NICU Nurses' Lived Experience

Caring for Infants With Neonatal Abstinence Syndrome

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ABSTRACT

PURPOSE: The primary aim of this qualitative methods study was to describe the lived experiences of neonatal intensive care unit (NICU) nurses with ethical and morally challenging issues.

SUBJECTS: The target population for the study was registered nurses working in the NICU. Interviews were completed with 16 nurses from 1 hospital.

DESIGN: A phenomenological method design was used to describe NICU nurses' lived experiences with ethical and moral issues encountered in the NICU.

METHODS: After obtaining signed consent, the principal investigator interviewed all participants, using a semistructured interview guide consisting of open-ended questions.

MAIN OUTCOMES: Ethical and moral distress related to neonatal abstinence syndrome was the predominant outcome.

PRINCIPAL RESULTS: Caring for infants, coping with families, and discharging infants home were the major concerns voiced by nurses in this study.

CONCLUSIONS: Nurses in this study struggled with issues of beneficence and nonmaleficence and were not aware of scientific evidence that guides methadone management of pregnant women.

Key Words: ethical distress, methadone treatment, moral distress, neonatal abstinence syndrome

Nurses must adhere to legal and ethical obligations while performing their professional responsibilities. Ethical expectations are delineated in the American Nurses Association (ANA) Code of Ethics,[1] which can be interpreted as a legal obligation. The ANA Code of Ethics denotes the "duties" owed patients, other healthcare workers, and themselves. The code demands that nurses consistently demonstrate moral agency that Taylor[2] defines as the capacity to consistently act in an ethical manner. Moral agency entails a set of competencies in ethical matters as well as moral character and motivation. Individuals, as moral agents, exist within complex relations, often complicated by differences, particularly in power.[2] Differences that mark and distinguish these relationships may facilitate the moral agency of an individual, a group of individuals, or an institution. In contrast, the moral agency of an individual or a group of individuals may be constrained by differences in relations. If this occurs, nurses may feel that they are not fulfilling their ethical obligations and have compromised their moral integrity by being unable to adhere to moral principles.[2] Maintaining or preserving one's moral integrity when faced with moral conflict has been found to be a core task among nurses at all levels of practice.[3]

Nurses working in environments with patients requiring highly sophisticated technological care are often exposed to situations and issues challenging to their moral integrity. Neonatal intensive care unit (NICU) nurses are at a particularly high risk for compromised moral integrity. The NICU nurse must contend with personal ethical obligations to provide the best possible care to the infant while providing support and guidance to the parent.

The primary aim of this qualitative methods study was to describe the lived experiences of NICU nurses

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The authors declare no conflict of interest.

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DOI: 10.1097/ANC.0b013e3182677bc1

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with ethical and morally challenging issues. One-on-one interviews revealed that moral distress related to neonatal abstinence syndrome was a significant concern. In this article, we present the participants' perceptions of the lived experience of caring for infants with neonatal abstinence syndrome (NAS).

SIGNIFICANCE OF STUDY

It is estimated that 5% to 10% of pregnant women abuse drugs during pregnancy, not including alcohol.[4] Newborns who experience acute drug withdrawal are diagnosed as having NAS. Newborns exposed to opioids in utero (48%-94%) will have NAS.[5] Infants experiencing acute drug withdrawal may present with a range of symptoms based on the drug or combination of drugs abused by the mother. Neonatal abstinence syndrome is a generalized syndrome characterized by central nervous system hyperirritability, respiratory distress, and gastrointestinal dysfunction.[6,7] The timing of the opiate drug withdrawal may occur minutes after delivery and up to 2 weeks of age; however, most infants demonstrate signs within 2 to 3 days of life. While most infants with opiate withdrawal present early, symptoms in neonates exposed to intrauterine methadone may not appear until as late as 14 days of age.

METHODS

Research Design

A phenomenological method design was used to describe NICU nurses' lived experiences with ethical and moral issues encountered in the NICU. One-on-one, semistructured interviews using open-ended questions were used to gather data from the participants. The interview was pilot-tested on 2 graduate nursing students, which resulted in clarification of the definition of moral distress.

Study Setting

The study was conducted in the NICU of a children's hospital. Since 2008, there has been a significant increase in the numbers of infants with NAS, and the highest volumes in the state are admitted to the children's hospital where this study was conducted.

Study Sample

The population for the study was registered nurses (RNs) working in the NICU. Eligibility criteria for NICU RNs included English fluency and willingness to interview on day off. A snowball, purposive sampling technique was used to initiate contact with potential participants and ensure inclusion of NICU nurses who have experienced ethical or moral issues.

Data Collection Procedure

Approvals to conduct the study were obtained from the institutional review boards of the hospital and university. The study was partially funded by an internal grant provided by the university. Information about the study was provided at information sessions, flyers, and e-mails. Signed consent was obtained from each participant to interview and record the interview. To ensure confidentially, each participant chose a confederate name. The principal investigator conducted all interviews, using a semistructured interview guide consisting of open-ended questions. Sixteen nurses were interviewed over a 2-month period, each lasting approximately 1 hour. Participants received a small gift card at the end of each interview.

Data Analysis

Data saturation in this study was confirmed after 16 interviews. The recordings were transcribed verbatim, and the recording was erased. Transcriptions were stored on a password-protected computer in a locked office. An electronic copy of interview was sent to each participant for member-checking.

Transcribed interviews were analyzed using the Atlas.ti software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) to identify themes common to all the participants. A list of themes and related quotations was generated, and team members reviewed the data to validate the identified themes or recommend alternatives. The data were reanalyzed and a final version of the themes and quotations was produced.

RESULTS

Sixteen female participants were interviewed for this study. The average experience in the NICU was 8.32 years. Eight of the participants held an associate degree in nursing; 5 had a BS in nursing; 1 held a master's in nursing; 1 had a DNP; and 1 RN was in a master's program. Sixty-three percent (n = 10) reported having taken at least 1 ethics course in a nursing program.

According to the nurses in this study, incidences of NAS are increasing. "Unfortunately … I don't know why it is more here, but there are so many more … here than I have ever seen in my entire life," stated one of the nurses. Another likened it to an explosion and reported that 5 years ago, there were maybe 4 or 5 of these infants in the NICU and now … "I think that we have at least consistently 30% of our babies … [have NAS] and possibly at times up to 50%."

Some believed that part of the influx is due to the increased use of prescription drugs distributed by "pain" clinics. "We have a lot of these babies now. … And they aren't really the crack babies anymore so much.. … But just the prescription drugs and oxycodone." Many of the mothers enroll in methadone programs when they discover their pregnancy. "A lot of the mothers only go into the methadone program so they don't lose the baby when they're born. Because if they are in a program when the baby is

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born, they can show that they are trying. So if the baby is born addicted to drugs, but she wasn't in any kind of program … they are more readily taken away from them." Although working in the NICU often causes distress in itself, the participants in this study described specific concerns related to caring for infants with NAS. Analysis of the interviews revealed 3 specific areas of concern: caring for the infants, coping with the families, and discharging the infants to home.

Caring for the Infants

Faced with an increased population of infants with NAS, the participants in this study voiced concerns about caring for these patients during their withdrawal experience. One nurse described the process of weaning. "They will be on that [morphine] for so many days and … then we gradually have to get them off of it. And those are the days that they are hysterical and all that. … They sweat like menopause night sweats. You go in and that baby will be soaking wet."

Many participants expressed distress and frustration at not being able to comfort or console the infants through the process. "Even when you touch them, they're like, 'What are you doing? Why are you touching me? I can't. No, no.' The only thing that really helps them is the morphine, phenobarb." Even efforts to feed the infant are rebuffed. "You put the bottle near the mouth, and they're like [desperate sounds] but he won't suck. You can't get him calm enough to suck." She felt badly because as a nurse she was not able to comfort this child.

Almost all of the nurses described the "high-pitched, neuro screaming" that characterizes these infants. "Something has to hurt," stated one nurse. "Something has to hurt for them to scream like they do." The cry was so familiar to the nurses that they could "walk into the room and look at them and you know what their diagnosis is." One nurse wanted to ensure that the mothers knew what their infants were going through. "I want to take a recorder and just record their crying, and have the mom have to sit at the bedside and whenever they fall asleep just put it on and say, Listen, we have to deal with this weaning process that you put them through. And you just get to come at the end of this and say, 'Okay, I'm ready to get my baby.'"

Several questioned the efficacy of caring for infants with NAS in the NICU. "And they do need care. No doubt, they can't go home, obviously, until they are through their withdrawal. But I don't think the NICU is the appropriate place to care for them. … You cannot have a term baby in a hospital for 2 months … 3 months, 4 months. It's just not right … how could that be good for anybody?" In addition, as NICU nurses, they were specifically trained to care for a different population and the skills needed for most of these infants could be handled by other healthcare providers. "We are trained as ICU nurses, not full-term drug-addicted baby nurses. … You know, that's not what we signed up for."

Coping With the Families

In a NICU setting that encourages family participation in care and considers families of hospitalized infants part of their patient assignment, coping with parents who are drug-addicted was a significant cause of distress among the participants. "And so then if we have 30–50% population of drug-abusing moms, that's who you get to visit with while they are here." Nurses reported abusive, aggressive behavior from parents who have access 24 hours a day to the hospital. "We've had parents fight against each other. We had a dad threaten to blow us up and come shoot us all. Yeah, so, all kinds of stuff."

However, the behaviors exhibited by many of the mothers were what particularly distressed the participants. "The mothers all have that same personality, whether they are prescription drug addicted, or cocaine addicted, they all have exactly that same. … They walk in defensive. If you're nice to them to try to break that defensiveness, then they try to use you."

Often, the mothers blamed the nurses for the infants' problems. "They are the hardest family to take care of because the mother [says] 'I love you, I love you, I'll do anything for you. And they won't let me give you my breast milk. And they won't let me do anything for you. And they won't let me hold you.'" One nurse described a situation in which the mother complained of being prevented from caring for her baby. The nurse told her that she could give the next feeding, but the mother stated that she would miss her bus but that she would spend next day entirely with her child; it was over 2 days before she appeared again.

In situations where they are being verbally attacked, the nurses resisted the urge to retaliate. "You just want to say, your baby is here because you wouldn't stop using marijuana, you wouldn't stop using cocaine, and you wouldn't stop oxycontin. And you can't say that to them. That's an issue too, where you have to be nice to a person that's blaming you for what they've done." Another nurse describes why saying what she really feels is not feasible. "In some way, in whatever way that is, even if it's in the most minute way, it's going to … come back on the baby. And so, even though you want to get so mad, you can't."

It seemed to several participants that despite drug addiction or methadone treatment, many of the women continued getting pregnant, even though they showed little interest in the care of their infants. "We have a child that was a drug baby. He's probably 7–8 months old, has never left the NICU, isn't going to be leaving anytime soon, and that mother is already pregnant with the next one."

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In another case, the decisions concerning an infant with neurological problems were left to a mother who would never be able to take him home because of her drug addiction. When contacted for consent for treatment, she responded with "'Yeah whatever you want to do, what are you doing this time?' … That's kind of hard to have someone say that. …"

Mothers often report that doctors assured them it was "safe" to continue prescription drug use during their pregnancies. "I can't imagine a doctor saying that, when the doctor told … our generation, 'Don't take aspirin … don't have caffeine'. And they're going to say 'okay?' I have never heard one say it was okay. It's worse for the baby." Several participants expressed their opinion that when a woman of child-bearing age is given pain medications or methadone, "then Depro should come with them all."

Despite the difficulties with parents, the nurses expressed strong attachments to the infants. "I love taking care of the babies, and I don't love when their families come in. That's when I don't love it as much."

Discharging the Infants

The nurses expressed many concerns about releasing the infants from the hospital once they were weaned. They were worried about the long-term mental and physical issues of the children as well as the types of environments to which they were being released.

Several nurses talked about the types of issues that infants with NAS could potentially face as they age. "These are the kids that are going to have problems with attachment. … ADD definitely. … Are they prone to the addiction too, later on down the road?" One nurse talked about the infant suffering and the potential impact. "When you see what these babies go through, there is no way they cannot be affected in some way. There is just no way. The pain … like, oh God, the pain. If you ever saw that …"

Many more of the participants feared what might happen once the infants were sent home. One nurse recalled a particularly difficult discharge. "I was just afraid he was going to be screaming in the middle of the night and she was just going to drop him, throw him at a wall, you know, that's what I thought …" Before the family left the hospital, the nurse met with the parents and the social worker and gave them a warning. "This baby is going to cry and you're not going to be able to stop him. … You need to promise me right now that when that baby does that, you will put him in his crib, put the side rail up on the crib, and walk out of the room. I don't want to read in the newspaper that you dropped him, that you threw him, that you drowned him, that you hurt him."

In addition to fears of abuse, there were concerns with whether these mothers were capable of caring for any infant, much less one who is extremely demanding. Infants are not discharged until they are off morphine, but still on phenobarbital that will be administered by drug-addicted mothers. Nurses raised concerns about the ability of these mothers to provide basic care such as feeding, because they may not have anyone to help them. "Because the baby is still going to have issues in some cases after they withdraw. They may have long-term issues, you know, learning disabilities and those things. But the baby is eating every 3 hours. Sometimes 6 feedings out of the day."

In another case, a mother was taking formula left in the room for her child. "We thought for a while she was selling it. And then the day I discharged her, the baby was discharged on a different formula than he had been on a month before. And she said, 'If I run out of formula, can I give him that [old] formula?' And I said, No, because we took him off that. It was making him gassy and he was crying on it. And she said, 'Oh, crap, and I've got so much of it.'" The nurse worried about the mother's ability to provide for her child's needs at home.

One nurse described her reluctance to release an infant. "I don't want to give this baby to this mother. … She [says she] does everything that she can for this baby … we just want to say to her … you took drugs during your pregnancy. You did so good." One mother kept denying that she had used drugs even though her denial required that painful tests be performed on her infant to determine why he was suffering. One participant summarized the problem she was having with the situation. "I do have a really hard time ethically … sending babies home with those mothers. Because you can see when they come that they're high; … that they're still using. I don't know how they get through the system. Or, how we can justify sending these babies home with these mothers because they are difficult to take care of … if you can't take care of yourself without using drugs on a daily basis, how in the world are you going to take care of child who is more difficult than most children? … I just think, how are we doing this … as a society, how are sending these children home with these moms and dads?"

DISCUSSION

The participants struggled with 2 moral principles: beneficence and nonmaleficence. Beneficence, the obligation to do good, was demonstrated in their feelings of inadequacy in caring for the patients and their families. They were unable to comfort the infants, using their nursing skills, and felt that many of their efforts were useless. Although unsure that the infants belonged in a NICU environment, they wanted to do all they could for them. Repeated comments about the painful crying distressed the nurses and made them fear the long-term consequences of starting life with so much pain during withdrawal.

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Likewise, they had difficulty caring for and communicating with the mothers of these infants, who were struggling with various stages of drug addiction. Nurses were angry about the drug behavior and the suffering it inflicted on the infants. They struggled to keep feelings hidden because they were concerned that inappropriate comments to the parents might cause them to take out their frustrations on their child. Just as they were not trained to specifically care for the infants with NAS, they had even less training on how to cope with mothers and fathers who are addicted.

Nonmaleficence, the principle of not causing or preventing harm, was evidenced in their apprehensions about discharging infants to unstable homes where they might be abused or neglected. Not only did they fear lawsuits from the consequences of releasing the infants to these homes, but they worried that the infants would not survive or would grow up to become addicts themselves. Despite doing everything they could to prepare the parents for what to expect once the infants were at home, they were not convinced that the infants would thrive.

Many of the nurses in this study were not aware of the scientific evidence that guides methadone management of pregnant women. They expressed concern that the methadone clinics were not systematically decreasing the methadone doses, and suggested that anyone frequenting a methadone clinic should be on birth control. Much evidence exists that supports methadone as the treatment of choice in opiate-dependent pregnant women. Pregnant women on methadone have better nutrition and weight gain and are more likely to have prenatal care and less likely to deliver preterm infants.[8,9] Although the infants of methadone-treated mothers are at risk for NAS, it is a much more stable and predictive environment. In fact, pregnant women on methadone are doing the best thing they can for their unborn infant. Recognition for their decision might help establish that trusting relationship so important to NICU nurses.

Substance-abusing parents present an additional level of complexity for NICU nurses. They may not, however, have the preparation or skill set to work with this challenging population. Orientation for NICU nurses usually focuses on the skills needed to assess and manage infants at risk, rather than engaging in a therapeutic conversation with an addicted parent(s). Although social workers are part of the healthcare team, these parents often visit in the middle of the night when few members of the multidisciplinary team are available. Nurses' discomfort in not possessing the needed therapeutic skills may underpin their belief that infants with NAS do not belong in the NICU and explain a significant source of moral distress. Fraser and colleagues[10] found that family-centered care was compromised in part by these same attitudinal factors. Nurses in that study reported that they recognized their own biases, but thought that additional education on substance abuse and its effects would be a better preparation.[10]

CONCLUSION

The results of this study echo those of previous studies of nurses' experience in caring for infants with NAS and are likely to resonate with NICU nurses.[10,11] As long as substance abuse remains a national problem, infants with NAS will continue to require nursing care to manage their withdrawal. At the least, NICU nurses need specialized knowledge to interact therapeutically with substance-abusing parents.

Areas of further study include interventions aimed at NICU nurses to improve patient outcomes. Nurses who have confidence in their ability to positively impact maternal parenting behaviors through education and skill building may impact patient care outcomes. Interventions can also be targeted at the substance-abusing mother and extended family, to help them demonstrate effective parenting behaviors and support the infant's unique needs.

Nurses, such as those interviewed in this study, have many daily challenges to their moral integrity. Despite this, the nurses remain dedicated to their profession as evidenced by the longevity of their employment as a NICU nurse and concern about the welfare of their patients. It is essential that challenging issues such as caring for infants with NAS are recognized by supervisors and administrators. Recognition of the stress nurses are experiencing is essential and hospitals may need to assist in developing debriefing sessions and other supportive services.

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