

WELBORN, AMBER, Ph.D. An Exploration of Discourses of NICU Nurses Caring for Infants with Symptoms of a Substance-Exposed Pregnancy. (2020)
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The opioid crisis continues to worsen nationally and has affected women who are pregnant and parenting across the nation. Mothers living in the southeast United States and rural areas have been disproportionately affected and experience multiple barriers to care. Infants born to mothers after a substance-exposed pregnancy (SEP) may experience symptoms of withdrawal after birth and need supportive care in the neonatal intensive care unit (NICU). Nurses who care for these infants and their families have previously reported negative attitudes surrounding care related to difficulty comforting the infant and frustration with families. Stigma against mothers who use substances in pregnancy further complicates the dynamic.

A qualitative study using interviews with NICU nurses who care for infants and families with a SEP offered the opportunity to investigate the nursing discourse in the NICU surrounding SEPs. Using Critical Incident Technique, participants were asked to share their most memorable experience caring for infants and families with a SEP, generating data ripe for critical discourse analysis. Data were analyzed for the presence of sociopolitical narratives, social narratives within the healthcare system, and the participant's word choices and style of storytelling to determine specific relevance.

Results show that tensions exist at the bedside between nurses, mothers, and providers, surrounded by a healthcare culture that highly values patient satisfaction, where nurses experience high pressure to meet the needs of the infant and family with

limited resources. Nurses verbalize concerns of safety and trust related to the mother's perceived ability to care for the infant after discharge and need time with the family to build rapport. However, within the constraints of a business-model of healthcare, nurses lack the time and energy needed to build trust with families and implement family-centered care principles. Additionally, elements of stigma may influence the nurse-family dynamic in a variety of ways and may be continued through the oral traditions of nursing.

As a part of the Quadruple Aim from the Institute for Healthcare Improvement to meet the need for high-value care, strategies to improve the experience of care by providers, patients, and families are necessary. This caregiving dynamic can be improved through a better understanding of the root causes of substance use and SEPs and organizational commitment to a supportive environment for both the mother and the nurse. Future research with a systems approach is positioned to investigate issues surrounding caregiving practices for families with a SEP and point to potential meaningful interventions.

AN EXPLORATION OF DISCOURSES OF NICU NURSES CARING FOR INFANTS
WITH SYMPTOMS OF A SUBSTANCE-EXPOSED PREGNANCY

by

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I dedicate this dissertation work to Jesus Christ, my Lord and Savior, through the calling to serve others as the foundation for my life's work. To my husband, Jon, and our daughters Isabelle and Olivia, who have shown their support in ways big and small, and without their continued support I would have been unable to meet my goals.

APPROVAL PAGE

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To all the women of the world who mother: Those who mother children they have birthed or adopted, those who yearn to mother but cannot, those who must watch someone else mother their children, and those who support mothers in all the many ways that are necessary to enable them to engage in the work of mothering. And finally, to the nurses who care for the smallest patients and their families. May we all work together to support, protect, and encourage one another.

“Each of you should use whatever gift you have received to serve others, as faithful stewards of God’s grace in its various forms” (1 Peter 4:10).

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CHAPTER I

INTRODUCTION

The complexity of the caregiving dynamic surrounding infants who have experienced a substance-exposed pregnancy (SEP) provides a wealth of research opportunities. The literature presents several perspectives supporting the caregiving environment as stigmatized against the infant's mother. The caregiving dynamic is influenced by the construed identity of the mother who uses substances in pregnancy as a "bad" or "unfit" mother (Reid, Greaves, & Poole, 2008; Terplan, Kennedy-Hendricks, & Chisolm, 2015). Power differentials at the infant's bedside contribute toward and perpetuate the stigmatized environment, impacting many facets of family-centered care known to improve outcomes for infants in the neonatal intensive care unit (NICU) and their family. Research to explore the construction of the identity of a mother who uses substances in pregnancy by NICU nurses and an exploration of the power differentials within the caregiving dynamic may offer opportunities for interventions to address the resultant stigma already presented in the literature. This chapter will introduce the problem and effects of substance use in pregnancy, stigma as a part of the problem, and the theoretical framework to be employed in this study.

Opioid use, as a part of substance use, in women of childbearing age has increased dramatically since the early 1990s, just as it has in the general population. The greatest risk of developing a substance use disorder occurs during the reproductive years

of 18–44 years old (Forray, 2016; Krans & Patrick, 2016). Specifically, chronic maternal opioid use in pregnancy has quadrupled during 1999–2014, from 1.5 per 1,000 delivery hospitalizations to 6.5, with trends continuing to rise with the ongoing national opioid epidemic (Haight, 2018; National Institute on Drug Abuse, n.d.; Tolia et al., 2015). The southern region (Hand, Short, & Abatemarco, 2017) and rural areas (Kozhimannil, Chantararat, Ecklund, Henning-Smith, & Jones, 2019; Villapiano, Winkelman, Kozhimannil, Davis, & Patrick, 2017) of the United States (US) have experienced disparate increases in maternal opioid use and consequential Neonatal Abstinence Syndrome (NAS).

Substance use disorders have been categorized as diseases of despair, associated with poverty, low education, and lack of opportunity. Currently, opioid misuse is a primary focus of the literature related to substance use disorders due to the increase in incidence. Pregnant and parenting mothers who misuse opioids reflect many of the patterns found within the general population. Maternal opioid use disproportionately affects low-income women, as most women with Opioid Use Disorder are White, non-Hispanic, under the age of 26, more likely to live below the federal poverty level, and be insured by Medicaid (Corr & Hollenbeak, 2017; Smith & Lipari, 2017; Winkleman, Villapiano, Kozhimannil, Davis, & Patrick, 2018). Some women who experience a cesarean birth continue to use opioids beyond the predicted timeframe of recovery. These mothers often have histories of illicit substance use and also report higher frequencies of chronic pain due to injury or illness (Bateman et al., 2016; Jarlenski et al., 2017). Due to rising costs of prescription opioids some individuals, including pregnant and parenting

mothers, begin using heroin, another opioid, as a cheaper alternative to prescription opioids (Jumah, 2016; Krans & Patrick, 2016). Individuals who use intravenous drugs, such as heroin, are at increased risk for blood-borne pathogen infections, such as human immunodeficiency virus and hepatitis C virus, and may experience heightened social stigma as compared to users of other types of drugs with perceived less risk (Krans et al., 2016; Mateu-Gelabert et al., 2005).

A direct consequence of maternal opioid use is NAS. NAS is characterized by neurological, gastrointestinal and autonomic reflexivity symptoms associated with the postnatal withdrawal of substance(s) that the infant had become dependent upon during gestation due to maternal use (Hudak, Tan, Drugs, & Newborn, 2012; Jones & Fielder, 2015). Approximately 5.8 of 1000 births meet the criteria for NAS, which reflects a 300% increase between 1999 and 2013, with many more infants showing symptoms of a SEP, but not meeting criteria for NAS (Ko, 2016). These infants average a 16.9-day length of stay in NICU (NIDA, 2015), as compared to slightly over three days for non-opioid exposed infants (Patrick et al., 2012), incurring over \$462 million nationally in hospital Medicaid costs (Winkleman et al., 2018). For infants requiring hospital stays related to maternal substance use, approximately 83% were related to opioid and opioid-like substances (Fingar & Weiss, 2015). Characteristics of the geographic incidence of NAS mirror the incidence of maternal opioid use with incidences higher in the southern areas of the US (Hand et al., 2017; Patrick, Davis, Lehmann, & Cooper, 2015).

Symptoms of NAS occur in approximately 54–94% of infants exposed to opioids in utero when the mother utilizes substances that cross the placenta, particularly opioids,

while the fetus is in utero (Hudak et al., 2012). Dependency occurs when the infant functions normally only in the presence of opioid exposure. After birth, the substance is no longer available and the infant experiences physical disturbances, sometimes labeled symptoms of withdrawal (Shearer, Davis, Erwin, Anderson, & Lindley, 2018). Symptoms of withdrawal include a spectrum of respiratory complications, central nervous system hyperirritability, dysfunctions of the autonomic nervous system, feeding difficulties, gastrointestinal disturbances, and irritability. Of infants who experience NAS symptoms, opioids are the most commonly used substance by mothers, including mothers who receive medication-assisted treatment as a part of treatment and recovery (Tolia et al., 2015). Significant increases in morbidity and mortality may be experienced without additional assessment and treatment of NAS (Finnegan & Kaltenbach, 1992; Hudak et al., 2012; Jones & Fielder, 2015; Patrick et al., 2012; Shearer et al., 2018). Some infants exhibit only mild to moderate symptoms. In the absence of a confirmed toxicology report or maternal admission of substance use these infants are suspected to experience NAS and receive similar treatment but are not officially diagnosed. Infants are usually cared for inside NICUs where the infant can be monitored for physiological compromises, fed by infant feeding experts, and treated with pharmacologic intervention if necessary.

Family-Centered Care

Since the beginning of the 21st century, family-centered care (FCC) has become a primary tenet in pediatric healthcare, including neonatal intensive care. FCC stems from the belief that parents should be integral in the planning and execution of care for hospitalized newborns, and that their presence and involvement have a positive influence

on the care provided. Principles derived from a strengths-based perspective evoke actions that respect the child and family as a unique individual unit, facilitating opportunities for making choices available to the child and family, and tailoring healthcare to meet the specific beliefs and values of the child and family. When families become a part of the healthcare team to make collaborative decisions with medical providers, families are empowered (Gooding et al., 2011; Ramezani, Shirazi, Sarvestani, & Moattari, 2014). Outcomes of FCC include increased parental bonding and attachment with their infant, decreased infant length of stay, improved satisfaction with care among parents, and improved job satisfaction and retention among nurses (Gooding et al. 2011).

Many NICUs have an open layout to provide visual access to patients by a variety of healthcare team members. This Principal Investigator (PI) has years of experience working in several NICUs, all with a variation of open and/or highly-visible patient care layouts. This layout differs from traditional hospital ward layouts with individual patient rooms, where both the patient/family and the nurse enjoy some level of privacy. In the NICU, rooms may be crowded with equipment, seating, and people. Nurses' work is more visible to families, and family dynamics are more visible to nurses and other families as compared to other healthcare spaces. The close proximity of caregiving and a high level of communication leads to high levels of emotional engagement with parents for the NICU nurse. Nurses report this closeness with parents as both rewarding and challenging, but an expected part of the professional role as a nurse in the NICU (Fegran & Helseth, 2009).

When experienced in the context of caring for an infant and family with a SEP, FCC may be even more challenging. Nurses report families with a SEP to be mostly absent and difficult to work with when present (Fraser, Barnes, Biggs, & Kain, 2007; Maguire, Webb, Passmore, & Cline, 2012; Murphy-Oikonen, Brownlee, Montelpare, & Gerlach, 2010; Whittaker et al., 2016). However, mothers with a SEP report negative experiences with nurses and other health care providers in the NICU, such as the extreme critique of holding and snuggling with their baby (Howard, 2015b). This type of intervention by healthcare providers, even if well-intended, is misaligned with principles of FCC. Additional factors such as potential punitive action against the mother and/or investigation into maternal fitness may decrease trust between the mother and nurse and contribute to negative communication patterns as well (Cleveland & Bonugli, 2014; Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Family empowerment is critical in promoting the self-efficacy of parents (Chou et al., 2018), and has been reported to shape the family's experience of care in the NICU (Atwood et al., 2016).

Stigma in Healthcare

Negative attitudes and biased care have been shown to negatively impact patient outcomes in other stigmatized populations through the decreased initiation of care, mistrust with caregivers, and non-adherence to treatment (Can & Tanriverdi, 2015; Chang, Dubbin, & Shim, 2016). Patients experience poorer outcomes by way of less than the standard quality of care, poor communication, and strained relationships with caregivers (Phelan et al., 2015; Puhl, Luedicke, & Grilo, 2014). Biases have been

reported by healthcare providers, generalists and other non-maternal-child specialists, towards individuals who misuse substances including negative stereotypes and purposeful avoidance of patients with substance misuse behaviors (Chang et al., 2016; Mendiola, Galetto, & Fingerhood, 2018).

Stigma toward Mothers who use Substances in Pregnancy

Nurses report negative attitudes towards mothers who use substances in pregnancy stemming from both the effects of substance use they witness while caring for infants with symptoms of NAS and the negative interactions with parents they have experienced. Over time, recurrent negative experiences with mothers who have experienced a SEP begin to influence the nurse's perception of all mothers who have experienced a SEP, thus creating a stereotype (Fraser et al., 2007; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher, Hill, & Cong, 2018; Whittaker et al., 2016). Link and Phelan (2014) describe this relationship dynamic as interactional discrimination, where the stigmatized person responds to the stigmatizer with reactionary behavior such as caution or less warmth, resulting in the stigmatizer disliking the stigmatized person. If this interaction repeats itself, the stigmatized person/group may be excluded or assigned less social status. Although stereotyping goes against the professional values of nursing, the nurse may stake his/her right to label mothers who use substances in pregnancy upon this mother's deviance from the cultural definition of a "good" mother (Reid et al., 2008; Terplan et al., 2015).

Effects of Stigmatized Care of Mothers

Mothers who use substances in pregnancy verbalize the perception of stigmatized care (Cleveland & Bonugli, 2014; Howard, 2015a, 2015b; Matthews, Dwyer, & Snoek, 2017; Phillips et al., 2007; Reid et al., 2008; Roberts & Nuru-Jeter, 2010, 2010; Stengel, 2014; Stone, 2015; Stringer & Baker, 2018). Mothers verbalize that they are treated differently by healthcare providers than mothers who did not use substances in pregnancy (Harvey, Schmied, Nicholls, & Dahlen, 2015). Some mothers perceived that their infants were scored more harshly on withdrawal symptom scales by NICU nurses who seemed to have more negative attitudes toward them (Harvey et al., 2015). Self-stigma among mothers may be related to internalized social stigma (Howard, 2015b; Matthews et al., 2017; Roberts & Nuru-Jeter, 2010). Mothers perceive this stigma in circumstances of both illicit and prescribed substance use, and across the continuum of use and recovery (Howard, 2015b).

Mothers verbalize that perceived stigma leads to lack of trust toward healthcare providers, which decreases their disclosure of behaviors, potentially negatively impacting the care they and their infants receive. Even previously established trust with the nurse is challenged if the mother perceives that the nurse is judging her in a separate caregiving interaction (Harvey et al., 2015). One of the primary coping mechanisms for mothers experiencing stigmatization is avoiding environments where they may encounter persons who stigmatize them, including healthcare providers, friends, and family (Harvey et al., 2015; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Powerlessness and self-stigmatization may serve as a trigger for substance use, even among women who are

sober (Cleveland, Bonugli, & McGlothen, 2016). In contrast, when mothers perceive a supportive and empathetic environment, they want to engage in learning, communication, and build a relationship with that caregiver (Harvey et al., 2015).

Power Dynamics that may Influence Stigma and the Mother-Nurse Relationship

Link and Phelan (2001) describe stigma as more complex than merely negative attitudes towards individuals or groups with perceived negative characteristics. The process of stigmatization involves labeling, stereotyping, and the resultant loss of status and discrimination in an environment of unequal power dynamics (Link & Phelan, 2001; Sheehan, Nieweglowski, & Corrigan, 2017). Multiple power differentials exist within the dynamic of nurses caring for families of infants with a SEP. Namely, differences in education, possibly household income, social status, and ability to navigate the NICU system are existent power differentials between the mother and nurse, described more in depth below.

The associated criminalization of mothers who use substances adds another layer of stigma upon the mother and additional social distance between the mother and the nurse (Angelotta, Weiss, Angelotta, & Friedman, 2016; Lester, Andreozzi, & Appiah, 2004). There is a large continuum of criminal offenses for which women who use substances in pregnancy have been charged, including illicit substance use while pregnant, child abuse, assault, manslaughter, and murder. Although criminal and civil statutes vary widely between states, southern states such as Tennessee, South Carolina, and Alabama have exhibited the most intense legal penalties upheld by state supreme courts (Angelotta & Appelbaum, 2017). Although some advocates for criminal penalties

propose that criminal charges deter substance use, it is also believed that the criminalization of substance use in pregnancy is closely tied to a morally influenced societal belief of substance use (Angelotta & Appelbaum, 2017; Angelotta et al., 2016). The barriers of stigma experienced through social stresses, social distance, and negative interpersonal experiences between mother and nurse reinforce stigma and resultant discrimination against the mother who uses substances in pregnancy (Howard, 2015b).

Broad social inequalities typically separate nurses from mothers with substance use behaviors. Most mothers who use opioids in pregnancy experience lower household incomes (<\$20,000/year) and possess a high school diploma or less education as compared to bedside nurses with a minimum of an associate degree in Nursing providing potential for competitive wages (Metz, Brown, Martins, & Palamar, 2018; K. Smith & Lipari, 2017). Differences in education and earning power contribute to differences in living environments, access to quality food and healthcare, and overall financial security.

The typical environment of care for infants experiencing symptoms of neonatal abstinence is inside the NICU, where nurses and other healthcare providers are the primary planners of care as compared to the non-intensive care areas where parents have more control (Maghaireh, Abdullah, Chan, Piaw, & Kawafha, 2016; Smith, Rogowski, Schoenauer, & Lake, 2018). This intensive care environment is overwhelming and intimidating for many parents due to the level of care, surrounding technology, and practices of infant care such as laying infants prone to sleep not visible in the normal newborn care area (Maghaireh et al., 2018). The nurse's understanding of the practices and workflow within the NICU and ability to provide infant care that parents may not be

able to provide affords more power to the nurse, as the primary caregiver for the infant, compared to the mother. This inequity of knowledge and ability creates a nurse-favored, baseline power differential with most families whose infant spends time in the NICU regardless of the reason for admission (Maghaireh et al., 2018).

The looming fear of child protective services (CPS) involvement was cited as the primary consequence of mothers countering the health care providers' plan of care (Harvey et al., 2015; Howard, 2015a; Reid et al., 2008; Stengel, 2014). The clinical interaction between the mother and nurse may become further strained when surrounded by a policy that evokes fear on mothers. In 2010 (Congress.gov, 2010), the Child Abuse Prevention and Treatment Act (CAPTA) of 1978 was reauthorized to include state requirements to address the needs of infants affected by parental substance use, in addition to traditionally defined child abuse and neglect cases (P.L. 111-320). The addition of the Comprehensive Addiction and Recovery Act (Congress.gov, 2016) in 2016 led CAPTA requirements to become much more specific. Healthcare providers were mandated to notify child protective services of all infants affected by legal or illegal substance use, thus beginning the inclusion of infants with abstinence symptoms caused by maternal Opioid use Disorder treatment using medication-assisted treatment. The establishment of plans of safe care for the infant as well as the health and treatment needs of the caregiver (mother) prior to discharge were also part of this mandate. The implementation of the policy has increased the frequency and intensity of CPS involvement in the discharge care plans for many families.

Although notification of CPS is usually executed by the social workers in the hospital, some mothers perceive that the nurse either notifies CPS, has a primary role in that process, or at the very least is a part of the power machine which may take away her child (Leppo, 2012). Mothers are fearful of CPS involvement in their lives due to the risk of losing custody of their child(ren) once there is a concern for the safety and wellbeing of the child within the home environment. The mother may see the nurse as an adversary who is attempting to build evidence that she is an unfit mother, based on perceptions of mistrust (Cleveland & Bonugli, 2014; Howard, 2015a; Reid et al., 2008; Stengel, 2014; Stone, 2015). The power struggle between the mother and the system of CPS then encompasses the nurse as well, further complicating the relationship between the mother and nurse. This tension tilts the power differential between mother and nurse even further in the nurse's favor, potentially further increasing the stigmatization and loss of status of the mother.

It is known that mothers who use substances in pregnancy are stigmatized (Reid et al., 2008; Terplan et al., 2015). Mothers who use substances in pregnancy report the perception of stigma by healthcare providers, and the consequential negative impact on the implementation of family-centered care (Cleveland & Bonugli, 2014; Howard, 2015a, 2015b; Matthews et al., 2017; Phillips et al., 2007; Reid et al., 2008; Roberts & Nuru-Jeter, 2010, 2010; Stengel, 2014; Stone, 2015; Stringer & Baker, 2018). Concurrently, nurses report negative experiences in caring for infants of mothers who use substances in pregnancy and provide examples of care influenced by stigma (Fraser et al., 2007; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018; Whittaker et al.,

2016). It is evident from different research reports that the caregiving dynamic is strained, and neither nurses nor mothers are generally pleased with the interactions.

It is also known that power dynamics are both influential toward and influenced by stigma (Link & Phelan, 2001), where stigma power creates and upholds social structures (Link & Phelan, 2014). The current literature has not presented a theoretically-based investigation of the socially constructed identities of mothers with a SEP by NICU nurses or the power dynamics within the NICU that could potentiate the stigma of these mothers. An investigation of these power differentials and constructed identities is needed to gain an understanding of the complex caregiving dynamic between NICU nurses and mothers with a SEP. A better understanding of the caregiving dynamic may assist in deconstructing and addressing stigma among healthcare providers who care for mothers and infants with a SEP.

Purpose of the Study

The purpose of the study was to illuminate potential power differentials within the caregiving dynamic and expose the interplay between language and sociopolitical discursive practices. Additionally, this study aimed to explore the caregiving dynamic between NICU nurses and mothers with a SEP through an understanding of the social construction of these mothers by the nurses who care for them. A qualitative study design using interviews with NICU nurses who care for infants and families with a substance-exposed pregnancy was utilized to address the aims of the study.

Feminism, Social Constructivism, and Stigma

Feminism and social constructivism provided the philosophical and epistemological underpinnings for this study, with the data being viewed through their theoretical lenses. The conceptualization of terms such as *stigma*, *bias*, and *power* may vary depending upon the theoretical lens from which they are viewed. Practices are examined in the context of culture, history, politics, and the economy in which they sit (Howard, 2015b). Therefore, it was important to carefully select a theoretical framework that considers the construction of stigma into the examination of issues that may impact the care and outcomes of mother-infant dyads experiencing a substance-exposed pregnancy. Feminism and social constructivism share similar assumptions and support the aims of the study.

Feminism

Feminist theory is the theoretical perspective of the larger concept of feminism. Inductive and broad, feminist theory arose as a method to explain women's oppression across the world (Carlson & Ray, 2011). Feminist theories are utilized to question the inequities of gender, challenge accepted norms about race, gender, and class, and explore socially-accepted gender roles (Carlson & Ray; Ferguson, 2017). The movement towards equal rights for women has arguable roots in ancient Greece, however, the formal movement began in the late nineteenth century with the industrial revolution and the rise of social politics. Women's suffrage was the primary focus of the leaders, many of who were white, middle-class women. The second wave of feminism arose in the 1960s and 1970s, as the activists aimed to separate and secure equal reproductive rights and issues

of sexuality. This wave included women of color and all income brackets, broadening the message of feminism to include issues of classism. The third wave, sometimes labeled post-modern feminists, began in the mid-90s influenced by the post-structural philosophical movement to consider more fluidity within concepts and challenged the concept of binary categories while celebrating differences between groups. The controversy between the women of the second and third waves incited when the younger generation began readopting many of the practices that the older generation rejected as signs of oppression. The third wave of feminism rejected the idea of feminism in the sense of the second generation's conceptualization, instead opting for a global, multi-cultural, anti-label, and anti-category movement (Carlson & Ray, 2011; Rampton, 2015).

Post-modern philosophers and post-modern feminists share common ground in their rejection of fixed meanings and their analytical approach of deconstruction. When a text is deconstructed, multiple perspectives or discourses may be revealed, particularly through the identification of the unheard, less powerful voices. The deconstructed, post-structuralist view of philosophers such as Michael Foucault, relates to the post-structural feminist's construct of a "woman" as a cultural construct, not a fixed binary category in which all women relate. Post-modern feminists challenge the validity of fixed categories but accept the usefulness of some categorization that provides a unique perspective of sub-populations of women (Sands & Nuccio, 1992).

Feminist theory has experienced a tumultuous history with heated debates surrounding core propositions, in an effort to improve the lives of all women. However, overarching propositions upon which most feminist theorists agree include: 1) opposition

to dualistic thinking and categorization, 2) the socialization to womanhood rather than its assignment by gender, and 3) the political enterprise of feminist theory which works to change the world in favor of equality, freedom, and justice (Ferguson, 2017; Maynard, 1995). Common analytic sensibilities include intersectionality, interdisciplinarity, and theory/practice feedback loops. Intersectionality offers the holistic environment of both place and history from which to view the phenomenon of interest. The approach is continuously open to new ideas and is critical of power inequities, creating inter-relational orientations of circumstance. Interdisciplinarity takes advantage of the insights and expertise of various disciplines to fully explore the breadth and depth of research interests, without the limitation of a singular discipline's perspective. Lastly, theory/practice feedback loops speak to the change agent enterprise that helps constitute a feminist theory. The process of examining data and practice while engaging in the scholarly conversation of theory allows practice and theory to both support and challenge one other (Ferguson, 2017).

Social Constructivism

The theory of social constructivism is rooted in constructivism, a perspective that suggests learning is a process where meaning is constructed, as compared to passively obtained, allowing people to make sense of their experience. Although believed to originate in the time of Socrates, twentieth-century development of philosophy and psychology are credited to formalizing the theory (Amineh & Asl, 2015; Jackson & Sorensen, 2006). Social constructivism adds the specificity of humanity to constructivism. Social constructivism asserts that truth is inherently relative, created

through a social narrative situated within a specific cultural and historical context where people make meaning of their experiences (Amineh & Asl; Kim, 2001). Practices are examined in the context of culture, history, politics, and the economy in which they sit (Howard, 2015b). The theory of social constructivism is closely related to Immanuel Kant's work of transcendental idealism, arguing that all knowledge is subjective because it must be filtered through our consciousness (Jankowiak, n.d.). This theory supports the idea that stigmatized views of mothers who use substances in pregnancy are rooted in cultural narratives within society and the healthcare environment and may contribute to a power differential where the mother is disempowered in the caregiving environment of her infant.

There are three major assumptions in the theory of social constructivism: 1) Reality is not predetermined, it is constructed through human experience, 2) knowledge is a socially and culturally constructed outcome of human experience, and 3) learning is a social process (Amineh & Asl, 2015; Kim, 2001). Although people derive meaning from a social context, that meaning is then internalized to create an individually-constructed reality that serves as a lens through which we view the world. When individuals share their individual perspectives, a collective understanding emerges (Amineh & Asl, 2015).

Experiences become meaningful when we assign value, context, background, and perspective to those experiences. All of the context to which we compare and contrast our experiences is gained from the perspective from which we view the experience. This perspective builds upon the values, morals, social norms, historical context, and previous life experience of the individual. The summative experiences of life inform our

knowledge of the world, and thus forms our personal reality. Under the theory of social constructivism, there are no two identical experiences (Amineh & Asl, 2015), and therefore no two identical realities, because there are no two people with the exact same perspective. However, individuals may share similar realities if their life experiences and perspective on the world are similar. Even if a perspective is biased and contradictory to another person's reality, both perspectives are arguably "true," as they are true for that singular individual.

Intersubjectivity describes the shared understanding among individuals with common interests and assumptions, creating the foundation for their communication. However, power relations are also integral to intersubjectivity. Ideas define the meaning of power, yet at the same time, dominant members of the group or those in power enjoy the benefit of determining normative values and beliefs (Jackson & Sorensen, 2006). Individuals and groups are then compared against these definitions of normative, and if deemed as too different or non-conformant, negative labels may be assigned and the process of stigmatization initiated. Those in power construct norms to mirror their own attributes, empowering individuals who conform to the norms and disempowering those who do not (Howard, 2015b).

The cultural and historical experiences of the community form intersubjectivity which influences the construction of knowledge within the group. The social world is comprised of thoughts, beliefs, ideas, concepts, languages, and discourses meaningful to the people who comprise and live within the group. Communication among group members centers on socially-agreed upon ideas, including social patterns and the use of

language. The process of intersubjectivity thereby constructs social meanings, evolving with ongoing communication. Reality is constructed through human engagement, and together the members of a society conceive the properties of the world (Jackson & Sorensen, 2006; Kim, 2001).

Because reality is a socially constructed perspective and conceived as a personal truth, once established, such perspectives are difficult to successfully challenge and offer an alternative lens in which to view the world. We see examples throughout history where accepted societal norms are unsuccessfully challenged for sometimes extended periods of time before a shift in the social perspective occurs. Even when social norms do finally shift, such as the condemnation of slavery or domestic violence, individual attitudes may vary, and may never shift within some individuals.

Complements of Feminism and Social Constructivism

The theories of feminism and social constructivism share many tenets, including the rejection of dualistic notions in favor of an intersectional view of the world. They are also complementary in the examination of issues of caring for families of infants with a SEP. These theories were utilized to generate interview questions necessary to elicit meaningful data from the participants. These theories will aid in data analysis, using a discursive technique, to adequately explore a complex social dynamic. Utilizing both theories in tandem, the caregiving dynamic between NICU nurses and mothers with a SEP was examined as both a stigmatized social construct and a representation of power inequity.

Through a social constructivist lens, knowledge and reality as constructed by the professional group of maternal/child nurses revealed common biases that are held as truths within the group and instilled in new members of the group through the process of socialization, thereby reinforcing stigmatized attitudes within the society of maternal/child nurses. The deconstructed, post-structuralist view of philosophers such as Michael Foucault, relates to the post-structural feminist's construct of a "woman" as a cultural construct, not a fixed binary category to which all women relate (Sands & Nuccio, 1992). Further, feminist theory offered the opportunity to examine the construction and functionality of intersectional (substance use and motherhood) stigma among nurses towards mothers who use substances in pregnancy as a social construct steeped in power inequities and social assumptions of motherhood (Abbott, 1994; Ferguson, 2017). Through the rejection of dualism, feminist theory rejects the dichotomy of good mother vs. bad mother, eliminating the "either/or" categorization of mothers with substance use behaviors (Abbott, 1994; Urek, 2005). This theoretical perspective offered the PI an opportunity to recognize construed stigmatized identities of mothers who use substances in pregnancy by NICU nurses.

The framework of this study can inform future work aimed at breaking down stereotypes and stigmatized views, thereby improving the caregiving dynamic. Meaningful interventions to address stigmatizing attitudes towards mothers with substance-use behaviors must address the values, morals, social norms, historical context, and previous life experience of the individuals who make up the society of interest. Although difficult to challenge group norms and established perspectives of a social

construct, new knowledge related to the various elements of the social construct may be helpful in designing such interventions. The theory/practice feedback loops of examining data and practice while engaging in the scholarly conversation of theory allow practice and theory to both support and challenge one other (Ferguson, 2017). This symbiotic relationship between theory and practice fosters the change agent enterprise that supports the analytic technique of critical discourse analysis, described more in depth in Chapter 3.

Assumptions

Assumptions that were utilized within the study relate to the theories of feminism and social constructivism, the study of discourse, and clinical norms within the NICU environment. The underlying ontology of this study aligns with the philosophical ideas of Michael Foucault (Sands & Nuccio, 1992), rejecting the notion of a singular universal truth to be discovered.

1. The design of this study was constructed under the assumption that individuals can maintain alternative perceptions of truth existing simultaneously.
2. Clinical norms were assumed for this study include FCC concepts as an accepted pillar of care within the NICU.
3. It was assumed that nurses desire infant and family outcomes that support safe, independent care of the infant after discharge.
4. It was assumed that nurses will be able to reflect upon their practice and share that reflection with the PI in an interview.
5. It was assumed that nurses will be honest and able to share both positive and negative stories of the practice experiences with the PI.

Conclusion

The problem of stigmatized caregiving toward mothers who experience a SEP is a current and relevant topic within maternal-child research. Due to the increasing incidence of substance-exposed pregnancies, more nurses are caring for infants and families with a SEP. Outcomes of stigmatized care, such as fractured relationships between mothers and nurses, do not support principles known to improve outcomes for high-risk infants in the NICU. A better understanding of the stigmatized identity that nurses create for mothers with a SEP is critical to guide future work to intervene upon stigma and power inequities. Research to identify the most significant power differentials within the caregiving dynamic may offer prioritization for interventions that increase the mother's perception of power, importance, and significance in the care of her baby and the nurse's opportunities to support her in the mothering role. Ultimately, a more balanced caregiving environment may improve outcomes for infants and mothers with a SEP and improve satisfaction in caregiving among nurses who care for them.

CHAPTER II

LITERATURE REVIEW

This chapter will offer exploration and synthesis of the current evidence surrounding the issues of nursing care for families and infants where a substance-exposed pregnancy (SEP) is suspected or diagnosed. The following areas/topics will be discussed: stigma surrounding substance misuse, the intersectional stigma of mothers who use substances in pregnancy, the caregiving dynamic between nurses and mothers of infants with symptoms of a SEP, and gaps in the existing literature.

Although strong opinion-based literature exists from established researchers and professional organizations, much of the literature is primarily supported by moral and ethical arguments and demographic reports (American College of Obstetricians and Gynecologists, 2014; Association of Women's Health, Obstetric and Neonatal Nurses, 2015). Supportive evidence such as the consequences of bias in other populations, outcomes of interventions involving relational care, and descriptions of the perceived stigma of mothers who use substances in pregnancy was identified but provided only ancillary support for the topic of issues of nurses caring for families or infants with a substance-exposed pregnancy. There is a dearth of evidence that provides data-driven insight into the complex and multifaceted nursing care of this vulnerable dyad.

Stigma and Substance Misuse

Substance misuse and addiction is a uniquely challenging health problem due to the misunderstanding of its etiology. Although classified as a chronic disease with no specific cure, many people, even healthcare professionals, view addiction as a moral failure (Corrigan, Kuwabara, & O'Shaughnessy, 2009; National Institute on Drug Abuse, n.d.; Yang, Wong, Grivel, & Hasin, 2017). Seminal work on stigma by Goffman (1963), reinforced by Link and Phelan (2001), describes stigma as the relationship between an attribute and a negative stereotype, where the attribute connects the person to undesirable characteristics within an environment of unequal power dynamics, ultimately resulting in the loss of status by the stigmatized individual or group. Goffman proposes that stigma may be comprised of tribal identities, such as race, physical abnormalities or differences, or perceived blemishes of one's character, such as addiction behaviors. The loss of status and character blemish associated with substance use may be particularly damaging for mothers under the societal trope of a "good mother". The misperception of addiction as a moral failure has stigmatized substance misuse through the linkage to negative characteristics.

Stigma is not static, but rather stigma is alive and adaptive to the society where it roams. It mobilizes attitudes into related behaviors. Although the consequences of stigma in this simplistic description may be visualized as individual discrimination within a variety of societal settings, stigma goes much deeper into the very fabric of society. Structural discrimination operates where accumulated institutional and organizational practices work to disadvantage groups that are unlike those who are in power, such as

those who do not comply with social norms. These practices and policies are embedded within the major structures of the society, and filtered down into all other structures, enabling the maintenance of power by the advantaged group. The consequences of structural discrimination may be more subtle than individual discrimination, easily overlooked, unrecognized, or even recognized but still accepted. However, the functionality of structural discrimination is overwhelming and all-consuming to the society where it operates, creating and obliging systems that maintain an “us versus them” dynamic. Individuals and groups who are stigmatized are unlikely to penetrate the boundary separating them from the advantaged group due to the practices that are in place to maintain their disadvantaged position related to the advantaged group. Additionally, as members of the societal structure, even the stigmatized individuals are vulnerable to the conceptions of stigma and may internalize the stigmatized views as self-stigma (Link & Phelan, 2001).

Thus, stigma is dependent upon power to function (Link & Phelan, 2001, 2014). Stigma uses power to function through a cultural acceptance of the stereotype, separation of “us” from “them”, and control access and engagement with major life domains such as education, career opportunity, and living communities. Even in the presence of labeling and stereotyping, if the group assigning the label lacks power, stigma is much less likely to proliferate. Due to the many variations of the associated constructs of stigma such as negative attributes, level of connectedness, and degree of separation, stigma lives on a continuum where the level of perception and consequences differ among individuals and groups (Link & Phelan, 2001, 2014).

In Chang and colleagues' (2016) study of interactions between providers and patients who use substances, biases were reported by generalist healthcare providers including negative stereotypes such as "unlikely to change" and the perception of treating individuals who use substances as a poor use of time and medical resources (Chang et al.). Mendiola's (2018) study comparing physician's attitudes toward patients with substance use disorders to other chronic conditions found that physicians had a lower regard for patients with substance use disorders than other medical diagnoses with a behavioral component to their illness, such as poorly controlled diabetes or chronic obstructive pulmonary disease. Some providers in both of these studies verbalized a preference against working with patients who misuse substances (Chang et al.; Mendiola et al.). Similarly, a study of 815 individuals within the general population of the United States, examining the level of danger depicted by the vignettes, found that individuals who used drugs were viewed as more dangerous and fear-evoking and the most likely to be avoided when compared to individuals with another mental illness or physical disability requiring a wheelchair (Corrigan et al., 2009). A study of psychology undergraduate students in Italy measuring beliefs and perceptions about a variety of mental disorders found that individuals with substance addictions were the most socially rejected and severely judged (Mannarini & Boffo, 2015). Similar biases and potential consequences are found in the literature describing healthcare surrounding mothers who misuse substances, as well.

Stigma of Pregnant and Parenting Women who use Substances

The perception of stigma can be different between women and men, and even more so with women who are pregnant and/or parenting. Women who use substances experience increased stigma compared to men. Stringer and Baker's (2018) study of perceived stigma by gender using the 2003–2010 National Survey of Drug Use and Health ($n = 1474$) found a statistically significant ($p < 0.01$) difference between women (26.3%) and men (20.2%) when reporting stigma as a barrier to substance use treatment. Other social demographics contribute to perceived stigma as a barrier to treatment as well, such as being white (42% higher odds, [$p < .05$]) and having a higher income (OR = 1.15, $p < .000$).

Nurses consistently report negative attitudes toward mothers with substance use behaviors, describing feelings of resentment, frustration, and anger when caring for families whose baby exhibits symptoms of withdrawal from substances after birth (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018). Mothers with a SEP are characterized as demanding, selfish, defensive, inconsistent, and mostly absent (Fraser et al., 2007; Murphy-Oikonen et al., 2010; Shaw et al., 2016). More detailed findings of these studies are described below.

A study of 14 female NICU nurses, aged 20–55 years, in an urban Canadian setting (Murphy-Oikonen et al., 2010) describes frustration in the type of care (intensive need for comfort and difficulty in sleeping and eating) that infants of a SEP require, often at the expense of time spent with other infants under their care. They also describe blame toward the mother for the “poor choices” and “the effect on her baby”. Another

qualitative study (Fraser et al., 2007) which examined eight Australian neonatal nurses' from four special-care nurseries, experiences of caring for infants with a SEP found that families were described as "chaotic" and "demanding," also resulting in described "frustration" by the nurses when caring for them. The tension between the family and the nurse during the caregiving dynamic is well-described, with one participant specifically noting that while family-centered care is desirable, the infant, rather than the mother, is the primary patient of concern in the NICU. Tension at the bedside also exists between nurses and other healthcare providers as nurses describe the frustration that their assessments of infant's symptoms are shunned (Romisher et al., 2018). It is unknown whether this perception by nurses is related to organizational climate, power inequities, or other workplace dynamics.

Ethical concerns of safety for the infant upon discharge to home are cited in multiple studies (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010). The nurses in Fraser and colleagues' and Murphy-Oiken and colleagues' studies express concern and feelings of responsibility surrounding the discharge of an infant with extra care requirements into an unknown and perceived unsafe home environment. Maguire and colleagues' (2012) qualitative exploration of the lived experiences of ethical and moral issues among 16 NICU nurses revealed that caring for infants with neonatal abstinence syndrome (NAS) was the primary source of experienced ethical and moral distress. This participant group had an average of 8 years of NICU experience, with 50% having earned a bachelor's degree. Additional demographic data were not reported for this sample. The results of this study specify the nurse's struggle with the moral

principles of beneficence and nonmaleficence. The struggle with beneficence was present through the nurse's feelings of inadequacy surrounding the provision of adequate care to both mothers and infants with symptoms of a SEP. The challenge of meeting the goal of nonmaleficence was described when nurses verbalized their apprehension in discharging infants to homes that they perceived may not be safe or able to meet their care needs. Specifically, nurses feared that infants may be abused or neglected in the mother's home. It is unknown whether some of these safety concerns are warranted and unrelated to stigma, or both warranted but also complicated by stigma.

Nurses in other studies also verbalized the frustration of being unable to meet the overwhelming comfort needs of the infant experiencing the discomfort of abstinence, although those studies did not assign the specific labels of beneficence and nonmaleficence to the nurse's described internal conflict (Fraser et al., 2007; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018). This experience was further complicated for some nurses through the perception of the inability to meet the needs of their other patients, as well, due to the time required to comfort infants with symptoms of a SEP (Maguire et al., 2012; Murphy-Oikonen et al., 2010).

Healthcare providers, including nurses, cited lack of visitation from parents, disruptive behaviors when visiting, infrequent communication patterns, and blaming behaviors toward nurses as some reasons for their negative attitudes (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018; Shaw et al., 2016; Whittaker et al., 2016). Nurses expressed resentment regarding inconsistent parental visitation patterns and negative communications with mothers

(Fraser et al., 2007; Maguire et al., 2012). Some nurses felt frustrated in their perception that their critical care skills were underutilized when caring for infants and families with a SEP (Murphy-Oikonen et al., 2010). Whittaker and colleagues (2015) found in their Scottish focus group study that their diverse sample of 18 healthcare professionals, including nurses, who provide collaborative care for parents with substance use concerns, that their primary practice is motivated to protect the child, as compared to support of the family as a whole.

A mother's lack or inconsistency of visitation of the infant in the NICU drew particular concern for nurses related to safety, specifically that the mother would not be able to meet the infant's caregiving and comfort needs at home (Fraser et al., 2007; Maguire et al., 2012; Romisher et al., 2018; Shaw et al., 2016; Whittaker et al., 2016). A particular risk was verbalized for rural families where services and assistance might not be readily available (Shaw et al., 2016). In addition to concerns related to health, nurses expressed concern over the risk of child maltreatment after discharge home, citing their own ethical dilemma of discharging the infant into the mother's care. Oppositional forces arose between prioritizing the desires of the mother to take the infant home versus the nurse's concern for the safety of the child in the mother's home (Maguire et al., 2012; Murphy-Oikonen et al., 2010; Shaw et al., 2016; Whittaker et al., 2016).

Evidence of Stigmatized Practice

Verbalizations of blaming mothers for their substance use behavior were found in some studies, citing selfish decision-making and irresponsibility as the assumed reason the mother used substances during pregnancy (Fraser et al., 2007; Maguire et al., 2012;

Murphy-Oikonen et al., 2010). Some nurses verbalized the opinion that women with pain management concerns or those who utilized MAT should avoid pregnancy (Maguire et al., 2012; Murphy-Oikonen et al., 2010). A study of 22 nurse midwives and staff in addition to 24 pregnant or newly parenting women in the United Kingdom utilized interviews and non-participatory observations to explore workplace discourse used in clinical practice with mothers who use substances in pregnancy (Radcliffe, 2011). No other demographic information of the sample in this study was provided, however, this study was a part of a larger study into the experiences of mothers' experiences of prenatal care. Although discourse analysis was not employed, this study revealed communication with blaming language and moral skepticism around otherwise mundane events, such as a missed appointment or lost provider notes (Radcliffe, 2011).

Even nurses who described the caregiving dynamic with a less negative tone use stigmatizing language such as, "I think their personalities, where they are a little fragile um, it's not conducive to looking after high-risk babies" and equated medication-assisted treatment to "drug use". Stereotyping was evident when these nurses described mothers who use substances in pregnancy as "chaotic" and a "demanding client group" (Fraser, 2007). Stereotyping was evident in other studies, as well. For example, the NICU nurses in Maguire and colleagues' (2012) study broadly characterized mothers as "... 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." Additionally, a comment from a midwife in Radcliffe's study reveals an assumption that is related to a stereotype of

mothers who use substances in pregnancy, “They aren’t in when the community midwife calls because they don’t want her to see their flat; they live in chaos.”

Conflicts within Findings

Self-reported biases of nurses sometimes contradict observed behaviors or alternative modes of data collection. The public stigma of substance use is overwhelmingly negative, and nurses are affected by that discourse as a part of the general public (Can & Tanrıverdi, 2015; Corrigan et al., 2017; Terplan et al., 2015). Professional education offers nurses an alternate discourse rooted in chronic disease evidence, as compared to moral or ethical agency (Maguire, 2014; National Institute on Drug Abuse, n.d.) Depending upon the degree to which the nurse subscribes to either the public discourse or the professional discourse, there may be alternate implicit versus explicit attitudes present within nurses who care for families of infants with a SEP. Explicit attitudes are described as the socially desirable attitudes which individuals exhibit through conscious decision, where implicit attitudes are described as attitudes for which an individual lacks awareness. Implicit biases are born out of negative implicit attitudes (Fazio & Olson, 2003).

One of the first studies to examine the attitudes of nurses caring for infants and mothers with a SEP investigated the attitudes of both nurses and nurse midwives in a neonatal unit in Scotland through a self-report questionnaire (Raeside, 2003). Of the 50 participants, the majority were between the ages of 30–39 years old, female (96%), and registered nurses (76%), with 80% having completed additional neonatal qualification, but only 20% having earned a Bachelor’s degree. Although 76% of participants answered

“I typically feel angry in reaction to a woman who uses drugs during pregnancy” with a negative attitude, only 44% expressed a negative attitude when answering “I do/would become judgmental or unknowingly punitive to the mother”. A discrepancy is noted as nurses disclose anger, but less judgment toward mothers who use substances in pregnancy. It is unclear whether this discrepancy is attributed to social desirability bias, survey design, or both. However, the discrepancy raises the question of potential dissonance between attitude and behavior.

More recent studies continue to show similar dichotomies between the attitudes of nurses. Shaw and colleagues’ (2016) grounded theory study of eight obstetric nurses practicing in large, urban birthing centers in Washington State report the acknowledgment of personal biases or perceived biases in their peers, but these nurses state that they intentionally set those biases aside to fulfill professional expectations. This sample was also predominantly female and white, ages 35–48 years old. In another study (Romisher et al., 2018) of 52 female, predominantly white participants from the New England area, critical characterizations of mothers such as “selfish” and critiques such as “I wish they would stop getting pregnant” were reported in open-ended statements. Almost 80% of these nurses verbalized frustration towards the mother who is infrequently present to provide care for her infant experiencing NAS symptoms. In contrast, only 27% of this sample agreed with the statement “I frequently blame the mother of an infant with NAS for the infant’s health problems”. These nurses were primarily between the ages of 31–60 years old, most with at least a Bachelor’s degree, and practicing at the bedside in the NICU (Romisher et al.).

In comparison, newly licensed advanced practice nurses in the United Kingdom (nurse midwives) report through a survey less blaming attitudes towards mothers who use substances in pregnancy as compared to midwives with more practice experience (Jenkins, 2013). In this sample, 38% of the midwives had never provided care for a woman who used substances in pregnancy, highlighting the potential change over time in attitudes towards women who use substances in pregnancy with increased experience caring for this population. Similar results were found in Fonti and colleague's (2016) study of nurse midwives (71%) and other healthcare professionals in a maternity unit, special-care nursery, and NICU in two Australian hospitals. Although there was no statistical significance found between any length of practice or age group, there was a statistically significant difference ($p=.01$) in the relationship between the mean scores for student midwives (37.85) and nurses (49.59) and practicing midwives (43.37), indicating a meaningful difference between the more positive attitudes of student midwives when compared separately to nurses and practicing midwives. The reason for the differences in attitudes between student midwives and nurses or practicing midwives is unclear. It is unknown if these differences may be rooted in differences in professional socialization, the influence of social desirability upon the participant's responses, the influence of implicit bias upon reported attitudes, differences in experiences, or other organizational power dynamics at play.

Perceptions of Stigma among Pregnant and Parenting Women who use Substances in Pregnancy

Research investigating the experiences of mothers who receive nursing care while pregnant or in the postpartum period offers an alternative view of nursing care. Insight into the mother's experience elucidates the effect of nurses' attitudes and behaviors toward the mother. Much of the current research around stigma and the mother's perspective is qualitative, which offers rich description and the opportunity for the mothers to use their own words. Stigma is both a product and contributor to discourse and therefore may have differing properties within alternate discourses. The mother's perspective is likely different from the perspective of the generalized public or healthcare professionals, particularly maternal-child healthcare providers (Link & Phelan, 2001).

Reid (2008) explored the discourse of mothering with substance use behaviors through focus groups comprised of 15 pregnant or parenting women attending treatment for substance addiction in Canada. Four primary discourses of the "good, bad, thwarted, and addicted mother" were found within a surrounding framework of "rights, risk, and evidence". These discourses, described by the mothers, emphasized the challenges that these pregnant and parenting mothers experienced while on the continuum of substance use and recovery. Mothers in this study verbalized the tenets of protective behaviors toward children that "good" mothers, including themselves even in times of substance use, inhabit. While participants described behaviors of "bad" mothers, such as repeatedly making poor choices in parenting, they negated the overall characterization of a mother who uses substances in pregnancy as "bad." They separate behavior from characterization

and describe the negative effects of such characterization from government agencies. The “thwarted” mothering discourse encapsulated their perception of living under the threat of the evoked power of government agencies due to past behaviors of substance use. The “addicted” discourse described the mothers’ awareness of the influence of substance use upon their lives.

Mothers consistently verbalize concern and love for their children, both during pregnancy and beyond (Phillips et al., 2007; Reid et al., 2008; Stengel, 2014; Stone, 2015). However, mothers also consistently voice feeling stigmatized by others (Stengel, 2014), and many perceive that they are treated differently from other mothers by nurses and healthcare providers, including being judged and ridiculed (Cleveland & Bonugli, 2014; Paterno, Low, Gubrium, & Sanger, 2019; Phillips et al., 2007; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015; Stringer & Baker, 2018). Descriptions of negative interactions with nurses align with conceptual descriptions of microaggressive behaviors in the literature surrounding other types of discrimination (Sheehan et al., 2017). Similar findings are shown in studies that examine the perceptions of women who use substances in pregnancy regarding social workers and those who work with government agencies associated with child protection services (Howard, 2015a, 2015b; Reid et al., 2008; Weinberg, 2006). Although described as an unpleasant experience, some individuals anticipate stigma and the accompanying consequences from their healthcare providers (Howard, 2015b; Matthews et al., 2017; Roberts & Nuru-Jeter, 2010). Mothers perceive this stigma in circumstances of both illicit and prescribed substance use, and across the continuum of use and recovery (Howard, 2015b).

Mothers describe feeling hurt and stressed by their perceived treatment by nurses and healthcare providers (Cleveland et al., 2016; Howard, 2015a, 2015b). Many mothers described a generalized lack of trust toward many individuals, including nurses and healthcare providers (Cleveland & Bonugli, 2014; Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Specifically, they lacked trust to fully disclose their substance use behaviors (Reid et al., 2008), and trust that they would provide warm, compassionate care for their infant (Cleveland & Bonugli, 2014).

Despite the primary negative tone of mothers when describing their stigmatization, some studies include themes of self-stigmatization, where the mothers felt they deserved to be stigmatized, and willingly accepted the label (Cleveland & Bonugli, 2014; Howard, 2015b; Stengel, 2014). They verbalized internal stigmatization while struggling with guilt, shame, and self-blame, especially when they visualized their infant experiencing symptoms of NAS or preterm birth (Cleveland & Bonugli, 2014; Cleveland et al., 2016; Paterno et al., 2019; Stengel, 2014; Stone, 2015).

Consequences of Perceived Stigma

Avoiding environments where healthcare providers may be encountered is one of the primary coping mechanisms for mothers who perceive stigmatization (Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Diverting healthcare allows the mother to avoid a negative, stigma-laden environment, but also deflects potential legal consequences of substance use in pregnancy. The primary consequence mothers desired to avoid was alerting Child Protective Services (CPS), for fear of losing custody of their child (Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). For

some women, the experience of stigma translated to infrequent visitation of their infants in the NICU, while providing motivation for others to be present and demonstrate behaviors that did not align with the healthcare providers' perceived norm of a mother who used substances in pregnancy (Cleveland & Bonugli, 2014; Cleveland et al., 2016; Howard, 2015b). Mothers who chose avoidance behaviors acknowledged they had also lost potentially beneficial services such as prenatal care and treatment for substance misuse, and often isolated themselves from friends and family (Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Self-stigmatization was observed, as some women verbalized feelings of maternal failure as a mother who used substances in pregnancy (Roberts & Nuru-Jeter, 2010; Stengel, 2014).

Mothers vacillated between being honest enough with their healthcare providers to attain the best care for themselves and their fetus, and being too honest with healthcare providers, resulting in the alerting of CPS (Stengel, 2014; Stone, 2015). Some mothers described the intentional choice to accept the perceived risk of stigma and CPS-related consequences in order to avail the best medical care for the growing fetus and infant at birth (Roberts & Nuru-Jeter, 2010; Stone, 2015). Mothers who were able to maintain sobriety or decrease frequency of use welcomed healthcare and screening opportunities as validation of their verbalized sobriety (Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015), again challenging the stigma of mothers who have used substances in pregnancy.

Not all mothers felt they were equal partners in their care and medical decision-making. However, due to the power inequities which accompany perceived stigma, some

mothers felt pressured into a particular plan of care, related to either obstetrical care or treatment for substance use. The looming fear of CPS involvement was cited as the primary consequence of countering the plan of care (Howard, 2015a; Reid et al., 2008; Stengel, 2014). These examples of mandated treatments or threats of custody loss may be perceived as coercive by mothers, with the emotional reaction to the incident impacting their well-being perhaps more than the coercive incident itself (Sheehan et al., 2017). The resultant powerlessness and self-stigmatization served as a trigger for substance use for some mothers (Cleveland et al., 2016).

Complex Relationships between Nurses and Pregnant and Parenting Mothers who use Substances

The quality of relationships between patient and healthcare provider may serve as an asset or liability to the potential patient outcomes associated with that care. It is in this complicated dynamic that nurses may serve as either allies or adversaries for mothers with a SEP. Support for mothers at their infant's bedside and through intentional communication are ways in which nurses may be viewed as an ally to mothers. Withholding information, directly or indirectly, or disengaging from communication with the mother are examples of adversarial behaviors of nurses.

The complex communication dynamic between the health care team and the infant's family may contribute additional stress to the bedside nurse and resultant negative attitudes. Nurses report families of infants with a SEP are difficult to work with, however, parents may be angry, frustrated, scared, and/or continuing to use substances which contributes to the negative behaviors perceived by nurses (Cleveland & Bonugli,

2014; Cleveland et al., 2016; Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Roberts & Nuru-Jeter, 2010; Whittaker et al., 2016). Nurses express a desire for honesty and full disclosure from mothers (Shaw et al., 2016), however mothers are cautious due to the potential for stigmatizing and/or punitive consequences (Cleveland & Bonugli, 2014; Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). Fear of the potential involvement from CPS and consequential loss of custody drive maternal behaviors to isolate, limit disclosure, and be guarded with communication and relationships with nurses and healthcare providers (Reid et al., 2008; Roberts & Nuru-Jeter, 2010; Stengel, 2014; Stone, 2015). However, these behaviors are seen as the most frustrating issue for nurses when caring for infants and families with substance use behaviors. A cycle of fear and guarded behavior in the mother and frustration in the nurses is noted.

Preliminary findings from a pilot study by this author suggest that the caregiving dynamic between the NICU nurse and the mother who used substances in pregnancy is complicated by both negative attitudes and experiences from the nurse, but also organizational culture and complex power dynamics within the healthcare team (Welborn, 2018). It was suggested that deliberately neutral behaviors were exhibited by nurses towards mothers in an effort to thwart a report of unsatisfactory nursing care by the mother. These nurses described an organizational culture of patient satisfaction where their nursing care of the infant was impacted by the consequences of negative patient-satisfaction evaluation, in particular, if the nurse implemented known best practices for the care of NAS symptoms such as a low stimulation environment. These nurses

described variations of power dynamics in the presence and absence of mothers with a SEP, parents of other infants in the room, and other members of the healthcare team. Although numerous limitations exist for this pilot, with only two participants, the interview data contained a rich description of power inequities between mother, nurse, advanced practice nurses, neonatologists, and support professionals in an environment laden with organizational power undertones. Together with other literature describing nurses' caregiving experiences of infants and their mothers in the NICU following a SEP, questions were raised about the complexity and contributors to the relationship between mother and nurse beyond the negative attitudes and stigma of nurses. Additional study is needed to further explore the caregiving dynamic.

Nurse as Ally

When the mother perceives the nurse as an ally, outcomes are potentially more positive (Racine, Motz, Leslie, & Pepler, 2009). Although most mothers anticipated being judged and stigmatized, those that do not experience the anticipated judgement by healthcare providers verbalized feeling relief and gratitude and were more comfortable visiting and learning how to care for their infants in the nursery (Cleveland & Bonugli, 2014; Cleveland et al., 2016; Racine et al., 2009). Mothers that felt accepted and supported by nurses and healthcare providers felt more comfortable disclosing their substance use behaviors and were more likely to be honest (Phillips et al., 2007; Roberts & Nuru-Jeter, 2010). The nurse and healthcare provider can also provide a sense of connection to the world when loneliness is a trigger for substance use in some mothers (Racine et al., 2009; Roberts & Nuru-Jeter, 2010).

A positive and supportive relationship between the nurse or healthcare provider and mother may serve as a moderator to substance use behaviors, thereby protecting both the mother and infant long-term (Racine et al., 2009; Roberts & Nuru-Jeter, 2010). Mothers who use substances verbalize that respect and empathy are personal characteristics of healthcare professionals that foster rapport and encourage them to engage in recovery and caretaking (Kramlich & Kronk, 2015; Phillips et al., 2007; Racine et al., 2009; Roberts & Nuru-Jeter, 2010). Although clearly stated in the results from Roberts & Nuru-Jeter (2010) and intervention outcomes reported by Racine and colleagues (2009), an overwhelming theme from literature capturing the mothers' voices was that of desiring to be equally valued by nurses and healthcare providers, as compared to the growing fetus and/or infant. Long-term positive outcomes such as maternal completion of treatment for substance abuse increased contact with their children and resulted in a higher incidence of custody, and maintenance of recovery is evidenced in relationship-based interventions (Racine et al., 2009).

Nurse as Adversary

Nurses and other healthcare providers are most frequently visualized as adversaries due to the perceived link to consequences, like CPS, as compared to an ally who offers treatment (Roberts & Nuru-Jeter, 2010; Stengel, 2014). Mothers also perceive that caregivers prioritize the well-being of the baby over the mother (Roberts & Nuru-Jeter). Experiences of being spoken about negatively by nurses evoked anger, frustration, and sometimes changes in behavior such as avoidance or passiveness (Cleveland & Bonugli, 2014; Cleveland et al., 2016).

Negative consequences for the mother viewing the nurse or healthcare provider as an adversary are numerous. They are less likely to reach out for help related to other concerns, such as mental health concerns, again citing the fear of alerting CPS (Stengel, 2014). Knowing that the nursery and NICU are environments where nurses and healthcare providers abound, mothers made varying decisions about how to cope with perceived stigma and negative experiences with nurses and healthcare providers. Some mothers visited as much as possible as a way to protect their baby from the perceived risk from the caregivers, despite physical complications and exhaustion, and expressed worry about their baby when they were not able to visit (Cleveland & Bonugli, 2014). Many women strategically planned visitation of their infant to avoid certain caregivers or eliminated their visitation altogether after negative experiences with nurses or caregivers (Cleveland & Bonugli, 2014; Cleveland et al., 2016; Howard, 2015a; Weinberg, 2006).

The stress of an adversarial relationship with the infant's caregiver can extend beyond the bedside. For some mothers, the experience of being negatively labeled, treated poorly by healthcare providers, and/or not feeling welcome in the nursery or NICU was cited as a contributor to relapse (Cleveland et al., 2016). In situations where mothers choose to not visit their infant, they lose the opportunity to bond with the infant. This creates an increased risk for child maltreatment post-discharge (Cleveland & Bonugli, 2014; Stone, 2015).

Gaps in the Literature

The current state of the science surrounding issues of nurses caring for families with a substance-exposed pregnancy is still evolving. From an abstract perspective, the

function of the concept of stigma within the discourse of the national opioid epidemic remains to be fully explored. Discourse is a socially constructed and socially conditioned construct that encompasses the circumstances, objects, perceived truths, social identities, and relationships between individuals and groups of individuals that ultimately creates and gives meaning to their world (Mogashoa, 2014). As the opioid epidemic continues to build, so does the discourse surrounding the phenomenon. Studies which analyze findings through the lens of the larger sociopolitical and professional climate are lacking. A study that investigates the complexity of the problem while considering the current sociopolitical influences is needed.

Current literature suggests that the relationships between healthcare providers and mothers with substance use behaviors are strained due to contrasting perspectives on the experience of care surrounding the infant, but research in maternal-child nursing does not explore the depth of the strained relationship (Cleveland & Bonugli, 2014; Cleveland et al., 2016; Fraser, 2013; Howard, 2015b; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Whittaker et al., 2016). Chang and colleagues' (2016) study of clinical interactions between healthcare providers and patients who use substances found unequal power dynamics. Power dynamics between key players in the caregiving environment such as mother, nurse, social worker, and healthcare providers, have not yet been explored within the maternal-child population. Further exploration between these power hierarchies and the overarching systems of healthcare, criminal justice, and social justice may provide deeper insight into the functionality of stigma and power inequities between mothers with a SEP and the nurses who care for their infants.

The existing evidence also suggests that further research is needed to explore the attitudes of bedside nurses caring for families of infants with a substance-exposed pregnancy. The four studies that examined this phenomenon through a qualitative approach utilized thematic coding of only interview data, limiting the ability to more comprehensively interpret the findings within the current sociopolitical climate (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Shaw et al., 2016). The quantitative and mixed-method studies, used with both bedside nurses and nurse midwives, each utilized attitudinal scales without psychometric validation or control for social desirability bias (Fonti, Davis, & Ferguson, 2016; Jenkins, 2013; Raeside, 2003; Romisher et al., 2018). Social desirability bias is the tendency of participants to respond to questions in a way that aligns with the perceived social norms and expectations of a particular group or culture (van de Mortel, 2008). When questioned about especially sensitive social topics like race or stigma, a person may, even unknowingly, choose to present a version of themselves that is more socially desirable (Legault, Green-Demers, Grant, & Chung, 2007; van de Mortel TF, 2008). Unfortunately, the reported results of these quantitative studies must be interpreted with caution due to the lack of established construct validity for the instrument used and consideration for the effect of social desirability upon the participant's responses. Contradictions between responses suggest that social desirability and/or the quality of survey design may be influencing results and thereby render them less useful in constructing meaningful interventions to improve relationships (Fonti et al., 2016; Jenkins, 2013; Raeside, 2003; Romisher et al., 2018; van de Mortel TF, 2008).

Of the nine studies found in the literature reporting the attitudes of nurses who care for families with a SEP, including advanced practice nurses, only three of those were conducted in the United States. Specific locations of those studies include Washington state (Shaw, 2016), New England (Romisher et al., 2018), and Florida (Maguire et al., 2012). Due to the unique history and nature of the opioid epidemic in the United States, a study is needed to explore the discursive practices in the southeast region of the United States, where disparities in healthcare and legal consequences for mothers who use substances in pregnancy are magnified (Angelotta & Appelbaum, 2017; Hand et al., 2017; S. W. Patrick et al., 2015).

This literature review presents the argument that many mothers with a SEP perceive stigma from some nurses, and that while many nurses report negative attitudes toward mothers with a SEP, they are less likely to claim associated negative behaviors. Experiences described by mothers who observe and receive care from nurses in the NICU suggest that nurses do sometimes exhibit negative behaviors, regardless of whether or not they are aware of such behaviors. Theoretical frameworks of stigma connect the perpetuation of negative attitudes within social networks to stigmatized ideologies, that when mobilized, harness power inequities to maintain the reduced social status of the disadvantaged group. In this situation, nurses may be perpetuating the social narrative of mothers who use substances in pregnancy as a group of women unworthy of social status equal to other mothers. There is a clear need for a study that utilizes a technique which investigates how practice arises from stigmatized ideologies and power relations to

address the functionality of power differentials within the caregiving dynamic of mothers with a SEP and the nurses who care for them set within the current sociopolitical climate.

Studies Framed by the Theory of Social Constructivism

Two studies on this topic follow a social constructionist approach to their research. As previously presented, Radcliffe (2011) examines the reproduction of stigma through the identity creation of women who use substances in pregnancy in the prenatal caregiving environment in the United Kingdom. The social constructivist underpinning serves to frame the study design to investigate the functionality of language in the social world to create meaning rather than simply reflect the meaning that is already present. Radcliffe supports this design by presenting healthcare workers as equally vulnerable, as compared to laypersons, to scapegoating certain patient populations that are considered to be responsible for their condition of illness. The language generated by the antenatal staff serves as a medium to investigate how the identities of mothers who use substances in pregnancy are propagated by ordinary and commonplace knowledge operationalized by staff within a stigma-laden healthcare environment.

Howard (2015b) also frames her study of the social construction of stigma in mothers who use substances in pregnancy with the theory of social constructivism. Geared towards the profession of social work, this interpretive phenomenological study describes the lived experience of mothers who use substances in pregnancy with the goal of presenting an understanding of how these mothers relate to the world and make meaning out of those interactions. In this study, the theory of social construction was employed to increase the understanding of the sociopolitical context of the mothers'

experience, thus providing a more holistic understanding of their experiences. Howard cites social constructivism as an ideal theory with which to investigate stigma as it challenges the idea of a single truth due to the influence of power upon the surrounding discourse, making way for the personal experiences of the mothers in her study to be presented as an important and valid perspective.

Conclusion

There are multiple areas surrounding issues of nurses caring for families after a substance-exposed pregnancy where dichotomies exist and questions remain. Both mothers who use substances in pregnancy and the nurses who care for them desire less stressful interactions, and increased transparency, with improved outcomes for mother, infant, and nurse. Many of the potential barriers elucidated within this review are system-level, rooted in power inequities of knowledge, ability to navigate the health system, and many times economics and class. It is suspected that additional power inequities within the healthcare team and larger healthcare organizations may be impacting the implementation of care and the relationship between the mother and nurse.

Mothers experience both internalized and externalized stigmatization, sometimes simultaneously. Power hierarchies exacerbate stigma and promote feelings of helplessness and loss of self-worth for those not in a position of power. Many mothers cope with the stigmatization by nurses and other healthcare providers by being economical with their engagement of healthcare or complete avoidance of healthcare activities and environments. The exceptional vulnerability of the population of mothers and infants experiencing consequences of SEP warrants additional investigation into the

complexities of power dynamics, stigma, and bias, and how those constructs potentially impact the relationship of the mother and NICU nurse.

The purpose of this study, then, was to illuminate potential power differentials within the caregiving dynamic and expose the interplay between language and sociopolitical discursive practices. Additionally, this study aimed to explore the caregiving dynamic between NICU nurses and mothers with a SEP through an understanding of the social construction of these mothers by the nurses who care for them. The study explored the discursive caregiving practice within the southeast U.S, where maternal opioid use and consequential NAS rates are high, thus exposing caregivers to numerous interactions with mothers who use substances in pregnancy. This investigation of how nursing practice arises from stigmatized ideologies and power relations addresses the functionality of power differentials within the caregiving dynamic of mothers with a SEP and the nurses who care for them set within the current sociopolitical and healthcare climate. A comprehensive continuum of care, including nursing practice impacted by stigmatized ideologies and stigma resistance, was visualized in the results. Results of this study inform future work to improve the caregiving dynamic surrounding infants and mothers with a SEP and their healthcare team through a better understanding of the complex relationship of nurses and mothers and surrounding power influences. This study design provided the opportunity to look deeply at a phenomenon that is currently unfolding, capturing a unique presentation of mothers who are in misalignment with the societal expectations and definitions of good mothering practices

and nurses who practice within a power-laden organizational culture that influences caregiving.

This study generated additional questions that encourage healthcare providers and researchers, administration and leaders, advocates and policy makers to step back and look critically at systems that may be causing more harm than help to disempowered populations and professionals who provide healthcare services to them. It is critical to continue to explore constructs of stigma and power dynamics within the environment of nurses caring for families with a SEP to gain a better understanding of the relationships between mothers and nurses, and how biases and power inequities, if present, influence caregiving practices, and patient outcomes. In turn, a better understanding of the functionality of stigma and power dynamics in this context may be useful in understanding the functionality of stigma and power in other caregiving environments.

CHAPTER III

METHODOLOGY

Language is more than the sum of its parts. Its constitutive properties connect history, time, and people through a social mode of understanding (Boutain, 1999). This chapter outlines the aims of this study and methods. The primary aim was to illuminate potential power differentials within the caregiving dynamic and expose the interplay between language and sociopolitical discursive practices. The secondary aim of this study was to explore the caregiving dynamic between neonatal intensive care unit (NICU) nurses and mothers with a substance-exposed pregnancy (SEP) through an understanding of the socially constructed identities of these mothers by the nurses who care for them. A discussion of the methodology, analysis, and protection of human subjects follows.

Methodology

A qualitative methodology was utilized to address the aims of the study. Due to the increasing frequency of infant admissions related to symptoms of neonatal abstinence (NAS), the NICU offered an ideal setting to explore the caregiving dynamic between NICU nurses and families with a SEP. A better understanding of the social construction of mothers who use substances in pregnancy by nurses who care for their affected infants offered insight into stigmatized care and the influenced patient outcomes.

The social construction of identity is complex and implicit, requiring a critical approach which seeks to understand the complexity and deny simple, dichotomous

descriptions (Wodak, 1999). To understand the social construction of any identity, the environment where the identity is constructed must be explored. Assessment of the interview text within the sociopolitical context connected the participant's language to the current sociopolitical landscape of a national, crisis-level opioid phenomenon (Hargan, 2017). This connection was crucial in understanding operations of power and ideology which function within the caregiving milieu of infants experiencing symptoms of withdrawal following a SEP. Critical incident technique (CIT) was used to collect interview data, with critical discourse analysis (CDA) guiding the comprehensive data analysis. These techniques are described more fully below.

Study Design

Using qualitative design, the caregiving dynamic and power differentials within the caregiving dynamic between NICU nurses and mothers with a SEP were examined through an analysis of language and sociopolitical discursive practices. Registered Nurses who live and work in a NICU in the southeast region of the U.S. were recruited to participate in interviews designed to elicit text describing their experiences of caring for infants and families with a SEP. The southeast region of the U.S. is unique in the incidence and issues surrounding substance use in pregnancy and offered an ideal environment to explore issues of stigma and power inequities. Increasing incidence of NAS in the south Atlantic and southeast-central areas of the US, coupled with more stringent policies surrounding child-welfare statutes and less utilization of medication-assisted treatment for pregnant and parenting women may create a unique power dynamic within caregiving environments in this region (Guttmacher Institute, 2018; Hand et al.,

2017; Patrick et al., 2015). Additionally, nurses who live and practice in the southeast may experience more social dissonance between professional and cultural ideologies due to these differences. Kentucky, Tennessee, Mississippi, and Alabama experience the highest rates of NAS in the U.S. (Patrick et al., 2015). Participants who live in Kentucky, Tennessee, Mississippi, and Alabama, or southeast bordering states (West Virginia, Virginia, North Carolina, South Carolina, Georgia, and/or Florida) were particularly sought for this study to explore the phenomenon from a regional perspective.

Using a CIT approach, an interview guide was used to collect stories, or events, from the participants, then probing questions were utilized to prompt the participant to expand upon the story to create a full picture of the experience, including peripheral characters and storylines. Shadow data (where participants describe their observations of others) were utilized for analysis and described as such in the results. Additional visual and textual data, related to substance use in pregnancy, from social media sources, news outlets, and professional nursing literature was collected and examined through critical discourse analysis, creating a fuller picture of the phenomenon constructed within the discursive environment of American culture related to the opioid crisis.

Sample and Setting

Inclusion and Exclusion Criteria

Inclusion criteria included: Registered nurses who were currently employed in bedside care at any level II or higher NICU in the southeast (provided care for moderately acute neonatal patients), averaging 20 hours per week or more, for at least three years, English fluency, and verbalized experiences that included caring for a variety

of infants and families with a suspected or experienced SEP. Similar inclusion criteria were used in a recent ethnography of NICU culture surrounding NAS nursing care (Nelson, 2016).

Experienced nurses are more likely to have increased exposure to families and infants with a substance-exposed pregnancy and are more apt to provide a rich narrative describing the phenomenon of care. Based on the potential effects of stigma upon nurses' caregiving practices, the medical diagnosis of neonatal abstinence syndrome was not required to meet the inclusion criteria of *caring for infants with a SEP*. The inclusion criteria aimed to capture nurses who provided care to infants and families who were categorized by the nurse as having been exposed to a substance during pregnancy requiring additional observation and/or care after birth.

Exclusion criteria included advanced practice nurses, such as neonatal nurse practitioners, that did not provide bedside care, charge/resource nurses that did not provide routine individual patient care, nurses with less than three years of NICU nursing experience, nurses whose main responsibilities did not include individual patient care such as managers, and nurses who self-reported limited nursing exposure to families with substance-use behaviors. Less experienced nurses were excluded from participation as they were unlikely to have experienced a breadth of clinical cases and may not have been able to speak to the typical experiences, perceptions, and beliefs of a NICU nurse.

Sampling and Recruitment

Review by the Institutional Review Board at the University of North Carolina at Greensboro (Appendix A) determined that the study was exempt from further review.

Purposive and snowball sampling was used to initiate contact with potential participants from the southeast. Recruitment methods began broadly through social media and professional neonatal nursing groups. Recruitment and participant enrollment was concurrent with data collection and preliminary data analysis. Critical incident “events” refers to an individual story presented by a participant. These events served as the unit of analysis (Flanagan, 1954). Event occurrence can exceed or fall short of the number of participants, depending upon the number of events described by each participant (Schluter, Seaton, & Chaboyer, 2008). Therefore, the number of events was not expected to equal the number of participants.

Recruitment ceased with event saturation. Event saturation was demonstrated by similar participant descriptions of incidents, characteristics, and information absent of new or unique information. Approximately 50 events were necessary to allow for variance in amount and quality of data procured from each participant to be sufficient for thorough analysis. (Schluter et al., 2008). Quality of data was assessed for rich descriptions of the event, which were adequate for deep meanings to be drawn out.

A Qualtrics form was created that restated the information sheet and collected contact information from potential participants. The information sheet (Appendix B) described the purpose of the study, inclusion, and exclusion criteria, and protection of participants. All interested participants were directed to the form through a link on the digital flyer (Appendix C) and were instructed to communicate interest and preferred communication methods with related phone number and desired email address. The Principal Investigator (PI) contacted the potential participants to validate their

professional experience of caring for infants and families with a SEP as a NICU nurse and screened them for inclusion and exclusion criteria. If the individual stated continued interest and was selected, the PI made an appointment to conduct the interview.

Modalities for identifying potential participants follow.

Social Media

Recruitment through the social media vehicles of Facebook and Instagram involved publicly available posts containing the flyer (Appendix C), across the length of the study, summarizing the study and desired participant profile posted by the PI. The PI asked her social media friends and followers to also publicly share the post and disseminate the flyers to potential participants. The PI also used purposeful sampling techniques on social media to seek out participants who self-identify as NICU nurses through hashtags and membership to online special interest groups.

Professional Neonatal Nursing Groups

State and regional chapters of the National Association of Neonatal Nurses were contacted, requesting that a recruitment flyer be posted to their website and added to any communications that may be disseminated to their members before September 2019.

Media Visuals and Text

Concurrently with participant recruitment, media visuals and text were collected to provide data describing the current sociopolitical climate. Sampling was approximately concurrent to participant recruitment. Exact time frames were not necessary, as the goal was to extrapolate major media samples related to substance use in pregnancy that were commonly shared and consumed, not identify specific texts that participants may have

consumed. Media such as articles, memes, original posts, engagement commentary, and emoticon interaction were collected. Media that portrayed a variety of opinions, perspectives, and language, including inflammatory verbiage that portrayed or opposed stigmatized views of mothers (Advocates for Pregnant Women, 2013) were sought. For example, a recent news article on Facebook presenting statistics on the incidence of NAS with several thousand emoticon interactions and/or comments, where infants are described as victims or young addicts was a text for analysis. Alternatively, a meme on Instagram with a picture of a crying baby, and a quote about the victimization of infants with a SEP was a media visual for analysis.

Data Collection and Storage Procedures

Interview Text

Data were collected via face-to-face or web-based video interviews. Face-to-face interviews were conducted at a private, quiet location of the participant's choice, other than on the grounds of their workplace. Web-based interviews were conducted using the personal room feature on the University's web-based meeting center (WebEx) on a computer away from the participant's work campus. The PI created a meeting room in the WebEx platform. The participant received an email with the meeting link, and instructions to join the meeting room. The meeting room served as a private space to conduct the interview. Data collection began after the participant reviewed the information sheet and communicated the desire to continue. Each participant chose a pseudonym from a list of available names to be paired with their interview and demographic data.

The participant completed the demographic questionnaire under the chosen pseudonym (Appendix D). Participants were asked to describe personal experiences with substance use related to friends or family. Participants were also asked about their use of social media platforms, news consumption, and primary sources of current professional knowledge to guide the investigation of the healthcare media and greater sociopolitical discourse.

Critical incidents for analysis were collected through interviews with participants using CIT. This technique decreased the potential for loss of significant information through engagement in an interactive interview with the unique advantage to clarify the meaning underlying participants' descriptions, as well as to support the participants in staying focused upon a specific issue (Norman, Redfern, Tomalin, & Oliver, 1992). Primary tenets of CIT maintain that participants' reports of their experience and human behavior are superior to opinions surrounding an experience or behavior. In order for events to be considered "critical" for this study, they must have made a significant contribution to elucidating the experience of nursing care of infants with symptoms of a SEP and their families (Flanagan, 1954). Shadow data from the interview text was considered for analysis if it was relevant to the nursing practice of infants and families with a SEP. Specifically, shadow data refers to interview data where a participant describes their observations and perceptions of other people or the environment.

The interview guide (Appendix E) included questions and prompts that encouraged the participant to describe their nursing practice from multiple perspectives, creating an avenue for the participant to describe parts of their practice that they may not

have initially shared. Interview questions were created through the best practices described by Schluter and colleagues (2008). Participants were asked to describe specific details within their stories and describe examples of both positive and negative actions.

The role of the PI as the interviewer was critical in prompting the participant to go beyond the superficial nature of describing the event. The PI utilized unique probing questions to elicit specific details, antecedents, and outcomes of each story creating a more complete and fuller picture of the experience (Flanagan, 1954). Field notes were taken during the interview. This interview guide was pilot tested by the PI with two NICU nurses and demonstrated success in eliciting the type of narrative data necessary to meet the aims of this study.

Approximately 48 hours prior to the interviews, participants were emailed (Appendix F) and/or called and asked to consider two scenarios involving the care of infants and families with a substance-exposed pregnancy that were memorable for any reason, had personal or professional significance or made a significant impact on them. Advising the study participants of the interview topic and prompting them to consider relevant experiences allowed ample time for the participant to thoughtfully consider their memories. Participants whose interviews were conducted via the web were emailed the demographic questionnaire, at this time. The participant was instructed to return the demographic questionnaire via email prior to the scheduled meeting. Participants who were interviewed face-to-face completed the demographic questionnaire at the time of the interview.

The structure of the interview began with broad questions, asking the participant to share how they came to practice the subspecialty of neonatal nursing. In anticipation of workplace climate concerns, participants were asked how they perceived the climate of the NICU where they practice, “Tell me what it’s like to work in your NICU.” More specific questions related to the significant events of their experiences caring for infants and families with a SEP followed. Stories that demonstrated opposite ends of the continuum were gathered through a technique of asking questions with a similar root, but which demonstrate opposing ends of the experience continuum. For example, “Some people think that caring for infants and families with symptoms of a substance exposed pregnancy would be rewarding. Do you agree with this statement? Can you tell me about a specific personal example that backs up your interpretation of this idea?” Followed with a parallel question describing: “Some people think that caring for infants and families with symptoms of a substance exposed pregnancy would be difficult or challenging.” Interviews lasted approximately 90 minutes.

Face to face interviews were recorded using two digital recorders for redundancy. Web interviews were recorded using WebEx, although only the audio portion was saved and transcribed. The researcher wrote field notes as needed to note the participant’s tone, affect, and body language for both types of interviews. At the conclusion of the interview, permission was sought to contact the participant to clarify any points or ask additional questions. Audio was uploaded to the university’s secure UNCG Box server within 24 hours. The original recordings from face to face interviews were deleted from

the digital recorders. The original recordings from web interviews were deleted from the hard drive.

Recordings were transcribed by a University-approved automated transcription program and checked for completeness and accuracy by the researcher. Demographic surveys and a notebook containing field notes and analysis work were stored in a locked box and a second locked cabinet in the home of the principal investigator. If participants experienced distress during the interview, they were encouraged to take a break or to stop the interview altogether. No participants experienced any continued distress or requests for further assistance.

Media Visuals and Texts

The focus of collecting visual and textual data was to gather a representative sample of the opioid epidemic and substance use in pregnancy-related media. Prior to and throughout interview data collection, Facebook, Instagram, and Twitter social media platforms, and Google were perused for popular visual, textual, and video media pieces. Additionally, the participant was asked to describe their commonly utilized platforms for obtaining professional education and information on current events in the demographic questionnaire. This information steered data collection toward any platforms that participants overwhelmingly consume or engage. Desirable media items contained content specific to health and healthcare surrounding infants and mothers who have experienced a SEP. Examples include professional journal articles, grey literature found in the public media domain, mainstream news articles, video clips, memes, and gifs. Although items with a specific number of observed interactions were not specifically

sought out, items with large numbers of interactions (emoticon engagement and comments) compared to other posts within the platform were gathered for analysis. Items were downloaded and saved to Box for ongoing analysis in tandem with interview data collection. Specific types of gathered media are described below.

Media Visuals and Text Created by and Geared toward NICU Nurses. Prior to and throughout interview data collection, online neonatal nursing special interest social media groups were perused for popular visual, textual, and video media pieces. Particular professional nursing journals, state Board of Nursing journals, or other platforms described online or by participants were also explored for related items. Approximately 10–20 items were anticipated to reach thematic saturation.

Media Visuals and Texts Designed for Greater American Public Consumption. The focus of collecting visual and textual data was to gather a representative sample of substance-use-in-pregnancy-related media that was readily available to the American public at-large through common social media platforms and news sites. Desirable items contained content specific to the opioid epidemic's impact on mothers and outcomes for infants of a SEP and/or related national or state policy.

Subjectivity and Reflexivity

The discursive nature of the qualitative research process necessitates the consideration of the potential influence of individual characteristics of the researcher and the participant upon the subsequent interview. A social constructivist view contends that remaining objective as a human instrument is impossible, but awareness of one's perspective and positionality to the subject matter, participants, and those spoken about is

both reasonable and desirable. The interviews and analysis of data in this study were led by the PI. I conducted a systematic method of bracketing during all stages of the project, including planning, data collection and analysis, and dissemination with the primary goal of acknowledging my own perspective in the service of creating availability to an alternative reality independent of my own (Fischer, 2009).

By describing my demographic profile, background, and relationship with the profession of nursing, maternal/child nursing specialists, and mothers with and without substance use behaviors, I am offering a transparent description of the point of location from which my view of the study and its parts are framed. The process of describing and continuously engaging in mindfulness regarding my vantage point served to prompt me to question, embrace, and/or alter that perspective as the study evolved, as well as share that perspective with readers. Readers may view the manuscripts with my perspective in mind, potentially offering an alternate understanding for them. Alternatively, readers can intentionally view the manuscript with their own perspective revealing additional understandings for themselves. Creating a mechanism for various interpretations of the data post-hoc may contribute to a holistic body of understanding (Fischer, 2009).

I am a white female who is 39 years old and a doctoral student in a School of Nursing. As a product of the rhetoric of the 1980s American War on Drugs culture, my personal perspective is influenced by the national campaigns and educational indoctrination of the perceived moral choice of substance use and characterization of a person who uses substances. I have extensive knowledge of the professional and academic literature on SEPs and stigma of substance use in pregnancy and have

conducted pilot research in the same area. I have practiced maternal-child nursing for almost 20 years and cared for many infants and families who have experienced a SEP. My political and ethical view of substance use has evolved throughout my lifetime, most recently incorporating the views of ideology-influenced discourses and substance use as a chronic disease.

My age, gender, and work experience were similar to many of the nurses I interviewed. Demographic data have remained stable with nurses in the U.S. predominantly female, white, and having an average age of early 40s (Data USA, n.d.; Minority Nurse, 2019). I have not personally experienced a SEP nor have I had friends or family that have experienced a SEP, although I have experienced mothering. I have acknowledged my own experiences of caregiving of infants and families who have experienced a SEP and made every effort to separate those from stories the participants share with me. My previous role within a team of NICU nurses has created my self-identification as a NICU nurse and a relationship with other NICU nurses. I have experienced both positive and negative experiences while caring for infants and families with a SEP and observed both stigmatized and empowering care by health care providers. I have begun to reflect and reconsider personal experiences and observed experiences of colleagues as my perspective evolves, with additional perspectives from the literature, conversations with scholars studying similar phenomena, and review of national policy affecting the phenomenon.

Reflexivity is a continual process with which I engaged at the onset of project planning. Upon writing my bracketed perspective as a memo, I re-engaged with that

memo continuously. A printed copy of the memo hung above my writing area, available to my consciousness when actively engaged with the project. This iterative process of reevaluation guided the formulation of new ideas, thoughts, perspectives, and shifts in understanding of the whole. As the project continued over time, I added thoughts to the memo to further develop the complexity of my perspective. I intentionally critiqued the data through an inquisitive lens that prompted me to question what else might be present in the data using an alternative perspective, in addition to what I saw through my primary perspective.

I reacquainted myself with my perceived positionality and perspective prior to any engagement with the project, including times of data collection, analysis, manuscript writing. Through engagement with the reflexive memo, I reminded myself to maintain awareness of the power inequity in the interview data, where the nurse is able to present their perspective of the caregiving experience, but the mother who is being discussed was not present and able to voice her perspective. With a natural tendency to relate more with the participants (nurse) than the family of an infant with a SEP discussed by the nurses, I continuously considered the literature presenting the voices of mothers in an attempt to include the mother's perspective into the analysis of data.

Finally, my positionality as a researcher afforded me the privilege of a platform to investigate this phenomenon and disseminate the findings to the profession of nursing. My position as a NICU nurse enabled me to speak to the healthcare community with the authority of a practitioner who has engaged in bedside practice caring for infants with symptoms of a SEP and their family. The language I used in the interviews was

intentionally warm and nonabrasive, to encourage rapport with participants as I asked them to disclose stories of experiences where they themselves or their colleagues potentially participated in less than ideal caregiving experiences. Due to my respect for and connection with nurses, dissemination of the results was language to preserve the integrity of the profession and the individuals that make up the profession. The ultimate goal of CDA is to produce social change, therefore dissemination focuses on bringing attention to opportunities to decrease the stigma of mothers who use substances in pregnancy and empower nurses to practice in ways that align with their own sense of beneficence and non-maleficence.

Protection of Human Subjects

The protection of human subjects is imperative to all research. However, there are increased risks to the participant who contributes to qualitative research through storytelling within a small pool of total study participants. Additional risks are present if the study investigates an issue with the potentially negative portrayal of the participant or study population. The investigation of issues surrounding the care of families of infants with a SEP presented such a circumstance, where increased measures were necessary to protect the participant through conventions of confidentiality (Kaiser, 2009). The primary principles of beneficence and non-maleficence were applied, aiming to increase the protection of the participants from negative consequences related to participation in research.

In addition to the standard procedures of applying and complying with IRB practices, principles of procedural ethics were employed to protect the participants of this

study. Utilizing guidelines from Creswell and Creswell (2018) and Kaiser (2009) to protect participants from the specific vulnerabilities inherent to qualitative research, confidentiality was addressed during the planning process and during data collection, data cleaning, and dissemination of results as described below.

If a potential participant accessed the information sheet through the Qualtrics link but did not leave contact information, the PI was unaware of this engagement and did not attempt to locate the individual. Additionally, the PI had no pathway to find these individuals because IP addresses were not collected within this Qualtrics form. The only individuals that were known to the PI were those that submitted contact information through the form.

After the participant verbalized consent, but prior to data collection, the researcher engaged in a discussion with the participant surrounding the confidentiality of all identifying characteristics including city, age, and ethnic background. This discussion included eliciting feedback from the participant to understand their desired level of confidentiality and conversation regarding the intended use of research findings. The participants were informed verbally and in writing, via the information sheet, of the research objectives, means of data collection, and the use of a recording device.

During data cleaning, the interview data were scoured for identifiable people and places to be redacted or replaced with non-identifiable terms, including contextual identifiers within stories. Details of examples or quotations were modified to prevent the identification of participants through deductive disclosure. Careful attention was taken to maintain the integrity of the original dataset. As a final option, data that posed a high risk

of deductive disclosure despite aims to remove or replace the data remained unpublished. Examples of high-risk data included rare demographic data, such as outlying age or years of experience or unique details of a story that might be recognizable to peers. Verbatim transcripts were available to the participants upon request. During dissemination, care was taken to ensure that the resultant publication did not reveal identifying characteristics of any individual or group.

Analysis Technique

CDA was the primary method of data analysis, utilizing Faircloth's approach (Smith, 2007). CDA systematically explored the relationships between discursive practices and social and cultural structures, investigating how practices arise out of ideologies shaped by stigma and relations of power (Bischoping & Gazso, 2016). This method of analysis helped reveal the power dynamics at work within the social and cultural microcosm of the NICU (Bischoping & Gazso, 2016; Mogashoa, 2014).

CDA required three levels of data collection and analysis. The text was analyzed at three levels of practice: sociopolitical, discursive, and textual levels (Figure 1). Each practice level was examined with alternate texts, with a final compilation of all levels resulting in this author's perception of the meaning of the participant's language, as it functions in the current social and historical context (McGregor, 2003). The sociopolitical environment of the American experience of the opioid epidemic and the healthcare environment was explored through the analysis of media pieces related to SEPs and began prior to the onset of interview data collection and continued throughout the entire data collection process in an iterative mode. Resultant themes of the

sociopolitical climate were used as a lens in which to view the interview data. The discursive practice investigated where and how the text functioned within this specific sociopolitical climate, bridging the interview text to the sociopolitical climate. The textual level of analysis explored the verbiage of the interview text for chosen vocabulary and style to create meaning. Thematic analysis was utilized to uncover general themes that were relevant to the holistic phenomenon.

Data collection was an iterative process, with feedback loops utilized to revisit data and field notes as the analysis progresses. Reflexive memos were separate from analysis memos and revisited as new ideas or breakthroughs emerged. The process began with data collection and analysis of media pieces. Analysis memos were created for each interview and combined with field notes to organize my thoughts and ideas specific to the data. During data collection of media pieces, interviews began as participants were available. After completion of each interview, transcription of the interview text ensued, creating a text for analysis. The interview texts were initially read as a whole for a broad understanding of the participant's interview, The initial read was followed by the written narration of episode profiles where each interview was summarized, and my immediate thoughts surrounding tone and affect were noted. The interview text was read again for a deeper understanding, highlighting power quotes and narrating their significance and relationship to media pieces. Each interview was then restoried, where the described critical events were cut and pasted together to present a chronological view of the events and served as a double check for counting the number of obtained critical events. This process was completed in batches of three to four interviews, concluding with memoing

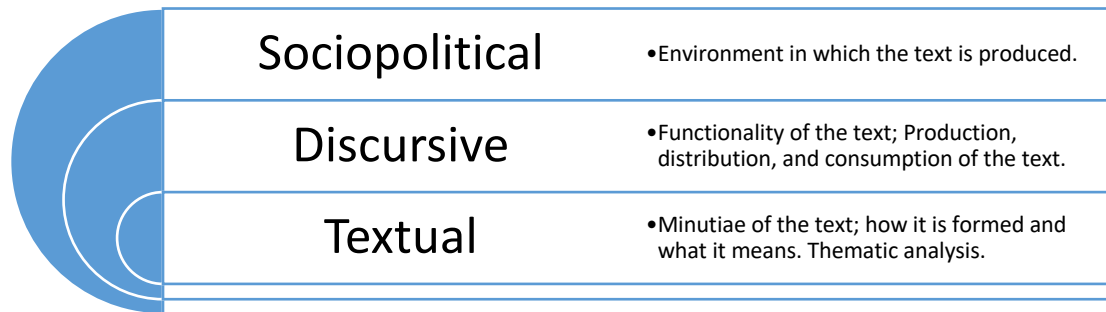
patterns noted across the data within that batch of interviews, and again across all interviews as a comprehensive data set. After all interviews were analyzed with the techniques described, additional memos were written to explore patterns across the data more deeply. As interpretative ideas were generated, I returned to the data to document support.

Reflexive memos were updated as data analysis continued, and ideas and thoughts shifted. This process of analysis of new data, reflexivity, integration of sociopolitical analysis with interview text analysis, and integration of new data into the analysis of data already explored was ongoing and flexible to meet the needs of the project as it unfolded. Dissertation committee members intermittently provided feedback on the memos, providing the opportunity to reconsider the analysis and memo those thoughts.

After analysis of each level of social construction, the layers were reintegrated to create a tapestry of results designed to present a comprehensive and critically explored social issue. The ultimate goal of understanding how the discourse of nursing practice surrounding infants and families with a SEP was underpinned by ideology positioned the researcher to argue for social change during the dissemination stage (Bischoping & Gazso, 2016).

Figure 1

Analysis: Levels of Practice



Sociopolitical Practice

The sociopolitical practice surrounding the opioid crisis phenomenon at the currently perceived “height” of this epidemic as a “macro” level practice was explored through media visuals and texts designed for greater American public consumption. Because nurses are also a part of healthcare and nursing culture, media pieces created by and/or geared towards nurses who care for newborns were also analyzed. For example, current (within the last five years) clinical and research articles, social media pieces, and grey literature (from State Boards of Nursing and other professional outlets) related to family-centered care, relational care, patient-satisfaction metrics, and mothers who use substances in pregnancy were analyzed to capture the specific healthcare culture in which care for infants and families with a SEP occurs.

Media pieces which contain content related to mothers who use substances in pregnancy were deconstructed to identify power hierarchies which are stated and implied through the chosen verbiage, connotation, and tone. Each media piece was initially read or consumed in an uncritical manner, followed by subsequent readings/consumption with

a critical, resistant view (McGregor, 2003). The overall tone was explored through the initial reading or viewing and reconsidered with the critical view. Literal and implied meanings were considered during a compare-and-contrast exercise, given the context and tone interpreted by the PI. Alternative interpretations, power differentials, and stigmatized characterizations were sought through the scrutinization of assumptions, relevant voices that were absent, and ideologies perpetuated within the piece. This was an iterative process, captured through a memoing process, with results reconsidered with additional incoming data.

Discursive Practice

The discursive level of analysis examined how the text was created, spoken or distributed, and heard and/or consumed (Smith, 2007). The text and media pieces were deconstructed to visualize and organize the speakers and listeners and who or what was being discussed. The positionality of the speakers and listeners were examined through an exploration of their role and influence upon the dynamic. The receipt of the media pieces by the consumers was examined through a review of the online comments and interactions for verbiage and tone (Bischoping & Gazso, 2016). Upon completion of deconstruction, the data were organized by themes, commonalities, and differences. Memoing activities documented the findings. All texts were examined for insight into dominant, contradictory, and/or silent discourses functioning within the caregiving dynamic (Wilson, 2001).

Textual Level of Practice

The textual level of analysis examines the text as a specific language and style where it produces unique meaning. The textual practice was explored through the analysis of the interview text gathered from NICU nurses. Best practices for CDA in nursing research offered options for the level of detail the PI aimed to explore (Smith, 2007). This study focused on thematic analysis as compared to a linguistics approach, although word choices were explored further if analysis pointed to specific relevance. For example, when nurses used a term such as “unsafe” that provokes a certain emotion among nurses, that term/label was explored with a linguistic approach. However, the entire data set was not approached with a linguistic approach. Specifically, this study utilized content and thematic level analysis to gain enlightenment of the social construction of mothers who use substances in pregnancy among nurses who care for the infant and family following a SEP, potential power differentials within the caregiving dynamic, and the interplay between language and sociopolitical discursive practices.

Modes of Analysis

Deconstruction, a key strategy in CDA, was utilized to speak to the primary aim of the study: to illuminate potential power differentials within the caregiving dynamic and exposing the interplay between language and sociopolitical discursive practices. This analysis technique deconstructed how power and ideologies are implicated in the creation and feedback loops of the discourse of nursing practice surrounding infants with symptoms of a SEP and their families. This strategy offered the opportunity to reveal the operationalization of oppressive discourses, the legitimization of power, the perpetuation

of ideologies, and inequalities and stigmas which are constructed and maintained (Bischoping & Gazso, 2016).

The technique of *recontextualization* was utilized to speak to the secondary aim of the study: exploring the caregiving dynamic between neonatal intensive care unit (NICU) nurses and mothers with a substance-exposed pregnancy (SEP) through an understanding of the social construction of these mothers by the nurses who care for them. This technique offered the investigator the opportunity to understand how discourses socially construct identities (Bischoping & Gazso, 2016; Fairclough, 2003). Through the analysis of data, the PI sought to view the recontextualization of the socially constructed (by NICU nurses) identity of a mother who uses substances in pregnancy into the alternative social event of the unique present-day opioid crisis. The PI looked for elements of the identity that were present versus absent in the data, the degree of abstraction versus generalization used to form the mother's identity, and what elements were added, excluded or provided explanations or legitimations from the described identity of the mother (Fairclough).

Memoing and diagramming were the primary methods of organizing the analysis. Although most analysis was completed through a variety of memoing techniques, previously described, diagramming was utilized to illustrate the deconstruction of data when deemed helpful by the PI. Data were deconstructed to visually present/diagram the speakers, those spoken about, absent voices, power differentials and hierarchies, assumptions from the speakers/writers, and other salient information for each piece of

data. Field notes from the interviews and the PI's reflexivity notes were integrated into the analysis during the organization of data.

Verification of Data

Reliability and validity for CDA cannot be approached in the customary manner for traditional qualitative methods, as these techniques are misaligned with a social constructivist framework (Stevenson, 2004). However, basic techniques to convey rigor of the process were employed. Clarification of researcher bias was acknowledged with a reflexive articulation of the PI's baseline understanding of the phenomenon through the evolution of thoughts and ideas throughout the project. This reflexive practice was incorporated into the analysis. Data collection and analysis techniques were reported in detail to provide a transparent account of the methods utilized in this study (Creswell & Creswell, 2018). Credibility was sought through prolonged engagement in the field, triangulation, peer debriefing, and negative case analysis. Transferability and external validity were increased through the narration of rich, thick description of the participants' stories (Lincoln & Guba, 1986).

Prolonged engagement in the field was achieved through time spent with pilot research work, preparation for this project, and time spent in the collection of data and analysis. Triangulation was conducted with pilot research data, collected interview data, observations during data collection, and media document analysis. The researcher consulted with the dissertation committee as peer examiners to brainstorm, identify alternate perspectives, and verify the path of the project. Additionally, after the initial analysis using the batch technique, power quotes were reanalyzed using the same

techniques but as a comprehensive data set. The two analyses were compared for similarities and differences and were found to be highly similar.

Techniques that improved rigor specific to CDA are as follows. The exploration of deviant cases was a primary method to assess the trustworthiness of findings (Bischooping & Gazo, 2016; Stevenson, 2004). Deviant cases, stories that contradicted the primary patterns of emerging evidence, were also sought in order to refine the description of the phenomenon and strengthen the description of the typical case (Morse, 2015). Rigor also included consideration of the overall problem under investigation, related to how the current social order needs the problem to support current ideologies (Bischooping & Gazo, 2016). This question was explored through the sociopolitical analysis.

Reliability was increased through a comprehensive description of the focus of the study, the researcher's role, the participant's role and basis for their selection, and the context from which the data was obtained. The analysis of sociopolitical media included the investigation of alternative interpretations of the media by various consumers through review of comments and interactions. This analysis provided evidence to support the perception of media by the participants, as compared to the singular perception of the PI (Bischooping & Gazo, 2016).

Definition of Terms

Operational definitions for this study include:

- SEP-substance-exposed pregnancy: a pregnancy where the infant demonstrates symptoms of withdrawal after birth such as irritability, feeding difficulty, or

neurological impairments. The withdrawal symptoms lead to suspicion of prenatal exposure to potentially harmful substances, such as opiates.

- Family of an infant with a SEP: biological mother and/or father of the infant.
- NICU-Neonatal intensive care unit: a nursing unit where newborns receive specialized care beyond the scope of normal newborn nursery.
- Nurse: Registered nurse practicing in direct patient care

Conclusion

This chapter summarizes the salient points of the study design, including data collection, analysis, and rigor. The unique properties of CDA are outlined, with methods addressed to speak to the underlying social constructivist framework. CDA offered a fusion of theory and technique to study complex social problems with the potential to make a case for social change.

CHAPTER IV
MANUSCRIPT ONE

Title: The Effects of Healthcare Culture on the Caregiving Experiences of NICU Nurses Surrounding Substance-Exposed Pregnancies

Submitted to: *Journal of Obstetric, Gynecologic, and Neonatal Nursing*

Objective: To investigate the impact of healthcare culture on NICU nurses caring for infants and families with a SEP.

Design: A qualitative study design using interviews with NICU nurses who care for infants and families with a SEP.

Setting: We recruited NICU RNs who lived and worked in the southeast region of the U.S.

Participants: The sample (n=9) was all female, with two-thirds having obtained a BSN or higher education, and a mean of approximately 10 years NICU nursing experience.

Methods: Using Critical Incident Technique, participants were asked to share their most memorable experience caring for infants and families with a SEP. Critical discourse analysis of interview data with NICU nurses

Results: Tensions exist at the bedside between nurses, mothers, and providers, surrounded by healthcare culture that highly values patient satisfaction. Nurses experience high pressure to meet the needs of the infant and family with limited resources within the healthcare system.

Conclusion: Nursing workload is increased by mental and emotional work which is exacerbated by a healthcare environment of inequitable power dynamics. As a part of the Quadruple Aim to meet the need for high-value care, strategies to improve the experience of care by nurses are necessary.

Keywords: substance-exposed pregnancy, NICU nurse, discourse, patient-satisfaction, workload, Quadruple Aim

Précis: The NICU nurse's workload in caring for families with a SEP includes physical, mental, and emotional demands, exacerbated by healthcare environments with inequitable power dynamics.

Callout 1: A culture of patient satisfaction is predominant in the current healthcare climate where high satisfaction metrics are viewed as indicators of unit success. Line 100

Callout 2: Changes in assignment due to parent complaints was cited as the primary example of the valuation of parent satisfaction scores being counterfeited as family-centered care. Line 314

Callout 3: Nurses describe reduced ability to maintain their professional obligations of patient advocacy and beneficence while meeting their own emotional and mental health needs in this healthcare culture. Line 334

Background and Significance

Chronic maternal opioid use in pregnancy has quadrupled during 1999-2014, from 1.5 per 1,000 delivery hospitalizations to 6.5, with consequential Neonatal Abstinence Syndrome (NAS) increasing five-fold between 2004 to 2014 and continuing to rise (Haight, 2018; Tolia et al., 2015). The southern region (Hand et al., 2017) and

rural areas (Kozhimannil et al., 2019) of the United States (US) have experienced disparate increases in maternal opioid use and resultant NAS. These infants average 19 days in neonatal intensive care units (NICU) (Tolia et al., 2015), as compared to slightly over three days for non-opioid exposed infants (Patrick et al., 2012).

Family-centered care is a primary tenet in neonatal healthcare, valuing parents as integral members of the healthcare team (Gooding et al., 2011; Ramezani et al., 2014). Nurses report more challenges to implementing principles of family-centered care with infants from a substance-exposed pregnancy (SEP) where families are reported as mostly absent and difficult to work with when present (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Whittaker et al., 2016). In a study examining workload, nurses caring for at least one infant experiencing withdrawal in their assignment experienced a significantly higher workload than other nurses. In addition to higher infant acuity, the families required more time from the nurse to address complex social needs (Smith et al., 2018).

A culture of patient satisfaction is predominant in the current healthcare climate where high satisfaction metrics are viewed as indicators of unit success. Nursing plays a primary role in many of the constructs measured, such as communication and consistency (Flagg, 2015). In the NICU, parent satisfaction is measured as a proxy for patient satisfaction due to the developmental limitations of neonates. However, this creates a complication since the direct recipients of care are unable to report their satisfaction (Coleman et al., 2020; Sikka et al., 2015). Differences might exist between the perceptions of care between parents and neonates, if infants were able to report their

experience. In the situation of conflicting goals, NICU nurses report that their primary role is to advocate and implement care that best meets the needs of the infant (Fraser et al., 2007; Maguire et al., 2012).

This healthcare culture impacts job satisfaction in the NICU, where poor teamwork and safety climates, perceptions of management, job satisfaction, and working conditions were all significantly related to burnout (Profit et al., 2014). The complexity of parent-satisfaction metrics and job satisfaction of nurses related to meeting families' needs in the NICU has not been studied. The Institute for Healthcare Improvement's Quadruple Aim provides a framework for the delivery of high value care in the United States, including the element of healthcare provider satisfaction (Sikka et al., 2015). Improvement in the provider's experience of caregiving was identified as necessary to achieve high value care. This study addresses the impact of healthcare culture on the NICU nurse caring for infants and families with a SEP.

Methods

Study Design

The study was found to be exempt by the Institutional Review Board of the University with which the PI is affiliated. NICU Registered Nurses who lived and worked in the southeast region of the U.S. (Kentucky, West Virginia, Virginia, Tennessee, North Carolina, South Carolina, Georgia, Mississippi, Alabama, and/or Florida) were recruited to participate in interviews to describe their experiences of caring for infants and families with a SEP. Additional inclusion criteria included current employment at a level II or

higher NICU averaging at least 20 hours/week for at least three years, English-speaking, and having cared for infants and families with an SEP.

Purposive and snowball sampling were used to recruit nurses through social media and professional groups. Interested participants provided their contact information, then the principal investigator (PI) contacted them to confirm that inclusion criteria were met and to obtain informed consent. Recruitment and participant enrollment were concurrent with preliminary analysis and ceased upon event saturation. Study participants chose a pseudonym, completed a demographics questionnaire and met with the PI for a recorded interview. Eight participants chose to be interviewed through a secure web portal and one participant was interviewed in person. Interviews lasted approximately 90 minutes.

Critical incident approach (Schluter et al., 2008) was used to collect memorable and impactful stories, or events, with follow-up questions prompting the participant to create a full picture of the experience, including peripheral characters and storylines. Participants described their nursing practice from multiple perspectives, using a semi-structured interview guide. Interview questions were created through the best practices described by Schluter and colleagues (2008). The PI utilized unique probing questions to elicit specific details, antecedents, and outcomes of each story creating a more complete and fuller picture of the experience (Flanagan, 1954). Participants were able to take a break or stop the interview at any time. Interviews were auto transcribed through Temi ©. The PI verified the accuracy of the transcription and documented tone of voice changes, laughter, crying, and other notable features of the interview. Identifying information was

removed from the transcript. Approximately 50 events were necessary for thorough analysis (Schluter et al., 2008); 51 events were obtained. Events were defined as individual stories from the participants related to caregiving in the NICU.

Analysis

Utilizing Faircloth's approach (Smith, 2007), Critical Discourse Analysis (CDA) was the primary method of analysis to systematically explore how nurse's knowledge about mothers with a SEP is produced within the social structure of the NICU, noting power dynamics within the caregiving environment (Bischoping & Gazso, 2016; Mogashoa, 2014). Data were analyzed for the presence of sociopolitical narratives, social narratives within the healthcare system, and the participant's word choices and style of storytelling to determine specific relevance. The events were examined both holistically and in a deconstructed form to evaluate how the descriptions created meaning and added to the participant's body of knowledge. Each event was also examined to determine the nurse's role and influence upon that event, illuminating the functionality of power within the event. The interview texts were examined collectively for insight into dominant and contradictory narratives, as well relevant narratives that were absent. Thematic analysis was utilized to uncover general themes among the participants' stories. The analysis was guided by the iterative process of exploring an overview of multiple pieces of data and deep exploration of small pieces of data, with ongoing written reflection. All authors participated in the analysis and came to agreement. The data below highlight the influence of healthcare culture on the participants' reflections of critical experiences caring for infants and families with a SEP in the NICU.

Results

The sample was comprised of all females, with at least 5 years of general nursing and 3 years of NICU nursing experience. Two-thirds of the sample held a BSN or higher and worked at NICUs representative of all levels of patient acuity. Most of the participants resided and practiced in North Carolina. Fifty-one events were collected across 9 participants over 5 weeks. Results are presented as a narrative storyline of the collective description of nurse's caregiving experiences of infants and mothers with a SEP, with quotations from the participants as examples. This method of description is in contrast to the categorical collection of themes common with other qualitative methods.

The Work Environment as Context

Although the nurse is the central character in this study, it was important to gain understanding of her positionality within the overall healthcare system and NICU care team in order to gain insight as to who held power and how power functioned. Interview questions about the nurse's perspective on the work environment and surrounding systems provided insight into the nurse's positionality within the healthcare system. To understand the environment where the nurse's experiences occurred, they were asked "What is it like to work in your hospital and NICU?" Most participants initially described the general culture of their healthcare organization as positive or neutral, with good teamwork among bedside nurses. However, many participants quickly turned toward concerns of loss of autonomy, poor communication, and nursing unit management that is only superficially involved with the realities of bedside nursing care. One participant was surprised at the vulnerability she experienced as a new nurse in the NICU, viewing

herself as a potential victim, “I didn’t realize I was thrown to the sharks.” Others expressed their concern around shifting healthcare culture.

In addition to kind of emotional turmoil we can experience is the direction that healthcare is going into more of a customer service aspect. I feel like some of the things that we're being told to do are not in the interest of patient safety and are in the interest of patient satisfaction and good scores rather than keeping them safe and providing them good care.

Although participants sounded frustrated and described a sense of powerlessness, they generally accepted this culture as the norm, “Unfortunately, that’s just the way it is.” These descriptions of workplace environment set a solemn stage for the nurses’ stories of caregiving of infants and families with a SEP who spent time in the NICU.

Participants describe a system where medical providers such as Neonatologists, Neonatal Nurse Practitioners, and Physician Assistants work closely with the bedside nurses as a part of the NICU team. The provider’s primary role is to plan overall care for the infant with short- and long-term goals with the rest of the team. Nurses typically have more time with infants and their families at the bedside while assessing, implementing the plan of care, providing most of the daily care for the infant, and teaching families. Providers perform their own daily assessments but rely on nurses for additional assessment information and status changes observed at waking and feeding times. While care planning is a collaborative practice, nurses are ultimately dependent upon medical providers for treatment orders, specifically medication additions and changes.

Nurses and Mothers with a SEP: Tension at the Bedside

Descriptions of caregiving consistently illustrate the intense mental, physical, and emotional workload of nursing care for infants and families following a SEP. Nurses describe the characteristic high-pitched crying and inconsolability of the infants resulting in the inability to meet the professional obligation of beneficence.

It's hard to care for a baby when there's, when you're doing everything that you possibly can do for them and it's still not enough. Like they're still suffering and they're still screaming, and they can't eat, and they can't rest, and they just can't, they can't develop normally because they're so neurologically agitated by this withdrawal that you just feel helpless.

Nurses report that this caregiving experience is unique to infants with a SEP, requiring a different approach to family-centered care and more mental and emotional energy expenditure. If parents are absent, nurses sometimes step into a pseudo-surrogate mother role. Although potentially rewarding, the emotional attachment and resultant vulnerability extends beyond typical professional obligations. One participant describes how an experience of an especially close bond with an infant affected her when she feared for the infant's safety.

And that day I realized no one had ever held him, in his whole life because she [mother] was in jail. ... We didn't have any good contacts. It was just a bad situation for this child. Um, so I picked him up as a primary when I realized that and made it so he was held by volunteers all the time. I would get him out and hold him, like we just kind of like really bonded. And um (voice cracks), it came time for his discharge.... Like, she wouldn't feed him for us to watch. She wouldn't give him his meds...her eyes were glassy, couldn't communicate, it was bad... Like she had custody and she was allowed to take the baby home and it was just very traumatic for all of us, for all of us at the hospital. Um, it was, that was probably the worst day I've had as a nurse.

Even when families are present, nurses consistently described frustration, especially when implementing a low-stimulation protocol for the infant.

They'll [parents] come in and you've just finally gotten this baby to sleep and then they want to hold them and talk to them and take pictures of them and play with them and then they stay for 30 minutes and then they leave and now you have a crying baby again. So that causes some tension.

The additional workload and stress that these situations created is described by nurses as a major point of contention and resentment. Recurring negative and traumatic experiences led nurses to dread, and avoid when possible, caring for other infants and families with a SEP. The participant continues, "Sometimes ...you just don't even want to deal with that patient because you don't want to have to deal with the family." Although nurses did report some positive and rewarding experiences of caring for these families, they were described as memorable because they were uncommon.

Building rapport and relationships with mothers was helpful in overcoming the initial caution they felt when meeting a mother with a SEP. Nurses described a manageable assignment as critical as it allowed them to spend quality time with the mother, which space to gain rapport and authentically connect. One participant was surprised that she was able to build trust with a mother a post-partum nurse had described as difficult, "Sometimes my initial gut reaction is to be judgmental and angry at the mom for what she did to the baby. And then I get an occurrence like this." Further describing the caregiving experience, she added that her assignment as light on that particular day, allowing her extra time to spend with the family, where the postpartum nurse's assignment did not.

They're supposed to be three couplets to a nurse and are sometimes four couplets to a nurse. Six to eight patients is a lot, especially postpartum. So I think it's very easy for them to be lost in the fray of things.

In this situation, the nurse's potential availability to engage with the mother and build trust was directly related to the structural and environmental influences that determine staffing ratios.

Nurses and Providers: Hierarchy of Being Heard and Trusted

The role of the nurse is to advocate for the patient by communicating the subtle changes of assessment findings to the provider, with the expectation that the provider will modify the plan of care accordingly to improve the patient's outcome. Some nurses reported feeling heard by providers when the infant's status had changed, but many nurses reported difficulty in getting the provider's attention or most frequently, having their communication overlooked or disregarded. One nurse described toggling between providers who she saw as humanized individuals and others that represented the power of their rank, "I can just speak to them as if they're another person, not I'm a nurse and they're a doctor. Um, with the other ones it's more of a hierarchy... So I have to adjust accordingly, and it can be tiring." She goes on to describe an experience when she notified the provider for increasing withdrawal scores in a baby with NAS, and implied that she had requested an order for medication, "I felt like I wasn't being taken seriously by a provider that's at the bedside for 10 minutes during rounds and has no idea how this baby truly acts." Her frustration arose from the inverse relationship between the amount of time she had to assess and monitor the baby compared to her ability to affect the plan of care, specifically related to medications.

Some nurses suspected that mistrust was the root cause of providers' dismissal of the nurse's report. One participant described a unit culture where the assessment and recommendation of nurses was not valued, based on a history of a few nurses making poor judgements that resulted in policy changes that reduced the autonomy of nurses. As a result, she described, "So I definitely feel like my knowledge and my skills are not valued. I feel like they're not trusted. I feel like the providers in general don't trust nursing to make sound decisions." The resultant feeling of powerlessness in similar circumstances was a dominant narrative among participants. Another participant described the outcome when she was denied the requested medication order to treat NAS symptoms,

I guess like they don't believe the symptoms they're showing are withdrawal so they're not treating and then you end up dealing with this baby who's in pain and showing you obvious withdrawal scores, but there's nothing you can do about it.

Nurses perceived that the power differential negatively impacted the team as a whole and ultimately impacted patient care.

There's been a disparity and I think it's causing trust issues between nursing and providers because nursing thinks that providers need to be doing more, providers think that nursing is not implementing the protocol properly, so they're less inclined to believe the scores. So, I think that there's a disconnect.

One participant believed that the power differential influences the mothers' view of her abilities as a nurse.

Because I feel like I'm not as confident. I'm pretty sure, or they probably look at me and like I'm not as confident because I don't understand the meds, or I'm not

givin' the correct dosage that they feel that the baby needs. I just feel like they're looking at me a little less.

Nurse managers are perceived by bedside nurses as ineffective advocates. Nurses recognized the elevated role of the unit manager, but also perceived the limits of power within the role due to the hierarchy of power within the unit, "I would say they hear us and they understand our frustration from the nursing aspect, but they have no ability to, um, I would say touch the higher level providers." In this circumstance, even the highest-ranking nurses on the unit maintained less authority and power than providers.

Nurses and Patient-Satisfaction Metrics: Caregiving in a Business Model

Nurses described the overarching culture of the NICU as parent-centered because healthcare leadership values patient satisfaction scores, which are actually completed by the parent. "It's a business...Even though the patient is the baby, the parents fill out the surveys. So parent satisfaction is what drives the unit and it's not parent satisfaction based on what kind of care their child was given." Nurses described potential tensions between nursing care that improves infant outcomes and care that keeps families happy, specifically a low-stimulation protocol. Parent satisfaction culture was perceived as very different from traditional family-centered care yet reported that unit management viewed them interchangeably. A nurse described how striving for high parent satisfaction scores influenced her nursing care, "My place is kind of really big with patient satisfaction scores. So it's one of those things where whatever the mom says, we agree with (laughs)."

In some instances, the most direct consequence of parent dissatisfaction was the removal of the nurse from their assignment after a parent complained, "It's something

that's learned as you meet that confrontational parent for the first time and get removed from your assignment and put on a list where you're blackballed from taking care of the baby anymore.” It was not uncommon for the nurse’s entire patient group to be changed to accommodate this request. Nurses frequently viewed this as a punishment, describing feelings of sadness and frustration. Some nurses described anger, perceiving unfair retribution for following principles of evidenced-based care and upholding professional behaviors of patient advocacy; the most common situation of conflict with the family after encouraging a low-stimulation protocol. This particular situation was cited as the primary example of the valuation of parent satisfaction scores being counterfeited as family-centered care.

“Backed into a Corner”: What’s a Nurse to Do?

The complexity of the power dynamic, where the nurse is unable to calm the infant and parents are distressed, is described by one participant as,

I think that kind of puts the nurse backed into a corner. And then you have providers that aren't willing to maybe give you an extra dose of medication that they would need to calm down. That makes it really difficult.

The perception of being caught between the medical provider and the infant’s family, without the necessary tools to calm and comfort the infant presented a lose-lose situation for the nurse,

Having the parents tell you, "Well, you're not doing enough, or what are you doing?" Or sometimes you have parents that don't want their babies swaddled... Um, having judgment from both ends or not having support from the providers and having judgments from the parents.

It is this complicated caregiving dynamic in an environment dominated by parent-satisfaction metrics where the nurse had limited autonomy and resources to meet the needs of all the infants in her assignment, limited power to maintain a low-stimulation protocol, and ineffective advocates that many nurses found themselves exhausted and distraught.

Then you feel like there a lot of times if they're not happy then they'll immediately go and complain to management and then they're just going to tell you to go ahead and let them hold them or they're going to do whatever it takes to make the parent happy...So you just kind of give up. It's like, well, what's the point? They're just going to get their way anyway.

Nurses described reduced ability to maintain their professional obligations of patient advocacy and beneficence while meeting their own emotional and mental health needs in this culture. While this experience is not isolated to caring for infants and families with a SEP, nurses described that the experience is heightened due to the unique challenges of these families.

Nurses are aware of the power differential between themselves and providers and described how it affects their experience of caregiving over time. Several participants cited the loss of autonomy and their position in the hierarchy of power as primary causes of job dissatisfaction, leading them to enter graduate programs. Other nurses described the desire to leave inpatient care of NICU due to negatively perceived culture of patient satisfaction, "I actually looked for jobs outside of the unit because I got burnt out from family centered care because it's not really family centered care." In this sample, only a

few nurses described themselves as content in their current position of bedside nursing in the NICU.

Discussion

As the opioid epidemic continues to impact women of childbearing age, NICUs experience ongoing admissions of infants requiring treatment for symptoms of SEPs. Much of the existent literature focuses on medical best practices in caring for infants. Other studies exploring the attitudes of nurses and other healthcare team members providing care for infants and families following a SEP report negative attitudes related to feelings of resentment, frustration, and anger (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018). This study aimed to dive deeper into the experience of the nurse providing care for infants and families with a SEP to better understand the complexities of the caregiving experience and point toward potential meaningful interventions at the systems level.

Nursing workload was uniquely described in this study, extending beyond the increased workload previously described by Smith and colleagues (2018) related to acuity and complex family situations. This study presents an additional description of mental and emotional workload, where nurses are sometimes unable to provide evidence-based nursing care due to fear of making parents angry and affecting parent satisfaction scores. The nurse struggles to meet the needs of the infant and family within a system with limited tools and resources such as medication to treat symptoms, time and staff to hold the infant, and time and availability to build a trusting relationship with the family.

It is possible that providers and nurses view and interpret infant withdrawal behaviors as differing levels of distress, resulting in differing perspectives on the plan of care.

Additionally, the nurse is held accountable for the experience of the infant through the proxy of the parent. Their experiences may be vastly different, but satisfaction is only measured from the parental perspective. In the current healthcare culture where patient satisfaction is highly valued, the nurse may be significantly impacted by the experience of someone who is not “really” the patient. To our knowledge, nurses’ perception and experience of patient satisfaction by proxy has not been investigated.

Although power dynamics were not explicitly investigated, Profit and colleagues (2014) found that negative climate of the NICU, reduced job satisfaction, negative perceptions of management, and poor working conditions were all significantly related to increased burnout among NICU staff. Those findings support those in this study where reports of job dissatisfaction and intent to leave bedside nursing in the NICU were related to loss of autonomy and job dissatisfaction. Some nurses understood the reasoning of some unit policy makers who streamlined protocols to minimize the damage caused by some nurses’ poor decision making. However, we note that even with an understanding of rationale, a wedge between nurses and providers was created. If nurses are not viewed as trustworthy enough to make sound recommendations and decisions within their scope of practice, they are in fact demoted to task-oriented deliverers of care requiring specific orders for everything, requiring them to be “managed” by members of the care team who are perceived as more trustworthy and capable. Nursing and medicine, therefore, are

sometimes not collaborating in the care for these complex families but are instead working in parallel or even antagonistically. Interestingly, Profit's (2014) study found that physicians reported significantly less burnout and perceived themselves as more resilient compared to RNs. It is possible that the physician's resilience is related to a power dynamic which is more favorable to providers compared to bedside nurses. This argument is further supported by Traynor's (2019) narrative of the oppression and farce of autonomy within nursing, as it points to the business of healthcare as the root cause for the frustration nurses experience in providing care.

The results of this study are more than the description of workload and the nurse's position within the care team. These results also capture issues of time and resource allocation as structural components that impact the quality of care provided to families and serve as either a support or barrier to family-centered care. This is a story of nurses who value what they offer to the care team and to families for whom they care and want to be appreciated for their unique contribution and value. Nurses want to be seen yet are made invisible by the business of healthcare. The power dynamic positions nurses in the middle of the care team, with the specifics of their power fluctuating shift by shift, environment to environment, circumscribed by other members of the care team and the organization where they practice. Ultimately, these nurses presented an experience where only they can understand their worth to the benefit of the team, but their positionality is defined by team members and parents who do not understand what nursing is or are so far removed from bedside nursing that they do not relate to its reality.

Implications for Practice

The Quadruple Aim is intended to improve patient outcomes through caring for the provider by providing pathways for accomplishment and a sense of importance in daily work (Sikka et al., 2015). Addressing the experience of NICU nurses when providing care to vulnerable populations is imperative to the creation of high value care where the nurse and family work together intimately to meet the needs of the infant. Creating systems that endorse compassionate and empathetic care to families is not realistic without the same provision of care and empathy to caregivers. The recommendations described here stem from the acknowledgement that bedside nurses are the primary deliverers of care in the NICU and should be more directly involved in planning and revising models of care. The concerns described by NICU nurses in this study speak to the need to improve the experience of providing care by increasing autonomy, improving trust and communication with providers, and revision of patient satisfaction evaluations.

First and foremost, nurses, unit managers, and other healthcare team members need to recognize vulnerability of nurses within the power dynamic. This may create an uncomfortable conversation in some environments, but acknowledgement of a power imbalance is critical to rebalance the dynamic. Buy-in from providers in the NICU is key, as they hold greater power compared to nurses, even nursing leadership. Unit leadership should be empowered to advocate for nurses and to be an effective resource in situations where the nurse is unable to provide high quality care due to systemic constraints. Specifically, leadership must seek the insight from bedside nurses to effectively advocate

for manageable nursing assignments where nurses can be more physically and emotionally available to families. Providers should utilize opportunities when communicating with parents to promote the worth of the nurse as a valued and critical member of the care team, thus empowering the nurse in view of the family.

Together, bedside nurses, unit leadership, and providers should address policies where the scope of the nurse's role has been limited and work to create systems to return autonomy to nurses and make space for more meaningful interdisciplinary teamwork. Workgroups where nurses and other members of the care team could collaboratively discuss barriers to consistent evidence-based care implementation for infants and families with a SEP are important to address unit specific issues. Transparency from providers about their concerns and perceived barriers to changing policy should be acknowledged and addressed. However, a culture of safety will make space for new or revised policy and procedure guidelines to address poor decision making and patient care by specific individuals (Profit et al., 2014), yet still retaining appropriate autonomy for nurses.

Alternative evaluation methods for patient satisfaction for units where the patient is unable to evaluate their experience, such as the NICU, should be investigated and tested. Pediatric patients and families have been found to be open to alternative methods of measuring inpatient satisfaction (Coleman et al., 2020). Tools to holistically evaluate all perceptions of patient care within models of family centered care are warranted to meet the Quadruple Aim (Sikka et al., 2015).

Additional research surrounding interprofessional education is also necessary to investigate potentially improved models of initial and continuing education for members

of the healthcare team. Such education has been shown to improve willingness to collaborate in patient care in maternal-child health settings (Olander et al., 2018).

Limitations

Nurses were recruited from the southeast region, but the majority of the participants were from North Carolina. A participant sample with more residential variation by state may have produced different results. Varying rates of SEPs and cultural norms specific to North Carolina and the greater Southeast region may have influenced the results. There may also be differences in this sample recruited through social media, where similarities of self-selected participants and additional influences of social media narratives may exist. Participants who responded to the recruitment flyer may have been recently impacted by issues presented in the flyer and therefore more attuned to or emotionally triggered by the phenomenon of SEPs.

Conclusion

This study addresses issues of the workload and emotional labor associated with nursing care for infants and families with a SEP within the NICU. The concerns described by the participants have their roots in healthcare culture and systems. Addressing systemic issues across professional education and socialization is daunting but critical. Improving patient and family outcomes by way of caring for the nurse is necessary to protect patients and mitigate caregiver burnout.

CHAPTER V
MANUSCRIPT TWO

Abstract

Title: Assessing Safety and Trust with Mothers in the NICU Following a Substance-Exposed Pregnancy

Submitted to: *Neonatal Network: The Journal of Neonatal Nursing*

Purpose: To explore the caregiving dynamic between NICU nurses and mothers with a SEP (substance-exposed pregnancy) by examining how nurses view these mothers compared to mothers without a SEP.

Design: A qualitative study design using interviews with NICU nurses who care for infants and families with a SEP.

Sample: The sample (n = 9) was all female, with an average of approximately 10 years of nursing experience in the NICU, and two-thirds having achieved a BSN or higher education.

Main outcome variable: Experiences of nurses working with families affected by a SEP

Results: Nine NICU nurses were interviewed. Nurses described concerns of safety and trust related to the mother's perceived ability to care for the infant after discharge and need time with the family to build rapport. Assessments extend beyond clinical concerns and professional-ethical obligations into potential pathways that endorse social stigmas related to SEPs.

Background and Significance

As the opioid epidemic continues to escalate across much of the United States (US), maternal opioid use and consequential rates of Neonatal Abstinence Syndrome (NAS) also continue to rise, specifically in the southern region of the US (Hand et al., 2017). Infants who require additional assessment and treatment for withdrawal symptoms from a substance-exposed pregnancy (SEP) average 19 days in the neonatal intensive care unit (NICU; Tolia et al., 2015). Family-centered care is a central model for neonatal care, where parents are valued as critical members of the healthcare team (Gooding et al., 2011; Ramezani, et al., 2014). Nurses describe increased challenges with family-centered care when a SEP is reported, specifically related to families who may be absent or difficult to work with when present (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Whittaker et al., 2016).

Nurses report negative attitudes towards mothers who use substances in pregnancy due to watching infants experience withdrawal symptoms and negative interactions with parents. Over time, recurrent negative experiences may create or reinforce stereotypes of mothers with a SEP (Fraser et al., 2007; Murphy-Oikonen et al., 2010; Raeside, 2003; Romisher et al., 2018; Whittaker et al., 2016). From another perspective, mothers with a SEP report that they have difficulty trusting and communicating with nurses when they perceive they are being judged (Harvey et al, 2015; Roberts & Nuru-Jeter, 2010; Stengel, 2014). Link and Phelan (2014) describe this relationship dynamic as interactional discrimination, where the stigmatizer may approach the caregiving situation with hesitancy or even excessive kindness, while the stigmatized

person reacts with cautionary behavior or less warmth, creating bidirectional obstacles for rapport and a positive relationship. As this interaction repeats itself, the stigmatized person/group may be excluded or assigned less social status. Although stereotyping goes against the professional values of nursing, nurses may feel entitled to judge mothers with a SEP because they do not meet cultural expectations of a “good” mother by using substances in pregnancy (Reid et al., 2008; Terplan et al., 2015). Differentiating mothers as “good” or “bad” based on the use of substances in pregnancy may increase social distance between nurses and mothers. Social distance is a system where people are compared to a set of social norms and consequentially kept close or pushed away based on how they compare to that set of norms (Karakayali, 2009). In this situation, social distance may then be one way in which women with a SEP are viewed as “other” or different from mothers who do not use substances in pregnancy. A primary aim of this study was to explore the caregiving dynamic between NICU nurses and mothers with a SEP by examining how nurses view these mothers compared to mothers without a SEP.

Methods

Study Design

The Institutional Review Board of the University with which the PI was associated found this study to be exempt. Registered Nurses who worked in a NICU and lived in the southeast region of the U.S. (Kentucky, West Virginia, Virginia, Tennessee, North Carolina, South Carolina, Georgia, Mississippi, Alabama, and/or Florida) were recruited to participate in interviews to describe their experiences of caring for infants and families with a SEP. Additionally, nurses needed to be English-speaking, have three

or more years of NICU bedside nursing experience, currently work at a level II or higher NICU averaging 20 hours/week or more, and have cared for enough infants and families with an SEP to share various experiences with the interviewer. Eight participants preferred to be interviewed through a secure web portal, while one participant was interviewed in person. Interview length was approximately 90 minutes.

Critical incident approach (Schluter et al., 2008) was utilized to gather stories, or events, from the participants that they considered memorable or impactful. Using a semi-structured interview guide, participants were asked to describe their nursing practice from various perspectives. Interview questions were written using best practices from the literature (Schluter et al., 2008) and were somewhat modified as interviews progressed to address relevant issues described by previous participants. Follow-up questions were asked to gather additional details of the stories to create a more holistic picture of the experience (Flanagan, 1954). As a former NICU nurse, participants told the PI their stories as a colleague.

Social media was utilized as the primary mode of recruitment with electronic flyers posted publicly and to pages of professional groups, where individuals were encouraged to share the flyer with other nurses. Interested participants provided their contact information to the PI using a web-based survey, then the PI contacted them to verify that they met criteria and provided informed consent. Participant recruitment and enrollment was simultaneous with early analysis and ended with event saturation. Study participants selected a pseudonym, completed a demographics form and sat with the PI for a recorded interview using a secure web portal. Participants were offered breaks

throughout the interview. Interviews were auto transcribed through Temi ©, followed by manual verification by the PI for accuracy of the initial transcription. Tone of voice changes, emotional displays, and other significant features of the interview were noted. The final transcript did not contain identifying information. The participants' stories related to caregiving experiences in the NICU were called "events." Approximately 50 events were required for the analysis technique (Schluter et al. 2008); 51 events were present in the data. To connect the participant's words with the current sociopolitical context, additional data related to SEPs such as professional journal and mainstream news articles, social media pieces, and website materials were also reviewed.

Analysis

Critical Discourse Analysis (CDA) was the primary method of analysis to examine how NICU nurses view mothers with a SEP (Bischoping & Gazso, 2016; Mogashoa, 2014; Smith, 2007). This analysis method allowed for an exploration of the relationships between the nurse's language, the social environment of the NICU, and surrounding culture through the lens of social constructivism. The theory of social constructivism supports a worldview with shades of grey, rather than simple categories of black or white. Social norms and values are specific to culture, social environment, and historical context. The ways in which people make meaning of their experiences can be different in various environments and/or communities (Amineh & Asl, 2015). These assumptions from Social Constructivism provided the opportunity to appreciate the complex interpretations of the data, specifically where nurses describe how they view mothers with a SEP.

As the interviewer, the PI listened to the nurses' stories for the actual story being told as well as how the story was told. Specifically, the analytic strategy of deconstruction illuminated the connections between the participant's chosen language and the sociopolitical themes observed in other texts to examine word choices for relevance and meaning. These methods provided insight into dominant and contradictory narratives within the caregiving dynamic, in addition to narratives that were absent (Bischoping & Gazso, 2016). Thematic analysis was used to uncover general themes within the data through an iterative process of examining individual data points deeply and multiple data points collectively, with ongoing written reflection. The data below highlight the participants' reflections of their critical experiences caring for infants and families with a SEP in the NICU, and how these experiences shaped their views of mothers on continuums of safety and trust related to their perceived ability to care for their infant compared to mothers without a SEP.

Results

This sample consisted of all female NICU nurses, with five years or more of general nursing experience and at least three years of NICU nurse experience. The participant group had an average of just over 10 years of NICU nursing experience and were employed at NICUs with variable levels of patient acuity. The participant's ages ranged from 28-60 years old, and most lived and practiced in North Carolina. Two-thirds of the nurses had completed a BSN or higher. Fifty-one events were gathered across nine participants over five weeks.

A View of Mothers through a Social Lens in the NICU

The caregiving dynamic in the NICU is typically social, referring to the interdisciplinary team who works together planning and providing care for high-risk infants. With some unit layouts and circumstances, team members may also communicate and indirectly care for infants and families who are not in their specific assignment, thereby having some knowledge of their history and reason for admission. This team interaction supports a web of storytelling about infants and their families among many care providers. Speakers and listeners may participate in the conversations in a variety of roles. At times the participants were in the role of storyteller; at other times, a listener. Differing roles may influence the content or tone of the story. As stories are told and retold in a NICU, details and meanings may shift over time, but listeners must judge the credibility and reliability of each story for themselves.

As early career NICU nurses are socialized to the profession, they are surrounded by more senior nurses who recollect memorable experiences of caregiving framed by their own perspective. Many participants recollected sharing more stories where mothers exhibited behaviors of bad mothering in the most extreme ways, as compared to experiences where mothers exhibited traits of good mothering, highlighting the potential to perpetuate a negative view of mothers with a SEP. For example, one nurse described quickly hearing the news of an infant who died of apnea shortly after discharge, having an apneic episode while disconnected from the home monitor, “Bad news travels fast... I don't know how, but the news came down to us and we were appalled, you know, all devastated how terrible that is.” When news of a poor outcome or tragedy reached the

care team, nurses described telling other nurses who were unaware of the situation, where they could debrief and grieve together. This process of storytelling and debriefing was also described surrounding events where a family member had a verbal or emotional outburst in the unit. During these conversations, the story of the infant's hospital stay and the team's experiences with the family were re-examined as a part of the discussion. More structured storytelling occurs with shift report. During this time of handing off patient and family information, nurses shared their own assessments, and those passed down from other nurses, regarding the infant's exposure to substances and perceptions of the family. "And so, that of course gets passed on in report from nurse to nurse to nurse and then that kinda becomes our personal judgment."

The nurses in this study framed their view of a mother with a SEP along continuums of infant safety and trust in mothers, relative to their observations and experiences with the mother and conversations with other team members about the mother's behaviors and perceived personality. Put together, these viewpoints shaped how the nurse perceived the mother's ability to provide a safe environment and independently care for her infant at home.

The Influence of Stigma: Mothering and "Othering"

When individuals are separated from the primary social group through the cultural acceptance of stereotypes, the stigmatized are viewed as "others" (Link, 2001; Link & Phelan, 2014). As described in this study, sometimes mothers with a SEP were viewed as "others" compared to mothers without a SEP. The few stories that narrate a positive caregiving experience described mothers who were in a recovery program, active in their

infant's care, and easy to work with. "Again, I felt like they owned everything that had happened and were willing to go in headfirst to make everything happen, in assistance with us. In other words, they didn't give us a hard time." These mothers were perceived as more like other mothers without a SEP. Nurses described more empathy and a closer proximity to good mothering ideals when the mother's story of substance use related to a history of physical or emotional trauma. "I can understand how you have gotten into a lifestyle of dealing, doing drugs to deal with the trauma, but she truly loved her baby and she wanted to, to get clean." However, the stigma of substance use as a personal choice remains visible in this statement.

How a nurse views a SEP, through a lens of moral choice or a lens of chronic disease, influences perceptions of social distance with the person who uses substances. Here we see two nurses with differing viewpoints describe how their empathy levels differed. One nurse perceived a great deal of social distance between herself and the mother with a SEP, "Because I didn't grow up in a family like that, so I don't know what that's like..., so I really can't put myself in her shoes because I'm blessed and I don't have substance abuse, you know." Another nurse described fear of being similarly at-risk for addiction, reducing the social distance when addiction began with a legitimate prescription following a motor vehicle accident and multiple bone fractures.

And I remember thinking so distinctly that that could happen to me. That could be me. Like I could get in a car accident and I could get addicted to painkillers and this is where I could end up, this could be me.

NICU Nurses Judge Potential Safety

Participants described several ideas surrounding safety within their stories. The primary consideration around safety related to maternal active substance use versus recovery. When nurses view mothers as “in recovery” they were perceived as less threatening to the infant’s safety as a caregiver, “But, if you are in treatment then you, um, are... I can see that you’re trying. You are more capable of, of caring for your child.” This nurse went on to describe how a positive experience with one mother with a SEP could impact her view of other mothers with a SEP,

So, she was extremely diligent. Um, and she breastfed that baby and she did all of his baths, I mean just took excellent care of him and that was super rewarding because it just kind of made me realize that sometimes this does work out.

Medication assisted treatment varied in how it was viewed; seen as active drug use by some nurses and as part of recovery by others.

Nurses described concern that mothers with active substance use behaviors might become impatient or lose their temper with high-need infants experiencing withdrawal symptoms, resulting in harm or neglect of the infant after discharge. Influences of stigma are visible here, as well, when an assumption was made about the values of the parent,

Parents are just trying to do anything to shut them up, especially if they are crying and they’re high or doing whatever they’re doing. And I mean, it’s frustrating for me to take care of a baby for 12 hours, much less someone who already is addicted to drugs and is more concerned about that, in my opinion, than their child.

When the infant was receiving care in the NICU, nurses provide care in the absence of parents or in addition to care by parents. But nurses were worried that the infant might not be adequately cared for independently by the mother with a SEP. For example,

He didn't really eat that much during that feeding [by parents]. So, I just made up for it the next time because I knew they were not gonna be there the next time, but at the same time those parents would take the baby home. So, then you wonder what happens when they are the only ones there feeding that baby.

Nurses also critiqued patterns of visitation as an indicator of infant safety with the mother. Nurses reported that many mothers verbalized a desire for their baby to be more comfortable and experience fewer symptoms of the SEP. Mothers that were frequently present and active in their infant's care were viewed as more genuinely caring and better able to meet their baby's needs, decreasing the nurse's safety concerns related to the mother's caregiving. When nurses viewed mothers as collaborators in infant care, they had more desire to teach the mother how to comfort and care for their infant,

So it was a good opportunity for me to go ahead and instead of me just independently doing it, when she was here all the time, I just told her we could tag team and do it. And she was very outgoingly, um, wanting to also, and so that just triggered me to offer.

When the nurse saw consistent visitation by mothers, there were more opportunities for the nurse to witness positive caregiving and bonding interactions. Seeing warm and caring interactions increased the nurse's perceptions of safe caregiving by the mother and decreased the nurse's fear of infant safety upon discharge.

Conversely, when visitation was rare or inconsistent, attributes of risky caregiving were more frequently described, “We’ve had parents that are just not actively involved and then, they can go as extreme as being, like unsafe.” Other nurses also used the word “unsafe” to describe some mothers with a SEP. The use of this particular word is significant. In the nursing profession, a description of “unsafe” usually triggers serious consequences. In this story, the nurse went on to describe the mother becoming angry and yelling in the hallway when she found her baby crying without attention by a nurse. Other descriptions of unsafe behavior by mothers included mothers’ falling asleep or appearing impaired while holding their baby and using substances in a private patient room while the baby was unattended and crying.

Concerns of Safety Influence Trust

When nurses try to discern whether a mother can be trusted, they assess both her character and her capability as a caregiver for the infant. One of the most frequently described situations leading to a lack of trust was conveyed through stories where a mother had a pattern of not following through on a verbalized plan to visit her infant. One nurse described attempting to meet a mother’s transportation need by sending a taxi to her address, “The cab goes to that address and then the cab company is calling us up saying, “Hey, I’m here at this address and there’s nobody here.” She went on to describe other reasons the mother may not have been there, but ultimately presumed the mother was not truthful in some way. Another nurse described a pattern of disappearance in a mother who did visit,

Like she would come, she would hold the baby, the baby would start crying, she put the baby down, and say I have to go get coffee or something and then she just wouldn't come back that day. And that happened day after day after day or you know, there may be a couple of days where she didn't come.

Maternal attributes of unreliability were powerful influencers in the untrustworthy characterization of some mothers with a SEP.

An additional, broader consideration of trust was related to the secrecy of substance use in general, beginning with the denial of a SEP, especially in the presence of a positive toxicology result, "Usually it's complete denial. No matter how many times we tell them like, 'Oh, your drug screen was positive for you and your baby.'" Nurses were particularly concerned when the SEP was unknown by some immediate family members, such as grandparents who visited the NICU. Prohibited by confidentiality rules, nurses cannot disclose medical information to family members without permission from the patient or guardian, however the situation made nurses uncomfortable, "It was not a good feeling. Made me feel like I was part of this dirty little secret in this family." Nurses did acknowledge that reasonable explanations existed in scenarios where the nurse suspected the mother lied or manipulated, but it was the pattern of behaviors with each mother and among other mothers with a SEP as a whole, that created a sense of mistrust toward this population.

Although nurses did not trust mothers with a SEP as easily as they did other mothers in the NICU, these participants did not think that mothers intended to harm their babies. Even more, nurses believed that mothers with a SEP loved their infants. Even in the stories where the infant was harmed, nurses assumed that mothers with a SEP did not

intend the harm but were either too distracted or consumed by their substance use to adequately focus on the care of the infant, “It really tends to just make me sad, because I know most of these moms don’t want to be addicted. They don’t want to hurt their babies.” Nurses described the presumption that mothers distrusted nurses as well, with a palpable baseline of skepticism among everyone involved. One nurse described the dynamic as, “We have mutual trust issues [laughs], you know, like we as a healthcare team have a hard time trusting them and they have a hard time trusting us.” Another participant says, “They’re just as cynical as we are, you know, we’re cynical on the inside because we’re like, ‘What’s this one going to turn out like?’” Nurses indirectly described perceived social distance and social stigma as a potential reason that mothers distrusted them,

I think that people who have used drugs, um, are often leery to be truthful ... they kind of have a wall up already because ... they know they are being judged based on their history and their reason for being here and that kind of thing.

Another nurse thought that mothers believed she didn’t genuinely care, “Because they feel like we are more there just because of our job...the majority of parents I feel like, ‘Nah, she can’t relate. She’s just here to do her job.’” Nurses were aware that mistrust between the mother and the care team may impact the relationship, “Yes, it is harder to build rapport because I think they are less trusting of us.”

For a caregiving experience to be perceived as rewarding or positive, there was generally some kind of personal connection described with the mother or extended family. When the nurse saw the mother as more human and social distance was

decreased, nurses seemed to desire more connection and experienced more compassion. This emotional availability seemed to open the caregiving dynamic for more of an authentic human connection. In some instances, the nurse was able to see the mother with a SEP as a “good” mother, a characterization more typically reserved for mothers without a SEP. This viewpoint resisted the continuum of stigma against mothers with a SEP. “So she seemed like, her interaction with her other child, even when the younger child would come or the older child would come and visit was, you know, promising too. You know, she was a good mother.”

Putting it all Together: “Can She be a Good Mother?”

The purpose of continual assessment of safety and trustworthiness of the mother with a SEP was to make a judgement as to her potential as an independent caregiver for the infant. Although the decision of custody and living arrangements after discharge is not in the nurse’s scope of practice, the nurse’s assessment does have weight to the people and systems that do make those decisions. When the nurse perceived the mother with a SEP as safe and trustworthy enough to independently care for her infant, nurses were more comfortable with a discharge plan that included the mother. However, when mothers were perceived as unsafe and untrustworthy, nurses were worried for the infant’s safety without an alternative caregiver.

I don’t know, I’m pro-family I want families to be united. I want them to be happy. I want them to work out. I want mom to get the help that she needs to get out of the situation that put her where she was, whether it was medically needed, whether it was an accident and she just kind of got stuck on this habit, whatever it was. I just want them to get fixed. But in that situation where that’s not going to happen within a feasible amount of time and the baby needs a home, a steady

home, or at least someone who's willing to give the effort a 100%, I'm all for it [foster care and adoption].

Discussion

Concerns about safety and trust with family caregivers identified in this study have been cited in other studies examining the experiences of nurses' caring for families with a SEP (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010). Caring for infants with a SEP was found to be the primary source of moral and ethical distress in one participant group of NICU nurses (Maguire et al., 2012). Fear for the infant's safety upon discharge and a perceived responsibility to protect the infant are additional commonalities between this study and findings in the literature (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010; Romisher et al., 2018; Shaw et al., 2016; Whittaker et al., 2016) and may be additional contributors to moral and ethical distress among neonatal nurses (Welborn, 2019).

Although classified as a chronic disease with no specific cure, many people, even healthcare professionals, view addiction as a moral failure (Corrigan et al., 2009; Yang et al., 2017). Seminal work on stigma by Goffman (1963), reinforced by Link and Phelan (2001), describes stigma as the relationship between an attribute and a negative stereotype, existing in an environment where the person under a stereotype maintains less power. The attribute connects the person to undesirable characteristics, resulting in the stigmatized individual or group losing even more power. Under this description, the nurse holds more power in the NICU than the mother with a SEP, and if the mother takes on additional undesirable characteristics such as unreliable, absent, or dangerous, the mother

will lose additional power within the healthcare environment. Therefore, we argue that the nurse's concerns about safety and trust extend beyond clinical concerns and professional-ethical obligations but are pathways that endorse social stigmas related to SEPs. This argument is supported by other studies that reported blaming behaviors towards mothers for their substance use behavior, where healthcare providers cited selfish decision-making and irresponsibility as the assumed reason the mother used substances during pregnancy (Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen et al., 2010).

When powerful stories are told within the NICU, these stories become a part of the culture of that NICU, embedded in the history and experiences of the caregivers that embody that unit. However, these stories represent the singular perspective of the storyteller, making way for that individual's influence and personal bias upon the story. A study investigating stigma related to mental illness through storytelling found similar reproductions of stigma when older family members told stories to younger family members (Flood-Grady & Koenig Kellas, 2019). In the situation of SEPs, storytelling among more senior nurses may potentiate stigma and bias in novice NICU nurses and may create a culture for socially accepted stigma and bias against mothers with a SEP to be normalized within the caregiving environment.

As NICU nurses share caregiving experiences, work together closely, and share oral history through shift report and storytelling, it is reasonable to assume that they share some understanding in the caregiving experiences of infants and families with a SEP. Viewing this data through a lens where knowledge is not gained in isolation but in a

social context, we argue that over time, nurses begin to weave together stories from their NICU with their own caregiving experiences, personal experiences outside of healthcare, and influence from the greater culturally-infused landscape. The culmination of these stories and experiences form the nurse's idea of "Who is a mother who uses substances in pregnancy," and question, "Is she capable of independently and safely caring for her infant?" This socially constructed view of the mother with a SEP then mobilizes to influence how the nurse engages with this family in the NICU. In studies where mothers with a SEP perceived judgement and stigma from the healthcare team, mothers reported avoiding the NICU as a consequence (Cleveland & Bonugli, 2014; Cleveland et al., 2016). The mother's absence from the NICU bedside then further reinforces the negative stereotype of mothers with a SEP as absent and unable to independently care for her infant, as well as contributing to a legal body of evidence arguing against her parental custody rights.

Implications for Practice

Strategies to resist stigma toward mothers with a SEP, promoting relationship and rapport between mothers and nurses in the NICU, are critical to create an environment where mothers feel comfortable visiting and learning the care needs of their infant. In turn, as mothers are more present and engaged with the care team, nurses may have more positive experiences with mothers and begin to shift the overall narrative through compassionate storytelling. This shift in storytelling is one way to break the cycle of judgement and reactionary behaviors between nurses and mothers and promote

empathetic care through the recognition of common humanity (Farr & Barker, 2017). In this same circumstance, feelings of trust and safety toward the mother may also improve.

Once nurses are aware of the potential for stigma towards mothers with a SEP, nurses must begin the sometimes difficult and vulnerable process of self-assessment, examining their own practice and identifying opportunities to resist stigma. Nurses in this study verbalized a desire for additional education on substance use in women, specifically related to the cycle of addiction and medication-assisted treatment in pregnancy and childbearing years. Learning more about substance use as a chronic disease, rooted in mental health disorders and trauma among other issues, may be especially helpful for maternal/child nurses to better understand the situation of the mother with a SEP. Considering the high prevalence of trauma in families, integrating a trauma-informed approach to family-centered care in the NICU may serve mothers without a SEP as well as mothers with a SEP (Marcellus, 2014). As some of the nurses in this study described, understanding trauma may increase empathy towards the mother and promote a warmer demeanor.

Nurses also require organizational support from NICU administrations to incorporate SEP concerns into the acuity algorithm when recommending staffing ratios. All previous recommendations are handicapped if the nurse lacks the time required to build rapport with families. The weight of implementing compassion and empathy is commonly placed on the individual nurse, but this task is extremely difficult to accomplish within a health system lacking a compassionate design. Infrastructure to fund resources for staffing promotes compassionate care design and may yield more positive

outcomes for the infant, family, and the caregiver (Crawford et al., 2014). Supporting a positive relationship between the nurse and mother may also serve as a moderator to substance use behaviors, thereby protecting both the mother and infant long-term (Racine et al., 2009; Roberts & Nuru-Jeter, 2010).

Future researchers should consider bringing together mothers with a SEP and nurses for a roundtable discussion on collaborative care provision and potential avenues to support one another. As cited in this study and in the literature, nurses fervently believe that mothers with a SEP love their infants and desire to care for them so they will thrive (Stengel, 2014; Stone, 2015). A mutually beneficial, synergistic relationship between nurses and mothers with a SEP has potential to shift away from stigma toward individuals who use substances.

Limitations

Although nurses were recruited from the entire Southeast region of the U.S., most of these nurses lived and practiced in North Carolina. Cultural norms and level of engagement with families with a SEP may vary from other states in the Southeast. Differences related to social media recruitment may also exist, where similarities and additional influences related to self-selection within social media may have impacted the results. It is possible that these participants may have been recently impacted by topics presented in the flyer and therefore more accustomed or emotionally impacted by the phenomenon of SEPs. It is possible that nurses who have also been impacted by this phenomenon, but in a less emotionally triggered way, did not request to be contacted for an interview.

Conclusion

This study explores the caregiving dynamic between NICU nurses and mothers with a SEP, addressing challenges of implementing concepts of family-centered care with this population. Nurses verbalize concerns of safety and trust related to the mother's perceived ability to care for the infant after discharge and need time with the family to build rapport. Elements of stigma may influence the nurse-family dynamic in a variety of ways and may be continued through the oral traditions of nursing. This caregiving dynamic can be improved through a better understanding of the root causes of substance use and SEPs and organizational commitment of a supportive environment for both the mother and the nurse. Bedside NICU nurses are positioned with immense opportunity to support mothers with a SEP, teach them how to provide care to a high-risk infant, and facilitate maternal/infant bonding.

CHAPTER VI

CONCLUSION

This chapter will briefly review the major findings of this study related to the care provision to infants and mothers by neonatal intensive care unit (NICU) nurses following a substance-exposed pregnancy (SEP). The primary results manuscript (Chapter IV) focuses on the NICU nurse's workload in caring for families with a SEP where physical, mental, and emotional demands are exacerbated by healthcare environments with inequitable power dynamics. The second manuscript (Chapter V) describes how nurses characterize a mother with a SEP in light of the norms of good mothering within the social milieu of the NICU. Additional findings from the dissertation study, as well as research and clinical implication are also described.

Additional Analyses

Social media platforms Facebook and Instagram were searched for relevant and timely content related to SEPs for the duration of participant recruitment and interviews. Collected pieces included news media, original public posts by laypersons, original posts by healthcare professionals within NICU-specific Facebook groups, memes and gifs, all with content relating to SEPs. Pieces with high engagement relative to other posts and shares were analyzed for overarching narratives and themes, word choice, and tone. Interview data were triangulated with these media pieces to identify similarities and differences.

Media pieces overwhelmingly focused on symptoms of withdrawal and described the infant's experience as "suffering" and "excruciating", positioning the infant as a victim of the mother's choice to use substances in pregnancy and many times labeled an "addict." Video pieces have dark and dramatic background music where infants are shown alone and crying in many pictures and videos. One meme with a high volume of interactions and shares presented a young girl with sad eyes and a flat affect, with the overlaid text "Dear addict, If [you're] in hell, imagine what your kids are going through." This and other similar memes evoked highly emotional responses from social media users with long comments, negatively characterizing individuals who use substances. The most empathetic comments spoke to the lack of individual control when substances are involved and that the "addict" is also suffering. Those kinds of comments received rare interactions from others, insinuating limited support for that perspective.

Mothers were characterized as "bad" mothers who selfishly choose substances at the cost of the well-being of their child. Media pieces that presented the mother's voice consistently positioned her as a bad mother who made poor lifestyle and parenting choices and consequently feels both guilt and shame. Of the few media pieces that characterized the mother in a neutral or positive light, her story was presented surrounded by guilt and shame, as well.

Original posts and discussions in NICU Facebook groups were similar but also discussed caregiving practices. Discussions around medication use for withdrawal symptoms included comments of feelings of sadness when watching infants experience withdrawal symptoms and difficulty comforting and consoling infants. One comment

stated, “We get a LOT of NAS babies, sadly.” Another comment in that same thread stated, “These poor babies are so sad.” Infants were positioned as victims of their mother’s poor choices, related to the display of withdrawal symptoms. The stigma of substance use was visible as infants with a SEP were positioned as victims, but other NICU infants were not described with victimization language.

Staffing concerns were stated across multiple posts and comment threads, describing the disconnect between the nurses and administration on safety with staffing ratios. Nurses describe a power-under position and not being heard or ignored. One poster wrote, “There goes consistency and Primary care in our NICU.. BUT Hey don't listen to the people WHO DO THE WORK.” Another nurse described less than optimal staffing patterns as “The algorithm of hell.... I want to find the person that invented it and slap them.” Frustration and anger were rampant across these threads and connected to the perceived misuse of the pillar principles of family-centered care, “We used to have them [touch time policies] but it seems explaining to parents about quality sleep and quiet times is quite archaic now. Family centered care means a free for all.”

Absent parents were described in a variety of narratives on social media within NICU professional groups surrounding SEPs, infant withdrawal symptoms, and new protocols such as “Eat, Sleep, Console.” “We don’t have cuddlers on the Night shift. So it falls on nursing to hold these babies ALL the time. I personally hate it [Eat, Sleep, Console protocol].” Another commenter wrote, “Lots of heroin and multi drug users. Families never stay and act offended if we ask them to. We have Cuddlers occasionally but only on dayshift. Falls primarily on the nurses.” This protocol was a concern for the

vast majority of individuals who engaged in this conversation. Few descriptions of positive caregiving experiences were described in these posts and commentary threads.

The results of social media content analysis support the findings from the interview data, where healthcare culture negatively impacts NICU nurses' caregiving experiences of infants and families with a SEP and nurses have concerns about mothers as independent caregivers related to safety and trust. Descriptions of these narratives related to SEPs better situated the interview data within the timeframe of the opioid epidemic and healthcare culture. These results added to the understanding of the caregiving experiences described by the interviewed nurses by creating greater context of the negative sociopolitical narrative of SEPs and the power-laden healthcare culture within NICUs.

Major Findings

Caregiving within Healthcare Culture

Nursing practice in this study was influenced by the culture of the specific healthcare organization of the participant and healthcare at-large. These influences may serve as barriers or support to nurses. The nurses in this study perceived the current larger healthcare culture to primarily revolve around values of patient satisfaction and reported that they received similar messaging from their own organizations. Nurses described a work environment where they experience intense pressure to make families happy under any circumstance due to patient satisfaction metrics, which were measured by proxy of the parent in the NICU. They described caregiving situations where they felt unable to provide the best care possible for the infant and family with a SEP due to systemic

barriers such as inconsistent assignments, inadequate staffing, and lack of time available to spend with families.

Power inequities among infant caregivers complicated the described situation further. Nurses described limited resources to meet the comfort needs of all infants in their assignment, including those with a SEP, yet their requests for additional resources were many times denied. Additional staff for lower nurse/patient ratios were unavailable, unit managers were ineffective advocates, and nurses described being ignored by providers when they asked for a consideration of revision in the infant's plan of care. Inconsistent caregiving practices among higher level providers also served as a systemic barrier for nurses to gain and maintain trust with families as nurses are the implementers of care and most accessible caregiver to the parent. When nurses are charged with the responsibility of parent satisfaction within an environment of limited resources, nurses described feeling emotionally exhausted and unable to fulfill their professional obligations.

The Influence of Stigma

Nurses in this study described numerous memorable experiences caring for infants and families with a SEP, primarily characterizing the experience negatively. These experiences existed in a feedback loop, where previous negative experiences of mistrust and harm to the infant framed a baseline of skepticism to which other mothers with a SEP were judged. Nurses engaged with the mother in various ways that mobilized stigma, prompting responses from the mother that were perceived negatively and thus reinforcing the nurses' baseline skepticism. As the nurse navigated this awkward

situation, her typical communication and caregiving practice were many times altered to reflect productions of stigma.

While the infant was in the NICU, nurses continually assessed the mother/infant dyad for indications of the mother's ability to care for the infant independently after discharge. These judgments of safety related to mothering influenced the level of trust the nurse felt toward the mother, which transitioned into a judgment of her predicted overall mothering ability. The cumulation of engagements and assessment of mothers, and subsequent storytelling within the unit, allowed social stigma to become embedded within the structure of the NICU and potentiated with the influx of additional infants with a SEP.

Linkages between the Results Manuscripts

Healthcare culture, where patient satisfaction metrics dominate the narrative, is a barrier to nurses resisting stigma as these systems do not create environments conducive to authentic human connection. The pressure cooker that is the business of healthcare leaves little time and space for nurses to consider the presence of stigma against mothers with a SEP in the NICU. Additionally, systems where parents are essentially grading nurses on care not directly aimed at them and that they may not fully understand encourages resentment and anger among nurses. These negative feelings among nurses do nothing to reduce the characteristics of stigma towards mothers with a SEP such as mistrust and negative characterizations.

A parallel can be argued between the two results manuscripts. The judgment of mothers with a SEP by NICU nurses and the judgment of NICU nurses by administration

and leadership of organized healthcare present similarities with the functionality of power in each dynamic. In both circumstances, the person in a reduced power position is expected to perform exceptionally well within a judgmental environment without necessary resources. Additionally, the person in a reduced power position is being judged by persons that may not have a realistic understanding of the burdens surrounding the person being judged. The potential consequences for both individuals of the failure to adequately perform are significant, and disengagement from the dynamic is visible in both situations. The role of power is evident in the results of this study, where the caregiving dynamic stages multiple power struggles simultaneously.

Additional Potential Topics of Papers from the Findings

This study has the potential for many additional manuscripts to be written. Additional results, briefly described below, became evident in the analysis phase, and while those topics were not in the aims of the study, their merit is worth noting. With additional analysis, these topics may be developed further and presented at a later date.

Moral and Ethical Considerations

Some participants described moral and ethical conflicts when caring for infants and families with a SEP. A deeper investigation of the antecedents, experiences, and consequences of ethical and moral deliberations through a theoretical lens of moral distress could provide a better understanding of the descriptions. A better understanding of the experience of moral deliberation and distress may be helpful in the creation of interventions to support NICU nurses.

The Arc of Redemption

A pattern of judgments of mothers was noted as participants described the caregiving experiences of infants and mothers with a SEP. This pattern has been named the *Arc of Redemption* as the pattern mimics religious themes of confession, atonement, and redemption as one pathway created by nurses for mothers with a SEP to redeem themselves as “good mothers” within the current social norms. The characterization of mothers with a SEP as either good or bad based on their engagement with healthcare providers was reported with the analysis of this study, but additional analysis related to this specific pathway back into the social category of “good mother” is warranted.

Reproductions and Resistance to Stigma

The presence of stigma was noted in the interview data of this study although the interview questions did not directly ask about perceptions of stigma surrounding caregiving. Additional analysis to seek out narratives in the data base from the participants that acknowledge stigma, participate in reproductions of stigma, or resist functions of stigma is necessary to present a full picture of the role of stigma in this study. Descriptions of stigma may be indirectly described and difficult to locate, therefore a team approach to such analysis would likely be more beneficial in elucidating a holistic view of the function of stigma within the dataset.

Limitations of the Study

Although nurses were recruited from the entire Southeast region of the U.S., most of these nurses lived and practiced in North Carolina creating regional limitations for the interpretations of results. Cultural norms specific to North Carolina and differing rates of

SEPs may vary from other states in the Southeast. Similarities between participants and additional influences related to self-selection within social media platforms may have impacted the results. It is possible that these participants self-selected due to recent caregiving experiences where they were impacted by topics presented in the flyer and were more accustomed to or emotionally impacted by the phenomenon of SEPs. It is possible that nurses who have also been impacted by this phenomenon, but in a less emotionally triggered way, did not request to be contacted for an interview. Data from social media platforms may have been influenced by social desirability, anonymity of the internet, or absent narratives.

Recommendations for Practice

Strategies to recognize and resist stigma within healthcare must be explored and considered for implementation. Because stigma is often poorly visible, caregivers and healthcare leaders must anticipate its presence in all settings where humans function. Seeking out stigma and stigmatized practices requires an acknowledgement of stigma as a byproduct of human nature, with the goal of making it visible to identify opportunities to resist its tendencies. A culture that endorses the identification of stigma and stigmatized practices is necessary to promote a practice of consideration of stigma within healthcare settings (Link & Phelan, 2014).

An examination of the healthcare culture focus on high patient satisfaction metrics as the perceived predominant value by leadership is also warranted. Either a reconsideration of values or the messaging to healthcare providers about those values is necessary to balance the scales in the perceived culture of healthcare. All members of the

care team, the patient, and their family must perceive that they are worthy of respect and care by others in the care team and leadership (Crawford et al., 2014). Improved systems are needed to gain feedback from parents about their experience of care for their infants while controlling for the issues presented when proxy feedback is used, such as the situation of pediatric care (Coleman et al., 2020).

Caregiving practices in the NICU must be reconsidered to reasonably meet the needs of patients, families, and care providers to achieve bidirectional high-value care. A focus on positive outcomes for only some of the members in the caregiving dynamic may put undue pressure or strain on other members in the dynamic. Leaning on recommendations from the Quadruple Aim (Sikka et al., 2015), interventions aimed at improving the experience of care for patients and caregivers alike will strengthen the system as a whole. Compassionate care must extend beyond patients and families to include all members of the care team, supporting them with resources and empathy in an environment free of threats (Crawford et al., 2014). As a part of this recommendation, healthcare leaders must investigate structural practices that are barriers to the nurse's autonomy within their scope of practice and ability to implement best care practices.

Implications

Research

Additional research is needed to explore the caregiving dynamic utilizing a method that is able to recognize connections and systems that produce individual's experiences. Structural level research surrounding care for infants and families with a SEP is necessary to examine the caregiving dynamic thoroughly, and avoid assigning

blame to individuals, when it is likely that systems are producing much of the behavior visible in individuals. A better understanding of the systems that underlie the healthcare environment may point to opportunities for meaningful intervention to improve outcomes for infants, mothers, and caregivers.

Additional research that directly examines caregivers' perspectives on the current healthcare culture is needed to provide a basis for recommendations to improve the experience of the caregiver, per the Quadruple Aim (Sikka et al., 2015). This study added new information to the body of knowledge surrounding NICU nurses' experiences, but that information was accessed indirectly, per the verbiage of the interview guide. A more purposeful and direct interview guide focused specifically on the culture of healthcare and its influences on caregivers is warranted.

Finally, additional research will be necessary to examine the caregiving dynamic between infants and mothers with a SEP and nurses as current practices are shifting. Participants in this study mentioned the addition of a treatment method "Eat, Sleep, and Console" (Blount et al., 2019), describing an increased demand on parents to stay at the bedside, a low-stimulation environment, and reduced use of medication. As this change in practice is implemented across NICUs and maternal/child nursing units, investigation on its impact upon individuals will be needed.

Education

There are many opportunities for education that stem from the results of this study and surrounding discussion. Interprofessional education that includes nursing, medical, and other health science students is one pathway to encourage early teamwork and

collaboration among potential care team members. Joint learning can assist in dissolving the silos of disciplines and creating a more unified team (Horsely et al., 2016). Collaborative learning experiences should be sought within healthcare organizations, considering collaboration the default as opposed to the exception.

Conclusion

This study has added new knowledge related to the caregiving experience of NICU nurses who care for infants and families with a SEP. System-level influences are at the heart of many of the concerns highlighted in this dissertation, and individuals are severely impacted through these systems within healthcare. There is much more work that needs to be completed to better understand what meaningful interventions at the system and individual levels might improve the caregiving dynamic and outcomes for all individuals who are involved.

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APPENDIX A

NOTICE OF IRB EXEMPTION



OFFICE OF RESEARCH INTEGRITY
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Federalwide Assurance (FWA) #216

To: Amber Welborn
School of Nursing
108 Princeton Court Advance, NC 27006

From: UNCG IRB

Date: 7/02/2019

RE: Notice of IRB Exemption

Exemption Category: 2.Survey, interview, public observation

Study #: 18-0169

Study Title: An Exploration of Discourses of NICU Nurses Caring for Infants with Symptoms of a Substance Exposed Pregnancy (SEP)

This submission has been reviewed by the IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

The purpose of the study is to illuminate potential power differentials within the caregiving dynamic between mothers who used substances in pregnancy and neonatal intensive care (NICU) nurses caring for their infants by analyzing the nurse's language and examining the sociopolitical discursive practices surrounding the dynamic.

Additionally, this study aims to explore the caregiving dynamic between NICU nurses and mothers with a SEP through an understanding of the social construction of these mothers by the nurses who care for them.

A qualitative study design using interviews with NICU nurses who care for infants and families with a substance-exposed pregnancy will be utilized to address the aims of the study.

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. **Please utilize the the consent form/information sheet with the most recent version date when enrolling participants.** The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

Please be aware that valid human subjects training and signed statements of confidentiality for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/university-policies/research_data/.

APPENDIX B
INFORMATION SHEET

University Of North Carolina Greensboro

Project Title: An Exploration of Discourses of NICU Nurses Caring for Infants with
Symptoms of a Substance Exposed Pregnancy (SEP)

Principal Investigator: Amber Welborn, MSN, RN

What are some general things you should know about research studies?

Participating in a research study is voluntary. There is no penalty if you decide that you do not want to be in the study. You may leave the study at any time for any reason. There may be risks to you being in a research study. Your relationship with the researcher and UNCG will not change based on your choices. If you have any questions at any time, you should contact the researcher named on this form. You will be given a copy of this form.

What is this study about?

This is a research study about NICU nurse's experiences caring for infants and families where substances are thought to have been present during the pregnancy. This type of pregnancy is called a substance-exposed pregnancy (SEP).

Why are you being asked to participate?

To be in this study, you must be employed at a level II or higher NICU within the southeast (Kentucky, Tennessee, Mississippi, and Alabama, West Virginia, Virginia, North Carolina, South Carolina, Georgia, and/or Florida) for at least three years averaging 20 hours per week. Your caregiving experiences must include caring for a variety of infants and families with a suspected or experienced SEP.

What will be asked of you if you agree to participate?

You will complete a questionnaire with general information such as age and work history. Immediately following the questionnaire, you will engage in a one-on-one interview about your experiences caring for infants and families with a SEP. You will be asked to recall stories of your experiences and describe what happened. The interview should take about an hour. There are no follow-up meetings, but, if you agree, you may be contacted later if the investigator needs to clarify something you have said.

Is there any audio/video recording?

Your voice will be recorded. You will not be videotaped.

What are the risks to you? Will it cost me anything?

There are very small risks to being in the study. You might experience emotion as you retell stories. Questions will be asked in a private area, and breaks will be taken as needed. If, at any time, you are not comfortable with a question, you may choose not to respond to that question. If you need to talk to someone after this session, we encourage you to see your primary healthcare provider.

There is a very small risk that the information you give to the researcher might be seen or revealed by those not part of the study team. We will take several steps to keep your information and answers secret and secure.

There are no costs to participate in this study.

If you have any concerns about your rights, how you are treated, concerns or complaints about this project or benefits or risks associated with being in this study, please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits for you participating?

There are no direct benefits to participants for participating in this study. There are some potential benefits to society as information gained may add to what we know about the caregiving of infants and families with a SEP. This information may help guide practice and inform future interventions.

Will you get paid to be in the study?

A \$25 store card will be given to those completing the study. If the participant chooses to withdraw from the study before completion, no store card will be given.

How is your information kept confidential?

Your information will be coded with a pseudonym (false name). No one will know who has that name. The pseudonym will not be on your gift card, nor will the name be on the receipt. Your information under the pseudonym will not be linked to your real name and cannot be connected to you. Your demographic questionnaire will be stored in a locked container at the researcher's private home. Electronic data will be stored in a password protected and firewalled personal computer at the researcher's home and on secure internet cloud storage.

What if I want to leave the study?

If you decide to leave the study, you may request that any information you gave the researcher be destroyed. The researcher can keep any information that does not have your name on it. The researcher has the right to stop your part in the study at any time. This could be because you did not follow instructions, because the study has been stopped, or because they feel it is too hard on your health.

What happens if there is new information or changes in the study?

If any new information about the study becomes available, this information will be given to you.

Consent by participant:

By participating in the interview, you are agreeing that you read the information sheet and you fully understand this document. You are openly giving your consent or permission to take part in this study. All of your questions about this study have been answered. You agree that you are 18 years of age or older and are agreeing to take part in this study described to you.

APPENDIX C

FLYER



NICU Nurse Study

Be part of an important study about nurses who care for infants and families with suspected substance-use in pregnancy.

- Have you been employed at a level II or higher NICU for at least three years?
- Do you practice bedside care about 20 hours/week or more?
- Have you cared for infants and families with prenatal substance-use?

PARTICIPANTS ARE REQUESTED TO:

- ✓ Participate in a one-on-one interview
- ✓ Share some of your experiences caring for this population

****Interviews may be in person or online, at your convenience.**

The purpose of this research study is to learn more about nurses' experience caring for infants and families in the NICU when the infant has symptoms of withdrawal following a substance-exposed pregnancy.



Participants who complete the study will receive a \$25 store card.

If you are interested in being contacted, click this secure link to provide your contact information xxxxxx.qualtrics.com or contact Amber Welborn at: nicuNurseStudy@unca.edu

APPENDIX D
DEMOGRAPHICS QUESTIONNAIRE

1. What is your age (in years)?
2. With what gender do you identify most? Please circle:
 - Female/Male/Other
3. How many years have you been practicing as a nurse?
4. How many years have you been practicing nursing in a NICU?
5. Which state do you currently work within?
6. Which state do you reside?
7. What is your highest earned degree in nursing? Please circle:
 - Diploma/ADN/BSN/MSN/DNP/PhD
8. Do you hold a clinical specialty certification? Yes/No
 - If yes, please state which one(s):
9. With what level of expertise would you categorize yourself? Please circle:
 - Novice/Advanced Beginner/Competent/Proficient/Expert/Not sure
10. Do you, or have you ever, considered yourself in a mothering role to any children?

11. About how many infants with a suspected or diagnosed substance-exposed pregnancy have you cared for in past year?
12. Do you have close friends or family with substance use concerns? Yes/no
- If yes, briefly describe:
13. Are you a parent or primary caregiver? Yes/no
- How many children do you have (biological, adopted, foster, etc.)?
14. What is the acuity level of the NICU where you are employed?
15. Is the NICU where you are employed located in a rural area? yes/no/don't know
16. Does the NICU where you are employed serve primarily rural or urban patients?
- rural/urban/don't know/both
17. Do you view and/or engage with Facebook and/or Instagram? Please circle:
- Facebook/Instagram/Both
18. Where do you keep up to date or read about current issues related to NICU nursing, specifically issues around substance use in pregnancy and related newborn care?

Please circle all that apply:

- Social media articles/NICU professional journals/professional social media groups/websites/general news outlets/Other, please list:

- Please list any specific journals or websites

APPENDIX E

INTERVIEW GUIDE

An Exploration of Discourses of NICU Nurses Caring for Infants with Symptoms of a Substance Exposed Pregnancy (SEP)

Aim: To gain understanding of the social construction of mothers who use substances in pregnancy by nurses who care for the infant and family following a SEP.

Interviewer:

I would like to learn more about your experience caring for infants and families in the NICU (Neonatal Intensive Care Unit) when the infant has symptoms of abstinence following a substance-exposed pregnancy. I would like you to include caregiving stories where a SEP was officially diagnosed and also when it was only suspected. I'm interested in hearing stories that exemplify the similarities and differences of infants and families with and without symptoms of SEP. I'll be asking follow up questions that help me understand the full story, including the background, contributing events and people, and afterthoughts. Take your time to respond completely and thoroughly. I'm not in a rush.

I will take notes as we talk, and may stop along the way to ask for clarification or more detail. I will focus on your stories, and would like examples of experiences, with as much detail as possible. If I have questions later, my I contact you for clarification.

1. What name did you choose for your demographic survey?

2. Tell me how you came to be a NICU nurse.
3. What is it like to work in your NICU? within the larger organization? How is your working environment (related to how people are treated by the leadership, how people are treated within the care team, communication within the unit and within the care team, and the valuation of nurses)
4. Can you tell me about the most memorable experience, for any reason, you have had caring for an infant with symptoms of a substance exposed pregnancy?
 - a. What other factors do think may have contributed to that experience being so memorable?
 - b. What did the people involved do or not do that had an effect on the dynamic of the nurse-family relationship?
 - c. What was the outcome?
 - d. What could have made the outcome better?
 - e. What could have gone wrong and led to a poor outcome?
5. Some people think that caring for infants and families with symptoms of a substance exposed pregnancy would be rewarding. Do you agree with this statement?
 - a. Tell me a story that describes a specific instance where you felt it was particularly rewarding?
 - b. What preceded and contributed to the incident?
 - c. What did the people involved do or not do that had an effect on the dynamic of the nurse-family relationship?
 - d. What was the outcome?
 - e. What could have made the outcome even better?
 - f. What could have gone wrong and led to a poor outcome?
6. What successes, particularly related to the family, have you experienced?
 - a. Can you tell me about a specific instance where you experienced this success?
 - b. What preceded and contributed to the incident?

- c. What did the people involved do or not do that had an effect on the dynamic of the nurse-family relationship?
 - d. What was the outcome?
 - e. What could have made the outcome even better?
 - f. What could have gone wrong and led to a poor outcome?
- 7. Some people think that caring for infants and families with symptoms of a substance exposed pregnancy would be difficult or challenging. Do you agree with this statement?
 - a. Tell me a story that describes a specific instance where you felt it was particularly challenging?
 - b. What preceded and contributed to the incident?
 - c. What did the people involved do or not do that had an effect on the dynamic of the nurse-family relationship?
 - d. What was the outcome?
 - e. What could have made the outcome better?
 - f. What could have gone wrong and led to a worse outcome?
- 8. When you think about caring for infants with symptoms of a substance exposed pregnancy, what problems or concerns related to their family have you experienced?
 - a. Tell me a story that describes a specific instance where you felt working with the family was particularly challenging or concerning?
 - b. What preceded and contributed to the incident?
 - c. What did the people involved do or not do that had an effect on the dynamic of the nurse-family relationship?
 - d. What was the outcome?
 - e. What could have made the outcome better?
 - f. What could have gone wrong and led to a poor outcome?
- 9. Do you find differences in the overall nursing practice of caring for infants and families with symptoms of a substance exposed pregnancy compared to other families?
 - a. Can you tell me a time when that happened?

10. What are some things that help you provide the best care? i.e.; unit policies, leadership, team dynamic, access to tools such a swings, unit layout, technology, etc.
11. Tell me about anything that is a barrier for you to provide the best care. i.e.; unit policies, leadership, team dynamic, access to tools such a swings, unit layout, technology, etc.
12. Tell me about the relationship between nurses at the bedside and the NP's and Neo's who are writing the orders? especially for meds for NAS babies.
13. If you were orienting a new nurse, what would you teach them about caring for infants and families in this circumstance that they may not learn from a text book? What advice would you give about this situation?
14. If you were designing an education program for NICU nurses, new or experienced, what would be important to include?
15. Anything else you'd like to tell me about this topic?

STOP RECORDING

How did you hear about the study?

Gift card to: _____

Call permission later?

APPENDIX F

EMAIL TO NURSES PRIOR TO INTERVIEW

Hi *Nurse*,

Just a reminder that your interview time is: ____day, XX:XX, at *location*.

I'd like for you to be thinking about a couple of experiences you've had while caring for an infant who had symptoms of a substance-exposed pregnancy. The infant may or may not have been diagnosed with neonatal abstinence syndrome. That detail is not the focus of this study. If you suspected that an infant was exposed to substances in pregnancy, please include those experiences in your consideration. Think of two examples of caregiving experiences

1. The best experience you can remember, for whatever reason.
2. The worst experience you can remember, for whatever reason.

As you consider these memories, try and remember as much as you can so that you may share as many details with me as possible. It's okay to consider a variety of experiences as you think about the best and worst. Those other experiences may help you answer other questions I ask about caring for infants and families with a substance-exposed pregnancy.

Thanks so much, and I look forward to working with you.