 2010; Raeside, 2003). Nurses face a variety of challenges when providing care for substance addicted women and their infants. Care of these infants is time-consuming and usually requires a significant amount of patience. Nurses also report that interacting with mothers

who are addicted can be a source of work-related stress (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003) as these women often have substantial comorbidities such as mental illness, poverty, and a history of trauma (Pajulo et al., 2001; Powis, Gossop, Bury, Payne, & Griffiths, 2000). A better understanding of the experiences of these women could lead to improved care for this high-risk population of mothers and infants.

To our knowledge only one study exists in which the authors explored the experiences of mothers of infants with NAS (Cleveland & Gill, 2013). The authors presented a secondary analysis of interviews from five substance addicted mothers who participated in a larger study on the experiences of Mexican-American mothers in the neonatal intensive care unit (NICU) (Cleveland & Horner,

2012a, 2012b). Findings indicated that the women felt judged by the nursing staff yet longed to make a personal connection with the nurses. Additionally, the women voiced concerns over inconsistencies in the use of instruments to measure NAS symptoms in their infants. They also felt a need to assert themselves as mothers. Although the findings presented in the Cleveland and Gill (2013) article are useful, the sample size was small and may not be representative. A more complete understanding of the mothers' experiences is needed.

Background and Significance

It is estimated that 16% of pregnant teens and 7% of pregnant women age 18 to 25 use illicit substances during pregnancy (Substance Abuse and Mental Health Administration [SAMHSA], 2011). Further, approximately 60% to 80% of all infants exposed in-utero to opioids such as heroin and methadone will develop NAS (Doberczak, Kandall, & Friedmann, 1993). In the United States, between the year 2000 and 2009, maternal opioid use during pregnancy increased fivefold (Patrick et al., 2012). This dramatic increase in incidences is likely related to the increased use of prescription opioid pain killers (Patrick et al., 2012). It is not surprising then that during this same time period the number of infants diagnosed with NAS increased threefold. The cost of caring for these infants has likewise increased over the past decade from an estimated \$190 million per year to \$720 million per year (Patrick et al., 2012).

In addition to financial cost, providing nursing care for infants with NAS can be challenging (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003). A few researchers have described the experiences of nurses who care for infants with NAS (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003). In these studies, nurses shared their commitment to the infants and their desire to provide quality care. However, some NICU nurses believed that this level of nursing care did not require specialized skills and could be provided somewhere other than in a NICU. They felt that caring for infants with NAS was not what they had anticipated when they became NICU nurses. Further, they described the high-pitched cries of the infants and the frustration they felt when trying to provide comfort to infants who were often inconsolable (Murphy-Oikonen et al., 2010). The nurses expressed concern about the mothers' ability to cope with an irritable, crying infant following discharge and worried about

Infants with neonatal abstinence syndrome frequently experience lengthy hospital stays and typically require a significant amount of nursing care.

the infant's safety (Macguire et al., 2012; Murphy-Oikonen et al., 2010). They also worried about the stability of the infant's home upon discharge from the NICU (Macguire et al., 2012; Murphy-Oikonen et al., 2010).

Nurses claimed that interacting with families with addicted members was stressful for them (Macguire et al., 2012) and acknowledged negatively judging mothers because they used illicit drugs (Fraser et al., 2007; Macguire et al., 2012). Further, the nurses described what they perceived as the defensive attitudes of the mothers when they visited their infants in the NICU. Several nurses recalled being verbally attacked by mothers and their family members. They also reported altercations between families in the unit, and one nurse even remembered a family member threatening her with violence (Macguire Webb, Passmore, & Cline, 2012). Lastly, some nurses described feeling that they lacked the necessary education in mental health and substance addiction to provide optimal care for families experiencing addiction (Fraser et al., 2007; Raeside, 2003).

In the one published article focused on the experiences of mothers of infants with NAS, Cleveland and Gill (2013) conducted a secondary analysis of data from a larger qualitative study to describe the hospital experiences of mothers of infants with NAS. The authors analyzed the data from these women separately because their experiences were uniquely different from the other NICU mothers who had participated in the study. They identified four primary themes: (a) "try not to judge," (b) "scoring the baby," (c) "share with me," and (d) "I'm the mother here!" All five of the mothers described events where they felt they had been negatively judged and believed that the nurses were unable to see past their drug addiction and recognize any of their positive qualities. At times, the mothers' sense of being judged kept them from visiting their infants in the NICU. The mothers shared their thoughts on the use of neonatal abstinence scales to "score" their infants describing the use of these instruments as highly subjective as the nurses scored the infants with great variability. The mothers valued the nurses' ability to communicate

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