The Experiences of NICU Nurses in Caring for Infants with Neonatal Abstinence Syndrome

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Abstract

Purpose: This study explored the experiences of NICU nurses in caring for infants with neonatal abstinence syndrome (NAS).

Design: A qualitative research approach was used with open-ended questions employing computer-assisted personal interviews.

Sample: Fourteen NICU nurses employed in a regional hospital provided responses.

Results: The nurses reflected a personal struggle between a desire to employ their technical and critical nursing skills and the need to provide expected maternal care to NAS infants. Other themes included frustration and burnout, challenges to values about parenting, and increased awareness of drug use in the community and at home.

Discussion: The results suggest that nurses underrate the skill required to care for infants with NAS. The level of knowledge, patience, and commitment to these newborns should be reframed to increase job satisfaction, and education should be offered to nurses about women struggling with addictions.

Drug use by a pregnant woman has implications not only for her own health, but also for that of her unborn child. One consequence of maternal drug use during pregnancy is the development of neonatal abstinence syndrome (NAS). Affected newborns exhibit complex physical, psychological, and social needs that require the collaborative efforts of an interdisciplinary health care team and lengthy hospital stays.[1,2] These high-needs infants present challenges to care providers and nurses in particular. In addition, the parents of infants with NAS can also present challenges to nurses related to their own substance use history. As a result, NICU nurses spend a large part of their time not only soothing the infant with NAS, but also educating and consoling the family. This is a demanding role that can be taxing for NICU nurses, yet the personal costs to the nurses of caring for these challenging patients have seldom been explored. The purpose of this study, therefore, was to gain a deeper understanding of the NICU nurses' experiences when caring for infants with NAS.

Neonatal abstinence syndrome represents a group of symptoms observed in infants experiencing withdrawal from maternal substance use in pregnancy. The symptoms range from a high-pitched cry, sleep disturbances, poor feeding, loose stools, and excessive suck to a hyperactive Moro reflex, tremors, increased muscle tone, and tachypnea.[3,4] It can lead to more serious health problems and death.[3] These infants often require specialized care in an NICU environment where their symptoms can be monitored accurately and they can be treated pharmacologically.[2] Parents often experience the NICU environment as stressful and difficult to understand.[5–7] However, the fears and concerns parents may have when their infant is in the NICU are often intensified for the substance-using mother. A fear of exposure as "bad" parents and a fear of losing their children

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to the child welfare system are common concerns among substance-using women.[8] This may result in mothers distancing themselves from their infants. Consequently, nurses not only assume much of the responsibility for nursing care of substance-exposed infants, but also, at times, are the only caregiver of the unattended infant.

Neonatal nurses are in a unique position to influence the parenting capacity of substance-using mothers while infants remain in the unit for intervention.[9] Several studies have reported the positive impact of supportive assistance in fostering the parenting role in new families.[10,11] For instance, in a study of guided participation for mothers of preterm infants where research nurses partnered with parents to educate the mothers on topics ranging from diapering to feeding, it was found that mothers who experienced this guided participation improved in their ability to relate to their infants before discharge from the NICU.[11] Although substance-using mothers might have some unique needs, having an infant admitted to the intensive care unit could be considered a moment of opportunity for nurses to influence the behavior of a substance-using mother.

This expectation placed on NICU nurses, however, of both caring for medically fragile infants and compassionately engaging and positively influencing their mothers could be stressful for nurses. Few studies have explored the impact of NAS on nurses. Thus, the purpose of this study was to explore the experiences of NICU nurses who care for infants with NAS.

METHOD

Research Design

An exploratory research design was used to investigate the experiences of NICU nurses who care for infants with NAS at a regional hospital in a medium-sized Canadian city. The aims of this study were to explore the nurses' experiences in (1) caring for infants with NAS, (2) caring for the families of infants with NAS, and (3) being personally affected by NAS.

The nurses responded to open-ended questions using a computer-assisted personal interview format. This secure web-based tool enabled nurses to answer questions within their chosen time frame, even on shift if time permitted. This allowed nurses to privately and confidentially disclose personal and sensitive information regarding their experiences, which was important because the unit under study was relatively small. Each nurse was assigned a unique numeric identifier to maintain the confidentiality of participants. This strategy ensured that no individual could be identified by the organization. Responses were stored in a secure, password-protected database. Ethics approval was obtained from the Research Ethics Board of the regional hospital. Written informed consent was obtained from the participants.

Participants

Nurses who were employed in the NICU longer than six months were invited by e-mail to participate in the study. The hospital was selected because of the high prevalence of infants with NAS in the NICU. A total of 24 full-time and part-time nurses were employed in the NICU at the time of the study. Those invited to participate represented a wide range of years as NICU nurses. They had the choice of mailing a signed consent form to the principal investigator (PI) or leaving it in a sealed envelope in the NICU for the PI to pick up. Upon receipt of signed consent forms, participants were sent a web link to the questionnaire, along with a password to be used to ensure security of data. They had a two-week time frame to complete the questionnaire. Following the two-week period, an e-mail reminder was sent to all who signed a consent form, allowing them an additional week to respond.

Participants were asked a series of open-ended questions regarding their experiences. Sixteen nurses completed consent forms, but only 14 completed the online questionnaire. All nurses were female. Their ages ranged from 20 to 55 years with a mean age of 37. Years of service as an NICU nurse ranged from six months to greater than 20 years with a mean of 8.4 years.

Questions Used in the Study

The PI developed the questions, which were subsequently reviewed by all members of the research team for refinement before being distributed to participants. The questions were open ended and invited responses about the nurses' experiences with neonatal nursing and caring for infants with NAS. The following questions were asked:

1. What has caring for babies with neonatal abstinence syndrome been like for you?
2. What are your experiences with the families of babies with neonatal abstinence syndrome?
3. How does working with infants with neonatal abstinence syndrome affect your life outside of work?
4. What suggestions would you make to improve nurses' experiences working with infants with neonatal abstinence syndrome?

Questions about gender, age, and years of service in the NICU environment as well as reasons for pursuing a career in the NICU were also included. The participants were asked to answer the questions in as much detail as possible.

DATA ANALYSIS

Following the three-week period allotted for the participants to respond, blinded copies of the nurses' written responses to the questionnaire were distributed to each member of the research team for initial review. This allowed the researchers to familiarize themselves with the responses before assembling as a group to participate in the analysis process. The data were approached through an immersion process.[12] The participants' responses provided a structure for organizing them in accordance with the specific subject areas of the questions. The responses were analyzed using thematic analysis to identify the patterns within them. The research team met initially over three stages to orally review

the responses and suggested patterns while one team member documented the emerging themes. The research team further reviewed responses to the questions during a fourth and fifth stage of review using the identified themes to confirm that the themes were consistent with the data and grounded in the responses of the nurses.

RESULTS

The analysis of the nurses' responses revealed two themes that emerged repeatedly for all the questions; (1) *a commitment to infants* and (2) *a contrast between technical competencies and expected maternal care.* Three more themes emerged from the subject area of the specific questions and represent a summary of the responses to those questions. These themes were (3) *a disconnect between the expectations of nurses and those of families;* (4) *stress, frustration, and burnout;* and (5) *increased awareness of drugs in home and work life.*

A Commitment to Infants

A clear theme of "a strong desire to help infants" emerged throughout the responses to the questions. The following comments reflect this theme:

"I always had a love for babies, even as a child. Before I knew that nursing was the career path I would choose, I knew that I would do something that had to do with babies or small children. I knew that this would be the only area that I would be happy working in."

"A love of babies was the first motivator coupled with the desire to be in an area of high-tech critical care nursing skills. An area that is always advancing and providing a challenge."

"I've always loved babies and taking care of them. I like working with parents and helping them through their experience with a premature or sick baby, and I love seeing a baby go home after a sometimes very lengthy stay in the NICU."

The deep commitment refers to the general rewards and challenges of working with critically ill infants. Although the nurses' responses, in this instance, were not directly in relation to the impact of caring for infants with NAS, they reflected a professional identification that provides the context for understanding the conflicts inherent in the nurses' role when providing care to infants with NAS.

A Contrast Between Technical Competencies and Expected Maternal Care

Nurses who are trained for the NICU have skills that extend beyond what is required for the healthy newborn. Neonatal resuscitation and critical care management are specialized skills required for the job. The cohort of nurses expressed their perception of their role as a "critical care" nurse, with "advanced skill sets" and the ability to care for "the compromised neonate." The conflict between a perception of the nursing role in the NICU as technically skilled and the frequently mundane role of caring for infants with NAS was a persistent theme throughout the responses in the study.

"I have always thought of NICU as intensive care, and the NAS baby tends to be a baby that needs extra time and loving, not intensive care."

"I pictured myself caring for acutely ill babies and parents who were going through every emotion in the book. But I find myself caring for demanding babies who NEVER stop crying, walking around and around the nursing station with a baby in my arms or in a stroller, spending up to one hour trying to get a baby to eat a small amount of formula, but the poor thing is too disorganized to figure out how to suck. Dealing with parents can be just as time-consuming and frustrating. I did not intend on becoming a social worker."

"I had never envisioned a career where my main job is to soothe infants who are inconsolable."

Despite the numerous symptoms that babies with NAS exhibit and the challenge of stabilizing the symptoms, nurses continued to see these newborns as "healthy" or less "sick" infants who require care beneath their scope of practice. This perception precipitated feelings of dissatisfaction and internal conflict for these NICU nurses as they express feeling separated from the more technically demanding work that they believe they were trained to do.

"It has been very frustrating, sad, and taxing, emotionally, mentally, and even physically. It is unbelievable how much time and energy these babies require. The level of care they require compromises the amount of time and level of care that the nurse(s) have with other babies in the unit. How can you properly care for a sick child when all of your time is spent trying to console, feed, and care for unruly babies that will not sleep, [or] eat, and scream all the time. It is disruptive to the other babies and the entire unit, especially when the majority of the babies at a specific time are NAS."

"I envisioned working with sick, premature, and compromised neonates, not healthy babies going through withdrawal. Actually, I never even considered that these NAS children would consume so much of my/our time."

The responses suggest that the meaning of critical care nursing for the respondents is more narrowly defined than the scope of nursing found in reality. This perception is consistent with a perspective based on the medical model, which treats signs rather than concentrating on holistic management of the patient.[13] Although the issues that present in infants with NAS are not easily resolved, the most demanding tasks are consoling the infants and responding to challenging parents, which the nurses regard as inconsistent with their highly specialized training.

A Disconnect Between the Expectations of Nurses and Those of Families

Consistent with the conflicted perceptions of the nurse's role, the disconnect between nurses and families further exemplifies the struggles for nurses as they seek to reclaim their focus as a critical care nurse. Unlike in other areas of the hospital, where working directly with families may be intermittent, the NICU nurse works with parents and family

members on a routine basis. Although nurses in the NICU are accustomed to this extension of their role when providing care to newborns, the NICU nurses involved in this study reported challenges when caring for families affected by NAS. An underlying innuendo found in nurses' responses implied feelings of blame toward parents whose poor choices caused their infant's distress.

"It is frustrating to think that mothers would put their own children through that, but at the same time I feel they have been enabled to do it."

"But sadly I find the majority [of mothers] are quite willing to go through the process of withdrawal [for their baby, not themselves] so that they can continue to carry on their drug use as they have become accustomed. I remember only one mom who returned to visit in the months following to tell us how bad she felt and how supportive we were that she vowed to become drug-free and she had done this and wanted to tell us and thank us. I would love my work more if this was the norm."

Although praise for one's work promotes feelings of efficacy, these nurses express an expectation of gratitude and ownership of the problem on the part of parents (particularly mothers). Feelings of empathy toward a vulnerable child are natural and exist particularly for NICU nurses who fill multiple roles such as health care provider, advocate, clinical liaison, and caregiver. However, it appears difficult for these nurses to extend empathetic feelings and sensitivity toward parents who are often struggling with their own addiction issues. The caregiving nature of the NICU nurses leads them to be concerned for the infant's welfare after the infant is discharged.

"I try very hard to be nonjudgmental with the parents. I still worry about what these babies are going home to and whether they will get lost in the cracks once they go home."

"It is also very frustrating because I find the mothers care more about themselves and their dilemma than they do for the pain their baby is in. I worry what their lives will be like going home to drug-addicted moms, as is so often the case. It is especially disheartening when the same mom is back with a second babe in withdrawal."

The discharge of newborns from the NICU can be a difficult transition for nurses who have often spent weeks or months providing nursing care to critically ill newborns. Nurses rarely have the opportunity to hear about the outcome for infants once the acute phase of illness is complete. For those caring for substance-exposed newborns, transitioning an infant to a home with substantial social issues assumes an inherent trust in the parenting capacity of those who have been a contributor to the infant's condition in the first place.

Stress, Frustration, and Burnout

For nurses in this study, stress and frustration evolve out of the commitment to the infants they care for in the NICU. Neonatal nursing is a profession grounded in high-risk critical care, coupled with an empathetic commitment to and patience for newborns with great needs. Whereas the adult population can communicate with nursing staff to express their needs or level of pain, the only means of communication for infants is crying, while the nurse is left attempting to determine the cause of distress. Infants with NAS present a challenge to NICU nurses in that they often have a high-pitched and nearly inconsolable cry. These infants are difficult to comfort. Nurses report feelings of frustration and burnout when caring for the needs of infants with NAS.

"In many instances, it is very frustrating. They are very difficult patients to have because in many cases you are unable to provide comfort. They don't settle easily, they don't tolerate their feedings. They require holding and comforting, which I would love to be able to do but can't as there are other infants that I am responsible for as well. A NAS infant would be happiest if held for the majority of my 12-hour shift. You can't hold one infant and provide care to another."

The sense of frustration extends beyond the inability to console. Neonatal nurses express feelings of stress related to balancing the many needs of infants with NAS while providing critical care nursing to infants who they perceive to be at a higher risk medically.

"It's easy to spend the entire 12-hour shift with one baby, holding, walking, feeding, and trying to soothe. On days when there are a lot of acutely ill babies in the NICU, it's not unusual to have to listen to a baby's shrill cry for hours on end because nobody has time to comfort him, and the parents are nowhere to be found. This is upsetting and makes me as a nurse feel that I am not meeting the needs of my patient."

Increased Awareness of Drugs in Home and Work Life

Nurses in NICU environments are familiar with caring for medically high-risk infants with conditions such as prematurity, hyperbilirubinemia, and congenital anomalies.[14,15] However, within the organization under study, there has been a dramatic increase in NICU admissions for substance-exposed infants. Surprisingly, this community problem has not increased the depth of awareness among the NICU nurses despite the prevalence of affected newborns. Nurses do report an awareness of substance use implications that extends beyond the walls of the NICU and into their home life, which includes an awareness of the role parenting may play in preventing future substance abuse. One nurse described the impact of this broader perception as follows:

"Working with NAS has certainly brought the subject of drug abuse close to my mind. In fact, rarely does a day go by when I am not thinking about the high rate of [drug] abuse in our community. This has led me to be very diligent about discussing drugs and how addictions happen with my children. We have role-playing situations where I pretend I am the person trying to convince my children to take just one joint or one 'hit.' I ask them to tell me how they will respond to a person or a friend who is trying to convince them that it is OK. I also spend some time educating my adult friends, and when the opportunity arises, I even discuss drugs with my children's friends."

Although issues of withdrawal are clearly challenging and pose anxieties beyond the job, nurses remain committed to their positions. Despite the multitude of opportunities for nurses, many have remained committed to NICU nursing for many years. Participants defined their level of awareness of drug issues and its stressful impact while continuing to express commitment to their career in the NICU:

"I had no idea it would have been such a huge problem. Alcohol and drug withdrawal were a major problem on adult medical, which is the issue that drove me out of that department."

"It is very disappointing that we have such a big drug problem in this city. I don't think I could have ever imagined that we would ever have so many babies withdrawing and needing morphine. It's very sad, but then again we must be here to help."

Incorporating this new reality into their daily lives was a consistent theme throughout the nurses' responses. Yet they maintained a commitment to affected newborns and adopted the "helper" role, which is fundamental to nursing practice.

DISCUSSION

The responses given by the NICU nurses in this study suggest that a central experience for them was a role conflict. It would seem to originate from the scientific advances that medicine has made to improve the survival rate of premature newborns.[14,16] This has coincided with greater technical specialization by nurses who provide the critical care for compromised neonates.[15] NICU nurses have become accustomed to applying a highly developed skill set that continues to be refined as they specialize and gain advanced expertise in their roles as neonatal nurses. Becoming an NICU nurse requires not only a critical skill set, but also a love of and commitment to newborns, which is reflected in the responses of the nurses in this study. Coincidentally, these two elements of NICU nursing are the very factors that contribute to professional conflict for nurses caring for infants with NAS. From the responses of nurses in this study, despite their frustrations and concerns, they maintain a strong commitment to the care of newborns.

However, the current social problem of drug use prevalent in many communities has added a dimension to neonatal nursing that includes caring for the substance-exposed neonate.[1] This places NICU nurses in a role of soothing distressed infants for a large part of their shift, which requires less skill and is not dependent on their technical expertise. As the responses of the nurses in this study show, this can be frustrating. One troubling component of NAS that is acknowledged throughout the nurses' responses is the inability to console these infants, which is viewed by nurses as a caregiving responsibility rather than a critical nursing skill.[3]

Under most circumstances, a partnership with parents is associated with positive outcomes, improved maternal-infant interaction, and greater job satisfaction for nurses.[17,18] But as the responses in this study indicate, working with the substance-using mothers whose infants have NAS poses significant challenges for nurses. One of these, noted in the nurses' responses, is their values and expectations that a mother's role is to care for and protect her infant. So it is not surprising that these nurses express frustration with mothers of substance-exposed newborns who are responsible for the infant's distress. In addition, the mothers of these infants often are unable to participate in the demanding care and soothing of their distressed infants.

Findings from the nurses' reports in this study demonstrate the commitment of neonatal nurses to the infants they serve, despite the adversities of a challenging population. The difficulty for nurses is to balance the competing priorities of meeting the physical needs of infants with NAS and caring for other critically ill infants assigned to their care. As the results demonstrate, the nurses' value-laden responses of blame toward substance-using mothers indicate a lack of knowledge about addiction related to substance abuse. The mothers of newborns with NAS have multiple social risk factors beyond the average mother of a critically ill newborn. In addition to addiction, often poverty, violence, and poor social supports are common among this group.[8,19,20] This causes further distress and psychosocial needs. The stresses experienced by parents with an infant in the NICU, arising from the separation of a mother from her infant due to the numerous technical barriers, have been well documented.[14–16] However, mothers with substance use problems face additional stresses and concerns associated with guilt and shame.[21] They also fear judgment.[8] These factors could result in further distancing of the mothers from their infants in the NICU. All of this can influence the quality of parenting offered to newborns with NAS.

Although a preliminary awareness of the issues facing substance-exposed mothers is a good start in contributing to nurses' understanding of the families they serve, the findings from this study suggest that a deeper awareness of these issues may be required for increasing sensitivity among nursing staff and for promoting a partnership with parents for the care of affected newborns. Despite a reported increase in awareness of addiction issues and the prevalence of NAS, the nurses in this study appear to lack a depth of understanding of the power of addiction and at times continued to express anger and disdain toward mothers of affected newborns. Stories from women who struggle with addiction highlight the issues of depression, violence and abuse, lack of supports, poverty, guilt, lack of role models, poor self-esteem, and a life filled with multiple stressors beyond their control.[8] Gaining a clearer picture of the social conditions associated with substance abuse has the potential to assist nurses and other health care professionals to appreciate that addiction is more than a choice made by an inadequate mother.

NICU nurses are in a unique position to not only meet the physical needs of infants with NAS, but also to facilitate family healing and positive maternal-infant attachment.[10,22] In a study of nurses as providers of support for mothers of

premature infants, Mok and Leung found that parents who were continuously informed about their infant's condition became more knowledgeable and active in caring for their baby. Additionally, nurse encouragement reinforced and strengthened feelings of the maternal role.[23] Support from nurses to premature infants clearly strengthens the ability of mothers to positively interact with their children. Substance-using mothers can also benefit from this support, and through positive reinforcement and role modeling from nurses, these mothers can assume a more active role with their newborns and recognize the value of their caregiving capacity in an effort to move forward.

Based on the nurses' responses in this study, a key issue that needs to be addressed is the attitudes that nurses hold toward substance-using mothers. This is consistent with the findings from other studies.[9] Families of infants with NAS and dealing with addiction appear to intensify feelings of judgment that do not necessarily exist toward other infant conditions such as prematurity. Further education regarding the context of addictions, as well as communicating and interacting with families of affected newborns, has the potential to increase nurse sensitivity to mothers with addictions.

Organizations must validate the strain of caring for infants with NAS. A commitment from organizations to support nurses through specialized training in this area as well as enabling creative scheduling solutions that provide opportunities for nurses to take a break or evenly distribute the high-needs infants and families will lessen frustration and increase positive nurse-family interaction. Through partnership in care and sensitive understanding, coupled with compassionate service delivery, nurses can expand the impact of their critical skills into the lives of these newborns for years to come.

In summary, the findings from the nurses' reports in this study demonstrate the commitment of neonatal nurses to the infants they serve, despite the adversities of a challenging population. The difficulty for nurses is to balance the competing priorities of meeting the high-risk physical needs of their patients with the psychosocial vulnerability of the entire family unit. To provide better care for these families within the NICU, the findings of this study suggest a need for education about addiction and substance abuse and attitude change by the nurses, accompanied by organizational support and recognition of the strain that caring for NAS infants and their mothers puts upon NICU nurses.

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