9-2021

Neonatal Opioid Withdrawal Syndrome and Promotion of Maternal Caregiving: Missing Voices of Mothers in Medication Assisted Treatment

Hedi Levine
The Graduate Center, City University of New York

NEONATAL OPIOID WITHDRAWAL SYNDROME AND PROMOTION OF MATERNAL CAREGIVING: MISSING VOICES OF MOTHERS IN MEDICATION ASSISTED TREATMENT

By

HEDI S. LEVINE

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2021

Neonatal Opioid Withdrawal Syndrome and Promotion of Maternal Caregiving:
Missing Voices of Mothers in Medication Assisted Treatment

By

Hedi S. Levine

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy

Date	Diane DiPanfilis Chair of Examining Committee
Date	Barbra Teater Executive Officer

Supervisory Committee:

Diane DiPanfilis, Ph.D.

Alexis Kuerbis, Ph.D.

Daniel Herman, Ph.D.

THE CITY UNIVERSITY OF NEW YORK

ABSTRACT

Neonatal Opioid Withdrawal Syndrome and Promotion of Maternal Caregiving:
Missing Voices of Mothers in Medication Assisted Treatment

By

Hedi S. Levine

Advisor: Diane DePanfillis, Ph.D.

Abstract:

In response to the increasing rates of opioid exposure among pregnant women and their infants, the Substance Abuse and Mental Health Services Administration (SAMHSA) published "Clinical Guidance for Treating Pregnant Women with Opioid Use Disorder and Their Infants" (2018). The expert panel, which was assembled for this clinical guidance did not include women who were the focal subjects for the guidance. The current qualitative study contributed the missing voices of women in methadone-assisted treatment (MAT) who gave birth subsequent to the publication of the guidance. The SAMHSA guidance was based upon a preponderance of evidence guiding recommended practices regarding rooming-in, breastfeeding, and positive relationships with healthcare providers, such as nurses and lactation consultants. Women in MAT who gave birth subsequent to the publication of the guidance described their experiences and identified recommended practices. The researcher employed narrative, descriptive/thematic, and comparative analyses to conclude the following: Current practices affected the women's caregiving opportunities. The women's recommendations largely aligned with those of the SAMHSA guidance. However, their experiences did not align with the recommended practices.

The researcher identified the need for systemic approaches to implementing the clinical guidance.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

CHAPTER ONE: INTRODUCTION

Introduction to Research Focus

The connection between caregiver and infant is universal to physical survival as well as social and psychological development (Small, 1998). Though infants' foundational needs remain comparatively constant, mothers give birth to infants in a wide variety of historical, social, and circumstantial contexts where those needs may be met. This study explores such a context – the particular intersection between the opioid epidemic, mothers who seek methadone treatment during pregnancy and childbirth, infants who may require observation and treatment in hospitals, and early care relationships that occur in that environment. Observation and treatment for infants who are opioid exposed are most frequently provided in neonatal intensive care units (NICU) of hospitals where institutional policies affect medical and nursing practices, which in turn affect interactions between mothers and their infants

Human needs are met in social environments, where the legacy of cultural values guides human behavior (Vygotsky, 1978). Institutions and the practices within them are thus socially constructed, affected by hierarchies of age, marital status, and previous and current alcohol and drug use. Erving Goffman has described power relations within institutions as affected by social stigma directed by those with power toward specific groups, including, he wrote, "drug addicts" whose defects are interpreted as a repudiation of the social order (Goffman, 1963 p. 143). Feminist sociologists Chase and Rogers also wrote about stigma and drug-dependence in the context of the "crack epidemic" in the 1980s and 1990s, describing the social construction of drug-dependent pregnant women as "bad" mothers - women who were the stigmatized objects of a larger social problem (Chase and Rogers, 2001, p. 41). These mothers were "deemed bad on the basis of their social characteristics or unfounded assumptions about the damage they cause

their children" (Chase and Rogers, 2001, p. 31). Likewise, mothers who undergo MAT to treat OUD are stigmatized despite their effort to seek treatment for addiction and healthcare during pregnancy.

These stigmatizing social attitudes may be enacted by policies and hospital professionals and affect the hospital experiences of women in medication-assisted treatment (MAT) when they give birth. A robust body of research demonstrates that like other infants, infants who are treated for opioid exposure thrive when their mothers stay close, hold, and breastfeed them and subsequently require fewer and briefer treatments (SAMHSA, 2018; Grossman, Seashore, & Holmes, 2017; Klaman, Isaacs, Leopold, et al. 2017; Boucher, 2017; Bagley, Wachman, Holland, & Brogly, 2014; MacMullen, Duski, & Blobaum, 2014). These mothering opportunities benefit women as well. Women have described their children as a motivating factor in their recovery (Villegas, Chodhury, Mtirani, and Guerra, 2016; Hines, 20012; Jackson and Shannon, 2012; McComish, Greenberg, Ager, Essenbacher et al, 2003; Scott-Lennox, Rose, Bohlig, and Lennox, 2000). Thus, positive experiences in the earliest days and weeks of parenting have the potential to help new mothers who are methadone maintained sustain their courses of treatment: "Adult development in the parenting role can potentially and profoundly modify the course of an addiction," (Suchman, Pajulo, & Mayes 2013, p. xix).

Despite the reciprocal value of methadone maintenance to both members of the mother infant dyad, we know little about how mothers, who are methadone maintained for opioid use disorder (OUD) during pregnancy and after giving birth, perceive the caregiving opportunities they are given, or not given, in the hospitals where they have given birth. Consequently, the value these women's perceptions of their hospital experiences with their infants might bring to planning practices and policies regarding treatment of pregnant women in MAT goes untapped.

Definition of Key Terms

Definition of opioids.

Opioids refer to the class of narcotic drugs that bind to the brain's pleasure and reward receptors; extended use alters both the function and structure of the brain (Upadhyay & Maleki, et al., 2010; Younger & Chu Et Al., 2011). Both historically and currently, opioids have been used medically as pain relievers, though they pose a high risk of addiction to patients using them either as prescribed or illicitly (Kolodny, et al., 2015). These highly addictive drugs include drugs that are manufactured synthetically, such as oxycodone, fentanyl, and methadone, as well as opiates, those opioids that are derived from opium poppy plant, such as heroin, morphine, and codeine.

Definition of Opioid Use Disorder (OUD).

In the Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition (DSM-5) opioid use disorder (OUD) is diagnosed when the patient demonstrates a problematic pattern of long-term opioid use accompanied by persistent desire for the opioid, cravings, despite persistent or recurrent social problems, including subjecting oneself to physical hazards. OUD is characterized by increasing tolerance for opioids and withdrawal symptoms when a person ceases using opioids.

Opioids as a Public Health Crisis

Beginning in the late 1990s, over-prescription of opioid pain relievers (OPR) led to an increase in opioid use resulting in an opioid epidemic - a public health crisis that continues to affect men, women, and children (Kolodny, Courtwright, Hwang, et al., 2015). According to the CDC analysis of the 2016 NSDUH data, 11.5 million people self-reported that they had misused

prescription opioids during the previous year. However, the opioid epidemic is not restricted to use of prescription OPRs. Indeed, the relationship between OPRs and heroin is well established. According to an analysis of the 2011-2013 National Survey on Drug Use and Health (NSDUH) data by Centers for Disease Control (CDC) people who are addicted to opioid pain relievers were 40 times more likely to become addicted to heroin. This translates into the lives of 7.6 million Americans who met criteria for substance use disorder: among them 6.6% used psychotherapeutic drugs including prescription opioids, and .3% used heroin (NSDUH, 2017).

Opioid Use Among Pregnant Women

With this prevalence in opioid use, there is also a widespread prevalence in the use of opioids among pregnant women. From 2000 to 2009, the number of pregnant women using or dependent upon opiates increased more than fivefold from 1.19 to 5.63 per 1,000 hospital births per year (Patrick, et al., 2012). Haight, Ko, and Tong, et al. (2018) used a later sample (1999-2014) to estimate a continued increase from 1.5 to 6.5 per 1,000 delivery hospitalizations of mothers with opioid use disorder (OUD). Most recently, according to Healthcare Cost and Utilization Project (HCUP) data through 2016, nearly one in five opioid related stays among women from 15 to 44 involved pregnancy and childbirth (Weiss, McDermott, & Hesline, 2019).

Among women who use opioids during pregnancy are women who use prescribed opioids for chronic pain or as part of their treatment for OUD; and women who misuse opioids or heroin, with untreated OUD. It is significant, however, that pregnancy influences women's use of illicit drugs by increasing motivation to seek treatment for opioid dependency. Among women between 15 to 44 years, 5.4% of pregnant women used illicit drugs, a rate lower than the 11.4% reported among women who were not pregnant. Furthermore, women reduce illicit drug use during each trimester of pregnancy: 9% report illicit drug use in the first trimester, 4.8% in

the second trimester, and 2.4% in the third trimester (SAMHSA, 2014). Accordingly, American College of Obstetricians and Gynecologists (ACOG) and American Society of Addiction Medicine (ASAM) note in their guidelines to obstetricians and gynecologists who may treat pregnant women with opioid use and opioid use disorder, by saying "Pregnancy provides an important opportunity to identify and treat women with substance use disorders" (Mascola, Border, & Terplan, p. 2017, p.3).

Opioid Agonist Maintenance Medications: Standard of Care for Pregnant Women with OUD

Both methadone and buprenorphine are medications approved by the Federal Drug Administration to reduce cravings and withdrawal symptoms as treatments for OUD (National Institute on Drug Abuse). Both treatments are considered more effective than abstinence in preventing relapse in general (Srivastava, Kahan, & Nader, 2017). While methadone is the standard of care for pregnant women, recent research demonstrates that buprenorphine, while less extensively studied, should be considered as a viable alternative for treatment for pregnant women with OUD (Jones, Kaltenbach, & Heil, et. al., 2010; Jones & Kaltenbach, 2013). Indeed, the SAMSHA clinical guidance recommends treatment with either methadone or buprenorphine (2018).

To encompass use of both medications to treat OUD pharmacological treatments may be referred to as opioid agonist treatment (OAT) or, more commonly medication assisted treatment (MAT). Methadone is a long-acting, synthetic opioid agonist administered by prescription and part of therapeutic treatment and recovery support. Buprenorphine is a partial opioid agonist, also known to reduce cravings and withdrawal symptoms. Properly administered (NIDA; Jones,

et al., 2010) both methadone and buprenorphine have benefits for the fetus and the mother. Both treatments, in comparison to heroin, stabilize the intrauterine environment, and reduce incidents of fetal distress and miscarriage, and the likelihood of maternal behaviors associated with illicit drug use, such as poor needle hygiene, and potentially hazardous efforts to obtain or use drugs. In addition, access to MAT is associated with increased access to prenatal care during pregnancy (SAMHSA, 2018; Enomoto, 2016; Kaltenbach, Berghella, & Finnegan, 1998, in Patrick et al., 2012; Jones, O'Grady, & MALFI et al, 2008, in Patrick et al., 2012).

Neonatal Opioid Withdrawal Syndrome: Epidemiology and Limitations of Data

When pregnant women use opioids regularly, their newborns are likely to experience withdrawal symptoms related to intrauterine opioid exposure referred to as neonatal opioid withdrawal syndrome (NOWS). As recently as 2019, this syndrome was more commonly referred to as neonatal abstinence syndrome (NAS) but the more specific term, NOWS, currently in use (Patrick, Barfield and Poindexter, 2020) distinguishes the use of opioids from other substances. MAT during pregnancy for either dependency upon heroin or opioid prescription pain relievers also frequently results in symptoms associated with infant withdrawal (Hudak & Tan, 2012).

Definition of NOWS and NAS.

Infants with NOWS have neurological and gastrointestinal symptoms that include irritability, increased wakefulness, high-pitched crying, seizures, poor feeding, uncoordinated sucking, vomiting, diarrhea, dehydration, and poor weight gain (Hudak & Tan, 2012). Caring for infants with these symptoms is challenging to primary healthcare providers and mothers and other family members. The term neonatal opioid withdrawal syndrome (NOWS) is specific to in utero opioid exposure. Until recently, NAS was more commonly used in both research and by

federal agencies, including the Federal Drug Administration (Patrick, et al., 2020) and SAMHSA.

Prevalence of NOWS

With this increase in opioid use and opioid use disorder among pregnant women, there has been a corresponding increase in the incidence and prevalence in babies born with NOWS. For example, from 2000 to 2009, the number of infants diagnosed with NOWS increased threefold. Patrick, Schumacher, and Bennyworth (2012) estimated the incidence of NOWS diagnoses increased from 1.20 per 1,000 hospital births in 2000 to 3.39 per 1,000 hospital births in 2009 (Patrick, Schumacher, Benneyworth, 2012). When data encompasses the years from 1999 to 2013, the increase in cases is 300 percent, culminating in 6 cases per 1,000 in 2013 (Ko, Patrick, Tong, Patel, et al., 2016).

NOWS and hospital care.

Infants diagnosed with NOWS may require treatment for withdrawal and that treatment is most often in the neonatal intensive care unit (NICU) of hospitals (Patrick, Schumacher, Benneyworth, 2012). The prevalence of infants born with the symptoms of NOWS has made demands upon the hospitals where they receive care. The National Institute on Drug Abuse (NIDA) estimates that every twenty-five minutes a baby is born who will suffer from NOWS (2015).

Treating Neonatal Opioid Withdrawal Syndrome

Research suggests that engaging mothers in direct care of infants with NOWS through proximity, breastfeeding, and swaddling may mitigate infants' symptoms and promote bonding (Mascola, et al., 2017; Kaltenbach, et al., 1998; Klaman, et al., 2017). The post-partum interval

after birth is a sensitive period for bonding and attachment (Klaus, Jerauld, Kreger, McAlpine, et. al., 1972). When hospitalization is a factor, bonding is aided by the practice of keeping the infant and the mother in the same room (rooming-in) rather than in a nursery. Rooming-in is also considered a means to protect, support, and promote breastfeeding, thus, it is an important element in the World Health Organization's (WHO) Baby Friendly Hospital Initiative. The association between rooming-in and breastfeeding is no less important for methadone- or buprenorphine-maintained mothers and opioid exposed newborns (Jansson & Velez, 2008).

Due to their special needs, infants with NOWS diagnoses have been most frequently treated in the NICU (Patrick, Davis, & Lehman, 2015; Murphy-Oikonen, Brownlee, Montelpare & Gerlach, 2010) where the treatment environment is itself a factor that influences the relationship between mother and infant. The NICU is recognized as a challenging environment for families, thus family-centered developmental care is conceptualized to mitigate the effects on parent-baby interactions (Craig, Glick, & Phillips, et al., 2015; Westrup, Sizun, & Lagercrantz, 2007). The protracted stay in the hospital for the infant with NOWS means that the hospital is the setting where the early relationship between mother and infant is established. The infant's length of stay in the hospital is therefore another feature of NOWS care, which may be problematic for the parent-child relationship. According to one estimate, hospital stays for infants due to substance use were approximately four times as long as other neonatal stays, with the mean length of stay 14.7 days (Fingar, Stocks, Weiss, & Owens, 2015). Patrick, Davis et al. (2015) estimated that infants with NOWS remained in the hospital an average of 16.9 days compared to 2.1 days for uncomplicated term newborns.

Studies of NOWS assessment and management are divided into assessment of NOWS severity, pharmacological or medical management, and non-pharmacological or supportive care.

Opioid exposed neonates suffering from neonatal opioid withdrawal syndrome (NOWS) require fewer and briefer medical and pharmacological interventions when mothers remain close by, hold, breastfeed, and otherwise participate in infant care, the so-called non-pharmacological interventions (Bagley, Wachman, Holland, & Brogly, 2014; Abrahams, 2007; Holmes, Atwood, Whalen, et al., 2016; Grossman, 2017). Concluding their analysis of the literature, Bagley and colleagues wrote, "Creating a more secure, compassionate, and comfortable environment for the dyad will likely optimize outcomes for both mother and infant" (2014, p. 8).

Best Practice Guidelines Established by Professionals

Based upon evidence about non-pharmacological interventions and the emergence of practice guidelines by American Academy of Breastfeeding Medicine, American Association of Pediatrics, and American Society of Addiction Medicine with the American College of Obstetricians and Gynecologists, both the World Health Organization (2014) and Substance Abuse and Mental Health Services Administration (2018) developed recommendations for effective treatment of pregnant and post-partum women and their infants diagnosed with NOWS. The consensus for their recommendations was robust. Those recommendations include: maternal proximity, mother-infant skin-to-skin contact, breastfeeding, rooming-in, and a quiet hospital environment—factors that support infant-mother bonding in the context of NOWS. In addition to recommending practices, SAMHSA and WHO guidelines addressed the need for professionals to respect the autonomy of pregnant and breastfeeding women, provide a greater level of education to promote shared decision-making, and recognize that stigmatization and legal policies remain barriers to care.

Missing Voices of Mothers in Medically Assisted Treatment

Pregnant women who were methadone-maintained and who have given birth to infants who were opioid exposed, have experienced the hospital environment during their infants' observation or treatment for NOWS. Given this experience and the importance of their maternal role in mitigating the symptoms of neonatal opioid withdrawal, their voices regarding the practice recommendations implemented at the hospital level are critical to the discourse about care of the infant and care of the dyad. Despite the critical role they play, mothers who are methadone-maintained have had minimal input in research interpreting the recommendations in practice.

Problem Statement

Robust parent engagement is a foundational element of NOWS treatment. But, without amplifying the mothers' impressions of the current state of treatment it is difficult to know what elements of practice are meeting the needs of methadone-maintained mothers and their infants during the post-partum period to attain the goal of robust parent engagement. Along those lines, in 2003, the National Academies Press summarized a roundtable about the clinical research enterprise urging, "systematic inquiry with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting (sic) change" (p. 1). To better understand how to engage mothers in infant care, mothers maintained on methadone must be invited to share their experiences so their perspectives can be incorporated into implementation planning and guidance.

Description of This Study

This dissertation research explored the missing perspectives of mothers who are methadone-maintained, using a qualitative approach. The purpose of the study was to gather

mothers' observations and commentary about practices that promote maternal caregiving of newborns who were opioid exposed by learning of mothers' experiences before and during hospitalization; to understand the effect of preparation and education, shared decision-making, organization of hospital structures and routines, and of hospital professionals' attitudes on mothers' participation in caregiving; and to elicit mothers' suggestions from a position of authority.

Research Sample: Women In Medically Assisted Treatment (MAT)

For this study, women who were in methadone-assisted treatment when they gave birth, and who were currently in treatment, were invited to participate in individual interviews. Mothers are important stakeholders who can contribute their observations, opinions, and suggestions to the professional discourse around clinical guidance about the care of newborns with NOWS and treating the dyad.

Methodology: Narrative Inquiry

This descriptive exploratory study (Marshall and Rossman, 1999) employed a research design that incorporated three levels of qualitative analysis: narrative, qualitative descriptive, and comparative. One essential feature of narrative research is preservation of individual identity in stories told (Reisman, 2008). Nevertheless, researchers can assemble individual stories into a "'fuller' picture of the individual or group" (Reiseman, p. 11). The researcher's analysis thus proceeded from the individual narratives, to thematic analysis, and finally to a comparative analysis in order to explore the women's experiences individually, collectively, and in comparison to the SAMHSA guidance.

The purpose of the study was to explore the post-partum caregiving experiences, in hospital settings, of women with opioid use disorder who were in MAT while pregnant. The

mothers were able to describe the phenomenon of interest – the support available for maternal proximity, breastfeeding, and caregiving - based upon their experiences and in comparison to accepted clinical guidance. The guidance, aggregated by SAMHSA also constituted data.

Implications for This Study and What This Study Adds

Current research and guidelines suggest the best outcomes for an infant born to a mother who is in MAT for opioid use disorder will be attained when that mother is the infant's primary caregiver who rooms-in with the infant and remains close by to hold, breastfeed, and console. No research to date has explored how mothers who are in or have been in MAT experienced the supports available to attain this model of care in the complex social environment of the hospital units where the infant care for NOWS is often situated. Current research has not compared the women's recommendations for practice to the SAMHSA recommendations. Nor has current research explicitly compared the women's experiences with the SAMHSA recommendations to determine if the SAMHSA guidelines were implemented in their cases.

Two sets of researchers have studied the family perspective about the hospital stay during treatment for NOWS. Atwood, Sollender, Hsu, et al. (2016) used a qualitative approach with the objective of using the families' experience to inform the direction of quality improvement in a hospital where infants were treated for NOWS in several hospital units. Approximately half the 20 interview participants were mothers, though they were not exclusively in MAT. The work of researcher Lisa Cleveland and her colleagues Rebecca Bonugli and Kelly McGlothen (2016; Cleveland & Bonugli, 2014) explored the mothering experiences in the NICU of women with substance use disorders in methadone treatment. The researchers identified themes including several that touch upon mothering as a motivation to stay in treatment, the value of the caregiving role in that regard, and interactions with the nursing staff.

The current study differs from prior research in the following ways: No studies to date have examined the specific experiences of mothers in MAT as primary caregivers and care partners during their infants' treatment for withdrawal in the weeks immediately after birth. Prior research has not specifically compared the mothers' experience to practice guidelines established by SAMHSA, or elicited their suggestions for improving maternal engagement in the care of their infants. The current study also uniquely explored maternal experiences in multiple locales, whereas previous studies investigated experiences in San Antonio, Texas and rural and urban New England. By seeking the perspectives of mothers who are in medication assisted treatment (MAT) regarding their experiences as their infants' caregivers in the hospital the researcher identified how they perceived the environment – both human (nurses and other professionals) and structural (routines, rules, accommodations) – as an impediment or support to the maternal primary caregiving role during their infants' hospitalization and treatment for NOWS.

Relevance to Social Welfare Scholarship

This Social Welfare dissertation study explored and described the experiences of mothers, who have opioid use disorder, are in medically assisted treatment (MAT), and who gave birth in hospitals. A recent United Hospital Fund report applied the metaphor of the "ripple effect" to the opioid epidemic, depicting a Bronfenbrenner-like ecological model radiating outwards from a mother with substance use disorder to family members and the community involved in providing care (Brundage & Levine, 2019, p. 6). Likewise, treatment for addiction cuts across multiple individual, community and agency levels. Indeed, collaboration between agencies and health care and addiction treatment organizations is globally recognized as a strategy to address the impact of the opioid epidemic (SAMHSA, 2016a), so that policy, treatment, and individual support are available to women with OUD.

The most recent SAMHSA guidelines aim to support clinicians in bringing these recommendations into practice for pregnant and parenting women with opioid use disorder and their infants (SAMHSA, 2018). The exploration and description of this cross-sectional problem is within the Social Welfare doctoral program's mission for scholarship for social change. By exploring the hospital experiences of the women affected by these policy and practice recommendations, this qualitative research contributes the voices of parenting women with OUD to the practice-relevant discourse that touches policy and practice across multiple human service organizations.

Organization of Study

In Chapter Two, the challenges facing women of reproductive age who are giving birth to infants with NOWS are situated within the overall surge of opioid use documented in epidemiological research. In the literature review, I briefly address elements of federal, state, and local policy that may affect women as caregivers in the NICU. Notably, federal, state, and local policies may criminalize and inhibit access to treatment for substance and/or opioid use disorder among pregnant women, or conversely, promote it.

Professional guidelines reflect both past research and institutional objectives for recommended practices. I draw parallels between objectives expressed in these guidelines and the closely aligned principles of family centered care and newborn individualized developmental care, all of which have influenced hospital practices to support parent involvement for all newborns with medical needs.

In the remaining section of Chapter Two, I focus upon characteristics of mothers, opioid-exposed infants, and nurses that intersect during the post-partum period in the hospital. In this section I describe factors known in existing research to affect the interactions of these three

stakeholders. For example, for many opioid-dependent pregnant women, MAT is a first step in caring for their baby, but non-addiction health care professionals, such as NICU nurses, may not be knowledgeable about methadone or buprenorphine as a mother's first step toward caring for the infant. Consequently, methadone- or buprenorphine-maintained mothers with newborns in the NICU may be affected by biased attitudes that may undermine implementation of guidance objectives. Infants with NOWS are characteristically challenging to soothe and feed, and mothers and nurses alike may be affected by the demands of caring for infants in withdrawal. Finally, I consider qualitative research exploring maternal encounters with professional staff and related challenges experienced by mothers with histories of opioid use disorder in the NICU, to identify methods and gaps in the existing research as they relate to this study.

Chapter Three includes a discussion of three related theories that inform the research. First, attachment theory describes a dynamic and interactive relationship between an infant's needs and maternal response. Bowlby (1969) and Ainsworth (1978) theorized that when the infant signals the mother responds contingently to the infant's needs. This theory underlies hospital practices that promote engagement between mothers and newborns, and will serve as a foundation in discussion of the particular mothers and newborns considered here. Second, social cultural theory describes learning as social and historical (Vygotsky, 1978). Within social relationships people learn as participants in immediate social interactions; more experienced or knowledgeable partners share specialized knowledge with those who are in the process of learning. All learning is cultural and historical because it is enacted using tools that have evolved over time; language, written expressions (like guidelines), and institutions (such as hospitals), are examples of culturally and historically evolved tools. Third, activity theory aims to study the system (Engestrom, Miettinen, & Punamaki, 1999) theorizing the relationship of all stakeholders

as active participants who experience meaning regardless of hierarchical notions of power or influence (Tobach, 1999). Activity theory identifies the hospital as a context for attachment between infants and mothers, maternal acquisition of caregiving skills, and where professional guidelines and practices are expressions of shared knowledge accumulated over time. Developed from Vygotsky's social cultural theory, activity theory posits a relationship between externalized structures and internalized meanings.

Chapter Four includes the rationale for the study's research design and the recruitment strategy, and the methods for collecting qualitative data. The SAMHSA guidelines and the mothers' narratives about their experience within hospital are data sources. The research design and analysis purposefully promotes dialogue between the SAMHSA guidelines, its reflection within the system of NOWS infant care, and maternal perspectives. The data collection plan specifies individual interviews to amplify previously unexplored perspectives of methadone-maintained mothers regarding specific support for their engagement in infant care during the post-partum period. In Chapter Four the researcher describes the analytic plan to include three levels of research data and analysis: narrative, thematic, and comparative.

Chapter Five includes the results of the study. As noted immediately above, the researcher presents results in three progressive sections. First, the researcher presents the four narratives, based upon the interviews with four participants. Within this chapter, the researcher then presents thematically organized data. The women's priorities regarding their experiences as revealed in this portion of the results align with SAMHSA guidance and also begin to reveal observations unique to the mothers' perspective. The third and final portion of results chapter is a comparative analysis. The researcher presents the participants' observations and recommendations in direct comparisons to the SAMHSA guidance.

In Chapter Six the researcher discusses the meaning and implications of the study results. The women who were interviewed for the study gave birth between 2018 and 2020. Their experiences provide a view into opportunities available to them during that period of time in relation to the SAMHSA guidelines. In addition, in Chapter Six the research identifies areas for further research.

CHAPTER TWO: LITERATURE REVIEW

Definition of Key Terms

Opioid use disorder (OUD).

In the Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition (DSM-5) opioid use disorder (OUD) is diagnosed when the patient demonstrates a problematic pattern of long-term opioid use accompanied by persistent desire for the opioid, cravings, despite persistent or recurrent social problems, including subjecting oneself to physical hazards. OUD is characterized by tolerance of and withdrawal from opioids.

Opioid agonist maintenance medications: Standard of care for pregnant women with OUD.

Both methadone and buprenorphine are medications approved by the Federal Drug Administration to reduce cravings and withdrawal symptoms as treatments for OUD (National Institute on Drug Abuse). Both treatments are considered more effective in preventing relapse in general (Srivastava, Kahan, & Nader, 2017). While methadone is the standard of care for pregnant women, recent research demonstrates that buprenorphine, while less extensively studied, should be considered as a viable alternative for treatment for pregnant women with OUD (Jones, Kaltenbach, & Heil, et. al., 2010; Jones & Kaltenbach, 2013). Indeed, the SAMSHA clinical guidance recommends treatment with either methadone or buprenorphine (2018).

To encompass use of both medications to treat OUD pharmacological treatments may be referred to as opioid agonist treatment (OAT) or, more commonly medication assisted treatment (MAT). Methadone is a long-acting, synthetic opioid agonist administered by prescription and

part of therapeutic treatment and recovery support. Buprenorphine is a partial opioid agonist, also known to reduce cravings and withdrawal symptoms. Properly administered (NIDA; Jones, et al., 2010) both methadone and buprenorphine have benefits for the fetus and the mother. Both treatments, in comparison to heroin, stabilize the intrauterine environment, and reduce incidents of fetal distress and miscarriage, and the likelihood of maternal behaviors associated with illicit drug use, such as poor needle hygiene, and potentially hazardous efforts to obtain or use drugs. In addition, access to MAT is associated with increased access to prenatal care during pregnancy (SAMHSA, 2018; Enomoto, 2016; Kaltenbach, Berghella, & Finnegan, 1998, in Patrick et al., 2012; Jones, O'Grady, & MALFI et al, 2008, in Patrick et al., 2012

Opioid use disorder (OUD), pregnant women, and NOWS.

Several epidemiological studies demonstrated an increase in maternal drug use between 2000 and 2009, which corresponds to the incidence of neonatal abstinence syndrome (NOWS) (Fingar, Stocks, Weiss, & Owens, 2016; Patrick, Schumacher, Benneyworth, Krans, McAllister, & Davis, 2012). Between 2000 and 2009 women reported using opiates during the prenatal period at a rate that increased from 1.19 to 5.63 per 1000 hospital births; during the same period NOWS was diagnosed in newborns at a rate of 1.20 per 1000 hospital births compared to 3.39 in 2009 (Patrick, et al., 2012). The data does not differentiate maternal methadone use, as part of a methadone maintenance program, from other opioid use at delivery. Both Haight et al. (2018) and Patrick et al. (2012) employed International Classification of Diseases, Ninth Revision (ICD-9) coding to document the association between maternal OUD and the increased incidence of NOWS, with limited specificity regarding the source of OUD. For example, Patrick et al. (2012) combined discharge data from ICD-9 codes diagnosing the following three categories: 1) dependency on opiates, 2) using opiates, 3) and taking long-term methadone.

Background: Shifting Orientation of NOWS Treatment

Coinciding with the emergence of epidemiological data, nursing and NICU literature aimed to establish best practices to manage and care for infants with NOWS. Historically, assessment of the infant's symptoms and pharmacological interventions were the subjects of research, guiding approaches to treatment of infants diagnosed with NOWS (Jones & Fielder, 2015). Practice as usual for opioid exposed infants and mothers, separated the infant and the mother to admit the infant with NOWS symptoms to the neonatal intensive care unit (NICU) (Abrahams, Kelly, & Payne, et al., 2007). This practice of separation occurred for mothers with NOWS despite abandonment of these practices for families with infants with other conditions in the NICU. For these other families, keeping the infant and mother together and involving the family in care were recommended and considered optimal care (Milette, Martel, Ribeiro da Silva, & Coughlin McNeil, 2017; Craig, et al., 2015; Hedberg Nyqvist & Engvall, 2009). With the surge in NOWS diagnoses, clinical opinion highlighted the primacy of supporting the dyad in treatment for infants with NOWS as well (Velez & Jansson, 2008). Measuring length of stay and need for pharmacological treatment, researchers reported the positive effects of keeping mothers and infants in the same room, called "rooming-in" (Abrahams, Kelly, Payne, et al., 2007); breastfeeding (Bagley, Wachman, Holland & Brody, 2014); and other non-pharmacological supportive approaches (Bagley, et al., 2014), such as maintaining a dark and quiet room for the infant, minimizing sleep disruption, and maximizing skin-to-skin contact (Casper & Arbour, 2014).

Emergence of Global and Federal Clinical Guidance

Practice guidelines.

The Institute of Medicine (1990) defined clinical practice guidelines as "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances" (p. 8). In response to the surge of opioid use among pregnant women, lead organizations in the fields of obstetrics, gynecology, breastfeeding and pediatrics developed guidelines to address the care needs of women who used opioids during pregnancy and their opioid-exposed infants. The guidelines emphasized the role of the mother as part of the dyad addressing a range of issues, from the suitability of breastfeeding and breast milk when a mother participates in medically assisted treatment, to minimizing infant narcotic medications in NOWS treatment because of the risk posed to infant-mother attachment. Likewise, the World Health Organization (WHO; 2014) evaluated research and incorporated professional guidelines to address the international need for treatment guidance for substance use disorder and pregnancy. Finally, the Substance Abuse and Mental Health Services Administration (SAMHSA; Substance Abuse and Mental Health Services Administration, 2018) reviewed the literature on which these organizations' guidelines were based as they integrated findings, guidance, and clinical opinion to inform best practices specifically for opioid exposed mothers and infants with NOWS (See Table 1.).

SAMHSA found that the evidence for non-pharmacological interventions for treating NOWS was robust. Research pertaining to dyad-focused, non-pharmacological interventions most frequently compared treatment as usual (separating the mother and the infant) with rooming-in and breast-feeding (Bagley et al., 2014). Based on this research and with expert

clinical opinion, SAMHSA (2018) formulated practical guidance advocating for non-pharmacological approaches that intervene with the infant and mother as a dyad.

Figure 1. Summary of WHO and SAMHSA Guidance

Figure 1. Adapted from Clinical Guidance for Treating Pregnant and Parenting Women with

According to the combined WHO and SAMHSA Guidelines, the following are recommended best practices for infants with NOWS and their substance-exposed mothers:

- Caregivers (mothers and formal providers) should be educated (SAMHSA)
- Mothers are encouraged to breastfeed (WHO, SAMHSA)
- Mothers are encouraged to read and respond to their infants' cues
- Skin-to-skin contact is encouraged between infant and mother (WHO, SAMHSA under comforting))
- Infants should be swaddled and provided other comforting techniques (WHO, SAMHSA)
- Environmental factors should be attended to, such as low lights, quiet (WHO, SAMHSA)
- There should be rooming-in (SAMHSA)

Opioid Use Disorders and Their Infants (SAMHSA, 2018) and Guidelines for the identification and management of substance use and substance use disorders in pregnancy (WHO, 2014).

The SAMHSA document also specifically addresses social dynamics between hospital professionals and the mother infant dyad that affect maternal involvement with the newborn. These contacts occur within the hospital, an institutional context, which neonatal care quality improvement network Vermont Oxford Network (VON) recommends to be a "compassionate culture" (Schumacher & Patrick, 2015, p. 2.) SAMHSA identified the impact of shame as a barrier to treatment affecting women with OUD, perpetuated by "misinformation among

healthcare professionals" (SAMHSA, 2018, p. 3). By recommending a wide dissemination of information to healthcare professionals that MAT is recommended in comparison to abstinence in pregnant and post-partum women with opioid use disorder (Jones, Martin, Heil, et al., 2008), the guidance document confronts ubiquitous misinformation among hospital staff. In recommending education, SAMHSA aligns hospital practices in the treatment of the methadone- or buprenorphine-maintained mothers and their infants with standard practices promoting parents as caregivers when infants require medical care after birth (Craig, Glick, Phillips et al., 2015; WHO, 1992/2009). Likewise, the SAMHSA guidelines recommend patient education about NOWS to prepare mothers who are currently in a medically assisted treatment program about the likelihood of NOWS. This psycho-education also includes what a mother can do during her pregnancy, what to expect, what she can do after giving birth, and how to plan for breastfeeding. The SAMHSA guidelines also identify rooming-in as the standard of care (2018, p. 87). In addition to the professional guidance noted above and related research, the SAMHSA guideline development process relied upon clinical opinion from an expert panel, which did not include women whose infants had been treated for NOWS.

Guidelines as a Context for Research and Literature Review

Objectives.

This research study focused on non-pharmacological treatment recommendations aligned with those recommended by SAMHSA, particularly preparation for birth, breastfeeding, rooming-in, and support for caregiving and responsive care in the weeks after giving birth when symptoms of NOWS may manifest. This literature review 1) summarizes the research about rooming-in and breastfeeding, taking into account the robust consensus surrounding recommendations; 2) examines exemplars of rooming-in, breastfeeding, providing comfort, and

caregiving in the available literature (how care should look); (3) identifies potential barriers to realization of these guidelines; and 4) identifies literature that presents the maternal perspectives relating to clinical guidance during pregnancy and post-partum for lessons to learn about best practices for treating NOWS. The literature included is evaluated for relevance as well as the quality of the evidence.

The review shows that, despite the critical role they play methadone-maintained and buprenorphine-maintained mothers have had minimal input in research interpreting the recommendations in practice. There is a gap in the literature about how these mothers are supported during the sensitive period immediately following birth to achieve the clinical guidance objective of supporting the dyad. Specifically, knowledge is scarce about the perspectives of mothers who are methadone maintained related to their experiences developing their caregiving competencies during the period their infants were treated for NOWS symptoms.

Review of the Literature

Identifying non-pharmacologic dyadic treatment

Systematic reviews have organized research about NOWS treatment into assessment (evaluation of symptoms), pharmacological (administration of pharmacotherapy) and non-pharmacological categories (rooming-in, breastfeeding, providing comfort) to examine and align intervention with accumulating evidence (MacMullen, Dulski, & Blobaum, 2014; Bagley, Wachman, & Holland, et al., 2014; Casper & Arbour, 2014; Boucher, 2017; Grossman, Seashore, & Holmes, 2017; Edwards & Brown, 2017; Klamen, et al., 2017). There is consensus regarding the value of non-pharmacological practices, which were associated with decreased severity of symptoms and reduced the length of stay. Three practices in particular were identified: 1) the presence of the mother through rooming-in as effective for reducing

pharmacotherapy and increasing rates of breastfeeding (Abrahams, Kelly, & Payne, et al., 2007; Bagley, et al., 2014; Holmes, et al., 2016; Hunseler, et al., 2013; McKnight, Coo, & Davies, et al., 2016; Saiki, Lee & Greenough, 2010); 2) breastfeeding as effective for reducing symptoms and promoting attachment (Abdel-Latif et al, 2006; McQueen, Murphy-Oikonen, Gerlach & Montelpare, 2011; Wachman, Byun, & Philipp, 2010; Jansson, Choo, & Velez, et al., 2008); and 3) supportive interventions such as swaddling, non-nutritive sucking, and a modified quiet environment (MacMullen, Dulski, & Blobaum, 2014; Bagley, Wachman, & Holland, et al., 2014).

Rooming-in

The practice of keeping babies and mothers together, or rooming-in, was a standard recommendation for women in maternity settings to promote breastfeeding and attachment (WHO, 1992/2009; Abrahams, Kelly, & Payne, 2007). But despite the demonstrated risk to attachment (Norr, Roberts, & Freese, 1989), opioid-exposed infants were routinely separated from their mothers as part of treatment as usual (Abrahams, Kelley, & Payne, et al., 2007; Grossman, et. al, 2017). The infant's opioid exposure defined the management approach regardless of whether the mother was using prescription opioids to treat addiction or pain, or illicit opioids including heroin.

Research has consistently demonstrated the efficacy of rooming-in as an element of care for the opioid exposed infant in comparison to separation of the infant and mother subsequent to NICU admission (MacMillan, Rendon, & Verma, et al., 2018). A meta-analysis of rooming-in findings with outcomes for NOWS included six studies; two examined retrospective cohorts (Abrahams et al, 2007; Hunseler et al, 2013) and four relied upon data from before-and-after assessments (Holmes, et al., 2016; Grossman, et al., 2017; McKnight at al., 2016; Saiki et al,

2010). When rooming-in was compared with standard NICU care, rooming-in was consistently and robustly associated with reduced pharmacology and shorter length of stay (Macmillan et al., 2018).

In an often-cited initial study, Abrahams et al. (2007) compared an intervention cohort of opioid exposed newborns of mothers using methadone or heroin (n=32) to two controls, an historical cohort (n=38), and a concurrent cohort at a different hospital (n=36), to evaluate the effect of rooming-in on NOWS symptoms and custody at discharge. The researchers found that the infants in the rooming-in group were less likely to require pharmacological treatment for withdrawal symptoms; and were more likely to be discharged to home with their mothers. They also found breastfeeding rates were statistically higher in the rooming-in cohort: 60% compared to approximately 10% in each of the controls. Breastfeeding is a desirable practice, prompting the researchers to observe that separation of the effects would be relevant only when breastfeeding is contraindicated, for example, when mothers are HIV positive. The study design did not permit separating rooming-in effects from breastfeeding effects (Abrahams, et al., 2007, p. 1728). Statistical outcomes also did not distinguish between mothers in methadone treatment from other mothers.

Rooming-in: Exemplar of a systemic approach to change.

Recognizing the value of non-pharmacological treatments in reducing length of stay and need for medication, researchers at Yale New Haven Children's Hospital and Yale University Schools of Medicine and Public Health altered the hierarchy of assessment, pharmacological, and non-pharmacological treatment decision-making to reduce barriers for non-pharmacological treatment (Grossman, et al., 2017), including rooming-in. When researchers began their initial plan-do-study-act (PDSA) quality improvement project in January 2008, all infants with NOWS

were admitted to the NICU, where rooming-in was not an option and where non-pharmacologic treatments were inconsistently administered. In addition to providing strong encouragement to room-in, the team standardized the following interventions in the course of their five-year study period for all opioid exposed infants: Rooms for infants were quiet, darkened low-stimulation environments; staff engaged parents to care for their infants - to feed on demand and comfort; staff was trained to prioritize non-pharmacologic treatments, and to increase parent involvement before beginning pharmacologic treatment; breast-milk feeding was encouraged when not contraindicated by either illicit drug use or HIV.

Interventions were particularly focused on mothers who were methadone maintained so that parents would anticipate the likely manifestation of symptoms of NOWS and be prepared for their "critical role in treatment" (Grossman, et. al, 2017, p.e5). In the weeks before the mothers gave birth, hospital staff shared expectations about rooming-in, explained the importance of the family member as "the most important part of their infant's care" (Grossman, et. al, p. e5). After the infants were born, nurses and physicians assumed the role of coaches supporting parents as caregivers. When morphine was necessary, doses were more rapidly reduced than they had been in the previous treatment model, and non-pharmacologic management was prioritized.

The changes in practice yielded significant results. At baseline data was collected on 55 infants when all infants were admitted to the NICU. At post-implementation, data was collected on 44 infants who were identified as opioid exposed, regardless of the opioid source. During the baseline period, from January 2008 to February 2010, the average length of stay (ALOS) at Yale New Haven Hospital was 22.4 days; at the end of the study period, from May 2015 to June 2016, the ALOS was 5.9 days. At the onset of the study period, when infants were automatically admitted to the NICU, 98% developed severe signs of withdrawal prompting the administration

of morphine. Post-implementation, only 14% of infants who had been opioid exposed required morphine.

As an exemplar of the effect of rooming-in on infant outcomes, this study demonstrates the impact of institutional policy on practice. By prioritizing rooming-in as the practice targeted for change, the institution reframed the problem from treating an opioid-exposed infant's symptoms of withdrawal in the NICU to supporting the dyad to reduce the occurrence of the infant's symptoms of withdrawal. This reframing, in turn, allowed the researchers/quality improvement leaders to bring multiple practices in line with their objective. At Yale New Haven Hospital, the shift in approach from pharmacological to non-pharmacological management, changed "a system in which parents were merely allowed to visit their infant to one in which they were empowered to be the most important part of their infant's care. By reducing NICU admissions, this approach employed the power of the maternal-infant bond to treat NOWS" (Grossman, et al., 2017, p. e5). Thus, rooming-in was associated with dramatic positive impact both on the infant and the cost of care in the context of an institutional approach to care of the opioid-exposed infant.

The results from the Yale initiative were generalized to another regional hospital. A similar comprehensive quality improvement program conducted at Boston Medical Center (Wachman, Grossman, Schiff, Philipp, et al., 2018) reported similar outcomes when a non-pharmacological care bundle was implemented. The latter quality improvement initiative reflected the determination to prioritize parental presence and engagement by shifting treatment away from the NICU, treating infants' symptoms pharmacologically.

In both studies, the authors' research methods were sufficient to support their conclusions and substantiate their results. They hypothesized that assessment methods traditionally

associated with NICU admissions for NOWS treatment undermined more effective non-pharmacological interventions. Through adequate statistical approaches they measured average length of stay and treatment with morphine, before and after their alteration of the guidelines. They found statistically significant effects resulting from their paradigm shift.

Breastfeeding

Breastfeeding is also associated with decreased need for pharmacological treatment and reduced length of stay for opioid exposed newborns (Bagley, Wachman, Holland & Brody, 2014; Abdel-Latif, Pinner & Clews 2006). Rates of breastfeeding among women on methadone are low, estimated by the CDC to be between ~24 to 46% compared to 77% for the general population (Demirci, Bogen, & Klionsky, 2015).

In response to these low rates of breastfeeding, Graves, Turner, Nader, and Sinha (2016) examined literature about breastfeeding and methadone through 2015 to inform the training of healthcare providers on best feeding practices (p. 43). Of the 43 articles reviewed, they found: (1) low levels of methadone and buprenorphine transfer into breast milk; (2) breastfeeding is associated with decreased rates of NOWS; (3) rooming-in reduces NOWS and increases breastfeeding; (4) women on opioid substitution therapy face barriers to breastfeeding; and (5) healthcare professionals lack training in supporting women on methadone to breastfeed (Graves, et al., 2016, p. 44-45).

Despite consensus regarding multiple benefits of breastfeeding - for improved bonding, decreased NOWS symptoms, reduced need for pharmacological treatment, and briefer length of stay - barriers persist, which are reflected in low rates of breastfeeding among women who are methadone maintained during pregnancy. Multiple factors influence breastfeeding, and these include maternal and professional attitudes and knowledge, as well as institutional criteria and

support for breastfeeding among methadone maintained mothers, and as the SAMHSA guidelines suggest (2018), these multiple factors must be addressed to promote desired change. Studies that document increased rates of breastfeeding following institutional changes are particularly relevant to the proposed study as they may illuminate the implementation of caregiving guidelines within the context of the hospital policies and practices.

Breastfeeding: Exemplar of a systemic approach to change.

At Boston Medical Center (BMC), Wachman, Saia, Humphreys, et al. (2016) studied the effect of altering institutional guidelines about breastfeeding eligibility on the percentage of women with opioid use disorder who chose to breastfeed. Previously, eligibility for breastfeeding was based upon a history of active drug treatment, prenatal visits, and consistent negative drug screens for at least four weeks prior to giving birth. This included women who had actively maintained their opioid agonist therapy (methadone or buprenorphine). The guideline revision was aimed to increase the hospital's breastfeeding rates for methadone-maintained mothers. In the revised guidelines for breastfeeding eligibility women were still required to be active in a treatment program and attend prenatal visits. Women who tested negative were immediately able to provide breast milk for their newborns. Eligible women with a positive urine drug screen less than four weeks prior to delivery had the option to pump breast milk until testing negative for three additional consecutive urine drug screens. In other words, BMC allowed for reconsideration of eligibility after a lapse in recovery.

As a WHO Baby-Friendly Hospital, BMC reported that 95% of eligible mothers in their general population initiated breastfeeding. In contrast, a chart review of women with OUD prior to the change in guidelines established that only 56% of women in the hospital's comprehensive prenatal substance use recovery program were found eligible, and of those, only 64% initiated

breastfeeding. The institution consulted medical and nursing staff to approve the final guidelines addressing points of controversy through provider education.

The implementation of the new guidelines resulted in an increase in eligibility rates to 82% of women in the comprehensive treatment program, with 60% of those mothers initiating breastfeeding. Researchers calculated a total increase of 15% because of the larger pool of eligible mothers. The authors also associated the institutional shift in breastfeeding to decreased length of stay from 22 to 17 days during the two study periods.

By factoring in relapse as a characteristic of opioid dependence, the institution supported women with positive drug screens who wanted to breastfeed by offering an option for re-testing in the weeks following their positive drug screens. In the revised guidelines, positive drug screens would delay initiation of breastfeeding, but staff supported women in pumping and saving their milk for testing so that their eligibility could be reconsidered weekly. The institutional goal guided revisions to policy that promoted greater participation in breastfeeding.

The research was designed to capture the results of a multi-step change in practice aiming to enlarge the group of women with OUD who could potentially breastfeed. In this practice-based research, the authors posited that by (1) sustaining breastfeeding readiness through pumping breast milk despite positive toxicology reports (2) women in MAT who had relapsed but remained motivated to breastfeed could eventually attain a negative toxicology report so they could initiate breastfeeding. The review of hospital cases before and after the change in policy yielded statistics that confirm the positive impact of policy on women's opportunity to breastfeed. Indeed, these results illustrate the means to achieve a key goal expressed in the SAMHSA guidelines; the results highlight the effect of a policy that takes relapse into account on decision-making about breastfeeding.

Maternal Involvement in Care

According to the principles of family-centered care, infants who are hospitalized due to medical needs require the mother and the family as primary members of the child's medical and caregiving team (Johnson, Abraham, et al., 2009) or as primary caregivers (O'Brien, Bracht, Macdonnell, et. al. 2013). When considered as part of treatment when infants required special medical care, NICU professionals are familiar with these principals to meet the neurological, developmental, and attachment needs of infants so as to "embed the infant in the natural parent niche" (Als & McAnulty, 2011, p. 288). The current SAMHSA recommendations for mothers with opioid use disorders and their infants thus align with established family-centered care objectives for involving the family in developmental care – to minimize the lasting effects of hospitalization on the infant-parent interactions (Craig, Glick, & Phillips, 2015, p. 57).

SAMHSA's (2018) guidelines for infant care for the opioid exposed dyad emphasize the importance of parent preparation taking into account the strengths and vulnerabilities of each pair. Motivation is a strength: 42% of mothers with dependent children entered treatment in order to maintain or regain custody of their children (Gerstein & Johnson, 2000), but issues of low self-esteem, guilt, and shame were factors contributing to stress they experienced as they recovered their mother role (Carlson, Matto, Smith, Eversman, 2006). Marcellus (2014) emphasized the importance of an institutional culture in which trauma informed care takes into account the needs of women with OUD to support strong early mother-child attachment.

These vulnerabilities require a commitment to family-centered care values and sensitivity to women with OUD**,** consistent with the "compassionate culture" described by the Vermont Oxford Network (Schumacher & Patrick, 2015, p. 2). According to implementation theorists, the construct of institutional culture describes an institution that may be more or less (1) people- or

patient-centered; (2) guided by effective leadership; (3) or dedicated to staff-development (Kitson, Harvey, & McCormack, 1998; Cummings, Estabrooks, Midodzi, Wallin, & Hayduk, 2007).

As noted above, the revision of the Boston Medical Center breastfeeding guidelines offering "maximum assistance for mothers with substance use disorders who are eligible to breastfeed" (Wachman, et al., 2016, p. 383), involved these levels of institutional complexity and cooperation. The authors explicitly described a number of influences that motivated their effort to introduce revised guidelines. These included a hospital culture already consistent with global breastfeeding guidelines as a WHO Baby-Friendly Hospital; seeking consistency with published national guidelines; and impending accreditation changes whereby BMC's overall breastfeeding rates would include women on MAT. In order to implement the desired changes, the authors dealt with controversy within their institution by standardizing education to providers, including in-person lactation education for all nurses working on pediatric and obstetric units; posting the revised guidelines to ensure provider access and familiarity; designating point people to consider eligibility case by case; and educating women in the substance recovery program.

As the studies of rooming-in and breastfeeding illustrate, institutional culture extends well beyond the nurses who are often the point of contact between families whose infants require care for NOWS. Nevertheless, in their influential review Velez and Jansson (2008) emphasized the importance of the three-way relationship between nurse, infant, and mother specific to women in treatment for SUD and nurses' potential as facilitators of maternal involvement with their infants (p. 113). Current research about nurses in the NICU caring for infants with NOWS and working with families (reviewed below) demonstrates challenges in implementation of

compassionate culture (Schumacher & Patrick, 2015, p. 2) and family-centered care values (Craig, Glick, & Phillips, 2015, p. 57).

Maternal involvement in care: Exemplar of institutional approach to increase family involvement.

A longitudinal multi-phase quality improvement research project by researchers at Children's Hospital at Dartmouth-Hitchcock, specifically aimed to increase family involvement as an element of care. (Holmes et al., 2016) During a two-year study conducted between March 2013 and February 2015 researcher/providers implemented multiple interventions, including prenatal education to prepare families for birth and post-birth, educating staff to improve staff/family communication, and minimizing patient transfers between units that interrupted continuous maternal presence. The researchers also incorporated strategies to develop greater consistency in evaluating infants for NOWS symptoms to reduce pharmacological treatment. The previous year from March 2012 to February 2013 was established as the baseline year.

In the first phase of the quality improvement project research, family members were interviewed using a semi-structured interview guide (Atwood, et al., 2016). Family members identified areas requiring improvement to enhance family motivation to participate in direct care. Family members wanted to be relied upon as partners in care, spoken to respectfully and without jargon, and supported as a parent in recovery rather than being judged. Parents objected to inconsistencies between nurses and units within the hospital, and wanted the professionals to generate more authentic and consistent infant evaluations.

Information obtained through qualitative interviews with families supported development of the interventions in later phases of the project (Holmes, et al., 2016). In response, the Dartmouth-Hitchcock Children's Hospital 1) developed more training for staff in NOWS scoring

to increase consistency; 2) improved outreach for prenatal education for families in treatment; 3) developed provider training to increase skill and sensitivity when working with families with SUD; and (4) eliminated routine transfers to the NICU, to increase the option to room in (Holmes, et al, 2016). Researchers included all birth hospitalizations with confirmed maternal opioid use.

During the study, half the mothers were in treatment, with either methadone or buprenorphine. At year one and year two of the study, researchers compared the percentage of infants receiving morphine, receiving a second pharmacological treatment, and length of stay associated with rooming-in, with baseline data. They found that their combined interventions significantly reduced pharmacological treatment and length of stay (Holmes, et al., 2016). However, despite the aim to increase family-centered care, the researchers didn't specifically report upon family-centered care itself as a measure of the intervention's success, nor did they follow up with families at the end of the study period.

Maternal caregiving: Exemplar of an approach to develop maternal competence.

Employing a single case report of one infant/mother dyad, Snelling (2017) described the role played by occupational therapists (OTs) at Good Shepherd Rehabilitation Hospital Pediatric Units to support parents and nurses in understanding the "activity demands of caregiving" (p. 24). The intervention, consistent with family-centered values, allowed for caregiving activities to be conceptualized as a series of tasks from which the mother could select what she could take on with confidence. The OT sometimes employed video to help the mother read her infant's cues, and supported the mother as she informed the nurses what would care activities she would like to do. In the case report, the author described an approach that is aligned with the objectives for families identified in the literature (Velez & Jansson, 2008; Marcellus, 2007; Teague, et al.,

2015) and clinical guidance (SAMHSA, 2018). The Good Shepherd program is unique as an approach to addresse maternal skills for observing the infant, maternal empowerment for communicating with nurses, and the development, through practice, of increasing parent participation in caregiving activities. In the case reported, the mother was able to identify the infant's cues when the infant was over-stimulated, to develop strategies to cope with the infant's needs, and to manage her own stress.

Policy: Context for Non-Pharmacological Dyadic Treatment

SAMHSA guidelines to promote practices supporting the mother infant dyad when the mother is methadone or buprenorphine maintained reflect a thorough review of evidence. Context and facilitation are factors that strongly influence the transition to practice in healthcare settings (Kitson, Harvey, & McCormack, 1998). State policies regarding criminalization of pregnant mothers affect attitudes and practices where women who are methadone maintained receive healthcare services. Women who use opioids while pregnant, even MAT, are highly stigmatized despite the evidence-based recommendations. Sociologist Erving Goffman observed, "We tend to impute a wide range of imperfections on the basis of the original one" (1963, p. 5). Using opioids, including MAT while pregnant, is a stigmatizing "imperfection", which, when directed by hospital and healthcare professionals toward mothers, may undermine the very objectives of the organization to engage them in the care of their infants with NOWS.

Influence of state policies on supporting the dyad.

A chronic disease model of addiction incorporating MAT de-stigmatizes addiction as a disease not moral failure, child abuse, or criminal behavior, but this view is not reflected in policies in every state (Goodman, 2015; Burns, Pacula, Bauhoff, et al., 2016). Guttmacher Institute (2018) reports 19 states, including New York, provide priority access to women who are

pregnant and seeking drug treatment; in 23 states healthcare professionals are required to report suspected drug abuse among pregnant mothers; and 24 states consider drug use during pregnancy child abuse. Consequently, efforts to seek treatment from formal healthcare providers are further complicated by risk of criminalization (Stone, 2015), which disproportionately affects the poorest and most vulnerable members of the population (Stone, 2015; Paltrow & Flavin, 2013). These policies in turn impact hospital policies and the behaviors of nurses with women who are in fact considered to be criminal in their behavior as a pregnant mother. In addition, non-pharmacological treatments will be less likely to be implemented in a hospital in a state that criminalizes pregnant opioid exposed mothers. The criminal justice aspects will take precedence rather than strengthening the dyad, by developing attachment through support of maternal proximity, breastfeeding and caregiving.

Researchers in the Dartmouth-Hitchcock study specifically cited New Hampshire and Vermont state policies, which did not criminalize women as likely positively impacting the effectiveness of their intervention (Holmes, et al., 2016). Along similar lines, researchers at Boston Medical Center identified performance standards introduced by The Joint Commission, an external healthcare evaluator, as motivation to change internal practices to increase breastfeeding among methadone-maintained women (Wachman, et al., 2016).

Barriers to Supporting Mother/Infant Dyad

The strong association between non-pharmacological practices that support maternal proximity (rooming-in) and promote attachment (breastfeeding) and reduced need for pharmacological treatment is evident in the literature and recommended by the guidelines. Nevertheless, there remains a need to identify barriers and facilitators for these practices from

the perspective of mothers who have experienced the hospital as an institutional context for the development of their mothering roles while their infants have been treated for NOWS.

Nurse attitudes and the need for education, maternal characteristics and experience with caregiving, and characteristics of the maternal infant dyad are barriers, reviewed below.

Nurse attitudes and misinformation as a barrier.

Fraser, Barnes, Biggs, and Kain (2006) identified a mismatch between family-centered care values of the NICU and nurse perspectives regarding their experiences with drug-dependent parents. Fraser et al. conducted group interviews with eight neonatal nurses about their experience in caring for newborns of drug-dependent parents. They affirmed the pivotal role played by nurses in promoting attachment and the necessity of education for nurses to support their relational skills.

Likewise, Maguire, Webb, Passmore, and Cline (2012) described the NICU setting for their study as an institutional culture supportive of family participation, but the nurses in this study expressed concerns that mothers on methadone were not a good fit with family-centered care. These researchers interviewed 16 NICU nurses to explore their experiences of ethical and moral conflict caring for opioid-exposed infants. The nurses reported the time-consuming demands of meeting the infants' soothing needs, conflicts with parents, and concerns about releasing the infants from the hospital into the care of parents with histories of SUD. In their conclusion, the authors identified the lack of specialized training in addiction and ignorance about methadone, which is the gold standard of opioid use disorder treatment during pregnancy, as potential factors that affected nurse attitudes and interfered with the establishment of trust with parents (Maguire, et al., 2012, p. 285).

In the study conducted by Murphy-Oikonen, Brownlee, Montelpare and Gerlach (2010) 14 nurses who worked with NOWS patients and their families completed web-based computer assisted open-ended interviews to explore their experiences. The nurses used the confidential format of the web-based interviews to express frustration with the care demands of the very sensitive and hard-to-soothe infants, which they considered outside the scope of their specialized training, and contrasted their empathy for the infants' suffering with their judgments toward the mothers who caused it.

Studies by Fraser et al. (2006), Murphy-Oikonen et al. (2010), and Maguire et al. (2012) employed a range of qualitative methodologies - group interviews, computer-assisted interviews with open-ended questions, and semi-structured interviews respectively - to explore the experiences and attitudes of neonatal nurses. The conclusions of these three studies strongly align with each other. Murphy-Oikonen et al. summarized the disconnect between families and the nurses: "An underlying innuendo found in nurses' responses implied feelings of blame toward parents whose poor choices caused their infants' distress" (2010, p. 310).

The attitudes reported in the nurse studies are consistent with the observations made by mothers who are methadone-maintained when they were interviewed about their experiences with nurses during their pregnancy and after giving birth, regarding breastfeeding (Demirci, Bogen, & Klionsky, 2015), participating in care (Atwood, Sollender, Hsu, et al., 2016), making complaints (Finney Lamb, Boers, et al., 2008), and their experiences in the NICU (Cleveland, Bonugli, & McGlothen, 2016; Cleveland & Bonugli, 2014; and Cleveland & Gill, 2013). The findings about the nurses' attitudes towards mothers whose infants had symptoms of NOWS are consistent with research in which the mothers describe their experiences with nurses. These studies, which explore the mothers' perspectives, will be discussed in greater detail below.

Methadone maintained women who were interviewed for Demirci, Bogen and Klionsky's, 2015 study about breastfeeding described their experiences making decisions about breastfeeding. Observing low rates of breastfeeding initiation, the qualitative researchers explored deterrents and barriers to breastfeeding experienced by the mothers they interviewed (Demirci, et al., 2015). Seven women participated in focus groups and interviews. The researchers identified three content categories: 1) fears and misconceptions; 2) motivation and benefits; 3) and sources of information and support and anxiety, which influenced breastfeeding decisions (p. 204). Women in the study reported that healthcare providers in drug treatment programs were more knowledgeable and supportive of the compatibility of methadone and breastfeeding in comparison to hospital-based nurses. In their analysis of the interviews, the researchers observed, "Women described these nurses as undermining their breastfeeding efforts, not taking the time to help with breastfeeding, not interested in breastfeeding, or unknowledgeable about breastfeeding among women and infants exposed to methadone" (p. 206).

Promoting breastfeeding is one significant component of dyadic support for the opioid-exposed infant and the methadone-maintained mother. Interviews with postpartum women offer insight into their experiences about breastfeeding in particular. When reflecting on caregiving engagement, the subject of the current study, methadone-maintained mothers may describe motivations, barriers, and potential supports that are similar to those they reported about breastfeeding. (The breastfeeding study is included here because the participants and the researchers identified nurse misinformation as a factor in the exchanges between the nurses and the mothers.)

Nurse education and preparation as a barrier.

Nurse researchers have concluded that nurses' attitudes influence the take-up of recommended practices but that there exists the potential for change with increased education. As the breastfeeding studies demonstrate, women in substance use treatment also identified the nurse misinformation as a significant deterrent in decision-making about breastfeeding (Demirci, et al., 2015). Indeed, researchers at Boston Medical Center found that the hospital's direct engagement with nurses through training influenced nurse attitudes toward practices promoting breastfeeding (Wachman, et al., 2016). Nurse education was an element in the systemic changes developed by Dartmouth-Hitchcock and Yale Children's Hospitals as well.

Maternal characteristics: trauma history as a barrier.

Women who give birth and who are methadone maintained are more likely than other women to be deeply affected by social and psychological problems than members of the general population (Goodman, 2015; Powis, Gossop, & Bury, et al., 2000), more likely to be recipients of Medicaid (Patrick, Davis, & Lehman, 2015), and more likely to be potential victims of trauma (Pajulo, Savonlahti & Sourander, et al., 2001). In one study of 715 women initiating substance use treatment, nearly 45% self-reported a history of sexual abuse; nearly 73% reported a history of physical abuse; and 71% reported emotional abuse when surveyed using the Violence Exposure Questionnaire (Velez, Montoya, Jansson, & Walters, et al., 2006).

Jansson, Velez, and Butz (2017) identified a history of sexual abuse as a maternal factor affecting breastfeeding in a case report of a woman who sought lactation support but did not successfully breastfeed during her infant's hospitalization for NOWS. The mother in their study was uncomfortable availing herself of lactation support, which involved exposing or touching her breasts. When the infant was unable to latch on, she insisted upon pumping rather than

accepting assistance. After the infant was discharged, she was able to integrate the information she had received to breastfeed at home, indicating that privacy was necessary in her case to deal effectively with these inhibitions. In their discussion, the researchers recommended a trauma-informed approach, validation, and "sensitive exploration and listening while maintaining maternal physical and emotional privacy" (p. 483). When considered in terms of implementation of guidelines, these authors recommended both health provider training and structural changes to the environment, such as rooms for rooming-in to support private breastfeeding.

The authors of this case study reported what Creswell (2013) describes an instrumental case to illuminate maternal needs and characteristics in relation to the breastfeeding objective. They illustrated the intersection of maternal trauma history and current needs with professional practices in relation to the breastfeeding outcomes. Though the types of research vary, both the Boston Medical Center study and the case report demonstrate the value of flexibility in sustaining breastfeeding until resolution of a variety of barriers are resolved.

Maternal self-awareness: Anticipating NOWS symptoms and understanding the infant's behavior as a barrier.

SAMSHA (2018) clinical guidance specifically directs clinicians to prepare mothers for the "possibility of neonatal abstinence syndrome" (p. 52) and to address "the mother's understanding of and responses to the infant" (p. 86), requiring mothers to attune to the needs of infants with NOW or NAS. The degree to which mothers are prepared to understand their infant's cues and respond to them contingently may complicate meeting this objective.

Researchers assessed substance-using mothers' knowledge of newborns care, feeding recommendations, child development, and knowledge about the effects of drugs use and alcohol on the developing fetus, before and after the mothers participated in a parenting program.

Embedded in a multidisciplinary substance abuse treatment program, the mothers participated in 90-minute group sessions once a week and individual sessions. During the individual sessions, the Brazelton Neonatal Behavioral Assessment Scale and the Denver Developmental Screen Test II were administered to the infants as a means to identify the infant's individual characteristics and to improve the mother's "knowledge, expectations and beliefs regarding appropriate child development" (Velez, Jansson, Montaya et al. 2004, p. 217).

To demonstrate responsiveness to parenting instruction Velez et al. (2004) developed and administered a Parenting Skills Questionnaire to 73 women in substance use treatment before and after the women attended parenting sessions. The topics covered in the curriculum were aligned with the assessment - newborn care, specifically relating to substance-exposed newborns, feeding, child development, and effects of drug exposure during pregnancy – included by the researchers in response to "frequent unhealthy parenting beliefs or practices observed by the staff" (Velez, et al., 2004, p. 217). The women's knowledge improved significantly in responding to a newborn's cry and recognizing signs of over-stimulation, areas that coincided with concurrent experience and where modeling from professional staff might have been most instructive when combined with exposure to new knowledge. Though knowledge does not conclusively translate to parenting skills, the authors cautiously posit the association between knowledge, attitudes, and behavior changes as steps toward improvement (Velez, et al., 2004, p. 220). Summarizing the objective of parenting training, they wrote, "Self-awareness of thoughts and feelings in tandem with response to the infants are at the core of the training," (Velez & Jansson, 2013, p. 272, Suchman, Pajulo, Mayes, eds.).

Results from this preliminary study are relevant to the current study. The research demonstrated the potential for mothers' maternal response to structured parenting support when

provided during the newborn period, and when mothers are in residence. In this regard, the authors put into operation an approach that treats the dyad rather than the child only.

Interaction between maternal and infant characteristics as a barrier.

Both maternal and infant factors affect maternal infant interactions. Opioid-exposed infants are irritable, difficult to soothe, fluctuate rapidly between quiet alert, over-stimulated, and drowsy states, may appear drowsy as a response to stimulation, arch stiffly and are challenging to relax, demonstrate disorganized suck and swallow coordination, are hyper-sensitive to stimulation, and frequently vomit (Jansson, Velez, & Harrow, 2004). Mothers who feel guilt about exposing their infants to opioids may interpret some of these behaviors as a rejection. As such, negative feeding experiences are associated with maternal depression (Watkins, Meltzer-Brody, Zolnoun, & Stuebe, 2011).

Maguire, et al. (2016) employed a comparative-descriptive research design to compare the interactions of 12 opioid exposed dyads with those of non-opioid exposed dyads during bottle-feeding. The results identified infant behaviors that contributed to mothers' difficulty in reading cues. Specifically, researchers found that infants with NOWS expressed their cues less clearly than infants who are not opioid exposed (Maguire, Taylor, Armstrong, Shaffer-Hudkins, Germain, Brooks, Cline & Clark, 2016, p. 301). In addition, NOWS-diagnosed infants were observed to be less responsive to their mothers' caregiving due to the symptoms of withdrawal, described above, for example, maintaining an active alert state during feeding, being consoled by the mother, or gazing at the mother. Furthermore, mothers may misread this lack of feedback from the infant as rejection. Anecdotally the researchers reported comments such as "He doesn't like me" or "She won't look at me" (Maguire, et al., 2016, p. 301).

But despite the potential challenges posed by infant characteristics, it is the mothers' characteristics that predict the child's functioning in the dyad at six months. When researchers in Norway compared the mother-child relationship of 38 opioid exposed infants (buprenorphine or methadone) to 36 low-risk infants they found that the mother's individual mothering characteristics, rather than the group characteristics, predicted the dyad's functioning at six months (Sarfi, Smith, Waal & Sundet, 2011). The women in the study, who were participating in opioid maintenance treatment, received what Sarfi et al. described as optimal interventions, including residential treatment, thus, in the authors' opinion, relieving them of the comorbid stressors associated with women with OUD. All mothers were observed in interactions with their infants and rated on sensitivity/responsiveness, intrusiveness, detachment, positive regard for child/positive affect, and negative regard for child/negative affect. In their discussion, the authors commented upon the parenting potential of mothers in treatment. "Our findings contradict the view of maternal opiate addiction as being unequivocally linked with parenting deficits: Generally, mothers under medically supervised use of methadone presented as good-enough partners in dyadic interaction when the infants were six months old" (Sarfi, et al., 2011, p. 586).

Meeting Objectives of Clinical Guidelines

Maternal perspectives.

Women express ambivalence about entering treatment, feeling on one hand treatment might help them avoid losing a child to protective services, and on the other being in treatment heightens their visibility and may increase the risk of losing the child (Powis, Gossop, Bury, Payne & Griffiths, 2000). Nevertheless, among American women from 15 to 44, pregnant women are less likely to use opioids than non-pregnant women of the same age, and opioid use diminishes in each trimester of pregnancy (Smith & Lipari, 2017). Consistent with these

statistics are the expressions of mothers interviewed soon after their babies were born who sought treatment for the "sake of their unborn child" (Cleveland, Bonugli, & McGlothen, 2016, p. 123). Thus, the transition to motherhood, beginning in pregnancy, is an explicit motivation for treatment. Concretely, entering methadone or buprenorphine treatment provides access to prenatal care, as well as a termination of other risky behaviors associated with illicit opioid use that endanger their own health, and, by extension, the health of the baby they are carrying. On an emotional level, these expressions are similar to Winnicott's transitional space (1951), and may reflect a wish to care for the future baby (Punamaki & Belt, 2013, p. 324). Thus, parenting support coupled with MAT meets the needs mothers have explicitly expressed when they are asked about their motivations.

Considered in this context, maternal caregiving begins during pregnancy and continues after the baby is born. In several studies that included interviews with parents whose infants were opioid exposed, parents expressed the desire to feel valued and respected in their role as partners with healthcare professionals in their infants' care. Atwood and colleagues grouped these sentiments under the theme "partners in care" (Atwood, et al., 2016). Cleveland and Gill identified the theme, "I'm the mother here!" (2013). However, mothers who were part of a MAT program while their children were in the NICU often felt judged as drug users, which may inhibit their participation and engagement in care (Cleveland & Gill, 2013).

In a series of qualitative studies, Lisa Cleveland and colleagues explored the NICU experiences of mothers in MAT, (Cleveland & Gill, 2013; Cleveland & Bonugli, 2014; Cleveland, Bonugli, & McGlothen, 2016) culminating in a study about their feeding decisions (McGlothen, Cleveland, & Gill, 2018). The 2013 study involved a secondary analysis of data to explore the particular experiences of five Mexican-American women in methadone treatment

whose infants were in the NICU treated for NOWS. To explore their experiences with greater intentionality, the researchers developed a second study exploring the NICU experiences of 15 mothers of infants with NOWS, specifically recruiting participants from two methadone treatment programs (Cleveland & Bonugli, 2014).

The mothers spoke about the effect of the power imbalance they experienced between themselves and the nurses, describing the aversive effect of the nurses' judgmental behaviors, such as whispering or making pejorative comments, on the mothers' comfort in the hospital environment. The mothers expressed their desire to participate in the care of their babies. Thus, they were especially frustrated with and resentful of the nurses when nurses seemed to take over the infant's care or diminish mother's role as a caregiver (Cleveland & Gill, 2013). Among the themes identified, the mothers' wish to be caregivers as an area of conflict with nurses is highly relevant for the proposed study. Building upon Cleveland et al. (2013), the current study seeks to explore in-depth the support available to the women for caregiving, and the impact of the social context of the hospital regarding that objective.

The researchers developed a third study to capture the perspectives of mothers about their transitions to mothering (Cleveland, Bonugli, & McGlothen, 2016). The mothers described their unplanned pregnancies as motivation to seek treatment, prompting associations of past traumatic births (miscarriages and engagement of child protective services), past negative encounters with healthcare teams, and fears about their baby's wellbeing, which were sources of stress and worry. Daily travel to methadone clinics was stressful and exhausting once their babies had been born. The mothers felt connected to their babies and explained in their interviews that holding onto their child motivated their sobriety and helped them make changes in their lives (Cleveland, Bonugli, & McGlothen, 2016).

The current study builds upon Cleveland et al. (2016) to explore the mothering role in relation to caregiving, and in particular, about caregiving support available to mothers in the hospital. The current study uses the SAMHSA guidelines as a standard to better understand the context for the mothers' experiences in relation to current practice guidelines promoting breastfeeding, rooming-in, and family-centered care as a means to promote feelings of maternal confidence, attachment between the mother and the infant, and to reduce the infant's symptoms of withdrawal.

McGlothen, Cleveland, and Gill (2018) described factors influencing the feeding decisions of women taking methadone, specifically whether or not the women chose to breastfeed or bottle feed. The SAMHSA guidelines emphasize the physical and behavioral health benefits of breastfeeding for the dyad (2018). The evidence collected by McGlothen et al. (2018) describes hospital social dynamics between nurses and participants that strongly resemble the team's findings from five years before (Cleveland & Gill, 2013) as well as those reported by Demirci, et al. (2015) that obstacles remain in the integration of SAMHSA's clear recommendations in practice. Mothers continue to report feeling judged and undermined in their decision to breastfeed, sometimes because of "misinformation among healthcare professionals" (SAMHSA, 2018) and sometimes because of stigmatizing views. When paired with the earlier studies of nurse attitudes (Fraser, et al., 2006; Maguire, Webb & Passmore, 2012; Murphy-Oikonen, et al., 2010), studies by the researchers working along with Cleveland (2013, 2014, 2016, 2018) suggest that experiencing judgment and the lack of appropriate supports are risk factors that may inhibit promotion of caregiving from the nurse perspective and take-up of caregiving from the maternal perspective.

Strengths and Limitations of Research

Commenting upon the evidence base for clinical actions, the authors of the SAMHSA Clinical Guidance (2018) wrote that randomized controlled trials are neither conducted with this population nor adequately detailed to apply in practice. Therefore, their expert panel rated treatment options based upon "expertise and clinical experience" (p. 5) in addition to available quantitative evidence. Due to the vulnerability of the subject, randomized controlled trials are an unethical and therefore inappropriate way to glean evidence about this group. Therefore, much of the evidence is collected via methods other than the "gold standard" of research.

The treatment for NOWS reflects a clinical landscape where multiple factors that influence outcomes in research and practice. For example, researchers could not separate breast-feeding from rooming-in effects because of the likelihood that rooming-in promoted breast-feeding, which subsequently produced desirable effects, such as shorter length of stay (Abrahams, et al., 2007) and attachment. Furthermore, when institutions make changes to respond to recommendations, they do not necessarily change practices individually but implement multiple changes simultaneously. For example, at Yale Children's Hospital, researchers simultaneously standardized non-pharmacological care, empowered parents, revised infant assessment procedures, reduced the intensity of morphine treatments, and bypassed the NICU. The constellation of changes included staff training, standardization of practices, alterations in physical space to lower lights and reduce noise, and explicit encouragement of breastfeeding.

Factors outside of the hospital also affect motivations to implement change. For example, the Boston Medical Center study documented multiple motivations to increase breastfeeding rates among methadone-maintained mothers. Wachman and colleagues specified contextual

motivators including their hospital's status as a WHO Baby-Friendly hospital, previously published national guidelines, and impending accreditation impacts (Wachman, et al., 2016). Like the clinician practitioners at Yale Children's Hospital, these researchers also specified the means they employed to implement the desired changes in practice, including intensive lactation education efforts supporting both mothers in MAT and professionals.

Gap in the Research

The studies by Cleveland and colleagues (Cleveland & Gill, 2013; Cleveland & Bonugli, 2014; Cleveland, Bonugli, & McGlothen, 2016; McGlothen, Cleveland, & Gill, 2018) are unique in foregrounding the perspectives of women in MAT who recently gave birth about their mothering experiences (Cleveland, Bonugli, & McGlothen, 2016) in the context of the NICU (Cleveland & Bonugli, 2014) and how their experiences affected their decision-making (McGlothen, Cleveland, & Gill, 2018). A gap remains in information about the experiences of mothers who were active in treatment when they gave birth to learn about how they were supported in their roles as caregivers. Furthermore, a gap remains in information from the perspectives of the mothers about hospital policies to promote rooming-in, breast-feeding, parent preparation to support proximity and family-centered care practices. Finally, there are no studies to date that explore practices from the perspectives of women in MAT about their experiences as part of opioid-exposed dyads and caregiving support in hospitals outside the San Antonio region where Cleveland et al. conduct their research.

To summarize, the gaps are as follows: 1) focus on preparation and support for caregiving; 2) use of SAMHSA guidelines; 3) location. While Cleveland et al. sought to answer the question, "What are the mothering experiences of women with SUDs?" (Cleveland, et al., 2016, p. 120), they did not explore the specific interventions that may or may not have been

provided according to SAMHSA practice guidelines. While Cleveland, et al., did not specifically describe interactions around caregiving, their findings reflect a possible connection 1) between feeling judged as a factor influencing maintaining proximity through visiting in the NICU when rooming-in is not supported; and 2) the wish to assume caregiving responsibilities but perceiving a conflict between themselves and nurse caregivers (Cleveland & Gill, 2013; Cleveland & Bonugli, 2014; Cleveland, Bonugli, & McGlothen, 2016; McGlothen, Cleveland, Gill, 2018).

The current study sought to gather observations and commentaries of women in MAT about practices that did or did promote maternal caregiving of their newborns who were opioid exposed before and during hospitalization. The current study sought to fill the gap left by Cleveland et al., by exploring the preparation and support for caregiving by an MAT maintained mother.

The current study differed from the Cleveland studies in a second respect. In order to make context explicit, this study positioned the SAMHSA guidelines as frameworks for practice and as professional expressions equivalent to women's expressions.

Third, this study differed from previous research in the diverse locations of the women and the potential of increasing the diversity of subjects describing their experiences. Cleveland's research is based upon a sample recruited in two methadone clinics in one city in the southwestern region of the United States, and according to the authors, most of the interview subjects were Mexican-American. The experiences of mothers in NICUs and/or nurseries in this study differ from the participants represented in the previous studies.

Despite the consistency of the guidelines across hospital settings and the immediate and long-term benefits for the dyad resulting from post-partum maternal engagement, there has been limited research on how these guidelines are interpreted in practice in general and few studies

examining the perspectives of mothers in MAT on caregiving in particular. In eliciting mothers' suggestions this study contributes to what National Academies Press described as part of the "systematic inquiry with the collaboration of those affected by the issue" (2003, p. 1).

The proposed research contributes to a better understanding of how women have been supported in their role as primary caregivers in alignment with these guidelines. Solutions to problems can and should be examined with an effort to generate feedback between the experiences of individuals and the institutions and policies that define those experiences, but no intervention can accurately meet unspoken needs. In the next chapter, the researcher describes the theoretical concepts that address the multiple levels relevant to this problem.

CHAPTER THREE: THEORETICAL CONCEPTS

Introduction and Overview

In this chapter, the researcher discusses three theories that inform the proposed study and illustrate the relevance for exploring and understanding a social problem. Together, the theories describe the social relationships between stakeholders after the birth of a methadone or buprenorphine exposed infant within the complex system in the hospital nursery or NICU, and which affect the mother and infant pair. First, attachment theory describes observable relational patterns that emerge between parent and child, theorizing development as occurring within a situated social context. Second, social cultural theory identifies language and institutional structures as tools, cultural legacies of historical efforts to communicate, to share knowledge between one person and another. When learning something new, learners – infants, mothers, or nurses - use these tools within a social relationship occurring between themselves and more experienced partners to develop new skills and abilities. Finally, activity theory views human activity as occurring within an activity system, encompassing individual relationships, social institutions, and mediating artifacts (Engestrom, Mietten, & Punamaki, 1999).

This study seeks to compare the values and practices reflected in clinical practice guidelines to the experiences of methadone-maintained mothers who have given birth to infants observed and/or treated for NOWS. Using the guidelines as institutional expressions per activity theory, the researcher will seek to identify areas of conflict and alignment, so that the experiences, opinions, and suggestions of these mothers can be considered along with current guidance.

Attachment Theory

Attachment theory, which describes a dynamic and interactive relationship between an infant's signals and maternal response, underlies contemporary hospital practices when newborns require special care. Bowlby (1969) theorized that when an infant signals and a mother responds contingently to the infant's needs, the infant experiences a sense of connection, safety, and security within the environment. Working in the years following World War II, Bowlby based attachment theory on observations of the effect of separation from parents on children who were institutionalized and hospitalized (Bretherton, 1992). Building upon Bowlby, Ainsworth (1978) established the connection between maternal sensitivity to provide contingent care in the early weeks and months to later secure attachment, which is reflected in the child's separation and reunion behaviors observable at twelve months.

In the NICU, contingent care is one principal of evidence-based Newborn Individualized Developmental Care and Assessment Program based upon careful observation, interpretation, and response to the infant's cues (Als, Butler, & Kosta, 2005). According to Als, whose research alerted the NICU to the neurological, developmental, and attachment benefits of developmental care in the NICU, the aim is to "embed the infant in the natural parent niche" (Als & McAnulty, 2011, p. 288) to avoid over-stimulation, isolation, and support self-regulation. Developmental care recognizes the needs of infant for the parent in the present as well as the potential impact on the future relationship (Als & McAnulty, 2011). Similarly, family-centered developmental care (FCDC) further emphasizes the centrality of the parent in infant care, both to improve outcomes within the hospital and attachment upon release (Craig, Glick, & Phillips, et al., 2015; Ishizaki, 2013).

Attachment develops in four stages (Bowlby, 1980). During the *pre-attachment* period,

from birth to six weeks, the infant relies upon "built-in signaling behaviors" (Berk, 1996, p. 266) such as crying, gazing, grasping, and smiling to help keep the mother close by. During this period, an infant can recognize the mother's voice and smell, though another adult can be of comfort. From six weeks to six-eight months, during the *attachment-in-the-making* phase, the infant begins to demonstrate different responses to the mother than to other caregivers when she has been a primary caregiver, demonstrated through vocalizations, the infant's observed sense of relief from distress, and length of face-to-face interactions between mother and infant. These are the phases of attachment that correspond to early hospitalization, and on which later stages of attachment build.

Feeding is one of the interaction patterns between mother and infant that Ainsworth and her research colleagues observed (Bretherton, 1992). Observations by Ainsworth and Bell (1969) about feeding situations were consistent with later analyses of the influence of maternal sensitivity in the early weeks with the dyadic functioning at assessment at 12 months. Summarizing the research, Bretherton noted that smooth feedings confirm the impact of contingency and caregiving on attachment. "For some mother-infant pairs, feeding was an occasion for smooth cooperation. Other mothers had difficulties in adjusting their pacing and behavior to the baby's cues. In response, their babies tended to struggle, choke, and spit up" (1992, p.765). Other behaviors examined by Ainsworth were mother-infant face-to-face interactions (Blehar, Lieberman, & Ainsworth, 1977), crying (Bell & Ainsworth), and affectionate contact (Tracy & Ainsworth, 1981). Opioid-exposed newborns observed for or diagnosed with NOWS are characteristically difficult to feed and soothe, so they may present obstacles to attachment in the absence support for mothers learning to feed and soothe them.

While the relationship between parent and child is one context for attachment, the larger

society also plays an essential role. In an overview of the development of attachment theory, Bretherton wrote that most summaries of attachment theory omitted Bowlby's inclusion of social networks as essential contexts for relationships (1992). Indeed, "Just as children are absolutely dependent on their parents for sustenance, so in all but the most primitive communities, are parents, especially their mothers, dependent upon a greater society" both for economic provision and social support (Bowlby, 1951, p. 84). Furthermore, according to Bowlby, attachment as perceived social support is reciprocal and experienced through the life cycle. "For not only young children, it is now clear, but human beings of all ages are found to be at their happiest and to be able to deploy their talents to best advantage when they are confident that, standing behind them, there are one or more trusted persons who will come to their aid should difficulties arise. The person trusted provides a secure base from which his (or her) companion can operate." (Bowlby,1973, p.359).

Attachment theory underlies both the risk within the hospital nursery and the NICU to the infant parent relationship (Ishizaki, 2013; Huhtala, Korja, Lehtonen, et al., 2012), and the potential for practices that promote engagement between mothers and newborns (Craig, Glick, Phillips, et al. 2015; Melnyk, Feinstein, Alpert-Gillis, et al., 2006) and will serve as a foundation in discussion of the particular mothers and newborns considered here.

Social Cultural Theory and the Zone of Proximal Development

Social cultural theory, developed by Vygotsky in the early twentieth century, is based upon two broad principles. First, cultural tools that have evolved over time shape human development; language, written expressions, and, institutions are examples of culturally and historically evolved tools. Second, Vygotsky theorized that an individual first experiences new understandings and skills in the social realm before internalizing them. For example, people

acquire and use language socially before employing it internally to guide thinking and behavior (Vygotsky, 1962; Vygotsky, 1978; Berk & Winsler, 1995).

During pregnancy and in childbirth, the social and the biological are intertwined. In contrast to maturational theories of development, in social cultural theory, biology may set the stage for development, but tools used within relational exchanges are the means to bring about behavioral transformation, or learning (Vygotsky, 1978, p. 7). For mothers, what do they need to learn about childbirth and newborn care when their infant has been opioid exposed during pregnancy? In a broader discussion of childbirth and care, medical sociologist Katz Rothman focused on learning to care, when she asked, "Where do you get the knowledge to do that kind of care of another person?" (2016, p. 55). Katz Rothman's answer, paraphrased here from her work with mothers and midwives, resonates with the kind of learning relationship Vygotsky theoretically described: The knowledge can come from experts who collectively have cared for a lot of infants who have been opioid exposed and can share their expertise with mothers whose personal experience is too limited (Katz Rothman, 2016, p. 56).

Vygotsky described learning as socially mediated with the learner scaffolded by experts who guide. He theorized the "zone of proximal development" (ZPD) as a social space where novel learning occurs, accomplished by activity on the part of the individual learner guided by the expert. Barbara Rogoff described this as "guided participation," (1991, p. 191) a relational exchange that requires social elements, such as shared attention and problem solving, to master challenging skills. "It is within social exchanges that we should look for advances in individuals' ways of thinking and acting that build upon cultural history through the practices of individuals with their social partners" (Rogoff, 1991, p. 195). In the hospital, this can be imagined when a nurse guides a mother to effectively soothe then feed her baby to deal effectively with the

challenges of the infant's withdrawal symptoms.

Socially mediated learning requires what Rogoff describes as a quality of "minimal benevolence" to establish the common ground for communication (1999, p. 201). The potential for productive exchange in the zone of proximal development is based upon establishment of trust. The "freedom to err in manageable ways"(Rogoff, 1991, p. 201) is an essential element in active learning. Along these lines, the specialized parenting skills for management of a dis-regulated infant with neonatal abstinence syndrome are best mastered with the guidance of an expert who can identify the mother's level of skill and benevolently support her learning through a process of scaffolding.

Activity Theory

Activity theory is particularly fitting for this topic and understanding of the social problem because of activity theory's relevance to applied practice and the problem of "externalizing ideals into new routines and procedures" (Blackler, 2009, p. 30). Activity theory posits that integrating relational, cultural, and system views necessarily guides finding solutions to complex problems. Blackler summarized activity theory's "mix of relationships" as a synthesis of micro, macro, and collective perspectives. "Although it is individuals who experience the dilemmas, contradictions and performance shortcomings of the systems of activity they work within, solutions can be developed only collectively" (2009, p. 29).

Inspired by Vygotsky, activity theory emphasizes the value of tension, conflict, and contradiction as tools to transform a system (Engestrom, 1999). According to activity theory, these tensions surface through a multi-perspective view of interactions (i.e. mothers', nurses', institutional expressions), required to improve and transform the system.

Mediating artifacts are central to activity theory. Building upon Vygotsky, Engstrom

emphasized that humans create and use mediating artifacts to "control their own behavior" (Engestrom, 1999, p. 29). Modeled by Engestrom, mediating artifacts, such as written or spoken text, actively draw a community's or a researcher's attention to central issues (tensions, conflicts, and contradictions) to spur debate and reflection, and the production of new tools (Engestrom, 1999, p. 30). In this light, SAMHSA and Baby Friendly hospital initiative guidance are both tools to promote change and artifacts that express institutional perspectives.

Artifacts mediate between the individual and the culture, permeating the line between the two. Specific to professional practice, Toulmin finds the application of activity theory descriptive of the process of professional enculturation, in which mediating artifacts such as particular manuals affect both practical procedures, and also the internalization of "the meanings and patterns of thought that are current in our culture or professions" (Toulmin, 1999, p. 58). Likewise, Blackler finds activity theory a means to identify difficulties in "extending ideals into new routines and procedures" (2009, p. 30). Both spoken and narrated text may serve as mediating artifacts. Thus, within this proposed study, published professional guidelines serve as mediating artifacts meant to promote change; likewise, narration by the mothers makes use of doctoral research as a culturally available tool for making and sharing meaning.

Activity theory and an activity meaning-system research design conceptualize these elements as part of a system where individuals and institutions learn. In describing the methods associated with activity theory, Engestrom wrote, "the mightiest, most impersonal societal structures can be seen as consisting of local activities carried out by concrete human beings with the help of mediating artifacts…" (Engestrom & Miettinen, 1999, p. 36).

Theoretical Integration and Research Questions

The hospital nursery and the NICU are parts of a complex system in which hospital

professionals respond to the needs of infants, mothers, and families when an infant has been prenatally exposed to opioids, specifically methadone or buprenorphine. Mothers who have used these opioids during pregnancy as part of MAT interact with doctors, nurses, and other healthcare professionals when neonates demonstrate symptoms of withdrawal.

The three theories described above identify levels of interaction that are the foci of this exploratory inquiry and inform the research questions.

Family-centered developmental care (FCDC) recognizes the need for standardized practices guided by the human needs of all babies, including those that require specialized medical care (Craig, Glick, Phillips, et al., 2015). Aligned with the premises of attachment theory - valuing proximity, sensitive reading of cues and signals, and contingent care responses - FCDC prioritizes the importance of sensitivity to mother/child attachment needs in the establishment of hospital practices. These needs have been explicitly identified in the NOWS population as well (Velez & Jansson, 2008) and are aligned with the principles synthesized in NOWS guidelines.

A mother who is in MAT with methadone or buprenorphine may give birth to an infant who experiences opioid withdrawal, and is therefore more challenging to soothe, feed, and care for. Aligned with the premises of social cultural theory and the zone of proximal development, hospital nurses and other professionals who have expertise in caring for many infants are therefore in the position of experts who can help an individual mother learn to care for her one infant. Situating this learning relationship between methadone- or buprenorphine-maintained mother and expert hospital professional within an historical as well as social context, social cultural theory describes the role of culture in developing tools (as broad as institutions and language, and as narrow as teaching materials) for learning new skills.

Within this historical perspective, social cultural theory also theorizes the necessary

characteristics of the learning relationships, including trust and benevolence. Cultural shifts occurring outside the NICU or hospital nursery, such as the understanding of addiction as a chronic illness rather than moral failure, also may influence the quality of the learning relationship as would issues of power imbalance, stigma, and poverty. In the hospital nursery or NICU, the quality of these learning relationships may affect mothers as they learn from expert nurses to soothe, feed, and otherwise care for methadone exposed infants who may be characteristically sensitive.

If the theoretical focus in attachment theory is the mother/infant dyad, and the focus in social cultural theory is the nurse and mother, the focus in activity theory is the system that shapes and contains these multi-directional relationships; the institution of the hospital itself. First, emphasizing the system, activity theory as a basis for research seeks a multi-perspective view and assumes the value of conflict or tension between multiple views. Second, activity theory identifies the utility of mediating artifacts as a stakeholder expression; in this research, these are professional clinical guidelines. These artifacts provide a view complementary to the mothers' narratives, and vice versa. Finally, activity theory invites analysis based upon the "values and norms guiding expressions" (Daiute, 2017, p. 182) of groups and individuals which underlie both formal and informal expressions.

Research Questions

The research questions posed by this study are:

- What are MAT-maintained mothers' experiences in the hospital after they have given birth when their child is observed or treated for symptoms related to intrauterine opioid exposure?

- What can mothers tell us about the effect of hospital accommodations, schedules and routines as well as their own methadone maintenance schedules and routines on their caregiving opportunities while their infants were in the hospital?
- How do mothers perceive the behaviors of nurses and other hospital professional staff, such as occupational therapists or lactation specialists, to facilitate or hinder their participation in care?
- How do mothers perceive the behaviors of nurses and other hospital professional staff, such as occupational therapists or lactation specialists, to facilitate or hinder their attachment to their newborn?
- How do mothers perceive the behaviors of nurses and other hospital professional staff, such as occupational therapists or lactation specialists, to facilitate or hinder their self-esteem, self-efficacy, or development of their mothering role?
- What can mothers tell us about specific caregiving instruction offered during the time their infants were in the hospital? Caregiving instruction would include support for breastfeeding, expressing milk, or bottle feeding, as well as other daily routines including bathing, dressing, and soothing the infant to sleep.
- What can mothers tell us about how the preparation for childbirth, breastfeeding, and caregiving of their infant who had been opioid exposed affected their caregiving in the hospital while the infant was observed or treated for symptoms of NOWS?
- How do women's perceptions of the support they received to care for their infants compare to the positions stated in the SAMHSA guidance?

CHAPTER FOUR: METHODOLOGY

Introduction to Methodology

"Neonatal Opioid Withdrawal Syndrome and Promotion of Maternal Caregiving: Missing Voices of Methadone Maintained Mothers" is a qualitative research study, designed to explore mothers' perspectives, opinions, and suggestions regarding their experience of hospitalization during pregnancy and after giving birth to their opioid-exposed newborns. The study specifically focuses on these women's caregiving experiences, including rooming-in, breastfeeding and other feeding, skin-to-skin contact, swaddling, dressing, and soothing, while their infants were in the hospital, being either treated or observed for NOWS symptoms.

This study additionally investigates how SAMHSA guidelines for clinical guidance and treatment of pregnant and parenting women with opioid use disorder (SAMHSA, 2018) are addressed (or not) by current hospital practices. As described previously, SAMHSA guidelines stipulate that opportunities to support maternal caregiving include rooming-in, breastfeeding, skin-to-skin contact, and support for the mother-infant dyad through parenting preparation and education. The SAMHSA recommendations prioritize a shift in practice from treating the infant at risk for NOWS to supporting the relationship between the mother and the infant when NOWS is a risk, due to a mother's MAT (methadone or buprenorphine maintenance). Significantly, these guidelines were formulated in the absence of direct input from mothers who are actively engaged in MAT. This leaves a notable gap with regard to understandings of what the women themselves can contribute based upon their lived experiences and observations. Further study in this area stands to determine what these women most value in terms of guidance, support and

treatment for themselves and their infants, and how current efforts to guide, treat and support these women meet the SAMHSA objectives.

Research Questions

This research study addressed the broader issues surrounding MAT-maintained mothers' experiences in the hospital after they have given birth and their child is being observed or treated for symptoms related to intrauterine opioid exposure. More specifically, the study addressed the following questions:

- What can mothers tell us about the effect of hospital accommodations on their caregiving opportunities while their infants are in the hospital?
- What can mothers tell us about the specific caregiving instruction, including support for breastfeeding, expressing milk, or bottle-feeding, and other daily routines such as swaddling, diapering, and soothing the infant to sleep, offered them by hospital personnel during their infants' hospitalization? How do mothers perceive the behaviors of nurses and other hospital professional staff, such as lactation specialists, as facilitating or hindering their participation in care?
- What can mothers tell us about how the preparation for childbirth, breastfeeding, and caregiving of their opioid-exposed infant affected their caregiving in the hospital while the infant was being observed or treated for symptoms of NOWS?
- How do mothers perceive the behaviors of nurses and other hospital professional staff, such as lactation specialists, as facilitating or hindering attachment between themselves and their newborn?
- How do mothers perceive the behaviors of nurses and other hospital professional staff, such as lactation specialists, as facilitating or hindering their self-esteem,

sense of self-efficacy, or development of their sense of themselves and their roles as mothers?

- How do mothers' recommendations align with or differ from those produced by the SAMHSA expert panel and reflected in the guidance?

Through qualitative inquiry, a picture of these mothers' experiences and of current hospital practices with regard to their and their infant's care, support, and treatment was developed, addressing the research questions listed above in the process. This study aimed to explore the mothers' experiences, both in relation to the SAMHSA recommendations as well as in relation to the mothers' understanding of their own needs.

In the following section the researcher describes recruitment, the plan for human subject protections, and the interview method employed. The section concludes with the analytic plan and limitations.

Recruitment

Participant inclusion criteria

This study focused upon women who are methadone- or buprenorphine-maintained, who have given birth to infants who were exposed to methadone or buprenorphine during their mothers' pregnancies. Eligible women included those who were in residential treatment or in outpatient treatment, and who began methadone or buprenorphine during their pregnancies. Inclusion criteria required that participants be 18 years or older and able to speak and understand English.

Following the researcher's presentation to the Hunter College IRB of a plan to align all aspects of the research study with Covid-19 safety, approval for the study was granted. The researcher then began conducting comprehensive recruitment as follows:

Eligible women were sought through a combination of methods, including a site-based approach (Arcury & Quandt, 1999) and convenience sampling. First, explicit summaries of the researcher's study and IRB approval were sent to more than 10 treatment programs through which the researcher intended to subsequently conduct participant recruitment. Several programs elected to first have their institutional review boards review the study and in other cases, based upon documentation that the study had been approved by the Hunter College IRB, other programs proceeded to distribute the recruitment flyers proposed by the researcher. Next, after sending recruitment materials to programs, as described above, the researcher awaited calls or emails from a potential participant. Finally, following a brief initial telephone conversation, the researcher and the participants scheduled a longer meeting for screening, consent, and interviews. Details of these procedures will be described below.

Additional recruitment through website

In addition to a flyer, the researcher created a website through the City University of New York Graduate Center so that participants could have access to detailed information about 1) the research study, 2) copies of the screening and consent forms, and 3) contact information for the researcher and the educational institution. This information was also offered verbally during telephone conversations during which the researcher conducted oral screening and obtained participant consent.

Website: Introduce and inform.

The website was designed to provide participants with an overview of the project as a step towards requesting an informed decision to participate. As a recruitment tool the website was designed to serve multiple objectives given the limitations of remote encounters: To inform

potential research participants of the purpose of the study in simple and accessible language, to establish the importance of their individual experience, and to acknowledge them as authorities as participants in the study.

Elements of the website.

The researcher developed the website to allow potential participants or administrators of programs for pregnant women and women who recently gave birth MAT, who might provide additional eligible recruits, access to information about the study. In addition to the researcher's email address and phone number, the website address was on the approved flyer. The website included the following elements: The *Home* page included the name of the study, the researcher's name and contact information (dedicated phone and Graduate Center email address) and information about the availability of a gift card for those who agreed to be research participants.

A separate tab entitled *Research Study* included explanation of the study in multiple forms, including a question and answer (*Q & A*) section, and a two-paragraph description of the study. This was followed by a sentence-by-sentence description of the study, presented in a series of frames, each containing simple statements about the study and its purpose. The reader could advance this description one frame at a time, making the description as accessible as possible.

A tab entitled *Forms* contained the downloadable screening and clearance forms. A tab entitled *Recruitment* contained a more comprehensive description of the study. This was directed toward MAT program administrators seeking more complete information about the study. A final tab entitled *Contact Information* repeated the researcher's contact information and that of the HRPP.

Plan for Human Subjects Protection

The protocol for protecting human subjects was submitted for review by the Hunter College Human Research Protection Program (HRPP) and, following the requirement to adapt all research studies to Covid-19 restrictions, was revisited and approved. During initial conversations with potential participants, including screening and consent, the researcher emphasized that even though participants may have been referred for the study by the treatment program she had attended, that each participant had full autonomy with regard to whether or not she chose to participate in the study without affecting access to services.

Participants were informed that they could withdraw from the study at any time, including during an interview, and that all participation was voluntary. (See Appendix A. for screening and consent form samples.)

The researcher observed the following practices in collection procedures, transcription, and data storage and modification, to ensure confidentiality. Audio recordings of interview data were stored digitally on a flash drive dedicated exclusively to this research project. This was stored in a locked box in a locked file cabinet in the researcher's home office. Before transcription, only the researcher and her faculty advisor had access to the drive. Before transcription, the researcher kept all data confidential and deleted audio recordings after recordings were transcribed and checked for quality.

The researcher stored supplementary field notes in a locked box in a locked file cabinet in the researcher's home office. No written material, including transcriptions and field notes, contain identifiers. There are no names of individuals, treatment programs, or hospitals, or of the locations of any of these notes. In addition, the program names, hospital names, and locations of these have been omitted in reports and in this dissertation.

Potential for Harm

In the development of this study, the potential for harm has been considered in relation to the potential benefit of the research. One convention of qualitative research involves acknowledging that the interview may cause distress to participants, due to the emotional nature of the interview content. This convention, addressed by Josselson in "The Ethical Attitude in Narrative Research" (2007, in Clandinin), places responsibility on both the interviewer, who must be "qualified to listen to and contain a wide range of human experience," and the interviewees, who "control what they share" (p. 543), and (p. 544).

Daiute et al. have noted that this convention involves a balance between recognizing the subjects' vulnerability and the potential for research to "put the policies, media commentaries, and advocacy organizations next to multiple reflections by the focal participants" (p.180). These authors note that by balancing thus, "…vulnerable groups are not made further vulnerable by research that shines a light only on them but also asks how the analysis examines the elites' principles" (Daiute, et al., 2017, p. 180).

Data Collection Methods

There were two sources of data collected for this study. Data collection methods included interviews of women in MAT who gave birth after 2018; and selection and analysis of content from *Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorders and Their Infants* published in 2018 (SAMHSA, 2018).

Interviews as Data: Recording and Transcription

All interviews were conducted by telephone appointment with participants. Interviews lasted approximately 60 minutes. Each individual interview was recorded and transcribed by the

researcher. To supplement recordings of individual interviews, the researcher made additional handwritten field notes to include her observations of affective elements, such as interviewees' emotional expressions, their long pauses, sighs, and laughter. Moments during which the speaker's voice was particularly emotionally expressive, tearful, or explicitly angry were also noted. The researcher conducted all interviews. The researcher interviewed participants about their experiences in relation to SAMHSA non-pharmacological guidance, and in alignment with the standards of descriptive qualitative research in general, the researcher used open-ended questions about the hospital environment (rooming-in, the NICU), breast-feeding support in the hospital, skin-to-skin contact in the hospital, and relationships with hospital professionals.

SAMHSA's category of non-pharmacological recommended practices for clinical guidance for treating pregnant and parenting women with opioid use disorder and their infants (SAMHSA, 2018) provided a content framework for the interviews. These recommended practices emphasized the following: 1) There should be rooming-in, and other environmental factors such as low lights, and quiet should be attended to; 2) Mothers should be encouraged to breastfeed, feed on demand, and otherwise learn to read and respond to their infants' cues; along those lines, 3) Skin-to-skin contact is encouraged between mother and infant; 4) Soothing techniques such as swaddling should be incorporated in care (SAMHSA, 2018).

Additionally, the SAMHSA guidance language is consistently worded to acknowledge the role that healthcare professionals play in the implementation of the guidance, for example, "healthcare professionals should…." or "healthcare professionals need to…." Taking this into consideration, with this practice, interviews included questions geared toward explicating women's impressions of the roles played by healthcare providers as individuals and within systems in their care. SAMHSA guidelines identify misinformed healthcare professionals and

systems as barriers to women receiving essential care. Accordingly, interview questions were designed to explore the women's encounters with healthcare professionals and hospital systems, as they pertained to the above-named recommended practices.

Drawing upon the SAMHSA guidelines and recommendations as a framework for the interviews, study participants who were actively in MAT were asked to 1) describe NICU/hospital support for rooming in, breastfeeding, infant care; 2) compare their own experiences with what the SAMHSA guidelines outline as recommended practice and; 3) express their opinions and recommendations for best practice, noting what already works and areas for potential improvement.

Within a research interview, the participants' narration is a relational activity (Daiute, 2014; Clandinin and Connelly, 2000): Storytellers choose a particular part of their story for a particular audience for a particular set of reasons. Accordingly, participants select what to share based upon their own reasons for participating and their understanding of the researcher's purpose. Thus, during the interview process the women were encouraged to "create their stories within the social process of mutual orientation according to their definition of the interview situation" (Rosenthal, in Josselson & Lieblich, eds., 1993, p. 64). Giving birth and becoming a mother are elements of a significant biographical event, however the women's stories were shaped by what Rosenthal described as a "thematically focused context" (Josselson & Lieblich, eds., 1993, p. 65), in this case, the women's caregiving experiences in the hospital in areas also present in the SAMHSA guidance. Thus, in response to the researcher's focus, the women interviewed aligned their birth and hospitalization stories with the researcher's interview questions. Employing narrative principles, the researcher aimed to capture details that were

unique to each participant including their reasons for deciding to be interviewed (what they hoped to accomplish).

The researcher sought to establish significant temporal reference points for the women's hospital experiences. In Table One the researcher describes significant chronological elements from each woman's story, such as the time that had passed since the women had given birth (infant's birthday and current age), the infant's length of stay in the hospital and the discrepancy between the infant's and the mother's discharge dates, and the 'age' of the SAMHSA guidance at the time each woman gave birth.

SAMHSA Guidance as Data

SAMHSA's "Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorder and Their Infants" is used as a data source for this study. The researcher selected key non-pharmacological guidance practice recommendations from the SAMHSA publication to "speak" for the institutional perspective. That is to say, the researcher employed the published guidance as a means to sample the perspectives of SAMHSA and its expert panel regarding recommended practices to support pregnant women with OUD and the dyad after birth. In this study, the women who have given birth offer their own perspectives, which were not represented in the development of the SAMHSA guidance. With the interview as a data source, these women are acknowledged as authoritative resources, whose perspectives can be compared to the recommendations and conclusions in SAMHSA's "Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorder and Their Infants" (2018). Presenting the women's recommendations along with the SAMHSA guidance in this study allows for the two groups' social influence to be equalized for a kind of dialogue between "the less influential participants as well as the more influential" (Daiute, 2014, p. 112).

Sample

In September 2020 the researcher began to recruit participants. Potential participants were given information about the research study through their medication assisted treatment (MAT) programs, either by word-of-mouth or by receiving the flyer. As previously noted, inclusion criteria were as follows: The women were 18 years or older; were in medication assisted treatment (MAT) with methadone when they gave birth; and were currently in MAT at the time of the interview. Four women agreed to be interviewed for the study. All four women spoke and understood English. No additional demographic data were collected (socio-economic status, marital status, education, or race).

The four women contacted the researcher either by the dedicated phone number or through her Graduate Center email address. As noted above, before oral screening and oral consent, the researcher explained the study focus to each potential participant, and then asked if they had questions about the study. Interviews were then scheduled and conducted at the convenience of the participants.

Data Organization, Presentation, and Analysis Procedures

Three approaches to data organization, presentation, and analysis, were utilized in three, progressive phases of data analysis. For the researcher, each phase of data analysis evolved somewhat organically from the previous. These three phases, each representing a distinctive approach to data analysis, involved: 1) Initially establishing the participants as individual authorities, based upon their experience through narrative inquiry; 2) Identifying common themes in the women's narratives, using qualitative descriptive/thematic analysis and finally; 3) Using comparative analysis to compare research participants' views and experiences to what the

SAMHSA guidance described as most appropriate and beneficial practices for pregnant and parenting women in MAT, and their infants.

In the initial phase of analysis, qualitative descriptive/thematic analysis was used to identify themes that were common in the women's narratives. This analytic procedure includes an informational summary of themes. Qualitative description and thematic analysis characterized the analytic approach for presenting the women's narratives in relation to each other.

In the second phase of analysis, through narrative inquiry, the researcher endeavored to retain the distinctive experiences each woman shared, with a focus on those experiences related to the SAMHSA guidance. Taking this guidance into account, the researcher presented each participant's story as an individual narrative. Several characteristics of narrative inquiry were relevant in this initial presentation. These included: maintaining a "sense of the whole" (Connelly and Clandinin, 1990), and providing readers and other scholars with an "invitation to the particulars" (ibid), including access to participants' emotions (Holloway and Biley, 2011).

In the third phase of analysis, the women's statements were synthesized to identify both what the women identified as important, and their recommendations for practice. Presenting these elements for analysis permits a final comparison of the women's perspectives to the SAMHSA guidance.

Below, please see a more detailed explanation of the rationale and analytic procedures associated with each form.

1. Descriptive/thematic analysis: rationale and process

Useful across theoretical and epistemological traditions, descriptive qualitative research requires a transparent description of process (Braun & Clarke, 2006; Nowell, Norris, White, & Moules, 2017). The analysis of descriptive/thematic research required ordering, structuring, then

interpreting the data collected (Marshall & Rossman, 1999). What follows is a step-by-step description of how the researcher conducted analysis to identify both pre-existing and emergent themes in the interviews and stakeholder expression to generate "a comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000). SAMHSA non-pharmacologic guidance suggested pre-existing (a priori) codes; the study's aims to include "missing voices" required identifying the emergent themes and codes within the women's stories that do not neatly align with themes and categories delineated in the SAMHSA guidance.

Procedures for qualitative descriptive/thematic data analysis

The process of analysis began with transcription of the interviews by the researcher. Transcription is an important step in becoming intimate with the data (Riessman, 1993). In addition to the women's words, the researcher noted pauses and inflection, the volume of the speaker, and occasions of theatrical delivery, usually when the speaker was quoting someone else, and expressions of emotion such as sighs, an angry tone of voice, holding back tears, or laughter. The researcher checked the transcripts against recordings for accuracy.

In the next step, the researcher read through the transcripts multiple times to establish a depth of familiarity with each interview. During an initial reading, the researcher identified common elements of the women's narratives from which were established a list of "reading" codes. These included 1) chronological markers (when things happened in relation to pregnancy, birth, hospitalization, discharge); 2) narratives about drug use, methadone, seeking help; mentions of the infant's morphine treatment; 3) negative statements; 4) positive statements; 5) narratives describing environments including hospital rooms and the NICU; 6) mothers' descriptions of their infants; 7) mothers telling about feelings; 8) mothers' encounters with healthcare professionals; 9) experiences of drug testing, including when the mothers used the

words *clean* and *dirty;* including comments regarding anticipation and fairness; 10) and encounters with Child Protective Services. For this initial coding the researcher used colored pencils associated with these reading codes so I could read the transcripts without stopping and easily underline statements with multiple colors to acknowledge overlapping codes.

Aligned with the research plan to compare participants' experiences to SAMHSA guidance recommendations regarding non-pharmacological interventions, the researcher thoroughly re-read the SAMHSA guidance from start to finish. The researcher then made a chart listing the codes of the guidance elements for non-pharmacological care, and began to look for connections to these in the women's narratives. These a priori codes are 1) rooming-in is the standard of care; 2) inform women about the benefits of breastfeeding and support when recommended; 3) promote skin-to-skin contact and swaddling; and 4) health-care providers should provide accurate information, support the dyad, promote maternal confidence. As previously explained, the interview guide was based upon the non-pharmacological SAMHSA guidance; thus connections between the women's interviews and the guidance were readily apparent. Differences between what SAMHSA recommended with regard to these elements were immediately apparent during the interviews, transcription, and initial review. When the researcher reviewed the women's transcripts alongside the SAMHSA guidance chart, patterns of the gaps and alignment between the women's descriptions of their experiences and what SAMHSA recommended for these women became increasingly evident. Most notably, the women's emotional expressions were not described by the a priori codes derived from the SAMHSA guidance. In the research data for this study drawn from participant narratives, participants' emotions were central, and thus were the source of relevant codes that captured these essential elements of the women's experiences.

The researcher reread each interview to determine if the a priori and emergent codes were adequate to characterize the data. The researcher compared the ten initial "reading" codes noted above to the SAMHSA non-pharmacologic guidance statements. Eventually, the researcher categorized the "reading" codes and the a priori codes into five themes, which contained the non-pharmacological elements of the SAMHSA guidance, the women's experiences in relation to the guidance, the women's emotional expressions in relation to the guidance (how they felt about it), and their recommendations for appropriate practice.

The five themes are: 1) mothers managing the environment; 2) mothers' feelings about feeding, breastfeeding, bottle feeding, and pumping; preparation and expectations; 3) mothers' feelings for the baby, including holding the baby; 4) the mother/healthcare professional relationship; and 5) mothers' recommendations. The emergent themes from the mothers' interviews included feelings about the babies and about being a mother, and mothers' recommendations, both explicitly and implicitly stated. This emergent fifth theme, mothers' recommendations, is the subject of the final section in which the mothers' and the SAMHSA'S recommendations are directly compared.

2. Rationale and process for narrative presentation of data and analysis

During initial exploration of the transcripts, as the researcher identified and developed themes, the researcher grappled with how to retain the narrative unity and emotional expression that made the women's stories meaningful and authoritative. Holloway and Biley (2011) identified the importance of emotion, and caution that a strictly thematic presentation may silence that meaningful expression. They note how it is the nature of qualitative research that in the process of collecting, summarizing, and interpreting data, some meaning might be lost. In

this study, narrative presentation and analysis addresses this potential pitfall by retaining the emotional expression in individual narratives.

A second reason to conduct a narrative analysis was to fulfill this study's underlying commitment to the notion that by virtue of their experience as women in MAT who gave birth, the women are authorities in this subject. In light of this commitment, the researcher documented the knowledge each interview participant obtained through her experience. Moving to thematic analysis in the absence of a fuller, though edited, presentation of each mother's individual story would have undermined the individual expertise of the participants as expressed in those stories. Thus, the researcher determined that it would be essential to present individual stories as whole narratives before abstracting the interviews for thematic analysis.

In her discussion of how narrative research might be represented, Byrne (2017) also refers to the search for form for representing the experiences of others. In a discussion of form and substance in narrative inquiry, Connelly and Clandinin (1990) used the term "narrative sketch," as a step they developed to attain an overview of their inquiry. My solution to the question of form was to present the four narratives individually to accurately respect each contribution, build upon the participants' knowledge, and retain meaningful detail.

Though approaches to narrative inquiry vary widely, a cluster of assumptions is common in most narrative research. These guided my rationale and procedures to present the women's narratives as four distinct stories. Narrative inquiry is characterized by presentation of the whole rather than the parts, a focus on particulars of the individual story rather than the general, and the way the person, place, and experience are knitted together. The narratives presented here are structured to include these elements:

- Concepts of temporality and chronology, events happening over time

- People or characters, and from the storyteller's perspective, their immediate history
- Context, which combines the spatial context – where the story takes place – with the timing and the people associated with the event
- Relational nature of the research - co-construction - explicit acknowledgement of the participant's purpose in engaging in the interview and the research process. (Clandinin and Connelly, 2000; Connelly and Clandinin, 1990)

The narrative elements above address questions of when, who, where, and why (relational) as components of inquiry. In the presentation of the narratives, the researcher included biographical details, or "immediate history," (Clandinin and Connelly, 2000) even if some of those details were outside the specific theme of the research. These biographical details provided the rich context for the research questions that the women could address.

The biographical details included in the narratives distinguish the women as individuals who opted to share their stories. In narrative inquiry an assumption is that the participant's purpose engaging in the activity of the interview would have guided the participant's individual narratives. During the interviews for this study, each participant spontaneously offered a statement of purpose. This is included in the narrative data. As Daiute (2014) has pointed out, storytellers tell their stories to someone for a reason (Daiute, 2014). In my study, the participants' reasons for telling their stories to me were identified in each one's statement of purpose. They explained that they wanted to share their knowledge, to help others, to make changes, and to compare good practice to previous experiences. In their statements-of-purpose, (see Table 2.), each woman defined a role for herself in the research project, in which as a witness she assumed "a responsibility for telling what happened" (Frank, 1995, p.137).

In summarizing these interviews into narratives or sketches, the researcher acknowledges Fine's observation that a *giving voice* approach, an effort to place less powerful voices in the forefront of research "involves carving out unacknowledged pieces of narrative evidence that we select, edit, and deploy to bolster our arguments" (in Braun and Clark 2006, p. e4). Along those lines, in presenting the narratives, the researcher acknowledges the interaction between the women's stories and how the analysis has shaped them by selection and the researcher's decision-making about what to include. Nevertheless, the researcher is aligned with medical sociologist Arthur Frank's claim that "even edited stories remain true" (1997, p. 22). By presenting the four distinct narratives, the researcher hope to respectfully amplify the women's distinct stories and individual perspectives.

3. Comparative Analysis: rationale and process for comparing recommendations of women and SAMHSA guidance

This section of the data presentation and analysis is influenced by the principles Daiute defines as an "activity meaning system," an approach to inquiry about meaningful activities within a specific environment, such as the hospital or NICU, in which the researcher gathers a variety of perspectives relying upon a variety of data sources. Consistent with this approach, the current study relies upon narrating as a tool to make sense of 1) culturally relevant activities in a culturally relevant environment; 2) where stakeholders such as the mothers and the SAMHSA expert panel have different perspectives; 3) which are expressed in a variety of sampling approaches, including documents, such as the SAMHSA guidance, as stakeholder expressions (Daiute, 2014).

The interacting stakeholders represented in this study are the expert panel whose views are represented in the SAMHSA guidance, and the women who were interviewed.
By employing this rationale a direct *comparison* between the recommendations of both stakeholders is possible. For this part of analysis, the researcher compared the explicitly stated recommendations of both authoritative stakeholders, for alignment and conflict.

Through the process of narrative inquiry and thematic analysis described above, the researcher identified the women's recommendations for comparative analysis. For this study, the SAMHSA guidance and the recommendations derived from the women's interviews are viewed as equivalent resources or data sources. For direct comparison, please see Table 4.

Though procedurally, the researcher began the analytic process with thematic analysis as described above, in the results section the researcher will share the results in an order that reflects the conceptual development of the women's narratives, moving toward their shared observations, and concluding with their recommendations. Consequently, the results section to follow begins with the narratives, followed by thematic analysis, and concludes with comparative analysis, proceeding from the most individual presentation to the most collective.

Author's Positionality

The researcher on this study is an advanced doctoral student in Social Welfare with a Masters degree in Special Education. The researcher brings two decades of clinical experience specializing in Infant and Parent Development working with infants, parents, and early intervention specialists. Previous research efforts include several non-published studies involving in-depth interviews with mothers whose children were hospitalized after birth in the NICU, and studies of parent professional relationships in early intervention.

I am sensitive to the medicalization of childbirth, what sociologist Barbara Katz Rothman describes as "the removal of birth from the lives and the spaces of women and families, and into the world of institutional management" (Katz Rothman, 201, p. 75). The NICU is a challenging environment for parents, in general. Personal experience as a mother whose daughter was treated in a NICU twenty-nine years ago, as well as an exposure to opioids as a patient with severe back pain, provides a particular lens for this researcher. These experiences have exposed the researcher to some of the potential and actual challenges encountered by the study participants. These challenges take on additional significance when the potential for stigma is as significant as it is for women who are methadone maintained.

The choice of subject emerged from the researcher's commitment to family-centered and family-implemented care as beneficial to infant and family when circumstances remove childbirth from the family's control. The researcher's growing awareness during the current opioid crisis of the structural challenges facing both hospitals and methadone-maintained women who are giving birth, illuminated the need for equitable access to family-centered care in the NICU and hospital nursery for this group of mothers and infants.

CHAPTER FIVE: FINDINGS

Introduction to Findings

As noted above, "Neonatal Abstinence Syndrome and Promotion of Maternal Caregiving: Missing Voices of Methadone Maintained Mothers" is a qualitative research study, designed to explore mothers' observations, opinions, and recommendations regarding their experience of hospitalization during pregnancy and after giving birth to their opioid-exposed newborns.

In presenting the results from the study, I have organized the interview data in three different sections. The first section addresses individual perspectives organized narratively. The second section addresses shared experiences organized thematically. The third and concluding section presents comparative views of the women's experiences and their recommendations with those of the SAMHSA guidelines for clinical guidance and treatment of pregnant and parenting women with opioid use disorder (SAMHSA, 2018).

As noted previously, this progression serves multiple purposes. Feminist psychologist Carol Gilligan writes about listening to the different voices of narrators as a crucial step that should never be skipped in analyzing qualitative research data (2015). In a related fashion, the researcher in this study has listened to the research participants through multiple qualitative research lenses. The researcher first presents the participants' stories in the form of individual narratives. In so doing, the researcher establishes each mother's individual voice and the authority the mother has gained by virtue of her experiences. The thematic analysis, which appears in the second section of results, identifies the shared observations, which emerge from the women's narratives. These observations center upon the research participants' experiences as

they relate to the SAMHSA guidance for pregnant and parenting women with OUD and their infants. The thematic analysis also includes the women's emotional expressions, an emergent theme.

In the third and final presentation of results, the researcher endeavors to directly respond to the inquiry posed by the study, to compare the women's experiences and recommendations to those of the SAMHSA guidance. This effort entails two comparisons. In this section the researcher compares the women's descriptions of their experiences of hospital practice to the recommendations within the SAMHSA guidance. The researcher also compares the women's recommendations to those within SAMHSA guidance.

In sum, the researcher has employed three analytic approaches – narrative, thematic, and comparative - and presented the results corresponding to each of the three analytical approaches. Gilligan describes this differentiation in approaches as allowing "…the researcher's question to become the rudder steering the researcher toward the voices in the text that speak to his or her inquiry" (Gilligan, 2015, p. 72). In differentiating the research approaches, the researcher was seeking to be steered "toward the voices in the text" that spoke to the inquiry posed by her study. In the process, the researcher likewise endeavored to distinguish and present the variety of messages voiced in the women's interviews.

Results - The Narratives

Within the presentation of the narrative data in this dissertation, narratives are ordered to reflect when the women gave birth, beginning with the mother whose child was the oldest at the time she was interviewed and ending with the mother whose child was the youngest. This order also reflects the "age" of the SAMHSA guidance. The guidance was most recent at the time the first woman gave birth and had been in place for the longest period of time when the last woman

gave birth. All the women's names have been changed. In this report when referring to agencies involved in determining custody Child Protective Services (CPS) will be used regardless of the local agency name. See Table 1.

Fiona. Within moments of beginning her interview, Fiona described her relationship with a particular supportive nurse practitioner as, "…really good, really good. She explained most everything." Fiona was on a stable dose of methadone when she learned she was approximately three months pregnant. She described herself as a "not heavyweight" smoker and she had used ecstasy. This was her first pregnancy and she said she felt "really scared." She described deep concerns that made her consider whether terminating the pregnancy would be the right thing to do. Despite her initial concerns she was counseled to remain on methadone, and, remembers being told, "What matters now is what you do from now on," and "how important" it was that she plan to breastfeed. She gave birth after a 38-week pregnancy. Her son was 27 months old at the time of the interview.

Fiona's doctors considered her pregnancy high-risk and referred her to a teaching hospital with the expertise to prepare Fiona for the remainder of her pregnancy and childbirth and treat neonatal abstinence syndrome/neonatal opioid withdrawal syndrome (NAS/NOWS). Fiona found it frustrating that she saw a different doctor and medical student every two weeks. And given the frequency of her visits she expressed frustration that there remained so many gaps in the information she received. In retrospect she was particularly bothered by the lack of information she received to help her anticipate procedures for subjecting both her and her newborn to drug testing.

Fiona spoke about drug testing several times during the interview. She was first informed that she would be subjected to a drug test when she began pumping to provide colostrum, soon

after she gave birth and later before his discharge. Fiona's son was immediately taken to the NICU after he was born. She explained, "Everyone in the delivery room told me they are going to check him and bring him but that didn't happen. So I had to go and find him in the NICU." She said that at first she "…didn't have milk but then I was trying to get some out with the breast pump. And I got this little amount," her voice rose expressively, "and I was so happy. And I go downstairs to the NICU and the nurse was like…" (Fiona's voice took on a stern tone), "'Oh he needs to be approved for this first.'" Fiona continued, "I didn't realize what she was talking about at first… after my nurse practitioner explained it to me that they were still waiting on my drug results to see if I was dirty for something before they can give him that. That wasn't explained to me in the beginning." Fiona observed a disconnection between the emphasis on breastfeeding during her pregnancy and the lapse of information regarding the steps, including testing. "It was a scary thing for a second – what is he getting approved for because the whole time they were telling me how important it is to get milk out…I knew they drug-tested me before I gave birth but I didn't know they were waiting on the results. So they could have told me that."

As the time of discharge approached, a social worker informed Fiona that there would be additional drug testing required to determine the infant's custody. Fiona lamented, "Just imagine how many people I saw. But I was never told this. The social worker's assistant comes into my room and says" (here Fiona's voice becomes theatrically haughty), "'I just want to let you know we're going to drug test the baby.'" Fiona continued, "This was stressful because you don't know what they're testing him for. I don't understand why nobody told me about this in the beginning." The testing of the newborn's meconium, she learned from the nurses, was going to be a factor determining her case with Child Protective Services to determine – and here Fiona

vividly remembered the social worker's assistant's exact words to describe this critical event - "whether he can come home with you or not."

After her discharge from the hospital two days after giving birth and 30 days while her son was in the NICU, Fiona went back and forth to the hospital every day - arriving in the morning, going home for a little while to shower, eat, or nap, but mostly to pump. She returned in the evening, sometimes with her husband. She described the routine. "I would pump and I would bring all the milk that I had with me. I tried to breastfeed, but I just didn't feel comfortable doing it in the big room. They would put those things around you when you're breastfeeding, but if anybody had to do something they could just poke their head in. It's weird." Fiona had access to a lactation specialist but she described the lack of privacy in the NICU as too daunting for her to overcome. This included the infant's challenges in latching on and his initial difficulties feeding overall.

Considering the environment of the NICU, Fiona described missed opportunities to be with her son, especially to breastfeed in a more intimate and private setting rather than pumping at home while he remained in the hospital. During these recollections she became audibly emotional. "Maybe if I was home with him and I had more time to just lay with him it would have been different," she sighed deeply. Her voice quieted to a near whisper as she said, "But it didn't work out." Despite difficulties breastfeeding, the visits appeared to have been meaningful for Fiona. "Every time I would come – he knew I was there. Wow! I'm going to get emotional. He recognized my voice right away. He would open his eyes." She then described participating in feedings. "When he was on a feeding tube, I would still hold the syringe for him."

Fiona's emotional tone varied depending upon the subject or the observation she shared. She described encounters with too many different doctors as frustrating; pumping and producing

"liquid gold" (colostrum) as making her so happy; but being scared when she learned that providing breast milk to her son required a 24-hour wait for drug test results. This was especially upsetting because her results were invariably negative. She described holding her son as "bliss," but trying to breastfeed in the NICU as "weird."

Fiona felt well cared for by a nurse practitioner who explained things initially and during ongoing treatment. The nurse practitioner supported Fiona's care of her baby in feeding and diapering; intervened with other nurses; contacted CPS; and validated Fiona's efforts and diligence in visiting and caregiving. Fiona explicitly mentioned that this nurse practitioner's son was in recovery from opioid use disorder (OUD), as was one of the delivery room nurses.

Fiona, whose son was ultimately discharged in her care, described her encounters with CPS as stressful, and "really, really, really scary." Though Fiona bemoaned the loss of intimate time between herself and her son during the 30 days he was in the hospital, she appeared to have accepted the of the NICU, such as lack of privacy, or her son's default placement there rather than in her room. In contrast, she reserved fierce judgment for the CPS, which she characterized as an organization, which "as a whole is horrible." Indeed, her explicit purpose in participating in the study was to contribute to changing this organization and other women's experiences with CPS.

Theodora. Theodora began her interview by stating that she had to "start way back" when she gave birth to her first child. She explained, "I have a six-year old. Unfortunately when I gave birth to him I was actively using. I was eighteen. The people at the hospital treated me horribly." As a woman who had been stable on methadone for the five years between her two pregnancies, she felt "normal" during her pregnancy. In contrast to her first experience, she

didn't feel like "a pregnant user." I didn't feel bad!" she said, "on methadone, you are normal. My body was – 'We got this.'"

Her pregnancy was unplanned. Despite the physical stability she described, when she learned she was pregnant she described feeling scared, mostly by the possibility of the baby going through withdrawal. She wanted to stop her methadone treatment but was counseled that stopping posed a greater risk to the baby than continuing. She gave birth after a full-term pregnancy to a baby boy; he was 19 months at the time of the interview.

The health professionals she worked with populated her story. "I had the same doctor throughout my pregnancy, through the whole thing. My doctor wasn't there when I went into labor, but at the last minute she came in and told me to push. Seeing her put me in the mood to do the work. That was very important. The delivery room can be chaotic and having the same doctor made a difference."

Theodora described the outstanding relationship she had with the lactation specialist and the nurses at the hospital, where she was able to room in with her baby until they left together after five days. Rooming in with her baby was a life-changing experience for Theodora. "When I was discharged, they let me stay in the room. The room was beautiful. I didn't want my baby out of my sight." Before giving birth, her biggest fear was, that like her firstborn, her baby "…would be ripped from my arms." She continued, "I needed to prove something. This experience was a three-sixty, so completely different from my first experience." Theodora described the importance of being in the room with her baby. "The days in that room were the best days ever. After you have a baby you're reborn kind of. I love my family, but being there with him alone, getting to know him, bonding, was magical."

Theodora described the nurses that attended to her while she was rooming in as supportive but not invasive. The nurses switched once each day and there were two she worked with consistently. In contrast to the nurses attending her firstborn, whose attitude she characterized as more like, "You're here, figure it out," the nurses who attended after this birth "…were like friends, not judgy, they assisted." She described the implicit message of their support as recognition that she was the mother and they were there to help. "Like with swaddling," she explained. "They said, 'Make it a little tighter, let me help.'" In fact, her only complaint was that they didn't anticipate questions, when she didn't know what to ask. But they gently helped her learn how to care for her baby. Theodora often used the expression, "*They made me feel*," commenting that the healthcare professionals she worked with after she gave birth made her feel as if she could speak up, ask questions, make her own decisions, deserve to be heard. "They made me feel like I could…They made me feel awesome."

Theodora described the lactation specialist as a "superhero," whose intimate instruction allowed her to successfully breastfeed. "Breastfeeding was so important to me. I feel like I redeemed myself." Theodora was specific in how she described actions taken by the lactation specialist to help her breastfeed. She identified the ways the lactation specialist had worked with her: She *helped me with colostrum and latching on, helped me with positioning, with not falling asleep, helped me learn the football position, helped me know when it was time to switch from breast to breast, massaged my breast to pump milk out, checked on me every day, observed me breastfeeding, offered assistance*. In addition to the specialized skills imparted by the lactation specialist, Theodora emphasized the importance of emotional support. She explained, "She was cheering me on. She makes me feel as if I'm doing a good job."

Throughout the interview Theodora contrasted her previous experience with her firstborn to the more recent experience. “With my firstborn,” she said emphatically, “I had none of that!” Theodora described the contrast between how she was treated as a woman in recovery and during her first experience, when the birth of her first son precipitated her successful transition to methadone. “For my first baby, I was not in recovery yet. I should have been treated like a person anyway.”

Theodora described a nurse bringing nursing students into her room. “The nurse would bring in a student nurse and say, ‘I’d like you to see what it looks like when it works. It is not often you see this.’” Ironically, Theodora could have said the same thing. She observed, “The biggest impact is that this is not only a new life for a baby but for the mother as well. I’m kind of glad honestly, I hate to say, but I have two different outlooks of what it could be like, and what it should be like.”

Finley. Finley wondered aloud where in her story to begin her interview. Should she share her repeated unsuccessful efforts to begin treatment earlier in her pregnancy, when she began her methadone treatment, or the moment when she finally landed in a residential program for pregnant and parenting women with OUD? She said, “Where does my experience start? For instance, there are not a lot of opportunities for pregnant women to know about the help they can get. Being in residential, knowing that they can get in a methadone maintenance program – that of course helps your chances of not losing the child temporarily or permanently.”

Finley learned she was pregnant four months into her pregnancy, and entered a detox program. She left the program immediately. Seeking help, she went to the emergency room of a local hospital where she remained, untreated, for 27 hours. Having been placed on waiting lists for methadone treatment before her pregnancy, she was discouraged until she learned that as a

pregnant woman she would have priority upon documenting her pregnancy. She initiated her methadone program as she began her eighth month, but did not achieve a stable dose immediately and continued to use street drugs to avoid withdrawal symptoms. She inquired about residential programs to no avail. As she approached the final month of her pregnancy and neared her due date, she saw an OB/GYN specializing in women with OUD who visited the program. The doctor directed Finley to a residential treatment program for pregnant and parenting women. She attained a stable methadone dose four days before giving birth. At the time of the interview she resided there with her daughter who was 12 months old.

Finley described her hospital experiences as consistently grim; first in the delivery room, then in her room as the baby was examined and where she received minimal breastfeeding support, and later in the NICU, where she characterized caregiving support as degrading, impatient, and nearly hostile. She said, " It was very cold. It wasn't like a loving or happy place." Finley's voice took on a flat tone devoid of expression as she imitated the nurse's comment during childbirth. She recalled, "When the nurse said, 'You can do this' it wasn't motivation it was like, 'Be quiet. If you're dumb enough to get pregnant, you can handle this.'"

In sharing her experience, Finley said, "I've asked other people that don't use and had a pregnancy and went into labor – and they had a pleasant experience other than the pain." After giving birth, Finley held her baby skin-to-skin - tummy time - before being moved into a room, which she described as uncomfortably overheated. The baby was in Finley's room for the first two days until Finley's discharge, and then the baby was placed in the NICU where she was treated with morphine for NOWS.

In Finley's room there was a dry-erase whiteboard with the name of a lactation specialist. She never came. Instead, breastfeeding support was provided by the nurse Finley described as

the kindest among the otherwise unsympathetic rotation of nurses. She was, Finley said, "The only one I felt was nice to me." Although the nurse made an effort to help Finley position the infant and help her latch on, and complimented her on having abundant milk, Finley found her instructions difficult to understand both because of a language barrier and the nurse's non-specific instructions. Finley recalled, the nurse would say, "'Like this,' and I'd say, 'Like what?' I didn't know what I was supposed to do to get the baby to latch on." Finley commented that she preferred pumping to breastfeeding. "Something about the latching on bothered me. I just felt more comfortable with the pumping."

Finley decided to pump and was further frustrated because the hospital staff did not provide support to acquire a breast pump as they had for other women in her residential program. In the end, she found a woman in the program willing to let Finley share her pump. Finley talked about the disconnection between the encouragement she received to breastfeed and the lack of support she had received breastfeeding and acquiring a breast pump. "They talk about breastfeeding so much and they talk about how good it is and how much they want to encourage it, but to not help me at all …not to provide me with that (breast pump). I was upset about that."

Finley described the toxicology result as an obstacle to breastfeeding, as test results determine whether the mother receives permission to provide breast milk for her baby. After she received a negative drug test result, the doctor and nurses told her she had to wait ninety days to provide breast milk, since her methadone dose had only recently been stabilized. "In my mind I'm thinking, 'Are you fucking kidding me? How can they take this away from me now? How come ninety days?' I was coming up clean!"

Knowing there was only methadone in her breast milk Finley was determined to provide her milk for her baby. She borrowed the breast pump, pumped milk, and brought it to the NICU

every day replacing the milk the hospital provided with her own breast milk. “To be honest, because you know I was not using, I brought in my breast milk and instead of giving it to them to hold onto, because I saw her every day when she was in the hospital, I would give it to her in-between feedings, or if I gave her a bottle I would give her half and then the other half my breast milk.” During the two months her baby was in foster care, she continued the practice. She explained, “You know I had no control over taking care of my kid since they already took her away from me because of my poor decisions and the lack of help that I had to get clean. But I figured, ‘they had already told me all I needed was a freaking letter and now, all of a sudden, it’s another story. It was a horrible, completely horrible experience.”

During the two days Finley was in the room with her baby, and later in the NICU, she described asking for instruction about caregiving, and being scolded rather than instructed. She used swaddling as an example. “They didn’t teach me how to do it the right way. Adopting a stern voice to imitate the nurses, she said, “They’d be like, ‘This is not how you swaddle her.’ And I’d be like, ‘Well can you teach me the right way because I don’t know.’” She concluded, “It was very uncomfortable. It was not a good experience at all.”

In the NICU she experienced the same tone from the nurses. She told about one occasion, right after she herself had been discharged from the hospital but her baby had not been. After going to court and losing custody, she brought new clothes and started to put them on the baby. When she took out the clothes and began to dress the baby the nurse said, “’No, no, no, no. What are you doing?’ and I said, ‘I’m about to put this on her.’” Finley altered her voice to imitate the nurse’s irritated, condescending tone, and continued, “’You can’t put that on her.’” She said, “I felt as if I almost hurt my daughter. Another time I dropped a blanket and was about to replace it when the nurse scolded me, ‘You have to bring that home and wash it.’”

Finley was not told to weigh diapers when changing her daughter, so the hospital personnel could determine if the infant was producing an appropriate amount of urine. She was thus similarly scolded for discarding a wet diaper before weighing it. On all these occasions and others, she said, "Instead of just teaching me it was like they felt, they're making me feel, like I wasn't going to be able to take care of her. Like when I didn't burp her the right way, instead of teaching me the right was they just took her and they fed her."

Finley found the NICU challenging in other ways. For example, on one occasion, just after Finely had finally gotten the baby to sleep, a nurse, taking shortcut past her baby's bassinet, repeatedly bumped into the bassinet. Appreciating that the baby was finally sleeping, Finley worried that her exhaustive efforts to get the baby to sleep might be wasted.

Finley expressed the contrast between her achievement of sobriety and the start to finish experience at the hospital. Soon after the birth when the doctors and nurses came into the room and began testing her daughter's reflexes, and later pricking the baby to complete a blood test, Finley observed that they just proceeded without explaining what they were doing or why. "I don't know if …it's just because I'm an addict they felt that they didn't have to tell me anything and maybe they thought I just didn't really care. But of course I did. So I asked."

These experiences, one after the other, made things "hard" and "uncomfortable" and "bizarre," but at the same time, Finley said, "It's supposed to be the happiest day of my life. I'm getting sober. I'm trying to do the right thing and my baby girl is here and so far she's pretty healthy." Finley regained custody of her baby after "two months and almost one week," pinpointing the precise time they were apart. "She is my life; I really just enjoy being a mom. I really just enjoy taking care of her, so you know, she makes it easy for me to stay sober."

Sawyer. Sawyer began her interview with a detailed description of her effort to attain what she referred to as a "blocking dose" of methadone, which would both prevent withdrawal symptoms and eliminate any euphoria from opioid use. She was still using lesser quantities of heroin when she learned she was pregnant. She described the powerful effect that learning she was pregnant had upon her struggle to battle active drug use. She explained, "So with the help of my dose and my own will and feelings about using while being pregnant, I really," she paused and sighed deeply, "battled it, you know, to get to the point where I was not using." Two weeks after learning she was pregnant, she was stable on methadone. Since her pregnancy coincided with Covid-19, she was allotted methadone for self-administration to limit clinic visits to twice a week.

Sawyer described an anxious pregnancy, because of Covid, lack of stable housing, and the limitations of her male counselor, who she felt had little support to offer to a pregnant woman. Though otherwise sober during the latter part of her pregnancy, she used alprazolam (trade name Xanax) and cocaine on two occasions, to cope with her anxiety. Looking back, although sympathetic to her own anxiety, she acknowledged, "Whatever my addiction was saying to me, I was going along with it." At approximately 30 weeks gestation, Sawyer's amniotic fluid began to leak, which was another cause for anxiety. She used alprazolam and cocaine a second time; when she felt the baby kick she remembered feeling strongly uncomfortable.

Sawyer's labor and delivery followed two days after she took alprazolam and cocaine, and four days after her amniotic fluid began to leak. Sawyer had given birth once before and had a medical history of caesarean delivery and a plan in place to give birth by C-section. The disruption of the plan resulted in a protracted labor, a delayed then emergency C-section, and

difficulty in removing the baby who she said, after a failed effort at vaginal delivery, was "stuck in the birth canal." Sawyer described the whole experience as traumatic, not in the least because her knowledge that her own anatomical condition, which required the C-section, as well as the existing medical plan, were overlooked. After giving birth she asked to see her baby. Sawyer described her infant daughter as having "that look you have when you were just scared by something. Her eyes were so wide open. She was bruised so bad by the procedure (to remove her from the birth canal), there were bruises on her arms, on her chest, on her back, on her legs." The baby was placed in the NICU where she breathed room air from birth, and was discharged after fifteen days.

Sawyer was an experienced mother, who had given birth, breastfed, and cared for an infant before her OUD. Her past experience affected her as she identified opportunities to care for her newborn while she was in the NICU. Observing her baby thrashing when she was not swaddled while under the light treatment for jaundice, Sawyer asked to have her infant tucked into a nest of rolled blankets. After "a day's worth of discussion" they helped her make the adjustments and the newborn was soothed.

Sawyer similarly advocated for her baby when the baby's severe diarrhea caused skin irritation. She suggested that her baby go without a diaper for a period of time so her "bottom" could heal. As a mother talking about her baby, Sawyer described these opportunities with warmth, affection, and pleasure. Her encounters with health care professionals at the hospital were less positive. In contrast to the obstetrician she worked with at her methadone clinic, who she described as both knowledgeable and supportive, she found the nurses and the lactation specialist at the hospital ill informed and detached.

The lactation specialist initially misinformed Sawyer, telling her that breastfeeding was not recommended for a mother in medication-assisted treatment. After the trauma of the birth had been layered upon the preceding anxiety, and consequent use of alprazolam and cocaine, Sawyer described her own response to the information. She recalled, " I was already having guilty feelings about being on methadone and also trying to not use throughout my pregnancy. And then to be told, because I'm on methadone that basically I would harm her. I felt honestly that my breast milk was damaged goods." She had breastfed her first child; but when she went back to work, he wasn't able to switch between bottle and breast. Once he began bottle-feeding, he no longer breastfed.

Sawyer perceived that this combination of her past experience with breastfeeding and present stigmatization of her as a breastfeeding mother on methadone, she required support within the hospital environment. But she never received this support. She lamented, "Anybody could have said 'You are able to breastfeed,' you know what I mean?" She talked about breastfeeding as a unique mothering opportunity, saying, "I can't speak for every mom, but I feel as a mom, when you're told you can't breastfeed, you almost feel like you're not even a whole mom. Like you're only half good."

In the NICU, Sawyer and the baby's father held the baby on their chests practicing skin-to-skin contact. The opportunity to engage in mothering, in the NICU, where nurses played such an important role in the infant's care, was important to Sawyer. She explained, "Every time we would do skin-to-skin, every symptom of prematurity, even NOWS, was null and void. It didn't exist, which was amazing! I loved it so much because, if I couldn't breastfeed, and this was helping her, then it was like at least I was able to do something." She added, "I don't know what

heaven's like - but it was close to it – very sweet and intimate, you know the bond and the love you have for this little creature."

Sawyer planned to begin a residential treatment program before her baby was discharged from the hospital, but the baby was healthy and discharged after 15 days just as Sawyer was scheduled to begin the program. So Sawyer's friend cared for the baby while Sawyer proceeded with her treatment. After she completed the program, another positive toxicology result for alprazolam and cocaine was decisive in a court decision to deny Sawyer custody; furthermore the judge refused to place the child with a family member who had come forward. This decision amplified Sawyer's anger, both toward the judge who Sawyer believed was hostile to women who have OUD, and at herself for having used the alprazolam and cocaine. She wondered about the judge, "Maybe she thinks drug use is going to be part of our lives forever?" After completing the twenty-eight-day program Sawyer found a placement in a longer-term mother-infant residential program. At the time of the interview she was awaiting a decision to restore custody of her four-month old daughter.

Table 1. Results – Narrative - Order of Events

Explanation: The following table is organized to establish the meaningful dates and sequences that are part of each mother's narrative, as well as those of interest to the researcher.

The important chronological elements include the date of infant's birth; relative "age" of the SAMHSA guidance, published January 2018, at the time the women gave birth; and the age of the baby at the time of the interview.

The table also includes data about the mother's length of stay in the hospital and the infant's length of stay, to measure the length of separation between mother and infant at discharge.

The final line in the table indicates if there was further separation due to foster placement.

Mother's name*	Fiona	Theodora	Finley	Sawyer
Infant's DOB.	April 2018	April 2019	December 2019	July 2020
Months since publication date SAMHSA guidance at the time of infant's birth	4 months	16 months	21 months	28 months
Infant's age at time of interview	27 months old	19 months old	12 months old	4 months old
Mother's length of stay	2 days	5 days	2 days	2 days
Infant's length of stay	30 days	5 days	21 days	30 days
Discharge information	Discharged in mother's care	Discharged in mother's care	Infant in foster care for two months; currently with mother	Infant in foster care at time of interview

*All of the women's names have been changed.

Table 2. Results – Narrative - Mothers' Statements of Purpose
Purpose identified by each woman for participating in the research study.

Fiona "I hope I can help somebody. I think the whole organization [child protective services] should be reorganized. I feel that women like me are paying for children that organization has failed. I feel like I have a duty to change the whole organization."
Theodora "I'll start way back. I have a six year old. Unfortunately when I gave birth to him I was actively using. They treated me horribly. With this birth, I couldn't ask for a better experience."
Finley "Where does my experience start? There are not a lot of opportunities for pregnant women to know about help they can get. Knowing they can get in a methadone maintenance program, that helps your chances of not even losing your child temporarily."
Sawyer "I can't speak for every mom, but I feel like as a mom when you're told you can't breastfeed you almost feel like you're not even a whole mom. Prior to knowing you or this study even existed, I felt this was important."

*All of the women's names have been changed to protect their privacy.

Table 3. Results - Qualitative Descriptive/Thematic Analysis: Themes

Primary Themes
Managing the environment, rooming-in, and the NICU
Feeding the baby, breastfeeding, pumping, and bottle feeding; preparation and expectation
Mother's feeling for the baby and about being a mother: establishing a stable methadone dose; they made me feel; and feelings for the baby; skin-to-skin contact, holding the baby
Mother healthcare professional relationship
Mothers' recommendations*

* Mothers' recommendations are represented full in Table 4. Comparative Analysis

Results – Qualitative Descriptive/Thematic Analysis

Qualitative descriptive/thematic analysis revealed several themes in the women's descriptions of their experiences in the hospital after giving birth to their babies who were opioid exposed: 1) the mothers' managing of the environment, focused upon the NICU or their experience of rooming in; 2) feeding the baby; breastfeeding, pumping, and bottle feeding; as well as their expectations based upon how they had been informed about the value of breastfeeding; 3) mothers' feelings for the baby and about being a mother, including establishing a stable methadone dose during pregnancy, skin-to-skin contact; holding the baby; 4) mother/healthcare professional relationships. A fifth theme, mothers' explicit and implicit recommendations about what would constitute best practice for other women like themselves, will be addressed in a comparative analysis in the final section. In this section, the mothers' recommendations with regard to how they believe women in MAT should be treated, as well as what opportunities should be available to them when they give birth, will be directly compared to the SAMHSA guidance.

These themes are described below and illustrated through examples from the women's narratives.

Theme 1: Mothers' managing of the environment, focused on the NICU or the experience of rooming in

Where the women were situated with their infants after giving birth appeared to strongly affect their breastfeeding and caregiving opportunities. The theme *managing the environment, the NICU, and rooming-in* describes mothers' views regarding the impact of the environment on opportunities to be with their babies from the start. After giving birth, the women had expectations about what would happen next. They wanted to know if their babies were okay and

wanted to see and hold their babies. Where they were and where their babies were – the NICU or private room environment - affected these opportunities. Two of the babies were immediately brought to the NICU and a third infant was brought to the NICU after two days, when her mother was discharged. The automaticity of these placements stand out in light of the predictable lag between birth and the onset of NOWS symptoms (Hudak and Tan, 2012) and SAMHSA's foundational recommendation that babies should room in and mild symptoms could be treated non-pharmacologically. Fiona's son was brought to the NICU before his mother saw him; Sawyer's daughter was born preterm, at 30 weeks gestation; she was breathing on her own but was placed in the NICU immediately after Sawyer saw her. Finley's daughter roomed in with her for two days before the mother's discharge when the baby was placed in the NICU; and Theodora's son roomed in with his mother for five days.

The mothers whose babies were in the NICU described the environment as less than conducive to nurturant mothering on their part. They had to travel back and forth from home to hospital to pump to provide breast milk, and to negotiate with the doctors and nurses about specific decision regarding the care of their baby. They encountered hostility and impatience as they learned to care for their baby in a specialized medical environment. In contrast, Theodora who roomed in with her baby described a positive experience; the private room she was offered provided an environment where she could comfortably bond with her baby with support available.

The theme *managing the environment, the NICU, and rooming-in* touched upon issues of breastfeeding, caregiving, and relationships with healthcare professionals.

“They took him right away.”

For Fiona, the NICU was associated with separation from her infant. She also felt that the lack of privacy in the NICU interfered with her opportunity to breastfeed her son.

> He had to be in the NICU. They took him right away; he was never in my room because they wanted to take him right away to the NICU. Everybody in the delivery room told me 'They are going to check him and probably bring him (to my room).' But that didn't happen, so I had to go find him in the NICU.
>
> I could stay the whole day or the whole night; just on a chair. But you know it was in the whole NICU with other moms.
>
> They had a breastfeeding specialist there. She would help me if I wanted to. But he wasn't latching on [voice goes up] and I just didn't feel comfortable doing it in the big room.
>
> They would put these things around you when you're breastfeeding. But if anybody had to do something they could just poke their head in. I remember this doctor coming in to tell me something. It's weird. [Laughs, stumbles with words] I felt weird. I felt weird. I'm sure other people don't, but I - it was weird for me."

“A day’s worth of discussion.”

Sawyer talked about having to negotiate care for her daughter with the doctors and nurses who could make decisions. On one occasion, Sawyer advocated for a nest of blankets when the baby couldn’t be swaddled.

> She couldn't be swaddled because she was underneath the UV light because of the slight jaundice. But unfortunately they were doing these lights for the first three days of her life. And in the first three days of life the infant needs to be swaddled. ... It almost looked as if she felt she was falling without being swaddled. I kept saying stuff to them. 'I understand you can't swaddle her with the blanket right now because of the UV lights. I understand what you're trying to do medically. Obviously I'm not going to interfere with that because that's helping her. But you know, how about making a little nest for her, squeezing it next to her you know, so she feels [emphasizes] secure. That was a day's worth of discussion. At some points even frustration. Like you know, this little girl is like swaying her arms, flailing her arms all around you know grabbing cords, pulling the air thing out of her nose. You know what I mean just adding extra stress for her. So you know we worked on it… And of course I got my way; we made a little nest for her so it was wrapped, not wrapped but tucked alongside her on both sides and along her head. And then it comforted [emphasized] her and she relaxed.

And on another occasion Sawyer advocated that her daughter be permitted to be without her diaper as a treatment for severe skin irritation.

> Her little butt was getting raw...so I pointed out to the nurses a couple of times and they like tried to put on a couple of different creams. And I was like 'Can't we just...from my experience air really helps... Like if you keep her in a moist diaper it's never really going

> to heal. ...So the nurse was like 'Oh, that's a good point. Well let me talk to the doctor.' And I'm like 'okay.' And sure enough she came back and was like' Okay that's a good point. We're going to take the diaper off and let her little hiney hang out.'

Sawyer also talked about the contradictory experience of feeling so connected when she and the baby's father experienced skin-to-skin contact, and holding her baby on her chest while in the NICU, with being watched and judged by the nurses.

> He felt silly, you know taking his shirt off at first in the NICU but once he held her, it was you know, the whole experience that comes with it. And for him you know, I can't put words in his mouth, I can only describe his face.

> It was like you felt like you could just close your eyes and fall asleep with her lying there for hours. And you couldn't because if you closed your eyes, they might interpret that as you're high. Or your methadone dose is too high, or something. You know what I mean?

"What are you doing?"

For Finley, the most difficult NICU experiences were the interactions with the nurses there, especially one who repeatedly scolded her rather than informing her. Finley talked about the experience of "visiting" her daughter after she had been discharged from the hospital, and after she learned she had lost custody, and how hurtful the nurse's tone with her was.

> After they discharged me I would bring her clean clothes and blankets and take the soiled ones and I would wash them and bring them back. I would always do that. And so once some of the stuff was new. And I'm taking it out and the nurse sees me and she goes, 'No no, no, no! What are you doing?" And I said, I'm about to put this on her.' And she goes,

'You can't put that on her '[imitates the nurse's irritated, condescending voice]. You have to wash it.' I said 'Oh my god, I didn't know. My god, I'm so sorry.' I felt so bad... I felt as if I almost hurt my daughter by putting something on her.

"The days in that room were the best ever."

For Theodora the experience of rooming in with her baby was an opportunity she had missed when her first son was born, before she was in methadone-assisted treatment. After her discharge as a patient, Theodora was able to room in with her baby until he was discharged and they left together. She valued the five days, which were so different from her first experience as a mother before she began her methadone treatment.

When I was discharged they let me stay in the room. ... I had amazing care. The room was beautiful. I didn't want my baby out of my sight. If I needed to sleep or shower I could walk him down to the nursery, but I tried not to, 'cause I felt like I needed to be there full time. I need to prove something, I don't know. I was afraid of something happening. I was super-nervous something was going to happen, so no matter how tired I was I tried to keep him with me.

The days in that room were the best ever. After you have a baby, you're reborn kind of. I love my family but being there with him alone, getting to know him, bonding was amazing.

They took pictures. I don't remember everything about it. It was busy. The baby was crying. But we have the pictures. When my firstborn was born, he was hooked up; he was in a cage. We have the photograph - he was in a cage. In the second photograph my

husband and I are looking at each other. We're in the hospital room. We will have the photograph forever. It is great.

As soon as I was in the room, I got some rest. Then it was mom and baby. Giving birth can be overwhelming, stressful, but also amazing and magical. You're excited; you're beginning a new journey. It was a peaceful time. The view of the city was amazing. It brought me peace.

For my firstborn, when I was eighteen and actively using, I was the bad guy. He was in the NICU. I had a hard chair. I arrived at 6 a.m. and stayed until 11 p.m. and then walked home.

Theme 2: Feeding the baby: Breastfeeding, pumping, and bottle feeding; preparation and expectation, barriers and facilitators

The theme of feeding the baby described the women's perspectives on breastfeeding and providing breast milk. The women all planned to breastfeed but only one out of the four achieved that goal. Two of the women who did not breastfeed invested meaningful energy into providing breast milk as an alternative means for caring and connecting with their babies. The fourth woman, who neither breastfed nor provided breast milk described a sequence of events, from misinformation to discouragement, as undermining her feeling about being a whole mother. This, she says, impaired a potential motivation for her to stay sober.

During their pregnancies, all four of the women responded to information encouraging them to breastfeed their babies. Fiona talked about being encouraged to breastfeed in the same initial conversation with her doctors that guided her to feel that she could safely continue her

pregnancy. Sawyer talked about the whiteboard in her hospital room that confirmed her choice to breastfeed. This, she explained was to inform the nursing staff of the mother's choices for infant feeding. Sawyer had breastfed her first child six years before, before she had returned to work. For Theodora successfully breastfeeding her newborn was part of a birth experience that she described as redemptive. Finley pointed out the contradictions between what she had been prepared to do with regard to breastfeeding and the lack of support she received from the hospital staff to follow through with this plan.

As a theme, feeding the baby overlapped with the women's feelings about being a mother, their relationships with healthcare providers (who helped or did not help), and with distress over the difference between the encouragement to breastfeed they had received and the actual support available for breastfeeding.

Barriers: Breastfeeding and drug testing.

Fiona spoke about the joy of producing colostrum soon after her baby was born and the fear and frustration of being informed that she would be drug tested before she could provide it to her baby.

> So let me tell you about first when they told me I should breastfeed him. The first day I didn't have milk but then I was trying to get some out, with the breast pump. I got this little amount [voice goes up expressively] and I was so happy. And I go downstairs to the NICU - this while I was still in the hospital - and the nurse was like [different stern voice] 'oh he needs to be approved for this first.'

Barriers: The NICU as a 'big room.'

After Fiona was approved to provide breast milk for her baby, she tried to breastfeed with the support of a lactation specialist. But she ended up using a breast pump to provide breast milk for bottle-feeding. Fiona's comments in the example below exemplify the multiple factors that affected her choices regarding breastfeeding. She identified as factors the infant's challenges, the limits of what resulted from her work with the lactation specialist, and effect of the NICU environment.

> So I would pump and I would bring all the milk that I had with me. I'll go home, pump some more... I actually tried doing this with him a couple of times. They had a breastfeeding specialist there. She would help me if I wanted to. But he wasn't latching on [voice goes up] and I just didn't feel comfortable doing it in the big room. You know, it was my first time [exasperated sigh]. You know, it just didn't work out for us I guess [disappointed voice].

Barriers: Misinformation and discouragement.

Sawyer had decided to breastfeed, as she had with her first child. The lactation specialist came to visit her in her hospital room after her caesarean delivery and delivered misinformation centered on negative effects of breastfeeding for a mother in MAT. Despite the lactation specialist's returning to Sawyer to correct the misinformation she had previously shared, Sawyer's breastfeeding story is a powerful example of the sensitivity of the women with regard to hospital staff's support or lack of support. The stigmatization they sensed from some hospital personnel may have affected the women's feeding choices.

Sawyer additionally commented on breastfeeding as a motivation to remain sober, as well as how she sensed the loss of her mothering role. She recounted:

So this woman came in - because I did want to breastfeed. I was told that it was good to breastfeed, especially with the methadone because it would help the baby not experience withdrawal.

So this lady says to me, 'All right, I understand you want to breastfeed.' And she was like, 'That's a great idea.' And she is telling me all the reasons why breastfeeding's good and things like that. Great. And then at some point, she must have seen my chart, and that I'm on methadone. She says, 'I don't think it would be a good idea for you to breastfeed because you're going to expose your daughter to the methadone [voice rises in imitation of speaker]. And she goes, 'Also your urine was dirty, you know, you need to wait a week, and have clean urine before you can breastfeed your baby.' I was like, 'So if I wait a week [voice rises in a question] then don't you think then it's going to be bad to expose the baby to methadone?' So push came to shove, I didn't breastfeed.

So… this lady came back and she came in on her own because she found out she misinformed me about breastfeeding while being on methadone. And she found out it was actually beneficial to the baby. So she knew she was wrong. She came in on her own just to tell me that. But at this point now - Friday, Saturday, Sunday - three days later, okay? My daughter has already been given donor milk - you know what I mean? I was sort of like torn.

Should I stop what she's doing and start? Now I've been sitting in my own pity for three days that I'm not going to breastfeed. Um, and you know, it was almost like [emotion in

> her voice] I don't know - I can't explain it to you really how I felt on Sunday when she said that to me - because like I had already almost come to the decision. You know what I mean - I had just accepted what was now the reality.

Sawyer had used alprazolam and cocaine in the week before giving birth. She suggested to the lactation specialist that she could continue to pump until her toxicology report was negative for everything except methadone. The lactation specialist discouraged her from doing so. Sawyer explained:

> I even asked her if I could pump for a couple of days just to stimulate the milk and so that I could breastfeed after, and she was like, 'That's not necessary. You know if you want to in a week you can. I would just wait until your urine is clean.' She was like 'If you're going to have trouble staying clean then you shouldn't breastfeed.' And honestly, I feel like, just a personal thought, that breastfeeding would also be a way for me to be – another motivation not to use."

> You know on top of being a mother, on top of having a baby, but now I have to breastfeed and I'm feeding my child. And if I use drugs, I'm going to feed my child drugs. I'm not a stupid person. I know that's wrong [sing-songs *wrong*]. Breastfeeding - all the other benefits that come with it and everything. The point is, because of this I opted out of breastfeeding and um, opted to give my daughter donor milk.

When Sawyer met with the obstetrician who had supported her preparation and care through the methadone program, she talked with her about the disruption set in motion by the misinformation provided by the lactation specialist at the hospital.

She was actually upset because she and I are the ones who talked about breastfeeding the whole pregnancy! So everything I talked to her about, you know prior to knowing about this study, or you even existed.

I said to her like how I felt, and how because as a mom you know what I mean. I can't speak for every mom, but I feel like as a mom when you're told you can't breastfeed you almost feel like I don't know, you're not even a whole mom or something. You know what I mean? Like you only half good, I don't know if I'm explaining it right.

Barriers: Nobody ever came.

No lactation specialist ever came to Finley's room before she left the hospital. Finley's story illustrates the effect that the absence of support for breastfeeding might have upon mothers' feeding choices.

They had this dry erase board and it said the day you came in, the date of the birth, the weight and height and all that, and then it said 'lactation specialist.' But nobody ever came in to the room to tell me how to do that. The only person who came was just another nurse. It was the same nurse who was doing other things. And she was actually the only one I felt that was nice to me.

She kept saying, 'Like that, like that.' I was 'Like what?' I didn't know at all what I was supposed to do, how I was supposed to get the baby to latch, and then she said, 'Oh well. You have a lot of milk already, so that's good.' And so that made me feel decent. At least I was you know - had some milk to give the baby if the baby was ever going to get latched.

Finley was not comfortable breastfeeding, but was committed to providing breast milk for her baby, especially in light of the emphasis put on the value of breastfeeding and breast milk. Thus, given her commitment to sobriety and being in a residential program, Finley's frustrations were focused on the unfairness of the 90-day rule, and the unavailability of a breast pump to help her provide breast milk for her baby.

> Because they talk about breastfeeding so much, and they talk about how good it is, and how much they want to encourage it, but then did not help me at all to do one simple thing - to provide me with the breast pump. I don't know, it seems... I was upset about that.

Facilitators: She helped me to learn.

Theodora described the lactation specialist as a superhero, whose ministrations helped her achieve her goal to breastfeed her son. Indeed, Theodora did not describe her breastfeeding without attributing her success, and pride, to the relationship between herself and the lactation specialist.

> She would massage my breast to help pump the milk out. I felt so close to her, so thankful. She saw me as a human being and as a mother. She came in as a professional and as a human.

> I was nervous when I nursed him on my side, nervous I'd fall asleep. She helped me learn to switch him from one side to the other. She would say, 'It's time to switch.' And that would keep me awake and kept the flow in both breasts. She helped me learn the football position to breastfeed him in bed, in a chair, lying down. She supported me in it. She was cheering me on. She made me feel as if I'm doing a good job.

Theodora's experience illustrated the contribution made by a lactation specialist working well with a woman who wanted to breastfeed. The level of detail that Theodora described - the positions, the tempering of anxiety, the technical support - all speak to the needs of women who are not experienced, especially with the potential difficulty encountered by mothers whose babies might be expected to have challenges latching on because of NOWS.

> She checked on me every day. She observed me breastfeeding. She offered assistance. In the room we were uninterrupted unless it was important. That was the best part of it - being with him. The bond. Breastfeeding brings you so close. Breastfeeding was so important to me. I feel like I redeemed myself.

Theme 3: The mother-healthcare professional relationship

The theme of the mother/healthcare professional relationship describes the powerful influence of professionals on the women throughout their pregnancies and post-partum period. The women refer to the influence of healthcare professionals, including doctors, nurses, and lactation specialists, as they made decisions, learned new skills, and cared for their babies in the hospital. As described above, Sawyer and Theodora provided a negative and a positive example of how the relationship with a lactation specialist affected the decision-making about breastfeeding. Sawyer described the inaccurate yet discouraging advice provided by the lactation specialist as resulting in her feeling of being "half a mother." Theodora described the support she received from the lactation specialist as resulting in her feeling of success in attaining competency as a breastfeeding mother, which was so meaningful.

Healthcare professionals affected the women in other ways as well. The women talked about the importance of information, guidance, and support throughout their pregnancies,

beginning with access to treatment and confidence that the pregnancy would be all right. Finley struggled to find treatment in the earlier months of her pregnancy. She specified the role played by a gynecologist visiting her methadone program who helped her identify a mother and infant residential program, where she finally established a blocking dose of methadone just days before giving birth, and where she resided nearly one year later at the time of the interview. Fiona considered terminating her pregnancy because she was on methadone, had been smoking cigarettes, and had used ecstasy but followed the advice of her gynecologist and her primary physician who told her, "What matters is what you do from today on." Sawyer wondered if a counselor more familiar with OUD and pregnancy would have been a better fit for her during the anxious months of her Covid pregnancy, rather than the male counselor she worked with who she found had limited understanding of her feelings. Theodora contrasted the fear she felt during her pregnancy with how she felt after, but acknowledged that the professionals she encountered at her methadone program, who counseled her to remain in MAT during her pregnancy, and at the hospital were sources of "a lot of information."

As a theme, this category describes the mothers' perspectives about how professionals share their specialized knowledge with the mothers, and the consequences to the women's feelings of confidence. The theme of mother's relationship with healthcare professionals overlapped with themes of the environment, breastfeeding, and caring for the baby and being a mother. The women were sensitive to information throughout their pregnancies, during the time in the hospital, and to positive feedback and negative feedback. Thus, this theme overlaps with the mothers' feelings, which are discussed as the following theme. Although the women themselves do not use the word *stigma* it pulses behind their negative experiences.

The professionals were trusted advisors who played decisive roles. For example, Theodora talked about wanting to stop her methadone treatment when she found out she was pregnant.

> There was one woman, the director who works with pregnant women. She was in a kind of panic. 'No, don't do that! It's unsafe for the baby.' I could lose him. I was adamant about the baby being healthy. She reassured me he would be healthy. She made me feel it would be safer to stay on methadone.

Confidence and feedback.

After they gave birth, women all talked about the nurses as affecting their feelings of confidence, both positively and negatively. Fiona described the support she received from the nurse practitioner who was "really nice," detailing the different roles this professional played while Fiona's baby was in the NICU. This nurse practitioner explained things to Fiona, to the other nurses, and to child protective services. The nurse practitioner, whose son was in recovery, was a sort of champion for Fiona. Fiona also commented on positive feedback from the other nurses, who noticed her baby's preferential response to her during her visits. Fiona contrasted her nurse practitioner with the other nurses who attributed the emergence of colic at the end of her baby's stay to NOWS and recommended that his morphine be increased. The nurse practitioner identified the baby's colic, normalizing his symptoms. Fiona pointed out that nurses were "fighting to increase his morphine doses. My nurse practitioner handled that for me."

Theodora appreciated the kind and friendly attitude of the nurses who assisted her during her five days in the hospital with her son. But her highest praise was reserved for the lactation specialist who she described as a "superhero." In contrast to the nurses, who were helpful in a

general way, Theodora's relationship with the lactation specialist helped her bridge the painful associations from her first birth experience, before she began treatment.

Mothering in the NICU.

The women's responses to the healthcare professionals occurred in the context of the physical space and the work environment of the neonatal intensive care unit, a specialized hospital unit usually reserved for premature or dangerously ill babies. NICU nurses' job responsibilities and associated NICU nursing practices influenced the resulting interactions and opportunities available for mothers to engage directly in care. For example, Sawyer talked about having to negotiate with the doctors and nurses when she had caregiving suggestions for supporting her baby with rolled blankets under the lights for treating jaundice or removing the baby's diaper so her skin could be dry and exposed to the air. In other ways, the NICU nurses task orientation might obliterate the everyday considerations afforded to mothers and babies elsewhere. Finley remembered a day when a particular nurse bumped into her sleeping baby's bassinet several times while she sat beside it.

> My baby was in the NICU. It was good for me in the sense that I enjoyed being with her. But was it the best circumstances? You know I remember the nurses. I just got her to sleep and a nurse - instead of walking around her bassinet I remember a lady like taking a shortcut. Instead of going around and going the long way she took a shortcut - twice - and nudged the bassinet. I remember being like Mama Bear, like, 'What are you doing? You're hitting the bassinet!' I didn't show anger but I was like, 'Can you not do what you're doing?'

"Teach me how."

During their interviews the women often altered the tone of their voices to convey the nurse's tone of voice during remembered exchanges with these professionals, especially when they had been unpleasant. Of all the women, Finley spoke most about the negative dynamic she experienced when seeking support as a caregiver, or meeting expectations in the NICU.

> Like when I was feeding her, I felt so dumb. They were just like, 'No, this is now you do it.' And, 'Oh well, what are you doing? She can't do this' and 'you're not supposed to do that.' Instead of just teaching me it was like they felt, they're making me feel, like I wasn't going to be able to take care of her. Instead of teaching me the right way, they just took her and they [emphatic] fed her. I figured it out, obviously.

> They would tell me like to swaddle her, but they didn't teach me how to do it the right way. I had to ask like, 'Can you show me how to do it better?' They be like, 'This is not how you swaddle her [stern voice]. 'Well can you [emphatic] teach me how to do it the right way because I don't know?' [chuckles remembering]. 'I'm just trying to do my best.' It was a very uncomfortable experience.

As noted above, under the breastfeeding theme, in contrast to the positive experiences described by Theodora, the lactation specialist role was negating in Sawyer's experience; ineffective in Fiona's; and absent in Finley's. Theodora was explicit about how being situated in a private room helped her with breastfeeding, as a context for the supportive intervention of the lactation specialist. Fiona was explicit about the impact of the NICU setting as discouraging for

her. Finley identified the nicest of the nurses, who was nonetheless ineffective as a lactation support.

Theme 4: Mothers' feelings, for the baby, and about being a mother

The mothers expressed feelings of surprise, worry, fear, anxiety, embarrassment, shame, guilt, sadness, anger, confusion, determination, gratitude, pride in themselves, love, delight, and pride their infants. Each woman first expressed feelings about their infant's wellbeing and health, describing their concern for the baby when they learned they were pregnant. Through the sub-themes of *stable dose, they made me feel, skin-to-skin and holding the baby, and telling about the baby and feelings for the baby,* the mothers talked about their connection to and responsibility for their babies at different stages, from pregnancy through sustained connection during the baby's time in the NICU or their own time in treatment, or during a foster placement.

This mothers' feelings theme overlapped with issues around breastfeeding, skin-to-skin contact, and relationships with healthcare professionals. As previously noted, these relationships affected the mothers' self-confidence and sense of themselves as mothers.

Seeking treatment and a stable dose.

The women had all been surprised to find out they were pregnant, and each one expressed worry and fear about the effect that their drug use or their methadone treatment would have on the baby they were carrying. Sawyer had not achieved a stable dose of methadone before she learned she was pregnant. Finley spent almost the entirety of her pregnancy seeking a methadone program, and eventually a residential program. Both attributed knowledge of their pregnancy as a source of their determination to achieve sobriety.

Sawyer was in a methadone program when she learned she was pregnant, but had not achieved what she called "a blocking dose." Eleven days after she learned she was pregnant she was stable on methadone. She explained:

> I really didn't struggle with using opiates at that point… So with the help of my dose and my own will and feelings about using while being pregnant I really [sighs] battled it, you know, to get to a point where I wasn't using.

Finley was not in a methadone treatment program when she learned she was pregnant. It took her nearly the remainder of her pregnancy to find first a methadone treatment program, then a residential treatment program where her needs as a pregnant woman could be addressed. She remembered:

> Obviously, I was surprised to find out I was pregnant. But when I did, I went to go get help, to get clean. And I went to a detox…it didn't work out. I didn't know I had an option of getting into methadone maintenance because last time I checked a methadone maintenance place was like a one year wait.

For Finley, after an initial effort to seek treatment in a detoxification program ended, she sought direction in a hospital emergency room. She waited in the hospital for twenty-seven hours; when she left the hospital without any new information she was in severe withdrawal. She said:

> I went to a hospital thinking they would help me get into a different detox… I'm pregnant and I need to stop using. I sat I a hospital for say twenty-seven hours. No medication, I was as sick as a dog…Finally, being an addict I said, 'You know what? I'm just going to get picked up.' And I got picked up within ten minutes, and I went and used within twenty minutes, so within a half hour I felt better. Of course I felt guilty [voice rises] but at least I wasn't in pain.

Finley was in her third trimester when she identified a methadone treatment program and began to taper her use of heroin but not to stop altogether. Her uncle prodded her further. She explained:

> It takes a while to build up your methadone to be able to feel better. So that being said my uncle said, 'What are you doing? You need to get into a residential place. You need to focus on the baby and figure out how to help yourself and help that baby and get clean all together and just be on the methadone. You need help!' So I'd say about twice a week I'd ask my counselor in the methadone maintenance program clinic… And she never had an answer [emphatic].

Finley began at the methadone program in October. In December, when the gynecologist visited the clinic, Finley was able to get the information she had been seeking.

The doctor looked at my toxes and she goes, 'You're still using!' And I said, 'Yes and no.' And she said, 'You can't be doing this! What's wrong with you?' And I said, 'I need help! I'm not getting the help I need.'

The doctor recommended a residential program for mothers and infants. Although Finley was worried that she would lose custody of her child, she proceeded. Approximately ten days later, and four days before giving birth, she was admitted to the mother and baby residential treatment program.

Talking about the baby and feelings for the baby.

This theme describes the mothers' expression of their feelings for their babies, during pregnancy and after giving birth. The women expressed their feelings for their babies in different

ways. Fiona reported on her son's withdrawal symptoms, how he was not eating much, was sweating, and had diarrhea. She was detailed in how she cared for him at each stage, seeking him out in the NICU when he was not brought to her room, feeding him with a syringe, pumping each day and night, and spending the day in the NICU at his side, often holding him. Fiona's voice cracked with emotion on several occasions: once when she described how her son recognized her by her voice, signaled by opening his eyes wide, and again when she talked about the missed opportunity of nursing and intimate time together, which she might have experienced with him either in a private room or at home. She described his needs through specific observations and remembered interactions, like participating in his earliest feedings with a syringe.

Theodora described her feelings for her son as bonding, strongly associated with their time together in the private room after she gave birth. She had described his health as her biggest worry when she learned she was pregnant and in MAT, and expressed that she was proud of him and herself for his good health. She boasted, "But he's healthy. ...I feel so proud!"

Sawyer articulated her concerns for her baby as she remembered them during pregnancy, then when she gave birth, and finally in the NICU. She expressed these concerns in the context of her use of cocaine and alprazolam, and feeling her baby kick. She then worried about the loss of amniotic fluid, leading her to challenge the doctors about her amniotic fluid loss. She consequently asked if there was adequate amniotic fluid for her baby.

Immediately after she gave birth Sawyer described listening for her baby's cry after the caesarean section. She remembered not hearing it. When she first saw her baby, she was bruised as a result of the failed vaginal birth. Sawyer said that this evidence of her baby's discomfort

during the birth was painful and disturbing to her. Later, she acted upon concerns as she cared for her daughter in the NICU. Sawyer recounted:

> So when she came out I asked if she was okay, because I didn't hear her. I never heard her cry at all. So then they bring her over and her eyes were so wide open, like, like the look that you have when you were just scared by something. On top of it, she was bruised so bad [pause] by the procedure, on her face, on her arms, all over her arms, on her chest, on her back, her legs, bruised. But she was three pounds and four ounces, 19 inches long, and she was healthy [emphasized]. She could breath on her own! She was born 30 weeks and one day!

Sawyer described her baby's needs in detail, as noted above, when she described her maternal advocacy in the NICU, once requesting a nest of blankets for her daughter who was under the jaundice treatment lights, and once when Sawyer felt a break from diapers would help the baby's skin heal. Both of these stories were associated with Sawyer's own pleasure and delight in parenting.

> So I took pictures of this too [laughs heartily] because it was so adorable and the baby's face was so just priceless because she was like 'What are we doing?' Oh my god, it was cute! ...But you know I just felt that I needed to be proactive for her.

Sawyer affectionately described interactions between her and her daughter when she sang "Twinkle, Twinkle Little Star" to her baby.

> I started singing 'Twinkle Twinkle Little Star' to her when she was born and every time I would hold her I would sing it very lightly you know, because I learned you know an infant as tiny as her doesn't like a lot of stimulation. It's like sensory overload for them.

> So something as basic as just holding her tight and singing to her was like just perfect enough to comfort her. She didn't require a lot, just that touch, that love, and that warmth.

Sawyer's daughter was discharged from the hospital on the same day that she was leaving for a residential program. Sawyer remembered the emotional challenge of the separation.

> My friend dropped me off first because she knew that if I went with her to pick up the baby that I wouldn't have gone.

Sawyer described the evolution of her feelings for her daughter.

> My values and my morals are strong when it comes to doing right by a child. ... Addiction is strong and a love for your child um you know doesn't start out as strong when you find out you're pregnant as it does when you begin to grow, feel the baby kicking and moving, you know...

Finley expressed her feelings for her baby in explicit and implicit ways. On one occasion before describing challenges with the nurses in the NICU, Finley simply stated, "She was in the NICU. It was good for me in the sense that I enjoyed being with her." Finley told about her determination to mother her daughter by providing breast milk to her baby, which required borrowing a breast pump, bringing the milk to her baby, discarding the formula provided by the NICU and substituting her own milk. Finley continued to provide breast milk while her daughter was in foster care. Finley expressed her feelings for her daughter in terms of the months that they were separated; she connected that loss to the challenges she faced getting appropriate treatment earlier in her pregnancy. Finley identified a system lapse – enormous difficulty finding the

information a woman in her situation needed to gain admission to a residential treatment program – and to others' losses as well.

> It's a shame you know. Because I know that there are other people who need help. It's a real big shame that women might have their kids taken from them completely because they didn't even attempt to get in a program.
>
> That would have helped me, definitely, because I would have been able to keep her, instead of losing for the first two months of her life.
>
> I've had her since March. She was born on December 24 and I got her back March first. So she was gone for two months and almost one week. But she's here. She's healthy. She makes it easy for me to stay sober.

Skin-to-skin contact, holding the baby.

Fiona talked about holding her baby as a time when she established a relationship with him, when he and she shared special moments. When Fiona described her baby's response, she identified the role of the nurses, who pointed out the baby's unique responses to her. Sawyer talked about experiencing a sense of connection to her baby when she held her skin-to-skin, an undertaking unique to mothering that was a meaningful substitute for breastfeeding. This was something she could do that set her caregiving apart from the nurses' caregiving.

The sub-theme of skin-to-skin contact overlapped with breastfeeding, mother's feelings for her baby, and her feelings about being a mother. The women talked about mothering in the NICU with a sense of the eyes of the professionals upon them.

Sawyer described participating in everyday care as well as skin-to-skin contact.

> Now day-to-day in the NICU, I would go in and visit, you know. I took part in her feeding, changing her diaper, her oral care. I was part of everything. I kept a journal of everything the doctor said, every person I talked to, any medication she was on, her weight.

Sawyer described her own contentment when she was able to provide comfort to her baby with skin-to-skin contact. For Sawyer, skin-to-skin contact was how she could mother best in the NICU.

> It was amazing. I did a lot of skin-to-skin therapy while she was in the NICU. Um, because she was a preemie and because we weren't breastfeeding... It's also a therapy that they like with babies who are experiencing NOWS even though my baby wasn't experiencing it a lot. She had erratic breathing, which is hand-in-hand with being premature. Every time we would do skin-to-skin, every symptom of even prematurity or even possibly NOWS was null and void. It didn't exist. You know um, which was amazing. You know I loved it so much because it was like if I couldn't breastfeed, you know, and this was helping her, then it was like at least I was able to do something.

> Because you think about it, while they are in the nursery, you know, all those nurses are like mother. They have to show her love and nourishment and comfort and you know, rock her when she's crying and such. But while I was there I was able to do that. And when I held her on my chest, honestly it was like - I don't know what heaven is like - but it was close to it, you know? And um, very sweet and intimate and um you know just like the bond and love you have for this little creature.

"They made me feel."

The women's feelings about mothering were sensitive to the feedback and instruction they received from nurses and other professionals they encountered, both positive and negative. Fiona commented on support from an individual nurse practitioner as well as the comments of the nurses who shared their observations about her baby boy's contentment when she held him in the NICU. Theodora said, "They made me feel like I could ask questions," and speaking of the lactation specialist, "She made me feel awesome." A nurse brought nursing students into Theodora's room to comment upon her and her baby as a positive example of methadone mothering gone right. She joked about her husband calling her 'big headed' because she felt so proud.

For Fiona, this theme demonstrated the way her own feelings about being a mother were tied to positive feedback from the nurses. When Fiona was in the NICU with her baby she fed him, changed him and held him.

> I mean the nurses knew when I was there, and I had him in my - like holding him. All the nurses passing by would just see that he's in heaven. That he was in such a bliss. They would tell me things. That he looks so -they were basically telling me that they can see that he loves it when I come and when I'm holding him. And he just loves it when I'm like holding him and he would snuggle in me and sleep.

Finley said, "After I gave birth and they recommended birth control right away, I felt embarrassed that they didn't want me to procreate again." And she said when they were

impatient in their instructions about caregiving, “They made me feel like I wasn’t going to be able to take care of her.”

Sawyer’s daughter’s discharge from the NICU coincided with Sawyer’s entry into a residential program. As part of the discharge, the hospital medical professionals informed Sawyer’s friend, who was taking care of the baby while Sawyer was in her twenty-eight-day residential program, about some issues related to the baby’s prematurity. These medical concerns, Sawyer explained, had not been discussed with her despite her regular visits and consistent requests for information and explanations.

> Because it made me feel once again less than, made me feel stupid, like I should have known. It actually, it – I don't know - it - looking back at - how like I was - it almost made me depressed for a little while because you know I'm still harboring feelings like I did something wrong or something, you know.

Finley summed up the effect on her feelings of her relationships with the nurses she encountered.

> I just felt like such a loser. Even though I’m an addict, I felt so shitty. I just really didn’t like the way I was treated.

Results - Comparative Analysis: Stakeholder Expressions, Alignment, and Comparison to Experience

This section of results identifies the alignments and misalignments between the recommendations of SAMHSA’s expert panel and the women who have given birth, as well as the women’s observations about implementation of the SAMHSA recommendations. The expert panel of doctors collaborated to generate the *Clinical Guidance for Treating Pregnant and*

Parenting Women With Opioid Use Disorder and Their Infants (2018), an official SAMHSA publication based upon a review of current research and the panel's shared clinical experience. Likewise, this section of the results presents the mothers' recommendations as summarized from their narratives and the thematic analysis.

As described on the SAMHSA product website, "This Clinical Guide provides comprehensive, national guidance for optimal management of pregnant and parenting women with opioid use disorder and their infants. The Clinical Guide helps healthcare professionals and patients determine the most clinically appropriate action for a particular situation and informs individualized treatment decisions." Based upon lived experience, the women in this study are also considered experts whose views should inform decision-making both as individual patients and collectively as contributors to practice guidelines. The women's recommendations and those of the SAMHSA panel are remarkably similar. In this section of the results their recommendations will be compared to those published in the guidance.

In contrast to the similarity observed in the recommendations, when the women described what they experienced as women with OUD in MAT giving birth and caring for their newborn infants in hospital settings, these comparisons yielded observations of meaningful differences. The women's observations reflect hospital practices that do not align with either SAMHSA's or the women's recommendations for women with OUD giving birth in hospital settings. Describing this level of comparison, this section delineates these misalignments between the SAMHSA recommendations and their implementation at the hospital, as evidenced by the women's descriptions of their experiences. In Table 4 below, the SAMHSA guidance is presented thematically along with the women's recommendations and observations. Although

the structure by necessity compresses the SAMHSA recommendations, the language of the recommendations is taken directly from the guidance. See Table 4.

Table 4. Results - Comparative Analysis: SAMHSA Recommendations, Alignment, and Comparison to Experience

Theme	Mother and SAMHSA Recommendations in Relation to Non-Pharmacological Interventions
Managing the environment	**SAMSHA recommendation:** Rooming-in is the standard of care; unless dictated by medical considerations rooming-in is the preferred environment for opioid-exposed infant; mild signs of NOWS should be managed with non-pharmacological interventions.
	Mothers' recommendation: The opportunity to breastfeed and bond with my baby in our own room made a difference in my bonding and breastfeeding.
	Alignment with practice and the women's experiences: Only one mother had the opportunity to room in with her baby. Other mothers observed the negative effect of the NICU on breastfeeding, and skin-to-skin contact, and nurse's attitudes toward caregiving.
	Summary of alignment with SAMSHA: Women were not generally offered rooming-in.
Feeding the baby	**SAMSHA recommendation:** Emphasize the benefits of breastfeeding; emphasize the act of breastfeeding rather than opioid agonist in the milk; provide clear directions about when women should or should not breastfeed; provide lactation support.
	Mothers' recommendation: Follow up recommendation to breastfeed with accurate and timely information, well-informed lactation specialists, and an environment conducive for practicing breastfeeding. Provide support for women who choose to pump by providing access to materials; support policies that do not undermine women's motivation to breastfeed or to provide breast milk; understand that providing breast milk has meaning beyond nourishment to mothers in recovery and support that meaning accordingly; share all the relevant information from the start.
	Alignment with practice and the women's experiences: Only one mother had the privacy and support required to breastfeed; other women commented upon privacy, misinformation and lack of information, and self-consciousness as reasons they did not breastfeed. The women commented on the disconnection between encouragement to breastfeed and hospital policies (such as the 90-day requirement) or undermining misinformation that actively discouraged follow through.
	Summary of alignment with SAMSHA: Women were not generally offered adequate lactation support.
Skin-to-skin contact	**SAMSHA recommendation:** Extended skin-to-skin contact, like rooming-in, swaddling, gentle handling, and quiet environment is a

	recommended non-pharmacological approach.
	Mothers' recommendation: Let me see and hold my baby after giving birth; skin-to-skin contact provides a rewarding opportunity to bond with the infant; to be a soothing presence; to be a mother.
	Alignment with practice and the women's experiences: Mothers who parented in the NICU were supported in providing skin-to-skin contact.
	Summary of alignment with SAMSHA: Women generally felt supported in providing skin-to-skin contact though healthcare professionals must avoid stigmatizing otherwise benign behaviors.
Theme	**Mother and SAMHSA Recommendations in Relation to Non-Pharmacological Interventions**
Mother healthcare professional relationship	**SAMSHA recommendation:** Misinformation by healthcare professionals (HCPs) is a significant barrier; HCPs should not view a return to substance abuse as a failure; HCPs decisions about care should be based upon a trusting and respectful therapeutic relationship rather than one toxicology report; HCPs should support the mother's observation of her infant to promote sensitive responses; HCPs should attend to mother's strengths and promote confidence.
	Mothers' recommendation: Even one nurse and/or lactation specialist, makes a difference in how mothers feel about their ability to care for their baby; HCPs have a very important role and can "make me feel" good or bad, like a success or a failure; even one nurse or lactation specialist who compromises that role can damage the woman's mental state, confidence, or recovery.
	Alignment with practice and the women's experiences: Two of the women identified special champions among the HCPs, a nurse practitioner and a lactation specialist, who made them feel confident and supported throughout their own stay and their baby's time in the hospital. The other two women had significant negative experiences with staff, when they were misinformed or felt that efforts to parent were met with discouragement or scorn.
	Summary of alignment with SAMSHA: Women valued partnerships with healthcare professionals; they reported mixed experiences, both extremely positive and extremely negative.

Rooming in.

The SAMHSA guidelines are unambiguous regarding the role played by rooming-in as "the standard of care and as such should be offered to all mother-infant dyads" (2018, p. 87). The guidance further acknowledges the likely relationship between breastfeeding and rooming-in: "Breastfeeding and rooming-in may go hand in hand" (p. 87). The private room as a context for mother-infant bonding during the immediate post-partum period is also explicitly recommended within the guidance, as is the premise that even mild NOWS symptoms should be managed non-pharmacologically and only situations in which infants are experiencing weight loss or failure to maintain hydration should transfer to the NICU be considered (p. 89).

With the exception of Theodora, the women who participated in the study did not consider rooming in a possibility. They acknowledged the lack of intimate time with their infants as Fiona did, rather than explicitly recommend the practice of rooming-in, as they did in response to other practices. Fiona became audibly emotional as she considered what rooming-in might have entailed, as she imagined what the effect might have been on the quality of the time she spent with her son. She tried to remember if rooming-in had been discussed as a future possibility. Only Theodora confidently contrasted what could happen with what should happen, describing the time she had with her son as a "magical" time devoted to bonding.

In contrast, the set of relationships between rooming-in and breastfeeding evident in the SAMHSA guidance as well as in Theodora's positive experience, were also evident in the mothers' negative experiences in the NICU. The women described experiences that demonstrated the benefits of rooming-in by explicit counter examples. For example, Fiona was devoted to visiting and providing breast milk for her infant but found the environment of the NICU a "weird" place to breastfeed despite the support of a lactation specialist and of a

champion nurse. The white board in Finley's hospital room identified a lactation specialist. However, in the two days of rooming-in she had with her baby before she was discharged, the only support she received regarding breastfeeding came from one of the nurses, not from a specialist. As Theodora's interview reveals, a lactation specialist offers guidance for many skills to support a new nursing mother. Furthermore, for a population with NOWS, a lactation specialist could sustain the mother in the difficult task of helping an infant with NOWS latch on. For any mother struggling to establish breastfeeding, the availability of a room and intimate time would appear to confirm the connection between the rooming-in and breastfeeding noted in the guidance. Although Finley stated that latching on made her uncomfortable and identified a preference for pumping, the effect of the lack of privacy cannot be discounted as a factor further discouraging her from efforts to breastfeed (Jansson, Velez, & Butz, 2017).

Breastfeeding.

Although the women all reported experiences aligned with the SAMHSA recommendation that women be *encouraged* to breastfeed, and all initially expected to breastfeed, they encountered numerous obstacles to breastfeeding. In addition to the lack of privacy, which would have been remedied with rooming-in, the women described being misinformed by healthcare professionals about breastfeeding recommendations for women in MAT. They moreover described a lack of trained lactation support. Hospital or institutional policies are another factor affecting the breastfeeding decision and opportunities for many women in recovery. In their thorough discussion of revisions of breastfeeding guidelines at Boston Medical Center, for women with OUD, Wachman and colleagues (2016) described policies requiring 30- to 90-days of negative toxicology reports as a "gray zone." Such policies appear as carryovers of stigmatizing views of recovery and return to substance use and do not

represent a necessary limitation on breastfeeding safety, nor are they consistent with the recommendation to encourage breastfeeding so that the benefits are available to the dyad (Wachman, et al., 2016). They concluded, that the requirement of 90-days of negative urine toxicology reports undermined their goal to promote breastfeeding and did not increase breastfeeding safety. BMC further determined that four weeks of negative tests was consistent with accepted milestone for sobriety. With the revised guidelines in place, the mothers at BMC had increased access to the benefits of breastfeeding. Those benefits include increased maternal confidence, better social functioning of the dyad, and improved mother infant bonding (Demirci et al., 2015). Finley expressed outrage at a policy that restricted her from providing breast milk until she could accumulate 90-days of negative toxicology reports. She in particular robustly voiced the recommendation that proof of sobriety and participation in a residential program should affect her opportunities. Indeed, those are two of the criteria observed in the BMC revision.

The women who participated in this study recognized that there may be conditions that could mitigate the initiation of breastfeeding, but they recommend that information about policies should be discussed with pregnant women as part of the preparation and encouragement to breastfeed during pregnancy. Likewise, the SAMHSA guidance specifies, "Mothers need to know when they *should* and *should not* breastfeed" (2018, p. 90). Sharing information about the benefits of breastfeeding, it would appear, is more adequately addressed than identifying factors that limit that recommendation.

Skin-to-skin contact.

The women who talked about skin-to-skin contact singled it out from the other practices as very meaningful to them, as a replacement for breastfeeding. They stated the value of skin-to-

skin contact as an opportunity to be intimate with their infants in their role as the baby's mother even in the NICU.

The SAMHSA guidance identifies skin-to-skin contact as a recommended non-pharmacological practice along with swaddling, gentle handling, and a quiet environment. However, SAMSHA did not explicitly address practices securing the opportunity to hold one's baby after giving birth. Highlighting this otherwise overlooked possibility, several of the women described having to ask to see the baby after giving birth, or having to find the baby in the NICU. Thus, the women implicitly recommended that the hospital ensure that mothers are consistently given the opportunity to hold their babies immediately after giving birth.

Mother/healthcare professional relationship.

The SAMHSA guidance included multiple statements that identify the role that should be played by healthcare professionals. The SAMHSA guidance emphatically addresses a return to substance abuse and cautions, "Patients and healthcare professionals must learn to recognize that, although return to substance use is discouraging, it is not a failure" (2018, p. 46). The guidance identified the following as barriers to supportive healthcare professional/mother interactions: negative interactions, characterized by misinformation, misjudging a return to substance abuse, or poor communication tainted with impatience or indifference. Examples of each of these were evident in the women's stories. These interactions undermined the women's confidence.

SAMHSA recommended that healthcare professionals' decisions about care should be based upon a "trusting and respectful therapeutic relationship" rather than a single toxicology report. The women each conveyed distress about drug testing as it affected breastfeeding, providing breast milk, and custody. They identified poor communication and a disrespectful tone

in conversations as negatively affecting their understanding of and response to these policies, separating the policy-driven outcomes from the process of communication. When discussing the circumstances around urine toxicology screening and results, the women themselves used the terms "clean" and "dirty." They used these stigmatizing terms to express their feelings about how they were viewed, describing what they perceived as underlying attitudes reflected in both the policies and the communication. The mothers wished to be communicated with respectfully, and informed in advance, when a policy would affect their opportunities and thus their decisions. In addition to drug testing, there was consensus among the women about the impact of communication with nurses, lactation specialists, and social workers on the women's feelings as mothers. They observed that even one nurse, lactation specialist, or social worker who compromises the SAMHSA values of "trusting," "respectful," and "therapeutic" interactions could damage a woman's mental state, confidence, or recovery.

The women's narratives provided both positive and negative examples of this value in practice. Whereas both Fiona and Theodora identified champions among the healthcare professionals in the hospital - a nurse practitioner and a lactation specialist respectively - Sawyer and Finley identified interactions with the lactation specialist and the staff of NICU that were undermining.

Stigma lurked for all of the women, in particular those closest to the beginning of their recovery. Theodora, whose baby was characterized by the nurse who came into her room with nursing students as 'what an ideal baby on methadone looks like,' poignantly compared her recent experience to her first experience when she began her methadone treatment after giving birth. This time, she said, "I didn't feel like a pregnant user." Finley, who established a blocking dose of methadone days before she gave birth, experienced intense stigma. She said, 'I just felt

like such a loser. Even though I'm an addict, I felt so shitty. I just really didn't like the way I was treated."

The study's findings, evident in the comparative analysis, are twofold: One group of findings pertains to recommendations, and one to practice. An initial finding emerges that the women's recommendations are, for the most part, similar to those put forth by the SAMHSA guidance. As they described their experiences, the women explicitly endorsed 1) breast-feeding, and providing breast-milk, 2) skin-to-skin contact, and implicitly endorsed 3) their constant presence at their baby's side.

SAMHSA's recommendation for rooming-in was the exception when it came to a direct comparison between the SAMHSA recommendations and the women's explicit recommendations. Only one woman had the opportunity to room-in, and only she confidently recommended the practice from her own experience. Of the three women whose babies were placed in the NICU, none of them initially expressed disappointment that they hadn't been given the extended opportunity to room-in with their baby during the infant's hospital stay. These findings demonstrate a failure of education as well as implementation of the guidance recommendation that "Healthcare professionals should ensure that she [the pregnant woman] is aware of non-pharmacological interventions that should be provided to her infant to reduce NAS symptoms, including rooming-in" (SAMHSA, 2018, p. 25).

In fact, when asked during her interview about rooming-in, despite it being a cornerstone of the guidance and of the research underlying the guidance, Fiona compared it to alternative treatments she had heard discussed. She recalled rooming-in and an aromatherapy treatment as two supports for her infant that remained equally vague and inaccessible. Fiona's most emotional moment surfaced when she was asked whether rooming-in had been offered and if she believed

it would have been desirable. She talked at length about traveling from hospital to home to pump, shower, and eat, only to return to the NICU. She was saddened that although she had a lot of time with her baby, she had no opportunity to be with him in a more intimate setting.

A second related finding centered on the following: Though the women's recommendations with regard to the treatment of pregnant and parenting women with OUD and their infants frequently corresponded to those of the SAMHSA guidance, the women's experiences indicate a persistent gap between these recommendations and hospital practice. Indeed, the experience of the mother who roomed-in with her baby, when contrasted with the experiences of the other mothers who were not offered rooming-in, points to a persistent unavailability of rooming-in as an option for mothers who gave birth while in MAT. Breastfeeding was another area where there was an evident gap between the SAMHSA recommendations and the women's experiences. The women who were interviewed expected to breastfeed their babies and did not, citing reasons that included an overly restrictive policy requiring 90 days of negative toxicology results (policy), inadequate support from a lactation specialist (support), the lack of privacy in the NICU (environment), and misinformation. Stigmatizing encounters with healthcare professionals was a third area in which the women's experiences demonstrated the failure at the hospital level of bringing the SAMHSA guidance to practice. The women encountered misinformation and surprise information. Finley described having to request explanations when her baby was examined. Not only was Sawyer misinformed about breastfeeding for a mother on MAT, she described significant information about her baby that was withheld until discharge.

CHAPTER SIX: DISCUSSION AND CONCLUSION

The SAMHSA guidance released in 2018 was based upon a body of research and the informed clinical opinions of a panel of experts. Although the description of the methodology and process for the development of the SAMHSA guidance references respect for patient autonomy (2018, p. 6), there is no mention of the direct involvement of women whose lived experience might have informed the panel of experts who wrote the SAMHSA guidance. Subsequently, there has been no research expressly designed to include the perspective of women who have given birth while in MAT in the content of the SAMHSA guidance. This study addresses that gap. More specifically, this study's comparative analysis facilitates direct comparison between the recommendations made by the SAMHSA panel for women who have given birth while in MAT and the recommendations such women have made, based upon their lived experiences. This study's seeking of input from women in MAT during their pregnancies and through their postpartum period while their infants were being observed and/or treated for NOWS recognizes these women as experts. It recognizes such women as individuals who can valuably contribute to the SAMHSA guidance and subsequent improvements in the treatment of women with OUD and their infants.

Study and Limitations and Strengths

Approval for this study was confirmed by the IRB in the summer of 2020 during the period of Covid lockdown. According to the CDC, mortality from opioids accelerated as early as Spring 2020, impacting the lives of the women who may have been participants. Consequently recruitment was affected, posing a limitation on the pool of potential research participants.

Consequently, the sample size for this study was a smaller than originally anticipated in the study design. Sample size is a factor in collecting data to adequately respond to an inquiry. Saturation is a criterion most frequently applied to qualitative research to denote a stage in data collection and analysis when data is considered sufficient to generate a response to the research question. Saturation is often paired with the number of interviews or participants. In thematic analysis saturation is most frequently signified by "similar instances" and the search for "diversity of data" (Glaser and Strauss, 1967, p. 61). The "Missing Voices" interviews yielded both similar incidents and diversity of accounts. The interviews provided examples that informed the pre-existing codes to examine alignment of experience with the SAMHSA guidance. Interviews also informed emergent codes, which reflected experiences the women described that were not stated in the guidance. However, the sample size of four does indeed limit the number of examples in each category. In this study, the presentation of narrative accounts is a countervailing value intended to offset the limitation of a smaller sample size. Saunders et al. observed that when the research approach is based upon narrative, or the accounts of individual informants, identifying the point of saturation is less straightforward (Saunders, Slim, Kingstone, et al., 2018).

The limitations posed by the small sample size of four were also mitigated by both the diversity of the women the researcher interviewed and the similarities in the experiences they described. The four participants reflect diverse experiences in relation to location, having given birth in Chicago, Manhattan, a small city in north New England, and a small city in upstate New York State. Additionally, having given birth between 2018 and 2020, the four participants proffer diverse experiences in relation to the publication date of the SAMHSA guidelines (2018). The women's stories reflect a continuum of experiences with regard to methadone treatment and

phase of pregnancy: Two of the participants had been in treatment with methadone before their pregnancies, one of the women was in the process of establishing a stable dose of methadone when she learned she was pregnant, and the fourth struggled throughout her pregnancy to find a methadone program, more specifically, a residential program that could meet her needs as a pregnant woman and new mother. Two of the women were married and described family situations that reflected stable housing. Of the remaining two women, one indicated a stable relationship with the baby's father, but described housing, especially proximity to "people, places, and things," as factors causing anxiety during her pregnancy. The fourth woman did not discuss the baby's father or describe her housing throughout her pregnancy. She did, however, volunteer that she was living in a residential program with her child at the time of the interview.

Another limitation of the study centers on the absence of demographic data as means to further contextualize the women's experiences. Despite the diversity in the factors described above in the women's methadone treatment and the years they gave birth, the researcher did not explicitly collect demographic data, so factors of race, socioeconomic status, education, and age were not available for analysis. These socioeconomic factors were not included in the original study design, due in part to their lack of emphasis in the literature. Nevertheless, their omission is the responsibility of the researcher.

An additional limitation is methodological. Given the reliance upon narrative accounts and the emphasis on women's voices, both follow up and member checking would have strengthened the study. However, having made the decision to ensure confidentiality by maintaining only oral consent records absent identifying information, the researcher foreclosed the opportunities to follow up with participants to expand their accounts during data collection or pursue a member-checking step as a final step in analysis. Thus the researcher acknowledges that

although the research relies upon the narratives shared by the women who chose to participate, the researcher has retained what Josselson calls interpretive authority (2006, p. 548).

Despite its limitations, the researcher believes that sufficient data was collected to respond to the research questions, 1) What are MAT-maintained mothers' experiences in the hospital after they have given birth when their child is observed or treated for symptoms related to intrauterine opioid exposure? 2) How do women's perceptions of the support they received to care for their infants compare to the positions stated in the SAMHSA guidance? And 3) What are women's recommendations for practice based on their lived experiences? Furthermore, the methodological choice to employ three qualitative analytic approaches helps to establish the study's "trustworthiness," allowing readers to recognize the women's experiences, to follow the researchers clearly documented process of analysis, and to transfer findings to other sites (Nowell, et al. 2017).

Conclusions and Implications

The twists and turns of these women's stories illuminate their multiple encounters with a variety of systems as they attempted to access the specialized treatment that pregnant and parenting women with OUD require, as outlined in the SAMHSA guidance. Studies to date have yet to explore the childbirth and postpartum experiences of women in MAT, using a narrative methodology. This study has provided unique information about connections between the women's perceptions of their pregnancies, their access to gender-based methadone assisted treatment, their birth experiences, and their postpartum experiences including breastfeeding and caregiving in the hospital. The continuity evident in their narratives reveals the challenges these women faced throughout pregnancy, during childbirth, and the post-partum period.

All four women gave birth in teaching hospitals. Despite this apparent advantage, systemic challenges to appropriately caring for pregnant and parenting women with OUD were identified in the women's stories. For example, one mother (Sawyer) described the hospital where she gave birth as one of the best hospitals for children in her region. Despite the hospital's status as a teaching hospital, rooming-in was not an option there; and her care was tainted by the stigma of her being in MAT. Furthermore, owing to misinformation with regard to women in MAT breastfeeding provided by the lactation specialist, she decided not to breastfeed. Moreover, upon her infant's discharge, she discovered that certain medical information about her baby had not been disclosed to her.

In contrast, one mother (Theodora) gave birth in a hospital where she was offered a room where she could stay with her baby until his observation period concluded. Here, an effective lactation consultant supported her decision to breastfeed. In a third example, one mother (Finley) identified the contradiction between the value placed upon breastfeeding by counselors and advisors preceding childbirth in the form of prenatal education, and the lack of support demonstrated by a missing lactation consultant. Additionally, there was a 90-day negative toxicology policy, meaning she was not allowed to breastfeed or provide breast milk until 90 days after her positive toxicology results. Moreover, there was no assistance available for her to acquire a breast pump. These observations on Finley's part identified the need for a hospital breastfeeding policy that balances caution with regard to toxicology and mothers' opportunities for breastfeeding, as recommended by the SAMHSA guidance.

Hospital policies explicitly affected the women's opportunities. The effect on the experiences of the women in this study by such elements as the lack of rooming-in, restrictive breast-feeding policies, the absence of lactation consultation, and stigmatizing treatment in the

NICU highlights the need for systematic change in hospital policy and practice, with regard to the treatment of women in MAT.

Several hospital quality improvement studies provide robust supporting data for this recommendation. When rooming-in was prioritized at Yale Children's Hospital (Grossman, et al., 2017) and Dartmouth-Hitchcock (Holmes, et al., 2016), researchers at these two institutions both reported a positive relationship between rooming-in and improved breastfeeding outcomes for pregnant and parenting women with OUD in MAT. In a third case, researchers at Boston Medical Center reported an increase in the rates of breastfeeding among women with OUD, following a policy change revising eligibility guidelines for breastfeeding from 70-84 days to 30 days, accompanied by the provision of lactation support and breast pumps (Wachman, et al., 2016). In individual articles describing their programs, all three institutions recognized the pivotal role of healthcare professionals in implementing the changes. Accordingly, they subsequently provided staff education to support the changes.

It is important to emphasize that the individual SAMHSA recommendations do not function in isolation. Rather, the evidence assembled in the above-described thematic analysis revealed important interconnections between rooming-in, breastfeeding, caregiving, and learning about caregiving within relationships with healthcare professionals. Importantly these recommendations addressed in the SAMHSA guidance overlap in the women's experiences. Furthermore, women's descriptions revealing the overlapping interactions of these elements led to the emergence of a new theme in the study's findings: the women's descriptions of their feelings about their experiences as mothers in MAT. For example, women had difficult feelings about managing the NICU environment because it was an impossible place to breastfeed. This appeared related to the fact that some healthcare professionals were uninformative or hostile in

how they communicated caregiving expectations to the women. This experience often left the women feeling stigmatized.

Similarly, women talked about the way healthcare professionals made them feel watched and scrutinized when they were engaging in skin-to-skin contact with their baby. This made them uncomfortable, despite the positive experience of feeling close to and comforting their babies in their mothering role.

In its unfurling and discussion of this theme, the women's feelings about their experiences, the thematic analysis confirms the pivotal role of healthcare professionals. Specifically, the analysis highlights the importance of consistency among the professionals the mothers described, and the negative effects of stigma confirming previous research (Recto, McGlothen-Bell, McGrath, Brownell & Cleveland, 2020). These findings align with the preponderance of research documenting nurses' negative attitudes (Fraser, Barnes, Biggs, and Kain, 2006; Maguire, Webb, et al., 2012; Murphy-Oikonen, et al., 2010) and programs designed to offset this (Marcellus and Poag, 2020).

Despite this study's confirmation of previous research identifying negative nurse attitudes, the interconnections between the various themes may provide evidence that the onus of stigmatizing treatment is not the exclusive responsibility of nurses and lactation consultants. The burden for addressing the negative stigmatization of mothers who give birth while in MAT during their treatment is not the sole responsibility of nurses and lactation consultants. Rather, addressing stigma as a barrier to change is the responsibility of institutions. Several hospitals documented their quality improvement processes, resulting in hospital policies and practices to improve support provided to opioid exposed mothers and infants. These quality

improvement projects specifically addressed staff needs and attitudes that may contribute to stigmatizing treatment of women on MAT.

Study authors from Yale Children's Hospital (Grossman, et al., 2017), Dartmouth-Hitchcock (Holmes et al. 2016), and Boston Medical Center (BMC) (Wachman, et al. 2016) have each pointed to the importance of healthcare professional participation when it comes to instituting systemic change geared toward offsetting the negative stigmatization of women who give birth while on MAT and improving infant outcomes, such as length of stay. Wachman and colleagues (2015) noted how when Boston Medical Center began efforts to change its breastfeeding policies, it was necessary to address the attitudes and resistance of healthcare professionals. They described "points of controversy," which were addressed when medical and nursing staff were asked to provide feedback before final guidelines were approved.

In his October 2018 talk to California Health Care Foundation (chcf.org) Yale Children's Hospital hospitalist Matthew Grossman candidly noted that altering the policy of placing opioid exposed infants in the nursery rather than the NICU required 18 months of negotiation with the staff in the nursery unit. The staff did not initially welcome the opioid-exposed mother-child dyad into their care. Grossman acknowledged, "We had taken this vulnerable family and made their experience much harder than every other family."

The separate reports from the three hospitals demonstrate an obvious conclusion, supported by the observations of the women who participated in this "Missing Voices" study. Stigma can continue to exist in the context of a healthcare environment where education, policies and practices perpetuate it. By the same token, healthcare education, policies, and practices have the potential to dissipate and reverse negative stigma of certain individuals and groups.

This study's thematic analysis demonstrates that the women interviewed felt connected to their babies. They described positive feelings about being with their babies and positive feelings about themselves as mothers, even in the NICU setting. The positive feelings about mothering they described in association with holding their babies and having skin-to-skin contact confirm assertions from previous research that contact and holding have considerable positive value for mother-infant bonding and maternal identity (McGlothen-Bell, Recto, McGrath, Brownell, & Cleveland 2021).

Previous research has demonstrated that when parenting style is taken into account, the mother's OUD status has no impact on the quality of the infant-mother relationship (Sarfi, et al, 2011). Along these lines, the women in this study specifically requested that they be seen as individuals, rather than representatives of a group of mothers, namely mothers with OUD. They wanted their individual decisions and capacities as mothers, rather than their status as women with OUD, to define them.

The women's descriptions of their infants appear to demonstrate "the capacity to think about mental states, in oneself and in others" (Bouchard, Target, Lecours, Fonagy, Tremblay, & Schacter, 2008, p. 47), a capacity referred to as maternal "reflective function" (RF). RF entails the capacity to think about the baby as a separate being with his or her own feelings (Pajulo, et al, 2012) and has been positively associated with attachment security. The mothers' descriptions of their infants frequently demonstrated that capacity: They substantively described their babies' experiencing NOWS symptoms, the babies' needs for support, their appearing consoled and content, or looking startled.

The guidance recommendation for maternal preparation, therefore, not only includes preparation for caregiving and breastfeeding, but also support for understanding and meeting

infants' complex needs (Jansson & Velez, 2012). That is to say, healthcare professionals are directed to care for the dyad, so that mothers are supported and encouraged in their efforts to interact effectively with infants affected by NOWS.

Although within this current study several of the mothers reported some positive interactions with healthcare professionals, they did not describe having experienced interactions with healthcare professionals that supported their ability to interpret their infant's NOWS-related regulation behaviors. Although one mother (Theodora) was very specific in the breastfeeding skills she learned in the hospital, neither her nor the other mothers' narratives detailed interactions with healthcare professionals geared toward cultivating mothers' sensitivity in understanding their infant's cues and needs.

Although encounters with child protective service agencies is a topic outside the scope of this study, all the women in this study talked about these encounters as 'scary,' even when they resulted in the baby coming home with the mother. The experiences of the women in this study with nurses and Child Protective Services (CPS) further point to the need for implementation of the recommendation to "cease criminal prosecutions and punitive civil actions against pregnant and parenting women based solely upon their substance use or substance use disorder" (SUD) as described in depth by Jessep, Oerther, Gance-Cleveland, and Cleveland (2019, p. 201). Only one woman mentioned her baby's subsequent need for early intervention. The combination of women's silence on the topic of intervention and the mothers' anxiety regarding CPS and custody in the mothers' narratives affirm the need for coordinated discharge. This needs to include information about access to services for the dyad and for supporting the infant's development (Patrick, Barfied & Pointdexter, 2020; Sutter, Watson, Bauers, Johnson, Hatley, et al., 2019). Cumulatively, punitive CPS policies, healthcare practices, and misinformation, and

other negative attitudes may erode the positive drive for sobriety prompted by pregnancy and motherhood each of the women described.

Recommendations

This study is focused on the SAMHSA-recommended non-pharmacological treatment of the methadone exposed mother and infant dyad. These recommendations include: accommodations for rooming-in, and the consequent provision of a quiet environment other than the NICU; support for breastfeeding, skin-to-skin contact; and prioritization of maternal presence through rooming-in and caregiving. The SAMSHA guidance also recommends that healthcare professionals develop positive relationships with mothers to promote maternal sensitivity to infant cues, competence, and confidence. Results from "Missing Voices" suggest that these elements do not appear to work in isolation from one another. Rather, as Theodora's narrative describes, they work best when implemented in combination so that rooming-in, breastfeeding support, and support from healthcare professionals can support the opioid-exposed dyad.

Systemic change should include mothers.

The SAMHSA-recommended practices and the objectives that drive them are based upon previous research. This study's results support the value of these recommendations, and point to the importance of hospitals and other medical institutions providing opportunities for systemic changes that would support the realization of these recommendations in practice. The changes in practice would best be conceived and implemented as a cluster, at individual hospitals. This cluster would involve first and foremost, educating mothers about recommended practices and giving mothers' voices a major role in the local change process, as well as informing the healthcare system of the mothers' needs. A final element of the cluster would entail ensuring an ongoing dialogue between healthcare professionals and women who give birth while in MAT in

the hopes that healthcare professionals' increased familiarity with such women might disassemble and diminish the negative stigma frequently associated with these women.

As noted above, physicians and participating authors at three hospitals –Yale Children's, Dartmouth-Hitchcock, and Boston Medical Center (BMC) - after conducting quality improvement projects associated with treating infants with NOWS/NAS collaborated on a description of a multi-stage quality improvement (QI) initiative (Wachman, et al., 2018). Their description included peer counselors as part of the initial multi-disciplinary QI team, along with physicians, nurses, social workers, and lactation consultants. Later on in the process, the BMC QI leaders included parents among the 24 stakeholders. The researcher if this study strongly recommends the integration of mothers' voices as part of any local project to implement change.

Educate mothers about rooming-in.

When the quality improvement project at Boston Medical Center was implemented, staff met with mothers at the treatment program to emphasize the value of being at the bedside. Along these lines, this study's findings likewise establish nursery or private room environments for "being at the bedside" as an essential recommendation, to be included in prenatal education for expectant and new mothers in MAT. By way of example, when breastfeeding was discussed with study participants – four out of four of the mothers interviewed for this study *intended* to breastfeed. Their commitment to breastfeeding illustrates the value of prenatal education in establishing expectations, even when those expectations were disappointed by inadequate supports. For mothers in MAT, preparation for rooming-in may generate increased opportunities for self-advocacy as a contribution to changing practices. However, it is important to

acknowledge here that prenatal education and resulting intention are initial steps in a process that can only culminate when there is institutional support.

Educate staff.

Front line staff, that is, healthcare providers who have the most frequent encounters with mothers in MAT during the time their infants are in the hospital, also stand to benefit substantially educational efforts focused on working with these mothers. As this study's findings have demonstrated, these staff members require support and education for practice in order to work most effectively with expectant and new mothers with MAT. As described by Goffman as well as Chase and Rogers, women on methadone-assisted treatment can be perceived as "drug addicts" (Goffman,1963) and "bad mothers" (Chase and Rogers, 2001). These socially constructed images of mothers in MAT elicit strong, negative emotions, such as feelings of anger and fear, from the hospital personnel rather than the more educated understanding as OUD as a treatable disorder. In research about healthcare staff regard, these negative emotions were associated with lower regard (van Boekel, Brouwers, and Weeghel, 2014). However, researchers identified the value of staff education in influencing staff regard toward people with substance use disorder; thus, regard is higher among professionals with more contact and education about this group (van Boekel, Brouwers, and Weeghel, 2014). Therefore, education of hospital staff, as well as increased communicative contact between women on MAT and staff, appear as essential to creating the sort of trusting, supportive, and instructive relationships between these two groups, as recommended in the SAMHSA guidelines.

Treat opioid-exposed mothers and infants as mothers and infants.

The SAMSHA recommendations for opioid exposed infants and mothers on methadone – proximity, rooming-in, and breastfeeding - reflect recommended practices for other mothers and

babies in hospitals. This is reflected in family centered care (FCC), practices that prioritize the family's role in care when infants and children are hospitalized. (Craig, et al., 2015). The SAMHSA recommendations arose because opioid mothers and babies had been excluded from these otherwise common family-centered practices.

A seminal recommendation of this study involves recognition and highlighting of the fact that the needs of an opioid exposed infant are similar to, not different from, the needs of other babies. Such a recognition points to a need to create a human and physical environments that facilitate meeting the infant's needs to eat, sleep, regulate, and bond with their mother. Grossman (2018) has summed up the principles behind this recommendation as follows: One, mother is the first treatment; two, treat the baby like a baby; three, treat the mother like a mother (chcf.org).

Future Research

The experiences, observations, and recommendations of the women in this study make audible the voices of women in methadone maintenance, as they initiate and continue their medication-assisted treatment through pregnancy and childbirth. Future qualitative research might further amplify their voices through studies which include a larger group of participants, comprehensive demographic detail, comprehensive participation that includes member checking and public presentation of findings at both academic and medical conferences, and subsequent collaboration between researchers from these and other fields.

Nurses and lactation specialists are given a significant role, both within the SAMHSA guidance and from the perspectives of the women in this study. Thus documentation of areas of alignment and conflict between the perspectives of nurses, lactation specialists, and expectant and new mothers in MAT might constitute a gainful avenue for future research.

Focus groups that include mothers, nurses and other hospital professionals could identify barriers to the pillars of the SAMHSA guidance. The sort of dialogue in real time that this might generate could add to the available data about barriers to change. Such data could provide further details with regard to how systemic change might typically proceed within a specific hospital. This research might constitute a step toward increasing what Cleveland et al. have described as "effective nursing interventions" (2016).

Finally, the research findings point to the need for qualitative research that examines hospital discharge practices for women in MAT and their infants. The importance of qualitative research that explores the potential value of parent-professional partnerships that aim to support the dyad, including early intervention, is likewise suggested by this study's findings.

APPENDIX A - Oral Informed Consent Script

THE CITY UNIVERSITY OF NEW YORK

Hedi Levine

Doctoral Program in Social Welfare

Silberman School of Social Work/The Graduate Center – City University of New York

ORAL INFORMED CONSENT SCRIPT

Title of Research Study: Neonatal Abstinence Syndrome and Promotion of Maternal Caregiving: Missing Voices of Methadone Maintained Mothers

Principal Investigator: Hedi Levine, MS Ed, MS Philosophy Social Welfare
Doctoral student in Social Welfare Program

You are being asked to participate in this research study because as a resident of the Lower East Side Service Center's Pregnant Women and Infants Program you have recently given birth to an infant who may have been treated in the hospital for symptoms of neonatal abstinence syndrome (NOWS).

The purpose of this research study is to learn from mothers who are participating in a program of medically assisted treatment (MAT) more about these hospital experiences. As a researcher, I want to get a picture from you to understand what professional practices and attitudes within the NICU affected your participation in your infant's care.

If you agree to participate, we will ask you to engage in an individual interview with me of approximately 60 minutes.

The NICU experience can be stressful and discussing your experiences may trigger negative feelings, which may be uncomfortable.

Women with substance use disorder may or may not have a history of illegal activity, which may be discussed in the interviews. Therefore, I am soliciting your consent orally as a first step to protect your identity, so you don't have to sign this form.

The interviews will be recorded. The audio recordings will be downloaded to a dedicated flash drive, which will be stored by the researcher in a locked box in a locked file cabinet.

I will remove all names and other identifying information from individual interview data; when the research is reported, your confidentiality will be protected by the use of pseudonyms and the absence of identifying information; for example, the names of the center, the program, and the hospital will be excluded from the reporting.

You will not benefit directly from this study, but your participation may help me learn more about mothers' experiences in hospitals.

Your participation in this research is voluntary. If you have any questions, you can contact Hedi Levine at hedilevineresearch@gmail.com. If you have any questions about your rights as a research participant or if you would like to talk to someone other than the researchers, you can contact CUNY Research Compliance Administrator at 646-664-8918 or HRPP@cuny.edu.

APPENDIX B. Interview Guide

Interview Guide

The interviews will focus on rooming-in accommodations and caregiving activities, including, but not limited to soothing (swaddling and holding); feeding (breast feeding and bottle feeding); bathing; sleep routines. The interviews will also focus on the ease or discomfort the participants experienced while in the hospital in relation to hospital staff practices. I want to learn what are MAT treated mothers' experiences in the hospital when a child is born after being opioid-exposed in utero.

1. *Ask the participants to establish a sequence for caregiving experiences and to begin to describe hospital experiences.* How old is your baby now? Was your infant diagnosed with neonatal abstinence syndrome? How long was she/he in the hospital after birth? Can you tell me about the time your infant was in the hospital? Can you describe a typical day?
2. *Ask the participants to tell me about the hospital accommodations for them.* Where did you stay in the hours, days, and weeks your baby was observed for or treated for neonatal abstinence syndrome? Were you able to room-in? How were the rooms arranged for privacy?
3. *Focus on caregiving experiences with their newborn infants, and experiences with health care professionals.* Please tell me about caregiving routines when you were at the hospital with your baby. What can you tell me about feeding, diapering, swaddling, bathing, for example?

4. *Ask the participants to talk about the hospital environment and specific hospital practices around caregiving routines and maternal participation.* Please describe the nighttime routine with your baby. What can you tell me about skin-to-skin contact or breastfeeding?
5. *Ask the participants to remember details about specific interactions, both positive and negative, which may illustrate institutional practice and professional behaviors for caregiving support.* How did nurses offer particular support to help you learn how to best care for your baby? Please tell me about a time when you needed someone to help you figure things out if you had difficulty (support/encouragement/guidance). Was there are time when you felt discouraged? Please tell me what happened then.
6. *Learn about <u>what</u> was taught as mothers were prepared for possible NOWS symptoms and the importance of mother's care and <u>who</u> helped prepare them. Learn if there were parenting education opportunities in the hospital before and/or after the baby was born.* Please think about how you learned about NOWS, and how you were informed as you made choices about your infant's care. For example, did someone talk to you about possible symptoms your baby might experience, whether to breastfeed or not to breastfeed, or to room-in or not to room-in? Please tell me about that.
7. *Ask participants to share their impressions of what worked and should stay the same, and/or how things could be better*. Please share these impressions speaking for yourself, from your own perspective. Please imagine what your baby might say about what worked or didn't work. Please imagine what a nurse in the hospital might say.
8. *And finally, invite the participants to draw their own conclusion about the research subject.* Do you have any thoughts or suggestions about this project?

REFERENCES

Abdel-Latif, M., Pinner, J., Clews, F., Lui, K., & Oei, J. (2006). Effects of breast milk on the severity and outcome of neonatal abstinence syndrome among infants of drug-dependent mothers. *Pediatrics 117*(6*)* e1163-e1169.

Abrahams, R.R., Kelly, S.A., Payne, S., Thiessen, P.N., Mackintosh, J., & Janssen, P.A. (2007). Rooming-in compared with standard care for newborns of mothers using methadone or heroin. *Canadian Family Physician,53*(10), 1722-30.

Ainsworth, M. (1978). Patterns of attachment: A psychological study of the strange situation. Hillsdale, N.J. : New York: Lawrence Erlbaum Associates ; distributed by Halsted Press Division of Wiley.

Ainsworth, M.D.S. & Bell, S.M. Some contemporary patterns of mother-infant interaction in the feeding situation. In A. Ambrose (Ed.), *Stimulation in early infancy*. London: Academic Press. (pp. 133-170)

Als, H. & McAnulty, G.B. (2011). The Newborn individualized developmental care and assessment program (NIDCAP) with kangaroo mother care (KMC): Comprehensive care for preterm infants. *Current Womens Health Review 7*(3) 288–301. doi: 10.2174/157340411796355216

Als, H., Butler, S., Kosta, S., McAnulty, G.B., Allen, M. C., & Lipkin, P. H. (2005). The Assessment of Preterm Infants' Behavior (APIB): Furthering the understanding and measurement of neurodevelopmental competence in preterm and full-term infants. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(1), 94-102.

American Society of Addiction Medicine (ASAM), and the American College of Obstetricians and Gynecologists (ACOG) and the Committee on Healthcare for Underserved Women (2012, reaffirmed in 2017 as Committee Opinion 711.)

American Society of Addiction Medicine (ASAM), Guidelines for the use of medications in the treatment of opioid use disorder (2015).

Arcury, T. & Quandt, S. (1999). Participant recruitment for qualitative research: A site-based approach to community research in complex societies. *Human Organization, 58*(2), 128-133.

Atwood, E., Sollender, G., Hsu, E., Arsnow, C., Flanagan, V., Celenza, J., . . . Holmes, A. (2016). A Qualitative Study of Family Experience With Hospitalization for Neonatal Abstinence Syndrome. *Hospital Pediatrics, 6*(10), 626-632.

Bagley, S., Wachman, E., Holland, E., & Brogly, S. (2014). Review of the assessment and management of neonatal abstinence syndrome. *Addiction Science & Clinical Practice, 9*(1), 19.

Barusch, A., Gringeri, C., & George, M. (2011). Rigor in qualitative social work research: Strategies used in published articles. *Social Work Research, 35*(1), 11-9.

Bell, S.M. & Ainsworth, M.D.S. (1972). Infant crying and maternal responsiveness. *Child development 43*(4) 1171-1190.

Berk, L. (1996). *Infants and children: Prenatal through middle childhood.* Boston: Simon & Schuster.

Berk, L. & Winsler, A. (1995). *Scaffolding children's learning: Vygotsky and early childhood education.* Washington, DC:NAEYC.

Blackler, F. (2009) Cultural-historical activity theory and organization studies. In Sannino, A., Daniels, H. & Gutierrez, K.D. (eds.), *Learning and expanding with activity theory*. New York: Cambridge University Press. pp. 19—39.

Blackmon, L. R., Barfield, W. D., & Stark, A. R. (2009). Hospital neonatal services in the United States: variation in definitions, criteria, and regulatory status, 2008. Journal of Perinatology, 29(12), 788+. Retrieved from http://go.galegroup.com.ezproxy.gc.cuny.edu/

Blehar, M.C. Lieberman, A., & Salter Ainsworth M. (1977). Early face-to-face interaction and its relation to later infant-mother attachment. *Child Development, 48*(1), 182-194.

Bogen, D.L.,Whalen, B.L.,Kair, L.R.,Vining, M., & King, B.A.. (2017). Wide variation found in care of opioid-exposed newborns. *Academic Pediatrics, 17*(4), 374-380.

Boucher, A-M. (2017). Nonopioid management of neonatal abstinence syndrome. *Clinical Issues in Neonatal Care 17*(2), 84-90.

Bowlby, J. (1951). *Maternal care and mental health.* World Health Organization: Geneva. Retrieved from University of Oregon. https://pages.uoregon.edu/eherman/teaching/texts/Bowlby%20Maternal%20Care%20and%20Mental%20Health.pdf

Bowlby, J. Attachment and loss. 1969 - Basic Books - New York.

Bowlby, J. (1973). Separation. New York: Basic Books.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* (3), 77-101.

Bretherton, I. (1992). The origins of attachment theory: John Bowlby and Mary Ainsworth. *Developmental Psychology, 28*(5), 759.

Brundage, S.C. & Levine, C. (2019). *The ripple effect: The impact of the opioid epidemic on children and families* (United Hospital Fund/Milbank Memorial Fund report). Retrieved from United Hospital Fund website: https://uhfnyc.org/media/filer_public/59/b2/59b20ad0-6acf-4980-ba9a-07ad5f565386/uhf-opioids-20190307.pdf

Burns R.M., Pacula R.L., Bauhoff S., Gordon A.J., Hendrikson H., Leslie D.L., & Stein, B.D. (2016). Policies related to opioid agonist therapy for opioid use disorders: The evolution of state policies from 2004 to 2013. *Substance Abuse 37*(1), 63-9. doi: 10.1080/08897077.2015.1080208. Epub 2015 Nov 13.

Byrne, G. (2017). Narrative inquiry and the problem of "Giving Voice," making meaning. *International Journal of Research & Method in Education 40(1)* 36-52.

Carlson, B. E., Matto, H., Smith, C. A., & Eversman, M. (2006). A pilot study of reunification following drug abuse treatment: Recovering the mother role. (Author abstract). *Journal of Drug Issues, 36*(4), 877.

Casper, T. & Arbour, M. (2014). Evidence-based nurse-driven interventions for the care of newborns with neonatal abstinence syndrome. *Advances in Neonatal Care: Official Journal of the National Association of Neonatal Nurses, 14*(6), 376-80.

Catalano, R., Gainey, R., Fleming, C., Haggerty, K., & Johnson, N. (1999). An experimental intervention with families of substance abusers: One-year follow-up of the focus on families project. *Addiction, 94*(2). 241-254.

Chase, S.E. & Rogers, M.F. (2001). *Mothers & children.* New Brunswick, N.J.: Rutgers University Press.

Clandinin, D. J. & Huber, J. (2010). Narrative inquiry. In McGaw, B., Baker, E., & Peterson, P. P. (Eds.), *International encyclopedia of education* (3rd ed.). New York, NY: Elsevier.

Clandinin, D.J., Murphy, M.S., Huber, J. & Murray Orr, A. (2010). Negotiating narrative inquiries: Living in a tension-filled midst. *The Journal of Educational Research 103(2)* 81-90.

Cleveland, L. M., Bonugli, R. J., & McGlothen, K. S. (2016). The mothering experiences of women with substance use disorders. *ANS. Advances In Nursing Science*, *39*(2), 119-129.

Cleveland, L. & Bonugli, R. (2014). Experiences of mothers of infants with neonatal abstinence syndrome in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 43*(3), 318-329.

Connelly, F.M. & Clandinin, J.D. (1990). Stories of experience and narrative inquiry. *Educational Researcher 19(5)* 2-14.

Cleveland, L. & Gill, S. (2013). "Try not to judge": Mothers of substance exposed infants. *MCN, the American Journal of Maternal Child Nursing, 38*(4), 200. Comprehensive Addiction and Recovery Act, S.524, 114th Congress (2015-2016).

Craig, J., Glick, C., Phillips, R., Hall, S., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal Of Perinatology*, *35*(S1), S5-S8.

Creswell, J. W. (2013). *Qualitative inquiry and research design* (3rd Edition). Designing a qualitative study (pp. 42-67); standards of validation and evaluation (pp.243-268). Thousand Oaks, CA: Sage.

Cummings, G. G., Estabrooks, C. A., Midodzi, W. K., Wallin, L., & Hayduk, L. (2007). Influence of organizational characteristics and context on research utilization. *Nursing Research 56* (4) S24-S39 doi: 10.1097/01.NNR.0000280629.63654.95

Daiute, C. (2014). *Narrative Inquiry: A Dynamic Approach*. New York, NY: Sage

Daiute, C. & Kovacs-Cerovic, T. (2017). *Minority teachers – Roma in Serbia – Narrate education reform*. Institute of Psychology, Faculty of Philosophy, University of Belgarde Association of Pedagogical Assistants of Serbia

Daiute, C., Stern, R., & Lelutiu-Weinberger, C. (2003). Negotiating violence prevention. *Journal of Social Sciences, (59)1*, 83-101.

Daiute, C., Todorova, R.S., & Kovacs-Cerovic, T. (2015). Narrating participation and power relations in a social inclusion program. *Language and Communication, (45),* 1-13.

Demirci, J., Bogen, D., & Klionsky, Y. (2015). Breastfeeding and Methadone Therapy: The Maternal Experience. *Substance Abuse,36*(2), 1-6.

Drew, N. (1986) Exclusion and confirmation: A phenomenology of patients' experiences with caregivers. *Journal of Nursing Scholarship* 18, 39–43.

Engeström, Y., Miettinen, R., & Punamäki, R.-L. (Eds.). (1999). *Perspectives on activity theory: Learning in doing*. New York, NY, US: Cambridge University Press.

Engeström, Y. & Miettinen, R. (1999). Introduction. In Engeström, Y., Miettinen, R., & Punamäki, R.-L. (Eds.), *Perspectives on activity theory: Learning in doing* (pp. 1-18). NY: Cambridge University Press.

Engeström, Y. (1999). Activity theory and individual social transformation. In Engeström, Y., Miettinen, R., & Punamäki, R.-L. (Eds.), *Perspectives on activity theory: Learning in doing* (pp. 19-38). New York, NY, US: Cambridge University Press.

Engestrom, Y., Engestrom, R. & Kerosuo, H. (2013). *Applied Linguistics (24)3*, 286-315.

Enomoto, K. (2016). A Healthier Start: Addressing Neonatal Abstinence Syndrome and Opioid Misuse during Pregnancy (Web log post) Retrieved from https://blog.samhsa.gov/2016/08/02/a-healthier-start-addressing-neonatal-abstinence-syndrome-and-opioid-misuse-during-pregnancy/#.W1NqfCMrLZs

Fingar, K. R., Stocks, C., Weiss, A. J., & Owens, P. L. (2015). Neonatal and maternal hospital stays related to substance use, 2006–2012: *HCUP Statistical Brief #193.* July 2015. Agency for Healthcare Research and Quality, Rockville, MD. http://www.hcup-us.ahrq.gov/reports/statbriefs/sb193-Neonatal-Maternal-Hospitalizations-Substance-Use.pdf.

Finney Lamb, C., Boers, M., Owens, A., Copeland, J., & Sultana, T. (2008). Exploring experiences and attitudes about health care complaints among pregnant women, mothers and staff at an Opioid Treatment Service. *Australian Health Review, 32*(1), 66-75.

Fraser, J.A., Barnes, M., Biggs, H.C., & Kain, V.J. (2007). Caring, chaos and the vulnerable family: Experiences in caring for newborns of drug-dependent parents. *International Journal of Nursing Studies,* 44, 1363-1370.

Gerace, L.M., Hughes, T.L., & Spunt, J. (1995). Improving nurses' responses toward substance-misusing patients: A clinical evaluation project. *Archives of Psychiatric Nursing, 9*(5), 286-294.

Gilligan, C. (2015). The listening guide method of psychological inquiry. *Qualitative Psychology, 2(1),*69-77.

Ginsberg, F. D. & Rapp, R. (1995). *Conceiving the new world order: The global politics of reproduction.* Berkeley & Los Angeles: University of California Press.

Glaser, B., & Strauss, A. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research. Mill Valley, CA: Sociology Press.

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L.S., Howse, J. L., & Berns, Scott D. (2011). Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins, Advances, Impact. *Seminars in Perinatology, 35*(1), 20-28.

Goodman, D. (2015). Improving access to maternity care for women with opioid use disorders: colocation of midwifery services at an addiction treatment program. *Journal of Midwifery & Women's Health*, 60(6), 706-712.

Goodman, D. & Zagaria, A. (2018). Improving care for pregnant women with opioid use disorders: a learning collaborative approach to best practice implementation. *Proceedings from the 10th Annual Conference on the Science of Dissemination and Implementation, Arlington, VA, USA. 04-06 December. Implementation Science, 13.*

Graves, Lisa E., Turner, Suzanne, Nader, Maya, & Sinha, Sucheta. (2016). Breastfeeding and Opiate substitution therapy: Starting to understand infant feeding choices. *Substance Abuse: Research and Treatment,* 43-47.

Grossman, M. R., Berkwitt, A. K., Osborn, R. R., Xu, Y., Esserman, D. A., Shapiro, E. D., & Bizzarro, M. J. (2017). An initiative to improve the quality of care of infants with neonatal abstinence syndrome. *Pediatrics, 139*(6), Pediatrics, June, 2017, Vol.139(6).

Grossman, M., Seashore, C., & Holmes, A. (2017). Neonatal abstinence syndrome management: A review of recent evidence. *Reviews on Recent Clinical Trials 12*(4) 226-232.

Grossman, M. (October 1, 2018). Reconsidering the standard approach to neonatal abstinence syndrome. *Addressing Opioid Exposure in Pregnancy for Women and Newborns,*

Presented at meeting of California Health Care Foundation, Fairfield, California.

Guttmacher.org (2018) https://www.guttmacher.org/state-policy/explore/substance-abuse-during-pregnancy

Haight, S., Ko, J., Tong, V., Bohm, M., & Callaghan, W. (2018). Opioid Use Disorder Documented at Delivery Hospitalization — United States, 1999–2014. *Morbidity and Mortality Weekly Report,67*(31), 845-849.

Holland, D. & Lave, J. (2001). History in person: Enduring struggles, contentious practice, intimate identities (1st ed., School of American Research Advanced Seminar Series). Santa Fe, N.M.: Oxford: School of American Research Press.

Holloway, I. & Biley, F.C. (2011). Being a qualitative researcher. *Qualitative Health Research 21(7)* 968-975.

Holmes, A., Atwood, E., Whalen, B., Beliveau, J., Jarvis, J., Matulis, J., & Ralston, S. (2016). Rooming-in to treat neonatal abstinence syndrome: Improved family-centered care at lower cost. *Pediatrics, 137*(6), 1.

Hudak, M.L. & Tan, R.C. (2012). The Committee on Drugs and the Committee on Fetus and Newborn. Neonatal Drug Withdrawal. *Pediatrics;*129; e540.

Huhtala, M., Korja, R., Haataja, L., Lapinleimu, H., Munck, P., & Rautava, P. (2011). Parental psychological well-being and cognitive development of very low birth weight infants at two years. *Acta Paediatrica 100,* 1555-1560.

Hünseler, C., Brückle, M., Roth, B., & Kribs, A. (2013). Neonatal opiate withdrawal and rooming-in: a retrospective analysis of a single center experience. Downloaded from PubMed.gov/US National Library/National Institutes of Health on 7/20/2018.

Ishizaki Y., Nagahama, T., & Kazunari, K. (2013) Mental health of mothers and their premature infants for the prevention of child abuse and maltreatment. *Health 5*(3): 612-616

Jansson, L., & Velez, M. (2012). Neonatal abstinence syndrome. *Current Opinion in Pediatrics, 24*(2), 252-8.

Jansson, L.M., Velez, M.L., & Butz, A.M. (2017). The effect of sexual abuse and prenatal substance use on successful breastfeeding. *Journal Obstetrical Gynecology Neonatal Nursing*, *46* (3), 480-484.

Jansson, L., Choo, R., Velez, M., Lowe, R., & Huestis, M. (2008). Methadone maintenance and long-term lactation. *Breastfeeding Medicine : The Official Journal of the Academy of Breastfeeding Medicine, 3*(1), 34-7.

Jansson, Lauren M., & Velez, Martha. (1999). Understanding and treating substance abusers and their Infants. *Infants and Young Children, 11*(4), 79-89.

Jessup, M. A., Oerther, S.E., Gance-Cleveland, B., Cleveland, L.M., Czubaruk, K.M., Byrne, M.W., D'Apolito, K., Adams, S. M., Braxter, B.J. & Martinez-Rogers, N. (2019). Pregnant and parenting women with a substance use disorder: Actions and policy for enduring practice. *Nurse Outlook (67)*, 199-204.

Johnson, B., Abraham, M., & Shelton, T. (2009). Patient- and family-centered care: Partnerships for quality and safety. *North Carolina Medical Journal*, 70(2), 125-30.

Johnson, R., & Gerstein, A. (2000). Treatment populations, services, and outcomes for cocaine and crack-cocaine dependence. *Journal of Psychopathology and Behavioral Assessment, 22*(4), 339-351.

Jones, H.E. & Fielder, A. (2015). Neonatal abstinence syndrome: Historical perspective, current focus, future directions. *Preventive Medicine 8*, 12-17.

Jones, H. E. & Kaltenbach, K. (2013). *Treating women with substance use disorders during pregnancy.* New York/London: Oxford University Press.

Jones, H. E., Martin, P. R., Heil, S. H., Kaltenbach, K., Selby, P., Coyle, Mara G., . . . Fischer, G. (2008). Treatment of opioid-dependent pregnant women: Clinical and research issues. *Journal of Substance Abuse Treatment, 35*(3), 245-259.

Jones, L., Woodhouse, D., & Rowe, J. (2007). Effective nurse parent communication: A study of parents' perceptions of the NICU environment. *Patient Education & Counseling*, 69, 206-212.

Josselson, R. (2007). The ethical attitude in narrative research: Principles and practicalities. In J. Clandinin, (Ed.), *Handbook of narrative inquiry: mapping a methodology* (pp.537-565) Thousand Oaks, CA: Sage.

Kaltenbach, K., Berghella, V., & Finnegan, L. (1998). Opioid dependence during pregnancy: Effects and management. *Obstetrics and Gynecology Clinics of North America,25*(1), 139-151.

Katz Rothman, B. (2016). *Bun in the oven: How the food and birth movements resist industrialization.* New York: NYU Press.

Klaman, S.L., Isaacs, K., Leopold, A., Perpich, J., Hayashi, S., Vender, J., … Jones, H. (2017). Treating women who are pregnant and parenting for opioid use disorder and the concurrent care of their infants and children: Literature review to support national guidance. *Journal of Addiction Medicine, 11*(3), 178-190.

Klaus, M.H., Jerauld, R., Kreger, N.C., McAlpine, W., Steffa, M., & Kennel, J.H. (1972). Maternal attachment. Importance of the first post-partum days. New England Journal of Medicine, *286*(9), 460-3.

Keeping Children And Families Safe Act, Public Law 108–36, 2003

Kolodny, A., Courtwright, D., Hwang, C., Kreiner, P., Eadie, J., Clark, T., & Alexander, G. (n.d.). The Prescription opioid and heroin crisis: A Public health approach to an epidemic of addiction. *Annual Review of Public Health, 36*(1), 559-574.

Kitson, A., Harvey, G. & McCormack, B. (1998) Approaches to implementing research in practice. *Quality in Health Care 7,* 149– 159.

Larsson, S. & Sjoblom, Y. (2010). Perspectives on narrative methods in social work research. *International Journal of Social Welfare 19* 272-280.

Lee, J., Hulman, S., Musci, M., & Stang, E. (2015). Neonatal Abstinence Syndrome: Influence of a Combined Inpatient/Outpatient Methadone Treatment Regimen on the Average Length of Stay of a Medicaid NICU Population. *Population Health Management*, *18*(5), 392–397. http://doi.org/10.1089/pop.2014.0134

Lee, Shoo K., & O'Brien, K. (2014). Parents as primary caregivers in the neonatal intensive care unit. *Canadian Medical Association Journal, 186*(11), 845-847.

Letourneau, N., Tryphonopoulos, P., Giesbrecht, G., Dennis, C., Bhogal, S., & Watson, B. (2005). Narrative and meta-analytic review of interventions aiming to improve maternal-child attachment security. *Infant Mental Health Journal, 36* (4), 366-387.

Ludvigsen, S. & Digernes, T. (2009). Research leadership: productive research communities and the integration of research fellows. In A. Sannino, H. Daniels & K.D. Gutierrez (eds.)

Learning and expanding with activity theory (pp. 240-256). New York, NY: Cambridge University Press.

MacMillan, K. D. L., Rendon, C. P., Verma, K., Riblet, N., Washer, D. B., & Volpe Holmes, A. (2018). Association of rooming-in with outcomes for neonatal abstinence syndrome: A systematic review and meta-analysis. *JAMA Pediatrics, 172*(4), 345–351. https://doi-org.ezproxy.gc.cuny.edu/10.1001/jamapediatrics.2017

MacMullen, N. J., Dulski, L. A., & Blobaum, P. (2014). Evidence-based interventions for neonatal abstinence syndrome. *Pediatric Nursing, 40*(4), 165.

Maguire, D.J., Taylor S., Armstrong K., Shaffer-Hudkins E., DeBate R., Germain A.M., & Brooks, S.S. (2016). Characteristics of maternal-infant interaction during treatment for opioid withdrawal. *Neonatal Network, 35* (5), pp. 297-304

Maguire, D.J. (2013). Mothers on methadone. *Neonatal Network,* 32(6), 409-415.

Maguire D.J.,Webb, M., Passmore, D., & Cline, G. (2012). NICU nurses' lived experience: Caring for infants with neonatal abstinence syndrome. *Advances in Neonatal Care: Official Journal of the National Association of Neonatal Nurses, 12*(5), 281-5.

Marcellus L., (2007). *Neonatal abstinence syndrome: Restructuring the evidence.* Neonatal Network Jan-Feb; Vol. 26 (1), pp. 33-40.

Marcellus, L. (2014). Supporting women with substance use issues: Trauma-informed care as a foundation for practice in the NICU. *Neonatal Network:NN, 33*(6), pp. 307-14.

Marcellus, L., Loutit, T., & Cross, S. (2015). A national survey of the nursing care of infants with prenatal substance exposure in Canadian NICUs. *Advances in Neonatal Care, 15(5),*336-344.

Marcellus, L. & Poag, E. (2016). Adding to our practice toolkit: Using the ACTS script to address stigmatizing peer behaviors in the context of maternal substance use. *Neonatal Network*, *35* (5), pp. 327-32

Marshall, C. & Rossman, G.B. (1999). *Designing qualitative research* (3rd Edition). Thousand Oakes, CA: Sage.

Mascola M.A., Borders A.E., & Terplan M. (2017). Committee Opinion No. 711: Opioid use and opioid use disorder in pregnancy. Obstet Gynecol. 2017 Aug;130 (2):e81-e94. doi: 10.1097/AOG.0000000000002235.

McGlothen, K., Cleveland, L., & Gill, S. (2018). "I'm Doing the Best That I Can for Her": Infant-feeding decisions of mothers receiving medication-assisted treatment for an opioid use disorder. *Journal of Human Lactation: Official Journal of International Lactation Consultant Association,* 890334417745521.

McGlothen-Bell, K., Clevelenad, L., Recto, P., Brownell, E., McGrath, J. (2020). Feeding behaviors in infants with prenatal opioid exposure. *Advances in Neonatal Care (20)5.* 374-383.

McKnight, S., Coo, H., Davies, G., Holmes, B., Newman, A., Newton, L. & Dow, K. (2016). Rooming in for infants at risk of neonatal abstinence syndrome. *American Journal of Perinatology 33*(05), 495-501.

McQueen, K.A., Murphy-Oikonen, & Desaulniers, L. (2015). Maternal substance use and neonatal abstinence syndrome. *Maternal and Child Health (19).* 1756-1765. doi: 10.1007/s10995-015-1689-y

Melnyk, B., Feinstein, N., Alpert-Gillis, L., Fairbanks, E., Crean, H., Sinkin, R.… & Gross, S.J. (2006) Reducing premature infants' length of stay and improving parents' mental health

outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics 118* (5): e1414-e1427

Milette, I., Martel, M-J., Ribeiro da Silva, M., & Coughlin McNeil, M. (2017). Guidelines for the institutional implementation of developmental neuroprotective care in the NICU. Background and rationale. A joint position statement from the CANN, CAPWHN, NANN, and COINN. *Canadian Journal of Nursing Research 49* (2)*, 46-62*

Milette, I., Martel, M-J., Ribeiro da Silva, M., & Coughlin McNeil, M. (2017). Guidelines for the institutional implementation of developmental neuroprotective care in the NICU. Part B: Recommendations and justification. A joint position statement from the CANN, CAPWHN, NANN, and COINN. *Canadian Journal of Nursing Research 49* (2)*, 63-74.*

Minear, S., & Wachman, E. M. (2019). Management of Newborns with Prenatal Opioid Exposure: One Institution's Journey. *Clinical Therapeutics,* 41(9), 1663–1668. https://doi.org/10.1016/j.clinthera.2019.07.001

Morgan, G. (2006). *Images of organization* (Updated ed.). Thousand Oaks: Sage Pub.

Moore, K., Coker, K., Dubuisson, A., Swett, B., & Edwards, W. (2003). Implementing potentially better practices for improving family-centered care in neonatal intensive care units: Successes and challenges. *Pediatrics, 111*(4, 2), E450-60.

Murphy-Oikonen, J., Brownlee, K.,Montelpare, W. & Gerlach, K. (2010). The experiences of NICU nurses in caring for infants with neonatal abstinence syndrome. Neonatal Network: The Journal of Neonatal Nursing, 9/1/2010, Vol.29(5), pp.307-313. DOI**:** http://dx.doi.org/10.1891/0730-0832.29.5.307

National Academies of Science (2003). Exploring Challenges, Progress, and New Models for Engaging the Public in the Clinical Research Enterprise. Downloaded from http://www.nap.edu/catalog/10757.html

National Center on Substance Abuse and Child Welfare. Technical Assistance. (04/20/2016). Retrieved from https://www.ncsacw.samhsa.gov/technical/

National Institute of Child Health and Human Development (2015). Advances in Pediatric Trauma and Critical Illness: Building the Field – Advancing the Science, Action Agenda. NIH: Bethesda, MD.

Neumann, A. (2013, November 20). Parenting and concerns of women in buprenorphine treatment. International Nurses Society on Addiction http://www.intnsa.org/Resources/webinar/2013_nov_20.pdf

Newman, A., Davies, G.A., Dow K., Holmes B., Macdonald J., McKnight S. & Newton L. (2015). Rooming-in care for infants of opioid-dependent mothers: Implementation and evaluation at a tertiary care hospital. *Canadian Family Physician*. *61*(12):e555-61.

Norr, K.F., Roberts, J., & Freese, U. (1989). Early postpartum rooming-in and maternal attachment behaviors in a group of medically indigent primiparas. *Journal of Nurse-Midwifery 34*(2) 85-91.

O'Brien, K., Bracht, M., Macdonell, K., McBride, T., Robson, K., O'Leary L., Christie, K.… Lee, Shoo K. A pilot cohort analytic study of Family integrated care in a Canadian neonatal intensive care unit. *BMC Pregnancy And Childbirth, 13 Suppl 1, pp. S12*

Ohio Perinatal Quality Collaborative (OPQC). Downloaded December 15, 2015. https://www.opqc.net/projects/NOWS

Pajulo, M., Suchman, N., Kalland, M. & Mayes, L. (2006). Enhancing the effectiveness of residential treatment for substance abusing pregnant and parenting women: Focus on maternal reflective functioning and the mother-child relationship. *Infant Mental Health Journal,* 37(5). NIH Public Access Author Manuscript.

Pajulo, M., Pyykkonen, N., Kalland, M., Sinkkonen, J., Helenius, H., Punamaki, R.-L. & Suchman, N. (2012). Substance-abusing mothers in residential treatment with their babies: importance of pre- and post-natal maternal reflective functioning. *Infant Mental Health Journal,* 33(1). NIH Public Access Author Manuscript.

Pajulo, M.,Savonlahti, E., Sourander, A., Helenius, H.& Piha, J. (2001). Antenatal depression, substance dependency and social support. *Journal of Affective Disorders, 65*(1), 9-17.

Paltrow, L., & Flavin, J. (2013). Arrests of and forced interventions on pregnant women in the United States, 1973-2005: Implications for women's legal status and public health. Journal of Health Politics, Policy and Law, 38(2), 299-343.

Patrick, S.W., Barfield, W.D., & Poindexter, B.B. (2020). Neonatal opioid withdrawal syndrome. *Pediatrics (146)5.* Downloaded from www.aapublications.org/news. 1-18.

Patrick, S.W., Davis, M. M., Lehman, C. U., & Cooper, W. O. (2015). Increasing incidence and geographic distribution of neonatal abstinence syndrome: United States 2009 to 2012. *Journal of Perinatology, 35*(8), 650-655.

Patrick, S., Schumacher, R., Horbar, J., Buus-Frank, M., Edwards, E., Morrow, K., . . . Soll, R. (2016). Improving care for neonatal abstinence syndrome. *Pediatrics, 137*(5), 1.

Patrick, S.W., Schumacher, R.E., Benneyworth, B.D., Krans, E.E., McAllister, J.M. & Davis, M.M. (2012). Neonatal abstinence syndrome and associated health care expenditures: United States, 2000-2009. JAMA, May 9, 307(18), p. 1934-40.

Peisch, V., Sullivan, A., Breslend, N., Benoit, R., Sigmon, S., Forehand, G., Strolin-Goltzman, J. & Forehand, R. (2018). Parental opioid abuse: A review of child outcomes, parenting, and parenting interventions. *Journal of Child and Family Studies, 27*(7), 2082-2099.

Popper, B., Anderson, B., Black, A., Ericson, E., & Peck, D. (1987). A case study of the impact of a parent advisory committee on hospital design and policy, Boston Children's Hospital. *Children's Environments Quarterly, 4*(3), 12-17.

Powis, B., Gossop, M., Bury, C., Payne, K., & Griffiths, P. (2000). Drug-using mothers: Social, psychological and substance use problems of women opiate users with children. *Drug and Alcohol Review, 19(2),* 171-180.

Pratt, M. (1991). Arts of the Contact Zone. *Profession,* 33-40.

Punamäki, R.-L. & Belt, R. (2013). Psychoanalytic-attachment-oriented group intervention for substance-abusing mothers and their infants: Transference, secure base, and secondary attachment to the "group mother". In N. Suchman, M. Pajulo, & L. Mayes (Eds.) *Parenting and substance abuse: Development approaches to intervention* (pp.321-343). New York: Oxford

Recto, P., McGlothen-Bell, K., McGrath, J., Brownell, E., & Cleveland, L. (2020). The role of stigma in the nursing care of families impacted by neonatal abstinence syndrome. *Advances in Neonatal Care, 20(5),* 354-363.

Reece-Stremtan, S. & Marinelli ,K.A. (2015). ABM clinical protocol #21: guidelines for breastfeeding and substance use or substance use disorder, revised 2015. *Breastfeeding Medicine, 10*(3):135-41. doi: 10.1089/bfm.2015.9992.

Reissman, C.K. (2008). *Narrative methods for the human sciences.* Thousand Oaks CA: Sage.

Reissman, C.K. (1993). *Narrative analysis.* Newbury Park, CA: Sage.

Rizzo, R., Neumann, A., King, S., Hoey, R., Finnell, D., & Blondell, R. (2014). Parenting and concerns of pregnant women in buprenorphine treatment. *MCN. The American Journal of Maternal Child Nursing, 39*(5), 319-24.

Rogoff, B. (1991). Apprenticeship in thinking: Cognitive development in social context. New York: Oxford University Press.

Saiki, T., Lee, S., Greenough, A., & Hannam, S. (2010). Neonatal abstinence syndrome—postnatal ward versus neonatal unit management. *European Journal of Pediatrics*, *169*(1), 95–98. https://doi-org.ezproxy.gc.cuny.edu/10.1007/s00431-009-0994-0

Savage, C. & Platt, K. (2014). Care of women who use opioids during pregnancy and the immediate postpartum period, *Journal of Addiction Nursing* (25) 1, 56-59.

Sarfi, M., Smith, L., Waal, H., & Sundet, JM. (2011). Risks and realities: Dyadic interaction between 6-month-old infants and their mothers in opioid maintenance treatment. *Infant Behavior and Development, 34*(4), 578-589.

Salihu, H.M., Mogos M.F., Salinas-Miranda A.A., Salemi J.L., & Whiteman V.E. (2015). National trends in maternal use of opioid drugs among pregnancy-related hospitalizations in the United States, 1998 to 2009. *American Journal of Perinatology 32*(3) 289-98. doi: 10.1055/s-0034-1384642. Epub 2014 Jul 31.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health 23* 334-340.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & Quantity, 52(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Savin, M. (2015). We can do better: An argument for improved care of the opioid addicted mother-infant dyad. *School of Nursing Faculty Papers & Presentations.* Paper 73. http://jdc.jefferson.edu/nursfp/73

Schumacher, R. E. & Patrick, S.W. (2015). Controversies in caring for infants and families impacted by neonatal abstinence syndrome. Vermont Oxford Network: Burlington: VT.

Schumacher, R.E. & Patrick, S.W. (2015). Vermont Oxford Network, NOWS Quality Improvement Toolkit, VON.

Slade, A. (2002). Keeping the Baby in Mind: A Critical Factor in Perinatal Mental Health. In *Special Issue on Perinatal Mental Health*, A. Slade, L. Mayes, & N. Epperson, Eds. *Zero to Three*, June/July 2002.

Slade, A. (2000). The Reflective function: A discussion of papers by Fonagy, Target, and Gergely. *Journal of Infant, Child, and Adolescent Psychotherapy*, 1, 42-48.

Small, M. (1998). *Our babies, ourselves: How biology and culture shape the way we parent.* New York: Anchor Books.

Snelling, C. H. (2017). Born addicted: Pediatric rehabilitation for neonatal abstinence syndrome. *OT Practice, 9/11/2017,* 22-25.

Srivastava, A., Kahan, M., & Nader, M. (2017). Primary care management of opioid use disorders: Abstinence, methadone, or buprenorphine-naloxone? Canadian Family Physician Medecin De Famille Canadien, 63(3), 200–205. Retrieved from http://search.ebscohost.com.ezproxy.gc.cuny.edu/login.aspx?direct=true&db=mdc&AN=28292795&site=ehost-live

Stone, R. (2015). Pregnant women and substance use: Fear, stigma, and barriers to care. *Health & Justice, 3*(1), 1-15.

Substance Abuse and Mental Health Services Administration (2018). *Clinical Guidance for Treating Pregnant and Parenting Women With Opioid Use Disorder and Their Infants.* HHS Publication No. (SMA) 18-5054. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Suchman, N.E., Pajulo, M. & Mayes, L.C. (Eds.). (2013). Introduction. In *Parenting and substance abuse: Developmental approaches to intervention* (pp. xvii-xx). New York/London: Oxford.

Suchman, N., DeCoste, C., Castiglioni, N., Legow, N. & Mayes, L. (2008). The mothers and toddlers program: Preliminary findings from an attachment-based parenting intervention for substance-abusing mothers. *Psychoanalytic Psychology,* 1(3), July, 499-517.

Suchman, N., Pajulo, M. DeCoste, C. & Mayes, L. (2006). Parenting interventions for drug-dependent mothers and their young children: The case for an attachment-based approach. *Family Relationships,* April, 55(2), 211-226.

Suchman, N., & Luthar, S. (2000). Maternal addiction, child maladjustment and socio demographic risks: Implications for parenting behaviors. *Addiction, 95*(9), 1417-1428.

Sutter, M.B., Watson, H., Bauers, A., Johnson, K., Hatley, M., Yonke, N., & Leeman, L. (2019). Group prenatal care for women receiving medication-assisted treatment for opioid use disorder in pregnancy: An interpersonal approach. *Journal of Midwifery & Women's Health, (64)2 April/May,* 217-224.

Teague, A. H., Jnah, A. J., & Newberry, D. (2015). Intraprofessional excellence in nursing. Collaborative strategies for neonatal abstinence syndrome. *Neonatal Network, 34 (6),* 320-328.

Tobach, E. (1999). Activity theory and the concept of integrative levels. In Y. Engeström, R. Miettinen & R-L. Punamäki-Gitai (Eds.), *Perspectives on activity theory.* (pp. 133-146). New York, NY: Cambridge University Press.

Toulmin, S. (1999). Knowledge as shared procedures. In In Y. Engeström, R. Miettinen & R-L. Punamäki-Gitai (Eds.), *Perspectives on activity theory*. (pp. 53-64). New York, NY: Cambridge University Press.

Tracy, R.L. & Ainsworth, M.S.D. (1981). Maternal affectionate behavior and infant-mother attachment patterns. *Child Development 52*(4) 1341-1343.

Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.

U.S. Department of Health and Human Services, Office on Women's Health (2016). White paper: Opioid use, misuse, and overdose in women. Retrieved from https://www.womenshealth.gov/files/documents/white-paper-opioid-508.pdf

Upadhyay, J., Maleki, N., Potter, J., Elman, I., Rudrauf, D., Knudsen, J….Borsook, D. (2010). Alterations in brain structure and functional connectivity in prescription opioid dependent patients. *Brain*, 133; 2098–2114. doi:10.1093/brain/awq138

van Boekel, L.C., Brouwers, E.P.M., van Weeghel, J. &B Garretsen, H.F.L. (2014). Healthcare professionals' regard toward working with patients with substance use disorders: Comparison of primary care, general psychiatry and specialist addiction services. *Drug and alcohol Dependence* 134 (2014): 92–98. Print.

Velez, M., & Jansson, L. (2008). The Opioid dependent mother and newborn dyad: Non-pharmacologic care. *Journal of Addiction Medicine, 2*(3), 113-20.

Velez, M.L., Montoya, I.D., Jansson, L.M., Walters, Svikis, V., Jones, H. E. . . . Campbell, J. (2006). Exposure to violence among substance-dependent pregnant women and their children. *Journal of Substance Abuse Treatment, 30*(1), 31-38.

Vygotsky, L.S. (1962) *Thought and language.* Cambridge: MIT Press.

Vygotsky, L.S. (1978) *Mind in society: The development of higher psychological processes* London: Harvard University Press.

Wachman, E.M., Grossman, M., Schiff, D.M., Philipp, B.L., Minear, S., Hutton, E.,…Whalen, B. (2018). Quality improvement initiative to improve inpatient outcomes for Neonatal Abstinence Syndrome. *Journal of Periontology (30)*, 1114-1122.

Wachman, E., Saia, K., Humphreys, R., Minear, S., Combs, G., & Philipp, B. (2016). Revision of Breastfeeding Guidelines in the Setting of Maternal Opioid Use Disorder: One Institution's Experience. *Journal of Human Lactation, 32*(2), 382-387.

Wachman, E., Byun, J., & Philipp, B. (2010). Breastfeeding rates among mothers of infants with neonatal abstinence syndrome.*Breastfeeding Medicine : The Official Journal of the Academy of Breastfeeding Medicine, 5*(4), 159-64.

Watkins, S., Meltzer-Brody, S., Zolnoun, D., Stuebe, A. (2011). Early breastfeeding experiences and postpartum. *Obstetrics & Gynecology 118* (2) 214-221 doi: 10.1097/AOG.0b013e3182260a2d

Weick, K. E., Sutcliffe, K. M., & Obstfeld, D. (2005). Organizing and the Process of Sensemaking. *Organization Science*, *16*(4), 409-421. doi:10.1287/orsc.1050.0133

Weiss, A.K., McDermott, K.W., & Heslin, K.C. (2019). Opioid-related hospital stays among women in the United States, 2016. Agency for Healthcare Research and Quality, Healthcare Cost and Utilization Project. Statistical Brief #247.

Westrup, B., Sizun, J. & Lagercrantz, H. (2007). Family-centered developmental supportive care: A holistic and humane approach to reduce stress and pain in neonates. *Journal of Perinatology. 27* S12-S18.

Wilson, D. & Shiffman, J. (2015, December 8). State policies deter doctors from reporting drug-endangered babies. Retrieved from http://www.reuters.com

World Health Organization (2014). Guidelines for the Identification and Management of Substance Use and Substance Use Disorders in Pregnancy.

World Health Organization (2015). WHO global strategy on people-centered and Integrated health services: Interim report.

World Health Organization (2008). Integrated Health Services – What and Why? Technical Brief No. 1.

Young, N. K., Gardner, S., Otero, C., Dennis, K., Chang, R., Earle, K., & Amatetti, S. (2009) Substance-Exposed Infants: State Responses to the Problem. HHS Pub. No. (SMA) 09-4369. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Younger, J.W., Chu, L.F., D'Arcy, N., Trott, K., Jastrzab, L.E. & Mackey, S.C. (2011). Prescription opioid analgesics rapidly change the human brain. *Pain.* August; 152(8), 1803-1810. Doi:10.1016/j.pain.2011.03.028