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## NICU Nurses' Varying Levels Of and Experiences With Moral Distress While Caring For Infants With Neonatal Abstinence Syndrome

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NICU Nurses' Varying Levels Of and Experiences With Moral Distress While Caring For Infants  
With Neonatal Abstinence Syndrome

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University of Connecticut, School of Nursing, Senior Honors Thesis

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## Abstract

**Background:** Opioid Use Disorder (OUD) is both a physical and psychological dependence on opioids. When a woman with OUD becomes pregnant, Neonatal Abstinence Syndrome (NAS) can occur in her child. NAS occurs when the infant shows manifestations of withdrawal, due to the exposure to opioids in the womb being abruptly discontinued once born. Nurses that care for mothers with OUD and their infants with NAS report varying degrees of moral distress related to preexisting stigmas, a lack of education on the chronic disease of addiction, and the multitude of ethical dilemmas experienced while caring for this vulnerable population of mothers and infants.

**Purpose:** To explore the frequency and intensity of moral distress among neonatal intensive care unit (NICU) nurses when caring for infants with NAS.

**Methods:** A mixed methods study was conducted by administering a survey consisting of multiple choice questions, open ended questions and the Moral Distress Scale (MDS-R) pediatric version to a group of Neonatal Intensive Care (NICU) nurses. The survey consisted of 10 multiple choice questions that were followed by open-ended responses where participants were asked to explain the reasoning for their answers to the multiple choice questions. The Moral Distress Scale instrument was used to quantify the frequency and intensity of moral distress experienced by the nurses.

**Results:** Findings illustrate that NICU nurses that care for infants with NAS whose mothers utilized illicit drugs during pregnancy experience varying levels of moral distress.

**Key words:** Neonatal Abstinence Syndrome, Opioid Use Disorder, Moral Distress, NICU, Addiction, Nurses, Stigma

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## **Background and Significance**

Addiction is a chronic disease that causes alterations in brain chemistry. Individuals may become addicted to anything from chocolate to prescription drugs. Chronic use and addiction to opioids that cause significant cognitive and physical impairment is known as Opioid Use Disorder (OUD) (Dydyk et al., 2020). According to a Center for Disease Control (CDC) study done in 2019, 7% of mothers self-reported using prescription opioids with 1 in 5 reporting that the opioids were obtained from a non-healthcare source. The long term use of these prescription opioids can lead to OUD and result in the infants of these mothers developing Neonatal Abstinence Syndrome (NAS) due to prenatal drug exposure. The first cases of NAS are believed to have been seen as early as 1875 when multiple deaths of infants born to mothers addicted to morphine were reported, but at this time it was called Congenital Morphinism (Pomar & Finnegan, 2018). It wasn't until the early 1970's that this illness was first identified as NAS by Dr. Loretta Finnegan and Dr. Phillip Lipsitz. Both doctors created tools used to measure the severity of withdrawal symptoms that would later help to identify NAS as the true cause of illness in the sick infants (Finnegan et al., 1975; Lipsitz, 1975).

NAS is quite complex and may have varying symptoms among newborns. Once babies with NAS are born, they exhibit symptoms of withdrawal within the first hours to a few days of life that may include mild tremors, irritability, fever, and even seizures (Cleveland & Gill, 2013; McQueen & Murphy-Oikonen, 2016). NAS affects many different newborn body systems including the respiratory system, gastrointestinal system, and central nervous system. Infants diagnosed with NAS may experience symptoms such as sneezing, nasal stuffiness, tachypnea or an increased rate of breathing, vomiting, weight loss, poor feeding, tremors, temperature instability, sleep disturbances, high pitched crying and many more (Buczowski et al., 2020;

McQueen & Murphy-Oikonen, 2016; Sweigart, 2017). These infants require lengthy hospital stays and a significant amount of nursing care and attention (Buczowski et al., 2020; Cleveland & Bonugli, 2014; Maguire et al., 2012; Sweigart, 2017). Nursing care for infants with NAS include both pharmacological treatments such as Morphine administration and nonpharmacological treatments such as frequent breastfeeding and rooming-in that have become the main focus of treatment (Buczowski et al., 2020).

According to 2018 data from the Healthcare Cost and Utilization Project (HCUP), 6.8 newborns for every 1,000 newborns hospitalized are diagnosed with NAS. Every 25 minutes a baby is diagnosed with NAS in the United States (Anbalagan & Mendez, 2021). The national average has increased from 2.9 per 1,000 newborns hospitalized in 2009 to 6.8 in 2018, meaning the rates of NAS have more than doubled in less than 10 years, reflective of the global pandemic as it relates to OUD. Addiction has become an epidemic in the United States that has led to an increased rate of NAS directly related to the increased incidence of maternal opioid use. However, rates are also increasing across the globe in countries including England, Australia, and Canada making the illness a global problem that warrants in-depth research (Anbalagan & Mendez, 2021; Marcellus, 2019; McQueen & Murphy-Oikonen, 2016). Pregnant women with OUD are vulnerable to judgment by society, as well as healthcare providers. The lack of understanding regarding the science of addiction as well as the misconception that addiction is not a chronic disease facilitates the presence of health disparities and demoralization among this vulnerable population of women and their families. While further research is warranted in exploring these topics, the disparities between this population and healthcare providers may increase health risks for both the mother and newborn. Therefore, exploration as it pertains to both qualitative and quantitative data on the experiences and perceptions of all relevant parties,

especially the mothers suffering from OUD and healthcare staff providing the care, may identify crucial information to increase understanding of both the chronic disease of addiction and NAS, as well as to identify therapeutic measures to improve the care of these mothers, their newborns and the family members supporting these women through their life-long journey of recovery.

Moral distress is defined as being “characterized by frustration, anger, guilt, physical symptoms, and/or anxiety due to a threat to one’s moral integrity” (Hamric et al., 2012, p. 2). Nurses often experience moral distress due to being taught that they have a moral obligation for the care they provide, yet do not have the authority or power to raise objections to the therapeutic regimen prescribed (Cavaliere et al., 2010; Mills & Cortezzo, 2020; Rushton, 2016). Moral distress is associated with high rates of burnout, compassion fatigue, and adverse effects on nurses that lead to leaving their positions in the healthcare setting they work in (Cavaliere et al., 2010; Epstein et al., 2020; Sannino et al., 2015; Sweigart, 2017). A recent qualitative study identified that up to 72% of both NICU physicians and nurses reported experiencing moral distress at least once a month in their current position (Mills & Cortezzo, 2020). It is also reported that one third of nurses report feeling symptoms of burnout due to moral distress, the emotional toll healthcare takes on a person, spending too much time at work, and the increased computerization of practice that can take away from time with patients (Mills & Cortezzo, 2020; Reith, 2018). Burnout and moral distress can also lead to decreased staff retention that contributes to the already serious nursing shortage that is occurring. The shortage of both NICU nurses and nurses in general has a widespread impact on the healthcare system contributing to factors such as increased hospital acquired infections, increased medical errors, and higher morbidity and mortality rates (Haddad et al., 2022; Cimiotti et al., 2012).

## Literature Review

### NICU Nurses' Experiences Providing Care to Infants with NAS

NICU nurses face many struggles, both internally and externally, in caring for newborns with NAS. Caring for infants with NAS places additional stressors on NICU nurses who already work in a highly intensive charged environment. Nurses report concerns with having to support and care for NAS infants during a process like withdrawal that can take so much time and cause so many varying symptoms (Maguire et al., 2012). Nurses also feel that too much time has to be dedicated to caring for and consoling newborns with NAS, not leaving adequate time to complete the other tasks required on their shift (Romisher et al., 2018). Historically, NICU nurses had not been educated in regards to maternal addiction, and the care of the newborn with NAS. This deficit in knowledge and appropriate training leads to nurses having feelings of inadequacy in the care they provide, more specifically because they are not able console the newborn exhibiting symptoms of withdrawal (Romisher et al., 2018).

Not only is time an issue for the nurses, but also the environment of the NICU. NICU nurses continually express their concern over the environmental factors of an intensive care unit and the negative effects they may have on newborns with NAS. Intensive care units are not meant for the sort of long term care newborns with NAS require. One study exploring attitudes among nurses caring for newborns with NAS, showed that 60% of the 54 participants disagreed or strongly disagreed that infants with NAS should receive care in an intensive care environment (Romisher et al., 2018). Intensive care units are quite bright, bustling with noise, and hectic. These environments are not therapeutic for caring for these newborns who are highly disorganized from a neurological standpoint - because it is often difficult to settle and soothe them for restful periods of sleep. The adaptations in caring for the newborn with NAS include

low lighting, use of soft voices, swaddling, vertical rocking, frequent skin to skin contact, and substantial amounts of one on one care are therapeutic and provide a non-pharmacological approach to care (Artigas, 2014). Many of these measures are the complete opposite of the loud, bright, and bustling environment of an intensive care unit, validating how caring for these newborns in the NICU is not appropriate. A quiet, soothing environment has been shown to promote weight gain, decrease neurological disorganization, promote sleep and feeding tolerance, and just improve the overall care and recovery of infants with NAS (Artigas, 2014; Grisham et al., 2019). Intensive care units also lack a proper room or space for mothers to stay, meaning the infants do not get an adequate amount of skin to skin contact and breastfeeding with their mothers (Romisher et al., 2018). This separation is a barrier to fostering the maternal and infant attachment process. Studies have demonstrated that babies with NAS who are breastfed have less severe symptoms and shorter lengths of hospital stays than the formula-fed NAS newborns, so a place for mothers to breastfeed is crucial to the care of the infants, but also not readily available in an intensive care setting (McQueen & Murphy-Oikonen, 2016; Romisher et al., 2020).

The demonstration of a more holistic approach needed to care for NAS infants has led to the creation of protocols such as the Eat, Sleep, Console (ESC) approach that accomplish the goal of not separating NAS newborns from their moms. The ESC method consists of the nurse conducting an assessment of the infant's feeding habits, amount of sleep obtained in between feedings, and if the infant is able to be consoled (Casavant et al., 2021; Grossman et al., 2018; Miller & Willier, 2021). If the infant is able to eat and sleep adequately, pharmacological interventions are not needed regardless of the Finnegan Neonatal Abstinence Scale. The approach also encourages the important aspects such as breastfeeding and skin-skin holding

(Miller & Willier, 2021). Studies have shown that this more holistic approach can decrease the length of hospital stay of these newborns and significantly decrease the number of newborns with NAS who require pharmacological treatment (Blount et al., 2019; Grossman et al., 2018; Wachman et al., 2018).

Despite the multitude of challenges faced by the NICU nurses in caring for infants with NAS, they still are able to form strong attachments to the newborns throughout the course of their care (Maguire et al., 2012; Sweigart, 2017). Literature also consistently shows that throughout the many struggles faced, the nurses are still fully committed to the welfare, health, and care of these infants (Welborn, 2019). A study done in 2018 by Romisher and Colleagues, explored the attitudes of nurses caring for infants with NAS reported that 68.5% of the nurses participating in the study agreed or strongly agreed that the rewards of caring for infants with NAS outweighed the challenges (Romisher et al., 2018). Nurses take an oath to do no harm and provide competent care to the best of their ability. Caring for newborns with NAS is no exception to this rule. Even though the sort of care required for these infants may not be satisfying professionally or personally, nurses remain determined to provide the highest quality of care possible.

### **NICU Nurses' Experiences Interacting with Mothers of Infants with NAS**

When caring for babies with NAS, nurses do not just take on the care of the infants. They are really caring for the mother-infant dyad together because the mothers with addiction often need some sort of support as well. NICU nurses have reported several different views on interacting with the mothers who have OUD that resulted in their newborn suffering from NAS, some of which are not always positive. On one side, nurses report that it is the families and caregivers that are the most difficult to work with due to defensive attitudes, a lack of

communication, and also a lack of consistency regarding visitation (Welborn, 2019). This history of preconceived negative prejudices towards the substance abusing mothers often cause nurses to become dismissive and leads to the mothers feelings of shame (Cleveland et al., 2016; Cleveland & Bonguli, 2014; Cleveland & Gill, 2013; Maguire et al., 2012; Raeside, 2003). This trend becomes a circle of negative emotions and dismissive actions by the nursing staff that lead to the mothers becoming defensive and this pattern just continues to cycle through. Nurses report that caring for the mother-infant dyad is made difficult because of impaired communication with the mothers, especially those who are also suffering from OUD. The nurses often perceive mothers suffering from addiction as incompetent and irresponsible, playing into the stereotypes these mothers face. Nurses report that these mothers all show the same defensive attitude. When the mothers feel stigmatization from the nurse occurring, they can become defensive therefore impairing communication. NICU nurses state that they often have feelings of anger towards the mothers because of the suffering their actions have inflicted on the infant and their lack of remorse (Maguire et al., 2012; Recto et al., 2020; Romisher et al., 2018). NICU nurses care for the sick infants and expect gratitude from the mothers, but are often disappointed by their poor attitudes and lack of appreciation (Romisher et al., 2018). Instead of being grateful for the care the nurses give their infants, the mothers will often try to blame the nurses for the problems with their sick newborns rather than taking any responsibility for their own wrongdoings (Maguire et al., 2012).

One of the most significant issues is the division in attitude and perceptions between the mother and nurses. Nurses will often separate themselves from the families and refer to themselves as nurses as an “us” and the families as “them” (Recto et al., 2020). This separation leads to the nurses feeling a sense of disdain for the caregivers. Nurses have intertwining feelings

of frustration and resentment towards the families and caregivers, especially the mothers suffering from OUD who used drugs during their pregnancy (Cleveland & Bonugli, 2014; Fraser et al., 2007; Raeside, 2003; Recto et al., 2020; Romisher et al., 2018; Sweigart, 2017). Many nurses report having a difficult time setting aside their own personal biases when trying to provide adequate care to these infants (Recto et al., 2020). NICU nurses are often guilty of playing into the stigma and stereotypes of addiction that mothers with OUD are subject to. The stigma surrounding addiction and OUD is intensified for pregnant women. These women are often shamed and ostracized and even labeled as “bad mothers” because they go against the societal role of nurturing that mothers are supposed to play (Cleveland & Bonugli, 2014; Maguire et al., 2012; Recto et al., 2020). Mothers with OUD often face exclusionary medical care and report feeling excluded from the mother-infant dyad, while their newborns are being cared for (Recto et al., 2020). Unfortunately, nurses are not free from bias and often contribute to the ostracization of these mothers because of the indignation they feel towards them for putting their newborns at risk.

However, for all of the nurses who feel this sense of frustration and resentment, there are just as many who just want to work with the mothers and caregivers to do everything possible to help the infants experiencing NAS. One of the major concerns nurses have with the mothers of these infants is that they do not visit or participate in the care of the newborns enough (Romisher et al., 2018). Skin to skin contact with the mother plays a large role in the recovery of newborns with NAS because of the soothing aspect it provides the infant (Artigas, 2014; McGlothen-Bell, 2021; Ryan et al., 2018). Nurses frequently report that increased mother-infant contact and family involvement is crucial to the care of the infants, but that the hectic intensive care environment and lack of consistent visitation by the mother provide obstacles to accomplishing

this only emphasizing the need to promote the ESC approach to care (Casavant et al., 2021; Romisher et al., 2018). Many NICU nurses just want to be able to build a partnership with these mothers, so that the babies can receive the care and attention they need to recover from NAS (Romisher et al., 2018).

### **Perceptions On Ethics and Moral Distress**

Nurses face moral distress and ethical dilemmas in response to many events they are faced with on a daily basis. Moral distress occurs when nurses “recognize ethical conflicts and their responsibility to respond to them but are unable to translate their moral choices into ethically grounded action that preserves integrity” (Rushton, 2016). Caring for newborns with NAS is one of the causes of moral dilemmas for NICU nurses. A significant amount of distress is caused by the nurses feeling as if the only thing they can do to actually aid the care of these infants is by giving them the medication used to treat withdrawal (Romisher et al., 2018). Nurses are often unable to console the infants or soothe them enough to even get them to stop crying, causing a great deal of frustration among nurses (Romisher et al., 2018). A nurse’s job is to care for and help patients feel better, so when they are unable to help comfort infants with NAS during their withdrawal process guilt and frustration may occur.

One of the major issues that NICU nurses face during the care of infants with NAS is properly employing the ethical principle of beneficence. Beneficence is defined as an obligation to do good (Maguire et al., 2012). The nurses’ feelings of inadequacy in caring for the infants and their families is a prime example of the challenges NICU nurses face regarding this ethical principle. Being unable to use their nursing skills or other efforts to comfort and care for the newborns experiencing NAS is one of the main ways nurses struggle with this value (Maguire et al., 2012). Nurses try to exhibit beneficence in caring for the mother-infant dyad by advocating

for infant needs, including the mother and caregivers in treatment, and trying to treat the symptoms of NAS as best as they can (Welborn, 2019). However, the treatment of symptoms of withdrawal in infants with NAS is less receptive to the traditional techniques used to treat newborns without NAS, causing care to be more difficult and overwhelming for the nurses (Welborn, 2019). Also, due to the increased amount of time nurses have to spend with infants with NAS, they often struggle to fulfill the care of their other non-NAS patients. This leads to nurses feeling as though they cannot meet any of their patients' needs and therefore cannot accomplish the principle of beneficence enough to fulfill their need to provide ethical care (Welborn, 2019).

Nonmaleficence is another ethical goal nurses have when providing care to their patients. Nonmaleficence is defined as preventing or not causing harm (Maguire et al., 2012). Nurses practice nonmaleficence by protecting infants from harmful caregiving practices or from others that may cause them harm, even if that person is their own mother. To prevent harm to infants with NAS, nurses may carry out acts as simple as discouraging others from waking the infant (Welborn, 2019). A more complex example of this principle can be seen in the apprehension that nurses face about having to discharge infants with NAS to homes that could be dangerous and unstable. An infant's home environment factors such as poverty and unstable housing may influence development even more than their prenatal drug exposure (Artigas, 2014; Oei, 2018). Due to this, nurses often worry that the mothers or caregivers will not be able to provide basic care such as feeding and bathing and that the home environment these infants will be released into could cause long-term physical and mental issues (Maguire et al., 2012; Sweigart, 2017). The perceived threat of releasing newborns into homes where they may experience physical or verbal abuse triggers significant amounts of moral distress for the nurses, as they worry they may

not be able to protect the infants from harm once released from the hospital (Welborn, 2019). There is a lack of community and often personal support to foster the mother's recovery and build a healthy family unit. This is another factor that makes nurses cautious to send the infants home because with a lack of a support system there is always the worry that nobody will be monitoring the infant or providing competent parenting after discharge.

While a NICU nurse's primary patient is usually the infant with NAS, they also treat the mother-infant dyad as a pair, so may feel the need to exhibit nonmaleficence and beneficence towards the mother too. Nurses often face the dilemma of having to choose whether to prioritize the mother or the infant. By protecting the infant from possible harm, nurses often feel that they are harming the recovery of the mother at the same time and are therefore not accomplishing nonmaleficence or beneficence with their caregiving practices (Welborn, 2019). Moral distress may negatively impact the care of the patient and is a factor that many nurses find themselves having to work through in order to provide ethically and personally satisfying care. It is crucial that nurses find a way to care for the mother-infant dyad experiencing the harmful effects of addiction in a way that does not compromise their own moral integrity and values (Welborn, 2019).

### **Purpose**

The purpose of this research study is to explore the frequency and intensity of moral distress among NICU nurses caring for infants with NAS. This information will serve to aid the healthcare system in better understanding the experiences of NICU nurses caring for such a vulnerable population and provide the support they need to decrease the presence of moral distress. A secondary goal of this study was to utilize the results to enhance the education of nurses and healthcare staff on the care of NAS, as well as to decrease the judgment and stigma

surrounding addiction, with the hope of promoting nurturing relationships between healthcare providers, especially nurses during their interactions with mothers suffering from addiction.

## **Research Methods**

### **Literature Review**

A systematic search of PubMed and CINAHL was conducted in September of 2020 with a focus on papers published in 2012 or later. Research on this topic continues to expand because of its increasing prevalence around the world, so the more current research was the main focus. Inclusion criteria included research articles that were written in English, in peer reviewed journals, and was conducted by a nurse researcher. Keywords used in the initial literature review search included *Neonatal Abstinence Syndrome, nurse, NICU nurse, perceptions, views, moral distress, experiences, and attitudes*. When narrowed to searching for nurse perceptions, PubMed was explored first and the search yielded two results. CINAHL was then utilized and the search yielded 25 results. The Boolean operator “and” was used to connect the ideas of NAS and nursing perceptions in the search of both databases. Each article was screened and analyzed for the appropriate information needed for the review.

Of the 27 articles the search yielded, 10 with focuses on NAS and the NICU nurses’ perception on the aspects of care required for this illness have been included in the review. Three articles describe research studies done in a mix of both quantitative and qualitative designs. The quantitative study was conducted in 2018 by Kobi Brooke Tobin on neonatal nurses’ perceptions of caring for infants with NAS and was a pre and post test design method. The pretest was administered to the 206 NICU nurses before the educational presentation on NAS and the post education questionnaire evaluated the effectiveness of the education. The other two studies were qualitative designs. One conducted by Maguire and colleagues in 2012 used an open-ended

interview method of 16 participants to look at NICU nurses' lived experiences caring for infants with NAS. The other was conducted by Romisher and colleagues in 2018 and utilized a cross sectional survey method of 54 participants to explore nurse attitudes and knowledge towards NAS. The other 7 articles used in this review included two literature reviews (McQueen & Murphy-Oikonen, 2016; Welborn, 2019) and 5 topical articles on NAS and addiction (Artigas, 2014; Dydyk et al., 2020; Gomez-Pomar & Finnegan, 2018; Recto et al., 2020; Rushton, 2016).

### **Study Design and Procedure**

This design is a pilot study that uses descriptive and correlational statistical methodology to address the levels of moral distress that neonatal nurses experience caring for newborns with NAS in the NICU setting. The study is non-experimental and descriptive. The primary investigator did not introduce an intervention. The presence of moral distress among the nurses caring for NAS infants was collected, but no causal relationship has been identified.

Correlational statistics explore demographic characteristics such as age, level of education, and nursing experience and how they are related to the degree and/or intensity of moral distress levels.

The Moral Distress Scale-R (MDS-R) Pediatric version was used to measure the frequency and intensity of moral distress in NICU nurses providing care to newborns with NAS.

The descriptive design utilized multiple choice and open-ended survey questions that allowed the primary investigator to connect demographics and personal experiences of the NICU nurses to the frequency and intensity of moral distress felt by the sample population in regards to the care given to newborns with NAS.

## **Sample and Setting**

The population sample for this study is made up of 27 Level III NICU nurses. The NICU was chosen as the setting of work for the nurses sampled, as the NICU has many opportunities for a nurse to experience moral distress through the life-saving and critical care decisions that must be made. The inclusion criteria for the study was identified as any neonatal nurse employed part or full time in the NICU. These nurses are the ones most frequently caring for infants with NAS. Exclusion criteria included any neonatal nurse employed per-diem, as they care for infants with NAS less frequently.

The setting for this study is a Level III NICU from a community medical center with 368 beds. The medical center is located in the Northeast region of the United States.

## **Measurements and Data Collection**

### ***Moral Distress Scale (MDS)***

The formal instrument used for the data collection was the Moral Distress Scale (MDS-R) pediatric version. The original MDS was developed to measure the frequency and intensity of moral distress with a 32 item 7 point Likert scale format with higher scores indicating a higher level of moral distress (Corley et al., 2001). Two stages were utilized to ensure content validity. The first phase consisted of reviewing the findings of interviews of nurses within the United States on the topic of moral dilemmas faced in a hospital. The second phase to quantify the content validity of the tool was completed by having the MDS reviewed by Jameton and Wilkinson, two experts on moral distress, and subsequently a panel of three doctoral prepared nurses with expertise on nursing ethics who agreed that all items were relevant. The MDS was also proved to be reliable with a Cronbach's  $\alpha$  ranging from 0.82 to 0.98 (Corley et al., 2005).

A shortened version of the MDS was created in 2012 by Hamric and colleagues that was identified as the MDS-R and contains 21 items instead of the original 38. The Likert scale was also altered from the original “0 to 6” scale to a “0 to 4” Likert scale. The scale for intensity ranges from 0 (none) to 4 (great extent) and the scale for frequency ranges from 0 (never) to 4 (very frequently). The MDS allows for the frequency and intensity to be examined separately, but also allows for the computation of a composite score to be used for multivariate analyses (Hamric et al., 2012). To compute the composite score, the frequency and intensity are multiplied for the 21 items to create a range from 0-16 and then the scores across the items are summed to create the composite score range from 0-336 (Hamric et al., 2012). The Cronbach’s  $\alpha$  for the MDS-R as it related to moral distress in the nurse population is 0.89 (Hamric et al., 2012). This study utilizes the MDS-R pediatric version to measure the levels of moral distress in the neonatal nurse population as they care for infants with NAS.

### ***Demographic Questionnaire***

A demographic questionnaire was created by the principal investigator to assess information such as age, education level, and perceptions regarding the moral influence pertaining to the care of newborns with NAS. The demographic information was collected through the use of a few multiple choice questions with room to elaborate on perceptions in an open-ended format at the end of the form. Gender identification was not used to ensure the privacy of the single male nurse involved in the study. The demographic information provides descriptive characteristics of the participants. Nominal levels of measurement are used for questions one through seven of the demographic questionnaire that include but are not limited to: age, education levels, and years of employment as a registered nurse. Questions eight through twelve denote ordinal levels of measurement and regard moral influence. Question thirteen is an

open-ended question that is used to validate the participants' response to question twelve. Table 1 presents the characteristics of the participants.

Table 1

*Demographics of Participants*

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Sample Characteristic	n (%)	
<hr/>		
Age		
20-29	1	(3.7)
30-39	5	(18.5)
40-49	13	(48.1)
50 years or older	8	(29.6)
<hr/>		
Highest Level of Education		
Diploma	0	(0)
Associate	10	(37.0)
Baccalaureate	15	(55.6)
Graduate	2	(7.4)
Doctoral	0	(0)
<hr/>		
Number of Years RN		
Less than 2 years	1	(3.7)
3-5 years	0	(0)

5-10 years	2	(7.4)
Greater than 10 years	24	(88.9)

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#### Number of Years in NICU

Less than 2 years	1	(3.7)
3-5 years	2	(7.4)
5-10 years	4	(14.8)
Greater than 10 years	20	(74.0)

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#### Number of Years Caring for NAS

Less than 2 years	2	(7.4)
3-5 years	3	(11.1)
5-10 years	6	(22.2)
Greater than 10 years	16	(59.2)

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### **Data Analysis**

The principal investigator who conducted the data collection and analysis is an advanced practice registered nurse who works with the recruited NICU nurse participants. Recruitment of participants was multilayered and was carried out by posting informational posters, discussion of the purpose of the study during pre rounding and staff meetings, and holding informational luncheons. Questionnaires were then placed in the eligible participants' mailboxes, along with an introductory letter that explained the instructions of how to complete the submission and that participation is voluntary, low risk, and anonymous. The participants were then asked to return

the packets to the NICU locked opinion box. IBM SPSS 24.0 PC program was utilized for data entry and analysis. Completed packets were opened and checked individually for completion before results were entered into a password protected computer.

Quantitative data was collected and analyzed using the Likert scale of the MDS-R to measure the ordinal data of the levels of frequency and intensity of moral distress felt by the nurses involved in the study. The measures of central tendency; mode, median, and mean were used for quantitative analysis. These measurements allowed for identification of the degree of moral distress that has the greatest frequency, the middle composite score of moral distress, and the average score of moral distress amongst the participants. A frequency distribution table was utilized to identify the measure of the dispersion of scores and a box plot aided in identifying the lowest, highest, and median levels of moral distress identified in participants. A histogram was utilized to analyze the frequency and intensity of scores.

Qualitative data was collected using a demographic questionnaire with the last few questions allowing for open ended responses. The responses were analyzed and coded for common themes and opinions shared by multiple respondents. The common themes include, but are not limited to opinions on the environment in which newborns with NAS should be cared for, satisfaction felt when caring for infants with NAS, and the amount of time or attention that NAS infants require.

## **Results**

### **Qualitative**

Qualitative themes were analyzed using the demographic questionnaire presented to each nurse involved in the study. Twenty two of the 27 nurses surveyed reported that NAS infants should be cared for in a specialized unit. NAS infants require more attention than the NICU

nurses can provide. Nurses responsible for their care spend so much time attempting to console the inconsolable infant, that they do not have time to complete the other tasks required during their shift (Romisher et al., 2018). The participants surveyed also mention that the NICU is not a suitable environment for NAS infants. A common theme among the responses given by the surveyed nurses is that babies with NAS require a low stimulus environment, not possible in the hectic NICU. This theme is also seen in multiple other studies that reinforce the importance of an environment with low stimuli, the opposite of the bustling NICU environment (Fraser et al., 2007; Loyal et al., 2019; Romisher et al., 2018; Sweigart, 2017).

Nineteen of the twenty-seven nurses reported feeling satisfied giving care to infants with NAS, while eight felt no satisfaction giving these infants care. A majority of the participants, while they don't agree that the NICU is the right place to care for NAS infants, do report feeling satisfied with the care given to them. A majority of the nurses still feel it is their responsibility to provide the best possible care to these infants and leave their shifts feeling satisfied that they did all they could to improve their patients' health outcomes. The participants who reported not feeling satisfaction have the common theme of feeling as though infants with NAS are too hard to console and need constant attention that they do not have time to give. When they have to leave the NAS infant's room to care for their other patients while the baby is still crying, the nurses report feeling frustrated that they were unable to console the infant. This is a common theme also found in the study done by Romisher and colleagues (2018) in which nurses felt that they could not provide sufficient care and giving withdrawal medications was the only way to see any real improvement.

Seventeen of the nurses surveyed would rather care for a 24 week preterm critically ill neonate than an infant diagnosed with NAS. Multiple nurses reported feeling as though taking

care of infants with NAS does not qualify as critical care. Nurses who work in the NICU are used to and prefer a fast paced environment where they have to provide care that is “intellectually challenging”. Infants with NAS require large amounts of attention and care that is not at the same level of difficulty as those that are critically ill. The nurses have to spend large amounts of time with these infants trying to console them, instead of providing skilled care at a quick pace. The participants also noted that while caring for a critically ill patient is ever changing, the care of NAS infants is monotonous and less fulfilling.

### **Quantitative**

The composite scores for the levels of moral distress were calculated by summing the result of the frequency multiplied by the intensity score ( $f \times i$ ) of each participant. The moral distress tool presented 25 clinical scenarios with a measurement range for the ( $f \times i$ ) score falling between 0 and 16. The total scores for each participant fell between 0 and 400. All of the participants experienced varying levels of moral distress. None of the participants had a score of 0 reflecting feeling no moral distress. The mean composite moral distress score was 58.9 with a standard deviation (SD) of 36.4. A score of 0 represents feeling no moral distress, while a score of 400 represents the most moral distress that can be felt. The frequency of composite scores are illustrated in Table 2.

Table 2

*Moral Distress Composite Scores (Frequency X Intensity)*

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Groups	Frequency
0-25	6
26-51	5

52-77	8
78-103	7
104-129	0
130-155	0
156-181	1

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### ***Frequency of Moral Distress***

Frequency scores were calculated for each of the 25 clinical scenarios presented and ranged from 0.04 to 1.70. The instrument has a total frequency range of 0 to 4 with 0 representing that the scenario never occurs and 4 representing that the scenario very frequently occurs. Question #25 identified the highest frequency score of 1.70 and stated “Interacting with substance misusing mothers or parents is often negative in nature due to mistrust and addictive behaviors demonstrated by the caregivers.” Nurses often have difficulty forming therapeutic relationships with the mothers suffering from addiction. The top 10 most frequently occurring clinical scenarios are listed in Table 3.

Table 3

#### *Top 10- Frequency of Moral Distress Clinical Scenarios*

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Rank	Scenario	Mean Frequency
1	#25 Interacting with substance misusing mothers or parents is often negative in nature due to mistrust and addictive behaviors demonstrated by the caregivers.	1.70
2	#3 Follow the family’s wishes to continue life support even though I believe it is not in the best interest of the child.	1.63

- 3 #17 Work with nurses or other providers who are not as competent as the child's care requires. 1.48
- 4 #21 Work with levels of nurses or other care provider staffing that I consider unsafe. 1.48
- 5 #23 Caring for newborns with NAS is time consuming and takes away time that should be afforded to critically ill preterm infants. 1.30
- 6 #4 Initiative extensive life-saving actions when I think they only prolong death. 1.22
- 7 #6 Carry out the physician's order for what I consider to be unnecessary tests and treatments. 1.22
- 8 #22 Caring for newborns with NAS is not professionally satisfying. 1.19
- 9 #20 Watch patient care suffer because of a lack of provider community. 1.11
- 10 #1 Provide less than optimal care due to pressures from administrators or insurers to reduce costs. 1.04

## Discussion

### Limitations

An important limitation of this study was the small sample size. The study was conducted with only 27 participants, so the correlation between moral distress and demographics was not statistically significant. Along with the small sample size all 27 participants were from a single healthcare facility in a specific geographic area limiting the representation to a specific location and population.

To go along with the specific geographic location, the demographics of the participants were also relatively homogenous. The NICU nurse participants were all similar in age, education

level, and years of experience. The small sample size and similar demographics of participants does not allow for the generalizability that a larger sample size does and is not representative of the views of the population of nurses throughout the United States, although there are published bodies of research that have similar findings to this study (Fraser et al., 2007; Maguire et al., 2012; Romisher et al., 2018; Sweigart, 2017; Tobin, 2018; Welborn, 2019).

### **Clinical Implications and Future Research**

For all of the research done, there has yet to be any formal studies exploring how demographics such as age, race, and education level affect a nurse's perceptions of caring for the newborn NAS and its direct correlation of the NICU nurse developing moral distress. There is also a lack of research related to how nurses perceive the lack of support from the addicted couple, not just the mother, as well as the frustration this may cause for the nurses. Caregivers are mentioned in many research articles and studies, however, usually, only one caregiver is mentioned at a time. There is an absence of research on both individuals of an addicted couple in the cases that both caregivers are present in the care of their newborn with NAS.

Another topic that requires more research and education is the fact that many studies support that NICU nurses have not received the proper training needed to care for newborns with NAS. As has been demonstrated, NAS can be a very complex illness requiring skilled long term care. The NICU nurses that are expected to provide this care are instead trained in acute intensive care that takes place in a bustling and fast-paced environment. A study done on knowledge of practice regarding NAS reported that 27.8% of the NICU nurse participants reported not having adequate knowledge about the effects maternal opioid use has on infants and 31.5% felt they did not have enough knowledge to work with mothers of the infants effectively enough to improve outcomes (Romisher et al., 2018). NICU nurses need to be trained in

therapeutic techniques to interact with substance-abusing parents and also interventions to improve patient outcomes with NAS (Maguire et al., 2012).

There also seems to be a lack of understanding and empathy in regards to the fact that addiction is a chronic disease. Many individuals do not understand the science behind addiction. Addiction chemically alters the human brain and is comparable to diseases like diabetes, yet has so much more stereotyping and stigma surrounding it. More research is warranted to explore practical strategies that may be implemented in health care settings to address the stigma that individuals suffering from addiction face (Cleveland & Bonugli, 2014; Recto et al., 2020). Many nurses are guilty of ignoring the obvious stigmatizing behaviors by both themselves and peers around them that negatively affect the nurse-patient relationship (Cleveland & Gill, 2013; Recto et al., 2020). This is in direct violation of the Nursing Code of Ethics all nurses are required to follow (Recto et al., 2020). The Code of Ethics states that “nurses are to practice in a manner that demonstrates respect for human dignity of all individuals “unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems” and the care of mothers with OUD and their infants with NAS are no exception (ANA, 2012, p.3; Cleveland & Gill, 2013). More studies need to be done on how to get nurses to stop looking the other way and actively confront the issue of stereotyping in the population experiencing addiction. Nursing is a unique profession in that there is always more to learn.

### **Conclusion**

Mothers of infants with NAS face many healthcare disparities, due to the stigma and lack of knowledge surrounding addiction. The care given to mothers with OUD and their infants with NAS by healthcare professionals is often viewed as non therapeutic (Cleveland & Bonugli, 2014; Cleveland & Gill, 2013). Mothers of infants with NAS often report being judged and feel as if

they are excluded from the care of their own child (Cleveland & Bonugli, 2014; Recto et al., 2020). When women feel excluded and judged, they are less likely to seek prenatal and postnatal care, putting both themselves and their infant at risk of harm (Chan & Moriarty, 2010; Recto et al., 2020). Nurses are often the healthcare providers that give the most direct care and interact with these families the most, so play an important role in ensuring there are no disparities in the care of mothers with OUD and their infants born with NAS. When mothers face a lack of care from their healthcare providers, they may feel disconnected from care, disempowered to make their own decisions, and may even have worse treatment outcomes in general (Sutter et al., 2017). Supportive nursing care fosters wellness for women and families with addiction and has been shown to decrease the need for pharmacological interventions to treat infants with NAS, while simultaneously influencing mother-infant bonding in a positive manner (Miller & Willier, 2021).

NAS is a complex illness that can lead to distress and frustration in the nurses involved in caring for newborns with NAS. NAS is time-consuming and at times overwhelming for the nurses, as there is so much that still needs to be researched about the topic. Many studies support the findings that increased education and an adequate environment to care for infants with NAS are among the interventions that could be implemented to decrease the moral distress nurses experience daily caring for infants with NAS (Loyal et al., 2019; Maguire et al., 2012; Romisher et al., 2018; Tobin, 2018). NAS and OUD continue to grow in prevalence and warrant continued training and research to ensure the strength of the nurse-patient relationship and a continued understanding of the chronic disease of addiction.

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