

Ethical issues related to caring for low birth weight infants

Nursing Ethics 2014, Vol. 21(6) 731-741 © The Author(s) 2014 Reprints and permission: sagepub.co.uk/journalsPermissions.nav 10.1177/0969733013513919 nej.sagepub.com



Mary S Webb and Denise Passmore

University of South Florida, USA

Genieveve Cline

All Children's Hospital, USA

Denise Maguire

University of South Florida, USA

Abstract

Background: Currently preterm births are the leading causes of newborn deaths and newborn mortality in developed countries. Infants born prematurely remain vulnerable to many acute complications and longterm disabilities. There is a growing concern surrounding the moral and ethical implications of the complex and technological care being provided to extremely low birth weight infants in neonatal intensive care units in the developed nations.

Research purpose: The purpose of this study was to describe the ethical and moral issues that neonatal intensive care nurses experience when caring for low birth weight preterm infants and their families.

Research design: A phenomenological method design was used to describe the lived experiences of nurses with ethical and moral issues encountered in the neonatal intensive care unit. One-on-one, semistructured interviews using open-ended questions were used to gather data from the participants.

Research participants: The setting for this study was a 97-bed neonatal intensive care. A total of 16 female nurses were interviewed.

Ethical considerations: Approval to conduct the research study was obtained from the institutional review board of the hospital where the study was conducted. Formal signed consent was obtained from each participant. To ensure confidentiality, each participant was asked to choose a confederate name to be used in the interview and the transcriptions.

Findings: The thematic analysis identified five recurring themes: (a) at the edge of viability, (b) infant pain and discomfort, (c) crucial decisions, (d) communicating with parents, and (e) letting go.

Conclusion: Neonatal intensive care unit nurses indicated that they often had challenges to their own sense of morality as they struggled to protect the infant from pain and unnecessary discomfort, provide care to an infant and their family whom they thought was faced with a lifetime of challenges and poor health, accepting decisions made by parents, and feeling as if parents were not adequately informed about outcomes.

Keywords

Extremely low birth weight infants, ethical issues, low birth weight infants, neonatal intensive care unit, neonatal intensive care unit nurses, nurse/parent interaction

Corresponding author: Mary S Webb, College of Nursing, University of South Florida, 12901 Bruce B. Downs Blvd., Tampa, 33612-4742 FL, USA.

Email: mwebb@health.usf.edu

Introduction

Currently preterm births are the leading cause of newborn deaths (those occurring in the first 4 weeks of life) and newborn mortality in developed countries.¹ Preterm births are those that occur at less than 37 weeks gestation. The frequency of preterm births is about 12%–13% in the United States; in Europe and other developed countries, preterm birth rates range from 5% to 9%.² Preterm birth rates have steadily risen in the past two decades in most industrialized countries despite advancing knowledge of risk factors and mechanisms related to preterm births.

The high number of preterm multiple gestations associated with assisted reproductive technology has been shown to be an important contributor to the overall increase in preterm births. There have also been a growing number of singleton preterm births in which labor is either induced or the infant is delivered by pre-labor cesarean section.^{2,3} Additionally, in the United States, many pregnant women still develop gestational diabetes, hypertension, and obesity, and do not receive the quality perinatal care that is necessary to sustain a pregnancy to the full gestation.⁴

Developed countries have made tremendous clinical and technological advances which have led to unprecedented survival rates for extremely premature infants. Over the same period of time, the limit of viability has been pushed back to a much lower gestational age.⁵ Currently, the threshold of viability seems to be dependent on the physiological development of the lungs that takes place around week 22-24.^{5,6} Unfortunately, infants at the lowest threshold continue to have poor survival rates, and the few who survive may have severe morbidity and disability. Population-based estimates on in-unit survival of very preterm infants were recently done in the United Kingdom on 2995 White singleton infants born at 23–32 weeks gestation. Approximately, 92% of the infants survived to discharge, with survival being significantly related to gestational age. For girls, survival ranged from 35.5% (23 weeks) to 99.3% (32 weeks). Boys had a slightly lower survival rate ranging from 27.7% (23 weeks) to 99.1% (32 weeks).⁷

Although gestational age-specific mortality rates have dramatically improved over the last few decades, infants born prematurely remain vulnerable to many acute complications, including respiratory distress syndrome, bronchopulmonary dysplasia, apnea, necrotizing enterocolitis, patent ductus arteriosus, and anemia of prematurity. Immune systems are immature and inefficient to protect against bacteria, viruses, and other pathogens, resulting in pneumonia, sepsis, meningitis, and urinary tract infections. Injury to the central nervous system is manifested in intraventricular hemorrhage, intraparenchymal hemorrhage, and white matter injury.⁸

There is growing concern surrounding the moral and ethical implications of the complex and technological care being provided to extremely low birth weight (ELBW) infants in neonatal intensive care units (NICUs) in developed nations.^{6,8,9} Nurses who care for these critically ill infants are at the bedside daily, managing infants who develop severe complications and require complex and often painful treatment. They also have extended contact with families who are often emotionally distraught and overwhelmed with the infant's condition. The day-by-day "lived experiences" of nurse's perceptions of their encounters with various moral and ethical dilemmas has been given minimal attention and a paucity of literature exists. The purpose of this study was to describe NICU nurses' experiences with the ethical and moral issues they encounter when caring for low birth weight preterm infants.

Methods

Research design

A phenomenological method design was used to describe NICU nurses' lived experiences with ethical and moral issues encountered in the NICU. Phenomenological research is a strategy of inquiry in which the

researcher identifies the essence of human experiences ("the lived experience") about a phenomenon as described by the participants.¹⁰ One-on-one, semi-structured interviews using open-ended questions were used to gather data from the participants. Open-ended interviews enabled participants to express additional information that may help the researcher when attempting to understand the participants' perspective.¹¹ The one-on-one interview method is typically preferred when participants are asked to describe phenomena that may be sensitive or emotionally charged.

Study setting

The setting for this study was a 97-bed NICU located in a 259-bed specialty licensed children's hospital. The target population for the study was registered nurses working in the NICU. At the time of participant recruitment, there were over 180 neonatal nurses employed in this setting. A snowball, purposive sampling technique was used to initiate contact with potential participants and to ensure inclusion of NICU nurses who may have experienced ethical or moral issues. Purposive sampling involves selecting information-rich cases for in-depth study.¹² Access to the NICU nurses was accomplished by collaborating with a neonatal nurse educator (co-principal investigator (co-PI)) who worked with all NICU nurses without administrative responsibility.

Study sample

A total of 16 female participants were interviewed for this study. Participants reported an average of 11.32 years' experience in a NICU unit (range: 1–30 years). The average number of years of experience in the NICU at the study setting was 8.32 years (range: 1–29 years). Of the 16 participants, 8 held an associate degree while 9 had a Bachelor of Science degree. Two participants held a master's in nursing or were completing a nurse practitioner program. One nurse had recently completed a nursing doctoral program.

Data collection procedure

Approvals to conduct the study were obtained from the Institutional Review Boards of the hospital and the University of South Florida. The study was announced by the co-PI at educational sessions held with NICU nurses. Printed flyers were also placed in lounges or locker rooms throughout the NICU. Interested nurses usually notified the co-PI of their interest; contact information was then forwarded to the PI. Each participant who expressed interest was contacted by e-mail and phone by the PI. All participants were informed of the study time commitment, assured of privacy and confidentiality, and given the opportunity to make an appointment with the PI at their preference. The majority of participants were interviewed in a private office made available to the PI at the hospital. A sign was placed on the door to deter interview interruptions. Participants met with the PI prior to their shift or arranged to meet on their day off. Two participants chose to be interviewed at the university where the PI works.

Formal signed consent was obtained from each participant. Prior to the signing, the PI explained what questions would be asked in the interview, advised them that they could stop any time if they became upset, and had the right to discontinue the interview. Participants were also told that the interview would be recorded using a digital recorder. To ensure confidentiality, each participant was asked to choose a confederate name to be used in the interview and the transcriptions. The PI conducted all interviews, using a semi-structured interview guide consisting of open-ended questions. A total of 16 nurses were interviewed over a 2-month period. Each interview lasted approximately 1 h. At the end of the interview, each participant received a US\$25.00 gift card that could be redeemed at one of the five restaurants in the metropolitan area.

Data analysis

Sampling is typically terminated in qualitative studies when no new information is forthcoming (data saturation); redundancy is the primary criterion. Data saturation in this study was confirmed after 16 interviews. After an interview was completed, the recording was transcribed verbatim, and the digital recording was erased. The transcriptions were stored on a password-protected computer in a locked office. An electronic copy of the interview was then sent to each of the participants for member checking.

Transcribed interviews were analyzed, utilizing the ATLAS.ti software to identify themes that were common to all the participants. A list of themes and related quotations were generated, and the research team members reviewed the data to validate the identified themes or recommend alternatives. The data were reanalyzed based on team input, and a final version of the themes and quotations was produced.

Results of thematic analysis

The final thematic analysis identified five recurring themes: (a) at the edge of viability, (b) infant pain and discomfort, (c) crucial decisions, (d) communicating with parents, and (e) letting go. Each theme is described in the following section and includes several quotations that add richness to the data.

At the edge of viability

The participants verbalized that they were concerned about the quality of life many of the infants experience during their stay in the NICU, and after discharge for those who survived. One participant explained that when she began working in the NICU, the sickest and smallest infants were no younger than 28 weeks. In contrast, many of the premature infants are now as young as 22–24 weeks gestation and are at extreme risk of severe sequelae, such as infections, sepsis, intraventricular hemorrhage, cerebral palsy, developmental delays, respiratory distress syndrome, and blindness. Most premature infants are hospitalized for weeks or even months.

One nurse indicated that she sometimes wished that "they could just die peacefully and be relieved of their tremendous suffering." Another participant described caring for an infant who was the size of the palm of her hand:

It was horrible. The infant looked like a fetus. But that one died, and that was okay. But then there are some of these babies that are 23 weeks that we save still. They end up having G tubes and trachs and [are] on ventilators, probably the rest of their life. Who's to say which babies we can save and which we can't? But a lot of these kids end up having severe long-term issues down the road.

Concerns about immature lung function were verbalized by a participant with many years of working with premature infants:

The extremely premature infants are the ones I really struggle with. We try to provide care for 24-weekers but to me the limit of viability, based on lung physiology, is still at least 26 weeks. You have to have some alveoli to be able to have some gas exchange. Embryology hasn't changed; only our technology has. You can give surfactant and it works for a while. But they are still in the NICU six months later. Many times the babies are still being artificially ventilated. Often our outcomes end up being the same as if we had done nothing. And the amount of suffering these babies experience is very troubling. Wouldn't it have been better [from my perspective] to have said to the family "Your baby is just too young, too premature. We can do all these things but chances are really good that your baby is not going to survive. And if she does survive she is going to be so damaged that she could be blind, have cerebral palsy, be deaf, and not be aware of her environment. She may experience no joy in her life."

Another nurse shared similar feelings of frustration:

We have the technology to keep almost anybody alive. But should we? Do we have the dollars necessary to do that? I know no one wants to face those decisions on who we keep alive, when you have parents in front of you [who] want everything done. You know that the outcome is only going to be so much, or [stop at] a certain point. It is upsetting to me personally to see we're keeping this infant; we're finishing the process of growing him, if you will, for what kind of life?

One participant commented that she felt the most serious moral issues arose from the smallest preterm infants (22–23 weeks):

Sometimes you feel like they are somebody's science project as opposed to a tiny infant. How long can we keep the baby alive? What else can we do to keep this baby alive that probably should not be here to begin with? And the doctors, I think, sometimes they don't give the parents the information they need to make informed decisions. They are the professionals, they are the ones with the knowledge and the expertise and they are not advocating on the side of the baby.

Others also expressed frustration about

... bringing these kids along and into what kind of life? That is very upsetting to me. And another part of this dilemma is that, and I never want this to be taken in the wrong context, because it is not all about money. However, health care dollars are extremely limited. We may spend a couple million dollars on an infant that is never going to have any quality of life. And there is his or her mother who can't even afford a mammogram.

Another nurse reported that

We had a baby here not too long ago who wasn't able to make her own cholesterol. You cannot live ... She wasn't viable but she was a term baby. She was a big baby. And they kept that baby alive for months.

Infant pain and discomfort

Several participants felt that in the process of providing highly specialized care for the infant, possible pain and discomfort were overshadowed by the intense technological treatment. During hospitalization, babies may also experience many uncomfortable and painful procedures such as frequent heel sticks, lumbar punctures, serum sampling, chest tube insertion, intubation, mechanical ventilation, central line insertion, and multiple peripheral intravenous insertions.

One nurse related, "we get into the habit of doing things and not even looking at the total picture of this baby." She described a situation where a baby with a severe genetic defect was being withdrawn from a ventilator and placed on a fentanyl drip. There were plans to extubate the infant after additional family members arrived at the hospital. Despite the terminal condition of the baby, there were still ongoing laboratory tests being done which required the infant having frequent blood draws. The nurse said, "No one thought to say 'This baby is dying. Let's not inflict any more pain on this infant.""

One participant described how difficult it was to care for an infant for weeks or months knowing their chances of survival are very poor. Additionally, their quality of life in the NICU is wrought with illness and discomfort:

You know, most of the babies that we care for ... get better and go home. It's a good thing because it does make you go on ... But every so often we get these babies that we know are going to be sick. You know, the short gut kids ... [that] don't have all their intestines. They vomit all the time. And they are susceptible to all kinds of

infections because their nutrition is bad and they're on TPN and it affects their liver. And it's just really a sad cycle. So, we'll have these kids for 6–7 months. And so you watch them grow and you get attached to them. They're smiling one minute at you and then they're vomiting and sick to death the next minute. Some of the things are real sad. It's hard, you know? Some of this nursing is very hard.

Several nurses verbalized that at times, they felt they were needlessly contributing to an infant's pain and discomfort:

If we have a baby that we know has no chance of survival, then I feel like we are torturing them.

Another nurse stated that

Sometimes they are getting a medication drip for pain, but even then, just doing a simple act of trying to move them, you know that it's uncomfortable for them. So, it can be really sad. You feel like you're [hurting them]. You don't want to touch them but you know that you have to.

Crucial decisions

Several participants reported that it is difficult for parents to let go of a baby who is critically ill. They cited the networks and media who show the miracle baby who survived against all odds. Everyone hopes that their infant will also survive and be fine despite the significant complications they are afflicted with:

They just can't let their baby go because they all think their baby is going to be the miracle. Their baby is going to be the one that they see on the network ... telethon, the miracle that was a 24-weeker or 23-weeker that made it despite the odds being against it. We have had 23- and 24-weekers that did phenomenally well. But, you know, they all think that no matter how sick their baby is that theirs is going to be the miracle.

Participants also verbalized that

Parents don't see the future. What they see is this cute little bitty baby. They don't see the 16-year-old spastic, totally dependent child who has to be fed, bathed. They're heavy, they drool ... many of them can't even sit in a wheelchair; they have to be strapped in wheelchairs. They can't communicate. They [parents] don't know. They can't. They don't see their future.

Another hypothesized that

It is very difficult to realize just how hard it will be to care for this baby when he or she is discharged. It is hard for them to conceptualize that [when] this baby goes home with a G tube or oxygen or a trach ... that means there is no regular babysitter for that. You can't just hire some high school student ... so you can have date night. Going to a grocery store is a totally different experience. You can't do anything really together anymore. I think that's hard too for parents to cope with and to understand sometimes because I think we all do. Because when you're married or something, you want to spend time together. You need free time, anybody does and they sometimes don't realize that this is a 24-hour thing. I saw a parent once ... this couple, they brought in their twins saying they weren't eating, all they were doing was crying, and then they're like, "So can we pick them up tomorrow? Cause we just want to get some sleep."

One nurse was concerned that

Parents are asked to make decisions that they simply are not capable of doing. They lack the knowledge, logical reasoning skills in the face of the emotionally charged situation, the ability to foresee the probable outcomes of their infant, and the ability to communicate effectively with physicians and nurses.

Additionally, parents may experience guilt, sorrow, disbelief, helplessness, and even feelings of failure to conceive and nurture a normal, full-term infant. In turn, physicians and healthcare workers may not always be as forthright as they need to be. There is sometimes a small window of opportunity in the NICU, but not everyone is prepared to make a decision, and parents must live with the nondecision. This thought was expressed by another participant:

I think we leave a lot of the decisions up to the parents at a moment in their life that they're unable to make that decision. [Imagine] you've just delivered a 23-week ... baby Since the moment you found out that you were pregnant, you've been waiting for that baby to arrive ... There is a very short period of time to say, "we're not going to resuscitate" ... Even if we have resuscitated and put him on the ventilator, [we can] take him off and allow him to die. And I think we leave that decision up to the parents, and there is no way they can have an informed decision at that point. There is no way they could understand the possible outcome ... And then once you keep them alive for a few days, then that window is closed. It's no longer available to them.

Communicating with parents

Several nurses thought that physicians, in particular, are not as forthright as they perhaps need to be. Many nurses advocated for more truth and forthcoming about the severity of the infant's conditions and to be straightforward when discussing the infant's future:

I think the biggest thing that bothers me still and throughout the years is that they don't tell the parents the truth. When they started saving babies at a younger and younger gestation, they always gave the parents the bright, sunny thing that this will be fine. "We've been saving babies at 24 weeks; 500 grammars will live." But they don't go into details about the sequelae that follows, the cerebral palsy that they are likely to have, the mental retardation ... "He's little but look at how perfect he looks, and he'll be fine."

Another participant suggested that if parents could be informed before the birth of their ELBW infant, they might be better prepared to make an informed decision. She wanted parents to know the number of infants who have severe cerebral palsy and mental retardation, and never walk or even see:

I think before the baby is born, if you have that opportunity, if you know a mom could go into pre-term labor, and she's 23 ... or 24 weeks, that you explain to them the number of babies that have cerebral palsy and have mental retardation, and never walk and never see. If you could at least inform them. And I know they're emotional at that time, but if they have the information up front. So that they can say when the baby is born, "Just wrap him up and hand him to me, and let me hold him." Or, "I don't want to see the baby" I don't think they get that information.

Letting go

Infants in the NICU may be there for weeks or months. Often the NICU nurse has served as their primary nurse for weeks or months. They witness the capabilities of the parents or mother to learn to bond and care for the baby. Some mothers, they report, are simply not prepared to handle the complex medical needs of an infant with long-term developmental issues. One nurse related a situation that had occurred with an infant she had cared for nearly a year:

There just wasn't any organ system that wasn't affected in this baby. And he had reached the point where we had done really all we could for him. He was stable in that way. But he was still very fragile, medically. He wasn't quite a year old but he was 8, 9 months at least. And the mother had only come in sporadically, usually didn't stay for very long, would hold him for a little bit, and then she would have to go. She had transportation problems, so it was hard for her to get here. She had an older child that reportedly had medical problems, but she could never

describe to you what the medical problems were other than that she was in some way sickly. And that was one of the other reasons that she couldn't come. And so, we [the nurses] were all very, very concerned. So, we had a meeting with the nursery administration, social workers, neonatologists etc. The doctors told the mother that she had to come in. We had a list of things the mother had to do. So she did those things. She came in for a day or two, and checked off all the things that they had required her to do. But we still felt like she didn't get it. That doesn't mean she didn't love her son, but we felt like medical foster care for a while would have been a better option for him. Until maybe he got older and maybe a little more stable. The baby was sent home anyway. And a few days after he got home, the baby started to run a temp. With normal kids, if they run a temp, if it doesn't go down within a day, you call the pediatrician. However, this mother delayed taking him right away to the doctor. She took him a day or two later, and he was dead within a week.

Participants reported that many of the very complexly ill infants have to go to a medical foster setting. Many infants ultimately have to be adopted or left permanently in foster care:

We had to send one kid ... to medical foster ... up in Tallahassee because that is the only place that they could place this child. Well, her mother is not going to visit her up in Tallahassee; her mother is not visiting her in the hospital. What kind of life is that child going to have?

Discussion

The participants in this study openly discussed their experiences with moral and ethical issues encountered in a NICU setting. Participants talked very freely and openly about their experiences and frequently expressed gratitude to the PI for taking an interest in their personal experiences. It was obvious that the participants truly cared about the infants and often showed signs of emotional distress when relating some of the cases. Despite these moral and ethical challenges, the nurses remained dedicated and devoted to this very fragile population as evidenced by the years of experience as NICU nurses.

NICU nurses indicated that they often had challenges to their own sense of morality as they struggled to protect the infant from pain and unnecessary discomfort, provide care to an infant and their family, whom they thought was faced with a lifetime of challenges and poor health, accepting decisions made by parents, and feeling as if parents were not adequately informed about outcomes. The findings suggest that the participants struggled with ethical principles such as beneficence, nonmaleficence, social justice, autonomy of parents, and veracity.

Beneficence, the obligation to do good, and nonmaleficence, the obligation to prevent or do harm, were demonstrated in their feelings of inadequacy and concern in caring for preterm infants that were perceived to be only minimally viable. Participants also expressed considerable concerns about the quality of life the infants who survived would experience in later years. Concerns such as those expressed by the participants are valid and have been documented in the literature. For example, an international comparison of treatment guidelines for the ELBW infants indicated that the threshold of viability seems to be limited to the physiological development of the lungs which takes place around 22–24 weeks. Survival rates at this age remain very low and are not expected to improve with our current technological resources.⁴ Many infants die before, during, or after birth in the NICU. For those who do survive, approximately half will have moderate to severe neurodevelopmental problems. Seri and Evans⁵ reported that survival of infants <23 weeks gestation and <500 grams birth weight is extremely unlikely with virtually no chance for intact survival. An intact survival as evidenced by participants reported concerns about the infants/quality of life were the most frequent concern expressed in this study.

Nonmaleficence evidenced in nurses concerns the pain and discomfort the preterm infants experienced while in the NICU. It was noted that even infants who had life support removed still underwent painful procedures such as frequent blood sampling or venipuncture. At times, participants felt like they were

"torturing" them and indicated that a simple act of turning a baby was very uncomfortable. This concern is also valid and has been empirically noted in a study by Matthews and O'Connor-Von¹³ who found that among neonates who had died after withdrawal of ventilator life support, the neonates who weighed less than 800 g were significantly less likely to receive comfort medication than their heavier cohorts. Additionally, about 28% of all neonates in the study sample (n = 171) never received any comfort medications during their death process.

Many participants expressed a concern for social justice, fair distribution of societal resources associated with the complex technological care, and the length of stay in the NICU. This was particularly apparent when infants were seen as having no chance of survival or having long-term neurodevelopmental disorders. Nurses questioned whether this was an appropriate use of healthcare dollars when one considered that many people cannot even afford preventive healthcare such as mammograms or dental care. Caring for preterm infants is a major cost to the society and is currently estimated to cost the United States approximately US\$26 billion a year or approximately US\$51,600 per infant.⁴ Maternal care, intervention services, special education for infants with learning difficulties, and lost household and labor productivity also contribute to the cost of these infants.

Perhaps the most challenging issue that NICU nurses encountered was decision making by the parents of a critically ill preterm infant. Participants expressed that the families were not always adequately informed by neonatologists of the infant's very poor prognosis and given hope for a "miracle" when it was not feasible. One nurse expressed that she felt the parents were asked to make decisions they simply are not capable of due to factors such as inability to foresee the long-term prognosis and outcomes, being young and having minimal experience with death, always hoping for a "miracle," and being under a tremendous amount of stress during the infant's hospitalization. Ensuring that families are kept well informed and given information in a honest but understandable manner is essential to ensure that families make decisions that they are comfortable with and represent what is in the best interest of the infant. A study conducted in France evaluated parental narratives 3 years after the loss of a newborn in the NICU.¹⁴ In this study, parents reported that it was valuable to express their personal opinions in the decision-making process regarding their infant. They also valued kind, nonjudgmental involvement and preferred a protective, sympathetic, and communicative ambience. Parents also preferred dealing with the same caregivers the whole time. Parents felt that this gave them confidence in the staff and allowed some to express feelings that were difficult but determinative for the decisions.

Limitations include generalizability of this study which may be limited as a homogenous sample was used in one NICU located in the Southeastern United States. The context of the NICU environment in the United States is uniquely different as our society does not provide universal healthcare to its citizens. This is a very significant issue for many pregnant women as their overall health status may be affected by a lack of consistent and comprehensive healthcare. Despite the differences among the NICU environment, similar results to the findings by Canadian and UK researchers have been reported.^{15,16} Further study would be appropriate to evaluate additional NICU nurses from other developed countries to determine whether the ethical issues expressed in this study are unique to the United States or common to all NICU nurses. NICU experiences from other healthcare professionals as well as patients' families would be another important area of future research, to provide a more complete picture of this environment and to improve patient outcomes through reducing moral stress in those most directly responsible for the care of these infants.

Conclusion

Caring for the ELBW infant results in ethically and morally challenging situations on a regular basis as delineated by the participants in this study. Because of the nature of this highly specialized form of nursing, NICU nurses can experience high levels of physical and psychological stress. Manifestations of stress may include low morale, mental fatigue, increased levels of absenteeism, and exhaustion. In turn, these feelings and behaviors may have a detrimental effect on safe neonatal care.¹⁷ The American Association of Critical Care Nurses published a position paper that reported that emotional and physical stress in intensive care nurses is a major contributor to nurses leaving the work setting and profession.¹⁸ It is critical that this issue is identified and delineated in order that interventions may be implemented to diminish this problem. Preventing these phenomena in the NICU nurses can lead to better retention and recruitment rates and better delivery of comprehensive of safe neonatal care.

Conflict of interest

The authors declare that there is no conflict of interest.

Funding

This research received intramural funding from the University of South Florida (USF) College of Nursing & USF Department of Sponsored Research.

References

- 1. Kinney MV, Howson CP, McDougal L, et al. Executive summary for Born Too Soon: *The global action report on preterm birth*. March of Dimes, Partnership for Maternal, Newborn & Child Health, Save the Children, World Health organization, 2012.
- Goldenberg RL, Culhane JF, Romero R, et al. Preterm birth 1: epidemiology and causes of preterm birth. *Lancet* 2008; 371: 75–83.
- 3. Lawn JE, Gravett MG, Nunes TM, et al.; GAPPS Review Group. Global report on preterm birth and stillbirth (1 to 7): definitions, description of the burden and opportunities to improve data. *BMC Pregnancy Childbirth* 2010 February 23; 10 Suppl. 1: S1.
- 4. Institute of Medicine. Preterm birth: causes, consequences and prevention, http://www.iom.edu/Reports/2006/ Preterm-Birth-Causes-Consequences-and-Prevention.aspx (2006, accessed March 2013).
- 5. Seri I and Evans J. Limits of viability: definition of the gray zone. J Perinatol 2008; 28: S4-S8.
- 6. Pignotti MS and Donzelli G. Perinatal care at the threshold of viability: an international comparison of practical guidelines for the treatment of extremely preterm births. *Pediatrics* 2008; 121(1): e193–e198.
- 7. Manktelow BN, Seaton SE, Field DJ, et al. Population-based estimates of in-unit survival for very preterm infants. *Pediatrics* 2013; 131(2): e425–e432.
- Fischer N, Steurer MA, Adams M, et al.; Swiss Neonatal Network. Survival rates of extremely preterm infants (gestational age < 26 weeks) in Switzerland: impact of the Swiss guidelines for the care of infants born at the limit of viability. *Arch Dis Child Fetal Neonatal Ed* 2009; 94: F407–F413.
- 9. Cuttini M, Casotto V, Orzalesi M, et al.; EURONIC Study Group. Ethical issues in neonatal intensive care and physicians' practices: a European perspective. *Acta Paediatr Suppl* 2006; 95: 42–46.
- 10. Creswell JW. Research design: qualitative, quantitative, and mixed methods approaches. Thousand Oaks, CA: Sage, 2008.
- 11. Mezirow J. Transformative dimensions of adult learning. San Francisco, CA: Jossey-Bass, Inc., 1991.
- 12. Patton MQ. Qualitative evaluation and research methods. 2nd ed. Newbury Park, CA: Sage, 1990.
- 13. Matthews AL and O'Connor-Von S. Administration of comfort medication at end of life in neonates: effect of weight. *Neonatal Netw* 2008; 27(4): 223–227.
- Caeymaex L, Speranza M, Vasilescu C, et al. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU. *PLoS One* 6(12), http://www.plosone.org (2011, accessed September 2012).

- St Ledger U, Begley A, Reid J, et al. Moral distress in end-of-life care in the intensive care unit. J Adv Nurs 2013; 69(8): 1869–1880.
- 17. Braithwaite M. Nurses burnout and stress in the NICU. Adv Neonatal Care 2008 December; 8(6): 343-347.
- Position statement: Moral distress. American Association of Critical Care Nurses, http://www.aacn.org/WD/Practice/ Docs/Moral_Distress.pdf (2006, accessed March 2013).