# AN EXPLORATORY GROUNDED THEORY OF BREASTFEEDING AMONG WOMEN WITH OPIOID USE DISORDER AND THE SUPPORT PERSONS

by

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With over 16 million women using opioids in the United States, neonatal abstinence syndrome (NAS) is increasing, and evidence suggests that NAS may be alleviated by breastfeeding. Yet, many women with opioid use disorder (OUD) experience stigma related to breastfeeding that potentially influences their decisions surrounding breastfeeding. No theoretical framework was identified that explained how perceived stigma influences breastfeeding decision-making in this population. Hence, the purpose of this study was to explore how women with OUD perceive breastfeeding, how stigma influences their breastfeeding decisions, and how support person perceptions influence breastfeeding among women with OUD.

A grounded theory study was conducted with 10 women in treatment for OUD who were between 18 and 54 years of age and who breastfed a child in the last three years. Women were recruited from a drug rehabilitation therapy agency, a high-risk obstetrical office, and a major medical center. Each woman was asked to identify a breastfeeding support person. Data were generated from in-depth interviews of the women and their support persons, then coded in three iterative and progressive phases: initial, focused, and theoretical, leading to a theoretical model. Memos and field notes were written, and a dyad profile was developed to analyze data from the

dyad perspective. Current professional organization guidelines on breastfeeding were reviewed to inform this study.

The women interviewed for this study were White, with an average age of 30. Most had some college but were unemployed and had one to six pregnancies each. Symptom management or social and environmental factors led the women through a pain-prescription or street drug pathway before they hit rock bottom and began recovery. The overarching theme was Breastfeeding Decision-Making in an Addiction Trajectory. This was characterized by the Recovery-Relapse Cycle and Breastworks. Women had multiple Recovery-Relapse Cycle experiences, which involved seeking, initiating, and maintaining recovery and at times relapse, that influenced breastfeeding decisions. Breastworks describes the empowerment of women for maternal breastfeeding decisions with the goal of protecting the infant. Support persons were White with an average age of 39; all had some college and most worked full-time. Support persons expressed an uncertainty about breastfeeding with OUD related to the infant's health and mother's potential to relapse. Yet this uncertainty did not deter them from providing both physical and emotional support to these breastfeeding women.

Uncertainty may be evident to women with OUD through good intentions of their support persons that are negatively perceived. Furthermore, such support person uncertainty and healthcare provider insensitivity may be perceived as stigma towards women with OUD, thus decreasing Breastworks effectiveness and risking newborn well-being. This study provides unique theoretical concepts that may be incorporated into the care of women with OUD, from preconception to postpartum, to support breastfeeding decision-making and infant well-being. Implications include development of a mobile breastfeeding education application, incorporation

of breastfeeding guidelines into continuing education, involving successfully recovered women as community health workers, and expansion of this study.

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A Dissertation

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East Carolina University

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by

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## DEDICATION

I dedicate this dissertation to several people. First, this dissertation is dedicated in loving memory of Carolyn Cobb, my Grandma who loved babies almost as much as I do. She was my inspiration for becoming a nurse in the first place. Oh, how I wish you were here to smile big as I walk across the stage! Though you are not here in person, I know you will shine down on me that day. I hope I have made you proud!

Second, I dedicate this work to Summer, Miranda, and Emily, my three beautiful and intelligent daughters. Let this be a reminder to you that you can do anything you want in life if you are willing to work for it. My hope is that each of you will reflect on these past five years and realize I did all of this for the three of you. I pray that God works through your lives to help others, just as I pray he does with me. You are each a unique blessing in my life. I love you!

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I would first like to thank God. I have been so blessed to have this opportunity. None of this would be possible without His divine intervention throughout my life. In the difficult times prayer was my solace. In the best of times I have praised Him.

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# CHAPTER 1: INTRODUCTION

Women with substance use disorder (SUD) are among the nation's most vulnerable populations. Almost 16% of women, ages 18 and older, used illicit drugs in 2016 and this continues to trend upward exponentially (Center for Behavioral Health Statistics and Quality, 2017). Many of these women are in the childbearing stage of life. Substance misuse during pregnancy increases risks of adverse maternal and infant outcomes. When a woman uses illicit drugs during pregnancy, especially opioids, the infant may go through withdrawal after birth, a condition known as neonatal abstinence syndrome (NAS). Symptoms of NAS include respiratory, gastrointestinal, and neurologic involvement that can be fatal (Pritham, 2013). Breastfeeding alleviates the severity of withdrawal symptoms in some cases because small amounts of the opioid are passed into the breastmilk and consumed by the infant (O'Connor, Collett, Alto, & O'Brien, 2013). Due to low bioavailability and weight-based dosing for infants, an even smaller amount of the opioid is absorbed into the infant's system, thereby slowly weaning the infants off the opioid as they grow (O'Connor et al., 2013). This natural environmental weaning from exposure to opioids and other substances often saves the lives of newborns (Welle-Strand, Skurtveit, Jansson, Bakstad, Bjarke, & Ravndal, 2013). Hence, breastfeeding among opioid exposed infants addresses one of the American Academy of Nursing national nursing science priorities, social determinants of health (Eckardt et al., 2017).

The Science Committee of the American Academy of Nursing identified the 2017 nursing science priorities as precision science, big data and data analytics, determinants of health, and global health (Eckardt et al., 2017). Determinants of health were further categorized as social and economic environment, physical environment, health care behaviors, genetics, and health care systems (Eckardt et al., 2017). Through breastfeeding infants experiencing NAS,

healthcare disparities are minimized, healthcare costs are decreased, and long-term infant health outcomes are improved, thus influencing social, economic, and healthcare determinants of health. Furthermore, the bonding that occurs during breastfeeding improves a mother's chances of abstaining from substance use (Pritham, 2013), thereby improving the infant's environment and the mother's health care behaviors. Ultimately, the infant is spared potential epigenetic changes that may occur from various negative exposure that are minimized by breastfeeding (Eckardt, 2017). Hence, breastfeeding by women with OUD (OUD) addresses several aspects of the determinants of health.

Women with OUD are less likely to breastfeed than women in the general population, further affecting the newborn's chance of survival (Bhutta et al., 2014; O'Connor et al., 2013). Despite current evidence-based practice guidelines, clinicians debate the benefits of breastfeeding among women who have an OUD. Clinician apprehension regarding breastfeeding in this population is due to potential consequences for infant health if mothers with OUD do not adhere to drug rehabilitation therapy (DRT) as intended (Wachman, Saia, Humphreys, Minear, Combs, & Philipp, 2016).

Due to potential legal or social consequences, women with OUD may be afraid to seek help for their OUD. The National Survey on Drug Use and Health reported in 2013 that of the 23 million people who needed treatment for OUD, only 2.5 million people actually received treatment (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). This study in eastern North Carolina (eNC) is timely since North Carolina ranks the second highest state with increasing death rates from opioid misuse in the nation (Botelho, 2018). Four North Carolinians die of drug overdose per day (North Carolina Attorney General Stein, 2018). Recent evidence shows women are affected differently than men by substance use. Due to

hormonal influences, women may become addicted faster (National Institute on Drug Abuse [NIDA], 2018). All ethnic and racial groups are affected by OUD, but it affects women of lower socioeconomic status most (SAMHSA, 2018). A lower socioeconomic status is reflected in North Carolina's overall poverty rate of 15.4% (United States Census Bureau, 2017), which is above the national 14.7% poverty rate (University of North Carolina School of Law, n. d.). In addition, some areas of eastern North Carolina have poverty levels as high as 32% (University of North Carolina School of Law, n. d.).

Statistics indicate low participation in DRT because some individuals with OUD avoid healthcare for fear of stigmatization (Gopman, 2014; Stone, 2015). Likewise, stigma influences other decisions of women with OUD, including breastfeeding. Stigma, which is historically prevalent, currently crosses every stratum of society (Cambridge University Press, 2018; Oxford University Press, 2018). Goffman (1963) wrote, "the issue becomes not whether a person has experience with a stigma of his own, because he has, but rather how many varieties he has had his own experience with" (p. 129), suggesting that stigma may be imposed on an individual by society or by the individual themselves.

## Background of the Problem

The misuse of substances likely began in the Neolithic period with the development of Shamanism to enter altered states of consciousness through psychoactive substances (Inaba & Cohen, 2014). Evidence of stigma towards those with SUD was noted around fourth century A.D. in Rome when heavy drinkers would be left in public, tied together with a cord thread through their noses (Inaba & Cohen, 2014). Historically, new substances have been created globally for religious, medical, or recreational purposes (Inaba & Cohen, 2014). Some of these substances have been medically beneficial. Other substances promoted OUD without medical

benefits. Social stigma surrounding each substance influenced the next drug use era. For example, President Richard Nixon initiated the first War on Drugs in the 1970s to reduce availability of illegal substances. Individuals created their own substances because the demand for drugs remained high. Such responses to societal stigma led to the current illegal drug trade (Inaba & Cohen, 2014), and more specifically the current opioid epidemic (Macy, 2018).

Currently, most available illicit drugs are impure from the use of non-consumable substances added during mass production. Non-consumable substances are incorporated to meet the growing drug demand (Inaba & Cohen, 2014; Macy, 2018). High demand may be attributed to drug tolerance, which is the requirement of more of the drug over time (Inaba & Cohen, 2014). Increased demand for drugs secondary to tolerance has likely contributed to the 400% increase in overdose deaths among women since 1999 (SAMHSA, 2015). Such an increase is problematic because the number of pregnant women with OUD is rising, endangering lives of both mothers and unborn infants with each drug use. The US government identified that opioid misuse was reaching rates like those of the Nixon administration era. To reduce misuse rates and mortality within this population, the government began DRT programs through legislation, such as the Drug Addiction Treatment Act of 2000, the Affordable Care Act of 2010 and the Comprehensive Addiction and Recovery Act of 2016. These DRT programs use methadone and buprenorphine to replace illegal substances, hold patients accountable with random drug screens, and incorporate behavioral therapy (Jansson et al., 2016; McQueen, Murphy-Oikonen, Gerlach, & Montelpare, 2011). In 2010, only 19 states had a treatment program for pregnant women, with only nine giving pregnant women priority for treatment (American College of Obstetricians and Gynecologists [ACOG], 2011). Despite efforts to improve maternal outcomes, perceived stigma may prevent women from seeking beneficial treatment for themselves and their infants. For

example, as of 2010, 15 states considered OUD to be child abuse, whereas three states involuntarily committed individuals to mental health or DRT programs (ACOG, 2011). Women with OUD in these 15 states likely avoid treatment for fear of legal consequences. Furthermore, DRT programs only minimize harm to the infant, as infant withdrawal remains a risk in spite of DRT.

Though DRT minimizes infant risks, NAS may still occur. Neonatal abstinence syndrome is the collection of symptoms experienced by infants during withdrawal (Pritham, 2013). Most often, NAS results from fetal exposure to opioids, both prescription or illicit. However, NAS also occurs from exposure to benzodiazepines or alcohol in utero (Pritham, Paul, & Hayes, 2012). Such exposures can cause neurologic, respiratory, and gastrointestinal symptoms of withdrawal (Wachman et al., 2016). For example, infants with NAS may have a disorganized sucking pattern and increased respiratory rate that contributes to the challenge of breastfeeding with OUD. Unlike adults, abrupt cessation of opioid exposure can be fatal to infants (Pritham, et al., 2012). Prompt identification and treatment of withdrawal is necessary to preserve the neonate's life.

Infants experiencing NAS are typically monitored for at least 72 hours. Approximately 50% of infants with NAS will have symptoms severe enough to require pharmacological treatment. The most widely used medication is morphine. Pharmacological treatments are generally administered on a scheduled basis (Abdel-Latif, Oei, Craig, & Lui, 2013; Bagley, Wachman, Holland, & Brogly, 2014; Balain & Johnson, 2014; Busch, 2016; Jones et al., 2012). Titration of the dose is dependent on the severity of infant symptoms, which are scored using a measurement tool, such as the modified Finnegan Scoring tool, and the infant's weight (Bagley et al., 2014). However, treatment for mild cases may include multiple nonpharmacological efforts, such as swaddling and offering a pacifier (Bagley et al., 2014; Pritham, 2013).

One of the nonpharmacological treatments for infants born to mothers with OUD discussed in the literature is breastfeeding. Benefits of breastfeeding overall include decreased risks of infection, obesity, asthma, and Sudden Infant Death Syndrome (SIDS) in infants (United States Department of Health & Human Services [USDHHS], 2011). A mother's risk for breast and ovarian cancers are decreased exponentially by breastfeeding, and postpartum depression is suppressed through bonding that typically occurs with breastfeeding (USDHHS, 2011). Additionally, breastfeeding has been linked to decreased length of stay for NAS infants (Pritham, 2013; Wachman et al., 2016). Although less than one percent per kilogram of the mother's body weight of the drug crosses into breastmilk (O'Connor et al., 2013), it is imperative that drug-addicted mothers understand the consequences of abrupt weaning and reintroduction of breastfeeding or expressed milk. A major consequence of abrupt weaning and reintroduction of breastmilk is the potential for reinitiating infant withdrawal symptoms that could lead to death if not identified and treated promptly. Breastfeeding education and support is necessary for women with OUD who breastfeed their infants to prevent the potential for setbacks in infant withdrawal progress due to weaning-reintroduction cycles . These well-known benefits of breastfeeding led to the Surgeon General's Call to Action (USDHHS, 2011).

The Surgeon General's report called for bolstered support from family members, the community, and clinicians to decrease disparities in breastfeeding (USDHHS, 2011). Breastfeeding rates among women with OUD are much lower than the general population (Reece-Stremtan, Marinelli, & Academy of Breastfeeding Medicine, 2015). This disparity in breastfeeding may be due to perceived stigma. Without breastfeeding, an infant's recovery from NAS is compromised, length of stay is increased, and healthcare costs rise (Bhutta et al., 2014; O'Connor et al., 2013; Pritham, 2013).

## Research on Influences of Perceived Stigma on Breastfeeding Decisions among Women with OUD

Only two studies were found that linked stigma to breastfeeding among women with OUD. The first study provided evidence that breastfeeding women with OUD are socially stigmatized. Mehta, Forbes, and Kuppala (2013) emailed an anonymous survey about breastfeeding with OUD to 383 leaders of different neonatal intensive care units (NICUs) in the United States. More than 25% of 179 respondents acknowledged that they "do not advocate breastfeeding" (Mehta et al., 2013, p. 321-322) in women with OUD. Demirci, Bogen, and Klionsky (2015) reported women with OUD experience stigma from the community, including their own family members or significant others, about breastfeeding their infants due to the fear of infant drug exposure and potential negative health outcomes. Demirci et al. (2015) described self-imposed stigma from mothers regarding breastfeeding as feelings that their breast milk was tainted, that the infant would refuse to breastfeed, and negative self-talk. Examples of negative self-talk include comments such as "I don't want her to be all high or nothing, you know, because I am on a high dose [of methadone]" or "…Because I definitely didn't want my baby to get that. My stupid mistakes going over to them." (Demirci et al., 2015, p. 205).

Despite lack of evidence about perceived stigma among women with OUD who breastfeed, numerous studies discuss stigmatization of other vulnerable populations, such as LGBTQ and persons with HIV or AIDS (Earnshaw, Smith, Chadoir, Rivet Amico, & Copenhaver, 2013; Mukherjee, McKinney, & Darrow, 2018). There are also known racial disparities among those with OUD regarding who is more likely to use illegal substances, who will reach out for help, and who will complete treatment (Mennis & Stahler, 2016; SAMHSA, 2018). While little is known about perceived stigma in women with OUD and breastfeeding, this

may be an indication of similar racial disparities and potential stigma among women with OUD who breastfeed.

Since the U. S. Surgeon General's call to action, three professional organizations have released position statements on breastfeeding with OUD. The American College of Obstetricians and Gynecologists (ACOG, 2015) endorse the view that women with current or past OUD should not be criminalized or excluded from breastfeeding without careful consideration of the individual situation and proper education. The Academy of Breastfeeding Medicine (ABM) endorses multiple criteria for supporting breastfeeding among women with OUD (Reece-Stremtan et al., 2015). These criteria include compliance with prenatal care, active participation in a DRT program, a negative toxicology screening at delivery, and abstinence from illicit substances for at least 90 days (Reece-Stremtan et al., 2015). The American Academy of Pediatrics (AAP, 2012) endorses the opinion that OUD is not a contraindication to breastfeeding if the woman is in a treatment program and has negative HIV and toxicology screens.

## Statement of the Problem

Stigma deters individuals with OUD from seeking treatment (Stone, 2015). The influence of perceived stigma on breastfeeding decision-making negatively impacts maternal and infant health outcomes. Therefore, stigma affects the national nursing science priority, determinants of health, by influencing health behaviors, such as breastfeeding (Eckardt, et al., 2017). In a recent pilot study with six women with SUD who had recent breastfeeding experience, the overarching theme was Breastworks, a phenomenon depicting the protective nature of breastfeeding (Cook & Larson, 2019). While debriefing with a colleague about the results of the study, a quick search of Civil War terms presented Breastworks, which was a military term used to describe chest-height man-made walls used for protection against enemy fire. Breastworks incorporated three

interrelated categories: The Battle, The Lockdown, and The Best Shot. The Battle the vicious cycle of using drugs, getting clean, and relapsing that influenced the mother's breastfeeding decisions. The Lockdown involved the social and legal consequences that must be overcome to bond with their infants. The Best Shot involved the corrective actions by the women and aspiration to a better lifestyle (Cook & Larson, 2019). The constant push-and-pull identified by the women is what led to questioning how perceived stigma influences breastfeeding decision-making processes among women with OUD.

## Purpose of the Study

The purpose of this study was to understand how perceived stigma influences breastfeeding decision-making processes among women with OUD. Although a number of theory-based studies explored breastfeeding in the general population, none specifically addressed stigma among women with OUD (Edwards, Jepson, & McInnes, 2018; Guo, Wang, Liao, & Huang, 2016; Lau, Lock, & Tarrant, 2018; McGlothen & Cleveland, 2018; McGlothen, Cleveland & Gill, 2018; Pitonyak, Jessop, Pontiggia, & Crivelli-Kovach, 2016; Primo & Brandao, 2017; Ryan, Team, & Alexander, 2017). Theory is necessary for understanding breastfeeding decision-making among women with OUD so that health disparities can be addressed and eliminated. Hence, a grounded theory (GT) approach was used to develop a theory on this topic. Grounded theory serves to develop a new theory from data collection where none previously existed or inadequately described the phenomenon (Charmaz, 2014; Creswell & Poth, 2018).

## Significance of the Study

Prior research has focused on (a) why breastfeeding is beneficial in NAS, (b) bonding experiences of women with OUD, and (c) perceived stigma of general care in women with OUD.

In addition, most research regarding stigma was from the clinicians' perspectives. Qualitative studies involving perceptions of stigma among women with OUD focused on general care provision rather than breastfeeding. Hence, the aim of this study was to understand how perceived stigma influences decisions to breastfeed among women with OUD. Findings from this study can help clinicians improve lactation support systems at the micro and macro level. Improvement in lactation support systems could enhance maternal self-efficacy, which could in turn improve maternal and infant health outcomes. In addition, the known benefits of breastfeeding for NAS further contribute to the significance of this study.

## Research Questions

This study answers the following research questions:

Research Question 1 How do women with OUD feel about breastfeeding based on their perception of stigma and does stigma influence breastfeeding decisions among women with OUD?

Research Question 2 How do perceptions of support persons influence decisions to support breastfeeding among women with OUD?

Research Questions 3 What lactation systems support is currently present at the local and national level in policies, protocols, and guidelines for breastfeeding among women with OUD?

## Operational Definitions

Stigma- Negative thoughts, perceptions, or actions towards women with OUD. There are two types: societal and self-stigma (Demirci et al., 2015). Societal stigma is imposed from outside sources, while self-stigma are internal thoughts (Demirci et al., 2015).

Breastfeeding- Any amount of ingested maternal breast milk regardless of route, (nasogastric, orogastric, bottle, or breast).

Opioid Use Disorder- A history of opioid use/misuse, whether licit or illicit.

## Assumptions

In grounded theory (GT), truth is constructed from the participants' experiences and accounted for from the researcher's experiences (Charmaz, 2014). Once trust is gained, it was assumed that participants with OUD would share their experiences regarding breastfeeding, stigma, and decision-making honestly and accurately. Based on ten years of the researcher's clinical practice experience caring for women with OUD and their infants, an assumption was that some participants may have missed opportunities of fully understanding the benefits of breastfeeding, especially in the context of societal and self-stigma.

## Summary

An understanding of how stigma influences breastfeeding decision-making processes among women with OUD is foundational to improve maternal and infant health outcomes. These health outcomes are national and international health priorities. Both the mother and infant affected by OUD stand to gain additional benefits from breastfeeding than the general breastfeeding population, yet women with OUD are less likely to breastfeed. The review of literature revealed societal stigma towards this population yet referenced self-imposed stigma minimally by women with OUD. No studies were found that explained how stigma influenced such breastfeeding decisions. This study explored how perceived stigma influences decisions to breastfeed among these women. Results of this study may bridge the gap between women with OUD and their support persons to improve breastfeeding rates and infant health outcomes, as well as inform health care professionals and health care systems of opportunities to support women with OUD.

The following chapter discusses the existing literature about influences of perceived stigma on breastfeeding decision-making processes among women with OUD. Next, a discussion of the GT methodology on research among the population of interest and a manuscript of the data gathered from the women with OUD is presented. Finally, a second manuscript discusses the analysis of data from the women along with data from their support persons.

# CHAPTER 2: LITERATURE REVIEW

This chapter provides a description of the sensitizing concepts of breastfeeding and the current science about influences of perceived stigma on decisions to breastfeed among women with opioid use disorder (OUD). Sensitizing concepts are broad terms from researcher knowledge that guide research inquiry (Charmaz, 2014). The literature review is organized by the following concepts: (a) OUD, (b) neonatal abstinence syndrome (NAS), and (c) breastfeeding. Additionally, OUD and breastfeeding concepts are addressed in relation to societal and self-stigma.

## Background and Significance

The incidence of NAS in the US increased 300% from 1999 to 2013 (Ko, Patrick, Tong, Patel, Lind, & Barfield, 2016). This marked increase is due to overuse and/or misuse of licit and illicit opioids over the previous 14 years (Bagley, Wachman, Holland, & Brogly, 2014). Substance use disorder is a complex disease that has numerous long-term effects on everyone involved, including those who use opioids. Unfortunately, women in the southern US region are more likely to be prescribed opioids but have less access to treatment for OUD (Ostrach & Leiner, 2018). Infants exposed to opioids in-utero experience withdrawal symptoms. Breastfeeding lessens such side effects of exposure to opioids through both skin-to-skin contact and a miniscule amount of the opioid transferred to infants through breastmilk (Welle-Strand, Skurtveit, Jansson, Bakstad, Bjarke, & Ravndal, 2013). Stigma about breastfeeding among women with OUD influences their decisions about breastfeeding (Demirci, Bogen, & Klionsky, 2015). Stigma that results in decisions against breastfeeding in this population have major short- and long-term implications on maternal and infant health, such as postpartum depression or

relapse for the mother and severe NAS symptoms or long-term behavioral issues for infants. However, it is unknown exactly *how* stigma influences such decisions about breastfeeding.

At the systems level, such as in hospitals, women with OUD have found themselves stigmatized through attitudes of the hospital staff (Cleveland & Gill, 2013). Investigators of a study of 179 US nursing and physician leaders in neonatal intensive care units found that more than 25% did not advocate for breastfeeding among mothers with OUD (Mehta, Forbes, & Kuppala, 2013). Other investigators found that new mothers felt judged for their substance use, which made them "feel ugly" and deterred them from bonding with their newborns (Cleveland & Gill, 2013, p. 203). These studies provide evidence that women with OUD experience stigma of breastfeeding from family, community, and society due to their OUD. Stigma may prevent women from obtaining adequate treatment, especially those who have children living with them, potentially leading to future "chronic health and social problems for the next generation" (Feder, Mojtabai, Musci, & Letourneau, 2018, p. 32). This may already be evident since readmissions among NAS infants is nearly double that of infants among the general population, many of which are related to injuries, abuse, and neglect often seen in children of women with OUD not in treatment (Witt, Rudd, Bhatraju, Rivara, Hawes, & Weiss, 2018). Many cultural influences affect the social and environmental factors surrounding breastfeeding, such as religious beliefs and familial practices of infant feeding. Hence, this research addresses one of the American Academy of Nursing national nursing science priorities, the determinants of health (Eckardt et al., 2017). McGlothen and Cleveland (2018) describe the disparity in breastfeeding among women with OUD as a social injustice that needs to be corrected. To address such a critical topic and serve as the first step in response to a call for social justice by McGlothen and Cleveland

(2018), this study was conducted to understand how perceived stigma influences breastfeeding decision-making among women with OUD.

**Opioid Use Disorder**

Historically a problem with licit or illicit drugs was labeled substance abuse. This label changed to substance use disorder in the 5th edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5; American Psychiatric Association, 2013). The diagnosis also expanded to a tri-level severity scale (mild, moderate, severe). The Substance Abuse and Mental Health Services Administration (SAMHSA, 2015) reinforced this definition stating, "Substance use disorders [are from] the recurrent use of alcohol and/or drugs caus[ing] clinically and functionally significant impairment … based on evidence of impaired control, social impairment, risky use, and pharmacological criteria" (Substance use disorders, para. 1). Opioid use disorder is classified as a type of SUD.

Many factors contribute to addictions such as OUD, including heredity, the environment, and compulsivity (Inaba & Cohen, 2014). Most of these factors influence dopamine levels or receptors in the brain. The $DRD_2$ $A_1$ allele gene is thought to be related to a lack of dopamine receptors in the brain, causing compulsive behaviors and the need for more of a substance to feel the desired satisfaction, which contributes to addictive behaviors (Inaba & Cohen, 2014). The CYP2D6 gene has been linked specifically to OUD (Inaba & Cohen, 2014). In contrast, the $DRD_4$ gene has been found to prevent addiction (Inaba & Cohen, 2014). Environmental exposures, such as positive home environments versus abusive environments, alter the chemistry of the brain through epigenetic adaptations (Inaba & Cohen, 2014).

According to Inaba and Cohen (2014), genetics and environment in combination contribute to drug use behaviors that lead to building tolerance over time. Hence, a progressive

dosage increase is required to reach a similar effect, resulting in overdose (Inaba & Cohen, 2014). One example is the global opioid epidemic (World Health Organization, 2014). Opioid overdose deaths in the U.S. have increased in women 400% since 1999 (SAMHSA, 2015). To address the epidemic, drug replacement therapy (DRT) programs were established with methadone implemented as the gold standard treatment (McQueen, Murphy-Oikonen, Gerlach, & Montelpare, 2011). Buprenorphine, a more recent DRT treatment, has also been used in place of illicit substances, such as opioids, with close observation and comprehensive care during pregnancy to treat OUD (Jansson et al., 2016).

Two additional concerns were identified in the literature. One concern was the need to increase the DRT dosage in the third trimester (Jones et al., 2012) or split the dose evenly over 24-hours to prevent withdrawal symptoms, thus preventing drug-seeking behaviors (Jones et al., 2008; McCarthy, Leamon, Willits, & Salo, 2015; Mittal, 2014). The CYP 450 enzyme, present during pregnancy, lowers DRT medication half-lives requiring divided doses of DRT medication (McCarthy, Leamon, Finnegan, & Fassbender, 2017). The second concern was that many women wish to transition from methadone to buprenorphine during pregnancy because of side effects, inconvenience, or varying insurance coverage between these two medication options. The concern with this transition during pregnancy is the risk of maternal health from accidental overdose and infant health related to severe withdrawal. Johnson and Martin (2018) trialed this transition with 20 women under close inpatient observation over four days. Almost 40% of women were strictly on buprenorphine at delivery and 80% felt it was successful (Johnson & Martin, 2018). Despite efforts to improve maternal outcomes, the influences of OUD, as well as medications utilized in DRTs, do not prevent infant withdrawal, but rather decrease severity of infant withdrawal.

## Neonatal Abstinence Syndrome

Neonatal Abstinence Syndrome (NAS) most often results from fetal exposure to opioids across the placental barrier, but may also occur with exposure to benzodiazepines, alcohol, or other prescription pain medications in utero (Inaba & Cohen, 2014; Pritham, Paul, & Hayes, 2012). Such exposures likely cause neurologic, respiratory, and gastrointestinal withdrawal symptoms. Unlike adults, abrupt cessation of opioid exposure can be fatal to infants (Pritham, et al., 2012). Exposed infants required a minimum of 72 hours of observation, often in an intermediate nursery during the delivery hospitalization. During this observational period, nurses typically score infant symptom severity using one of the following tools: (a) Neonatal Abstinence Syndrome Score (NASS)/Finnegan Score, (b) Narcotic Withdrawal Score/Lipsitz score, (c) Neonatal Narcotic Withdrawal Index, (d) Neonatal Withdrawal Inventory, and (e) MOTHER NAS Scale (Bagley et al., 2014). Despite concerns about reliability and validity, the most widely used scoring tool in the US is the modified Finnegan scoring tool (Bagley et al., 2014; McQueen et al., 2011). In contrast, some researchers suggest that clinicians only monitor feeding, sleeping, and weight gain to make decisions regarding treatment, rather than using the modified Finnegan scoring tool (Grossman et al., 2017).

Exposed infants often underwent NAS to an extent that required pharmacological treatment. Although results varied between studies from 0% to 100%, most investigators noted at least 50% of infants with NAS needed medication (Abdel-Latif, Oei, Craig, & Lui, 2013; Balain & Johnson, 2014; Busch, 2016; Jones et al., 2012). Pharmacologic treatment historically involved paregoric (Klaman et al., 2017) and diluted tincture of opium; morphine is now the gold standard treatment (Bagley et al., 2014). Currently, the recommended treatment of morphine is administered on a routine basis ranging from every three to twelve hours (Abdel-Latif, Pinner,

Clews, Cooke, Lui, & Oei, 2006). However, a more recent evidence-based practice is to provide morphine on an as needed basis only (Grossman et al., 2017). Second-line treatment included clonidine and phenobarbital (Bagley et al., 2014). Although Bagley et al. (2014) suggested that buprenorphine was promising in the treatment of NAS, buprenorphine's safety in infants requires further validation.

Prior to and during pharmacological treatment, nonpharmacological interventions were reported to soothe NAS infants. Interventions included swaddling the infant, keeping stimulation at a low level, and sucking (Pritham, 2013). Several studies suggested that breastfeeding may decrease NAS severity (Bagley et al., 2014; Balain & Johnson, 2014; Crook & Brandon, 2017).

## Breastfeeding

The literature operationalized breastfeeding in various degrees. Crook and Brandon (2017) defined breastfeeding as infants receiving greater than 50% of feedings by breast or expressed maternal milk into a bottle. In contrast, Abdel-Latif et al. (2006) described breastfeeding as less than or equal to two formula feedings on the fifth day. According to Abdel-Latif and colleagues (2006), by the fifth day of life breast milk supply should be at full capacity. McQueen et al. (2011) defined breastfeeding as receiving breast milk via any route more than 75% in a 24-hour period. Yet another definition of breastfeeding was any amount of breast milk received regardless of route of ingestion (O'Connor, Collett, Alto, & O'Brien, 2013). For the purposes of this study, breastfeeding is defined as the provision of any amount of maternal breast milk to her infant by directly putting the infant to breast or expression of breast milk via pump and given to the infant via bottle, nasogastric, or orogastric tubes for any duration.

**General Breastfeeding Benefits.** Although the definition and operationalization of breastfeeding varied, its benefits are well known and supported with substantive evidence

(Balain & Johnson, 2014; Busch, 2016; Crook & Brandon, 2017; Holmes, Schmidlin, & Kurzman, 2017; Kocherlakota, 2014). Benefits of breastfeeding for mothers include decreased risk of breast cancer and depression, improved weight loss, and increased parenting confidence (American Academy of Pediatricians [AAP], 2018). Infant benefits include improved immunity, decreased risk of obesity, decreased risk of childhood cancers, and time-specific situationally-tailored nutrition (Crook & Brandon, 2017). Situationally-tailored nutrition means that breastfeeding infants receive exactly what they needed nutritionally at the exact time needed, rather than nutrition provided by formula that is based on average infant nutrition requirements.

**Benefits of Breastfeeding with OUD.** Mother-infant dyads with OUD and NAS receive additional breastfeeding benefits. Breastfeeding among women with OUD promotes a stronger bond between the mother and infant compared to their non-breastfeeding peers (Busch, 2016). Breastfed infants experiencing NAS have an improved sense of comfort and security compared to infants not breastfed (Pritham, 2013). Breastfeeding also decreased the risk of Sudden Infant Death Syndrome, which is higher in NAS than the general population (Edwards & Brown, 2016). A mother's guilt from observing NAS in her infant was abated with breastfeeding (Demirci, Bogen, & Klionsky, 2015). Skin-to-skin contact and direct breastfeeding soothed infants with NAS (Pritham, 2013). Breast milk was found to contain only small amounts of methadone or buprenorphine that could be consumed by infants while breastfeeding, thus deeming breastfeeding safe for infants of mothers in DRT (Pritham, 2013). In some instances, breastfeeding alleviated the severity of NAS symptoms (Welle-Strand et al., 2013). In spite of evidence supporting the benefits of breastfeeding in women with OUD, these women were less likely to breastfeed than women in the general population, further limiting the newborn's recovery (Bhutta et al., 2014; O'Connor et al., 2013). This may be due to cultural influences,

such as accuracy of family members' knowledge of infant feeding practices and personal beliefs (Karmacharya, Cunningham, Choufani, & Kadiyala, 2017; Lok, Bai, & Tarrant, 2017), that affect social and environmental factors surrounding breastfeeding decisions. Therefore, breastfeeding in this population addresses one of the national nursing science priorities, the social determinants of health (Eckardt, et al., 2017).

**Disadvantages to Breastfeeding with OUD.** Clinicians remain concerned that women in DRT programs may not adhere to the program, putting their infants at risk if they misuse drugs and breastfeed (Holmes, Schmidlin, & Kurzman, 2017; Pritham, 2013; Wachman, Saia, Humphreys, Minear, Combs, & Philipp, 2016). However, investigators found that women who are aware of the risks do not wish to harm their infant and will do what is necessary to protect them (McGlothen, Cleveland, & Gill, 2018). Some of the manifestations of NAS may influence breastfeeding, such as increased muscle tone that contributes to a disorganized suck and infant weight loss (Holmes, Schmidlin, & Kurzman, 2017). No other disadvantages to breastfeeding among women with OUD in a DRT program have been presented in the literature. Despite the controversial nature of breastfeeding with OUD, many organizations support breastfeeding in this population (Holmes, Schmidlin, & Kurzman, 2017).

**Stance of Professional Organizations on Breastfeeding among Women with OUD**. There are position statements regarding breastfeeding among women with SUD and OUD, from organizations that have influenced the development of guidelines and policies at state, national, and international levels. In 2009, the World Health Organization (WHO) released a document on acceptable reasons to provide a breast milk substitute, which supported breastfeeding with OUD if caution was used. In 2011, the U.S. Surgeon General's call to action on breastfeeding included a need for greater support from family members, the community, and clinicians to decrease

disparities in breastfeeding (U.S. Department of Health and Human Services [USDHHS], 2011). The AAP (2012) supported the stance of the WHO and endorsed the opinion that OUD is not a contraindication to breastfeeding if the woman is in a treatment program and has negative HIV and toxicology screens. The American College of Obstetrics and Gynecology (ACOG, 2015) endorsed the view that women with current or past OUD should not be criminalized or excluded from breastfeeding without careful consideration of the individual situation and proper education. The Academy of Breastfeeding Medicine (ABM) endorses multiple criteria for supporting breastfeeding among women with OUD (Reece-Stremtan, Marinelli, & ABM, 2015). These criteria include compliance with prenatal care, active participation in a DRT program, a negative toxicology screening at delivery, and abstinence from illicit substances for at least 90 days prior to delivery (Reece-Stremtan et al., 2015). The North Carolina Perinatal and Maternal Substance Abuse Initiative conveyed support for breastfeeding while on medication-assisted therapy for OUD, as well as when to transition medications during breastfeeding (North Carolina Pregnancy and Opioid Exposure Program [NCPOEP], 2018).

## Societal Stigma

**Opioid Use Disorder.** Corrigan and Nieweglowski (2018) state that stigma of OUD is "legally and socially sanctioned" (p. 44) as compared to other medical conditions, such as mental illness. Society views OUD as a dichotomy: a disease or a moral decision (National Institute on Drug Abuse [NIDA], 2014; NIDA, 2016). Henderson and Dressler's (2017) residual agreement analysis provided supportive evidence of this medical disease versus moral decision dichotomy with their study involving interviews of undergraduate college students about the causes of addiction. The dichotomy contributes to stigmatization of individuals with OUD (Henderson & Dressler, 2017). This dichotomy is also evidenced by political discussions, social media, and

daily individual interactions. Findings from two qualitative studies further support this dichotomous viewpoint. Cleveland and Gill (2013) found themes related to stigma among Hispanic mothers of infants with NAS. Stigmatization of women with SUD was evident as the mothers described their experiences with hospital staff who discouraged them from participating in their infant's care, which made them feel less in control (Cleveland & Gill, 2013; Howard, 2015). Cleveland and Bonugli (2014) conducted interviews with 15 Hispanic mothers of infants with NAS. The importance of trust between mothers and nurses was a unique finding that was evident in mothers' fears of being reported to child protective services (Cleveland & Bonugli, 2014). Hatcher, Mendoza, and Hansen (2018) also caution that to avoid inadvertently isolating the mothers, treatment options should be based on individual needs rather than preconceived notions.

Further, professional organizations such as SAMHSA deem stigma of OUD as a barrier to reducing addiction in the US (Corrigan & Nieweglowski, 2018). Howard (2015) echoes this thought in her phenomenological study of 30 women with OUD. The overarching theme of the study was perception of self with a subtheme of external stigma (Howard, 2015). External stigma was presented as the punitive nature of actions or statements by others that hindered women's desire to go to prenatal appointments or visit their infants in a prolonged hospital stay (Howard, 2015). Ostrach and Leiner (2018) also stated that stigma of OUD leads to ambivalence about adherence to treatment medications, which may cause relapse. Those who desire to attend a narcotics anonymous group may be rejected if they are in a DRT because such groups do not view medication assisted therapy as being completely clean, adding to their ambivalence and negative self-thoughts (Sederer & Marino, 2018).

**Breastfeeding.** The breast is viewed by mainstream American society as a sexual object rather than for provision of infant and child nutrition (Newton-Francis & Young, 2015). This notion is supported by results of a study of online responses to a woman being forced to leave a retail store for breastfeeding in public via social media and a news source commentary section (Grant, 2016). While only 2% of over 1000 comments on social media were negative, 85% of the 884 responses on the news source were negative (Grant, 2016). Negative comments stated support for the store making the woman leave.

### Self-stigma

**Opioid Use Disorder.** Women with OUD often stigmatize themselves for becoming addicted to opioids (Howard, 2015). Corrigan and Kosyluk (2014) described a self-stigma model in which individuals become aware of the stigma, agree with it, apply the stigma to themselves, which negatively impacts their self-esteem and self-efficacy. This process contributes to a "why try" effect (Corrigan, Bink, Schmidt, Jones, & Rüsch, 2016, p. 16) effect, alluding to the thought that there is no reason to try because the individual feels they are not worthy or capable. Both Oexle et al. (2018) and Wang, Link, Corrigan, Davidson, and Flanagan (2018) found that self-stigma among individuals with mental illness decreases self-efficacy, further supporting Corrigan and Kosyluk's (2014) model.

**Breastfeeding.** An online survey of breastfeeding mothers ($n$ = 845) revealed that 15% of women felt guilty about their feeding choices, 38% felt stigmatized, and 55% felt that they had to defend their feeding choices (Komninou, Fallon, Halford, & Harrold, 2017). Guilt among women who decided to breastfeed stemmed from external influences related to breastfeeding in public, while guilt in women that supplemented their infants with formula was from internal influences, such as feelings of failure or inadequacy as a mother (Komninou et al., 2017).

Brouwer, Drummond, and Willis (2012) suggested that self-stigma related to breastfeeding is not unique to the United States. In fact, such self-stigma may stem from decisions to breastfeed or avoidance of breastfeeding regardless of location. This is indicated by a study of Norwegian women who felt as though they had broken a law when they weaned their babies from breastfeeding prior to the socially accepted timeframe of six months to one year (Hvatum & Glavin, 2016).

**Current Theoretical Perspectives**

Although several theory-based studies were found that explored breastfeeding in the general population (Edwards, Jepson, & McInnes, 2018; Guo, Wang, Liao, & Huang, 2016; Lau, Lock, & Tarrant, 2018; Pitonyak, Jessop, Pontiggia, & Crivelli-Kovach, 2016; Primo & Brandao, 2017; Ryan, Team, & Alexander, 2017), none specifically addressed stigma among breastfeeding women with OUD. Breastfeeding decision-making, maternal self-efficacy, lactation education, and lactation support were important concepts from the literature that served as sensitizing concepts for this study. However, the dearth of research about breastfeeding decision-making in women with OUD supported the need for a grounded theory (GT) study of the topic (Charmaz, 2014).

Despite the vast amount of literature regarding stigma on SUD and breastfeeding separately, evidence of stigma related to breastfeeding and women with OUD was minimal. Several researchers discussed societal stigma in this population and offered potential rationales, but few were rigorously supported. Two investigators suggested that women with SUD who breastfeed were stigmatized (Mehta et al., 2013; Balain & Johnson, 2014). Mehta et al. (2013) emailed an anonymous survey to 383 nursing and physician leaders of various neonatal intensive care units (NICUs) in the US. More than 25% of the 179 respondents acknowledged that they

"do not advocate breastfeeding" (Mehta et al., 2013, p. 321-322) in the population of women with SUD despite current evidence to support its safety. Balain and Johnson (2014) provided a literature review, discussing a survey of 30 medical and nursing staff regarding their attitudes towards breastfeeding with SUD. The researchers found 13% of clinicians felt breastfeeding should not be encouraged and 11% felt that breastfeeding was harmful to the infants (Balain & Johnson, 2014). Lack of support for breastfeeding among women with SUD was related to infant safety, but evidence was not presented to support this concern (Jansson et al., 2016; Pritham, 2013; Wachman et al., 2016).

One qualitative descriptive study about stigmatization of breastfeeding women with SUD was identified. Women with SUD participated in individual interviews or small focus groups and reported experiencing stigma from the community, which included immediate family or significant others, about breastfeeding their infants due to the fear of infant drug exposure (Demirci et al., 2015). Mehta et al. (2013) established that there is likely stigma from clinicians caring for this population. Hence, there remains a disconnect between best practice and actual practice regarding breastfeeding in this population. Compounding this is a mother's own lack of confidence in her decision to breastfeed her infant. Women with OUD need support at the micro and macro level to maintain a drug-free lifestyle and in choosing to breastfeed.

Numerous investigators have identified guilt associated with self-stigmatization regarding breastfeeding in women with OUD (Crook & Brandon, 2017; Jansson & Velez, 2015; Pritham, 2013; Sutter, Leeman, & His, 2014). Jansson and Velez (2015) also suggested that maternal anxiety related to the infant's health was indicative of self-stigmatization. Demirci et al. (2015) described self-stigma from mothers regarding breastfeeding, such as feeling that their breast milk was tainted, the infant would refuse to breastfeed, and negative self-talk. Several investigators

suggested that low maternal self-efficacy in women with SUD contributed to early cessation of breastfeeding, if they decide to breastfeed at all (Busch, 2016; Jansson & Velez, 2015; Welle-Strand et al., 2013). However, Crook and Brandon (2017) suggest one way to reduce societal and self-stigma would be to include family and clinicians in lactation education.

## Critical Evaluation of Existing Knowledge

Existing literature about how stigma influences decisions to breastfeed among women with OUD is minimal. Most of this literature is anecdotal from clinical practice or other non-empirical evidence. The empirical evidence primarily focuses on the clinicians' perspectives. Most of the studies were retrospective cohort studies, few were prospective studies. One qualitative study about experiences of pregnant and postpartum women on methadone and breastfeeding decision-making had several methodological flaws (Demirci et al., 2015). First, the researchers collected data in different ways, through interviews of antepartum women and focus groups of postpartum women but analyzed the data together. The two focus groups had two people in each group, despite recommendations that focus groups include at least three people (Krueger & Casey, 2015). The study is further limited by use of a single geographic location for recruitment and no variation in the sample (Demirci et al., 2015).

## Gaps in the Literature

The benefits of breastfeeding among the general population are well known. However, a greater understanding of how breastfeeding mitigates NAS symptoms and improves infant outcomes is needed. Uncertainties related to breastfeeding among women with SUD, including those with OUD are (a) whether the amount of drug that transfers into breastmilk affects NAS, (b) whether skin-to-skin contact provides comfort, or (c) whether it is the act of breastfeeding itself that calms the infant. Further studies are needed about the effects of

methadone/buprenorphine dosage on NAS severity and the effects of varying degrees of aggressiveness in NAS treatment on hospital length of stay. Although stigma is known to affect women with OUD, little is understood regarding how stigma is perceived by pregnant or postpartum women with OUD and how that perception affects their decisions regarding breastfeeding their infants. Most of the existing literature surrounding women with OUD are retrospective chart reviews and systematic reviews that lack sufficient detail for replication. The few prospective studies available lacked rigor in research design, especially regarding methodology. No studies were found that used a conceptual model in addressing breastfeeding decisions among women with OUD. This literature synthesis provides evidence of the need for a well-developed qualitative study exploring women's perceptions of how stigma influences breastfeeding decision-making among women with OUD. In addition to perceptions of women with OUD, perceptions of their support persons regarding how stigma influences breastfeeding decisions could inform future clinical practice. Enhancements in breastfeeding support, on both the micro and macro levels, regarding women with OUD can improve infant health outcomes.

## Summary

The purpose of this chapter was to present the existing literature about the influences of perceived stigma on decisions to breastfeed among women with OUD. It is well known that OUD contributes to NAS, and that breastfeeding may alleviate NAS symptoms. Yet, women with OUD are less likely to breastfeed than the general population. Stigma likely influences decisions to breastfeed among women with OUD, but how it does so is uncertain. The literature presented about influences of perceived stigma on breastfeeding decision-making among women with OUD lacks the perspectives of women with OUD. This study aimed to develop a theory that helps explain the influences of stigma on breastfeeding decision-making from the perspectives of

women with OUD. Future nursing and medical practice will benefit from knowledge gained from this study.

# CHAPTER 3: METHODOLOGY

The purpose of this study was to understand influences of perceived stigma on breastfeeding decision-making from the perspective of women with opioid use disorder (OUD). To understand these decisions and gain the women's perspective, a grounded theory (GT) approach was used to elicit their perceptions of how they made decisions to breastfeed. A discussion of constructivist GT methods regarding (a) design, (b) sample, (c) data collection, and (d) data management and analysis is presented.

## Theoretical Framework: Grounded Theory

This study used GT to explore influences of perceived stigma on breastfeeding decision-making through individual semi-structured interviews of women with OUD and the support persons they identified. The research was guided by the constructivist paradigm (Charmaz, 2014), in which exploration of this phenomenon led to an explanation of the breastfeeding decision-making process where description was previously nonexistent (Creswell & Poth, 2018). According to Charmaz (2011), constructivism is specifically used in GT "to advance understanding of how power, oppression, and inequities differentially affect individuals, groups, and categories of people" (p. 362). This statement was particularly fitting for exploring how women with OUD perceive the influences of stigma on their decisions to breastfeed (Cleveland & Bonugli, 2014; Cleveland & Gill, 2013; Gopman, 2014). Lincoln, Lynham, and Guba (2011) and Scotland (2012) wrote that constructivism is related to relativism. Relativism proposes that there are several truths or realities that can be constructed by individuals or groups based on contextual features. The methods of GT are inductive, following patterns of events or documented notable behaviors to determine a theory for those patterns. This study featured various realities constructed from data collected through the women's voices. By foregrounding

the voice of participants, researchers were closely engaged with participants and the data that originated from responses about their environment and daily life. Relativism and the emic-etic synergy between researcher and participant were necessary to ensure the research findings reflected the participants' own understanding while acknowledging the personal experiences of the researcher (Lincoln et al., 2011). To accurately reflect the experiences of women with OUD, perception of stigma in the context of breastfeeding and the researcher's personal experiences and background were explicitly stated so that findings were derived from the data rather than researcher beliefs and experiences, thus minimizing researcher bias.

## Entrée in the Study

The researcher's context (personal experience) was included in GT data collection and analysis. My clinical background includes ten years of experience in maternal-infant care and six years of experience as an International Board-Certified Lactation Consultant. I have experienced various disparate scenarios related to caring for infants who experience moderate to severe neonatal abstinence syndrome (NAS). I have been present when mothers were incarcerated and unable to remain with their infants. I have witnessed infants removed from the mother's custody by Child Protective Services. In other instances, mothers with OUD have remained at the bedside actively caring for the infant but were discouraged from breastfeeding by clinicians or family members. I have listened as mothers expressed their confusion about breastfeeding with OUD and yet, other times as a mother with OUD breastfed her infant and bonded effectively. Researcher context informed participant data through memos and field notes, to construct multiple individual realities (Charmaz, 2014).

## Pilot Study

In a pilot study of six women with substance use disorder (SUD), actively enrolled in a drug rehabilitation therapy (DRT) program, who had recently breastfed, I explored the influences of SUD on breastfeeding decisions. The overarching theme was Breastworks, which depicts the empowerment of women in their breastfeeding decision-making to protect their infants. There were three supporting categories: The Battle, The Lockdown, and The Best Shot. These three interrelated categories described the vicious cycle of recovery and relapse, The Battle, often leading to social and legal consequences for these women, The Lockdown. Breastworks was a way the women found to overcome this cycle and bond with their infants, aspiring to an improved lifestyle (Cook & Larson, 2019). The constant push-and-pull from the women's voices led me to explore the influences of perceived stigma on breastfeeding decision-making among women with OUD for this study, given the current opioid epidemic.

## Protection of Human Subjects

Participants were protected in this study a variety of ways. First, I obtained letters of support from all study sites. Next, institutional review board (IRB) and agency ethics committee approvals were obtained (Appendix A). For IRB purposes, a waiver of signed informed consent was obtained for the participant (Appendix B). Women with OUD also identified and recruited a support person to participate in the study. The support persons were required to sign a written informed consent for IRB purposes (Appendix C).

## Protection of Privacy

I conducted each one-on-one interview in a private location agreed upon with the index participant or support person. I audio-recorded and transcribed the interviews. Identifying information was removed and a pseudonym was given to each participant. All recordings and

electronic copies of the transcripts were saved on an encrypted, password protected computer in a locked office within the university. Once transcription was completed and verified by a faculty with expertise in qualitative research, the audio files were deleted. Hard copies of transcripts were kept in a locked cabinet in a locked office of the university. Participant demographic data was filed separately from the interview transcripts. All electronic and hard copies will be kept for at least three years. After that time, all data files will be destroyed.

## Setting and Sample

### Study Sites

In the pilot study, recruitment of six participants occurred over 11 months from a single site. Additional protection of this vulnerable population and organizational challenges contributed to lengthy recruitment efforts. Hence, for the current study I recruited women from three locations: an outpatient DRT program, an obstetrical-gynecological (OBGYN) practice, and a major medical center. The outpatient DRT program offers treatment options for men and women with mental illness, SUD, and intellectual or developmental disabilities. Three of the branches of the DRT were approved by the agency ethics committee for recruitment sites in the pilot study by Cook and Larson (2019). These same three branches were also approved for this study. The OBGYN practice serves women of all ages within the reproductive and menopause years, specializing in high-risk pregnancies such as those among women with OUD. The major medical center serves women and children from 29 surrounding counties in eastern North Carolina (eNC) through its specialty hospital.

### Sampling Strategy

A purposeful sample of women with OUD who had recent breastfeeding experience were recruited from one of the three study sites. Sample inclusion criteria were: (1) women with an

OUD, (2) involved in an outpatient methadone or buprenorphine DRT program in eNC, (3) 18 years of age or older, (4) speak English, and (5) have breastfed her infant in the last three years. For the purposes of this study, breastfeeding was operationalized as directly latching the infant to the breast or providing expressed breastmilk via bottle or nasogastric tube. During recruitment efforts in a preliminary study of this population (Cook & Larson, 2019), women often mentioned they would be interested in participating if the time since breastfeeding was not as restrictive (greater than two years versus the less than two-year requirement). Though recall bias may be of concern, Gresham et al. (2015) reported that women recall child-specific perinatal outcomes from at least four years prior with 95% accuracy when compared to medical records. In the same study, Cook and Larson (2019) only included women between 18 and 44 years of age. However, as unintended pregnancies are a risk of OUD and age of first-time mothers increased 23% over 35 years of age, it was determined that the inclusion of women 45 to 54 years old was reasonable (Mathews & Hamilton, 2016). Exclusion criteria were women younger than 18 and over 54 years of age, those who did not speak English, women who breastfed their child more than three years ago, and women with OUD obtaining inpatient treatment.

Women were recruited via face-to-face individual or group presentations of the study purpose with invitational flyers provided at the recruitment presentation (Creswell & Poth, 2018). Theoretical sampling was obtained from different age, parity, occupational and educational statuses (Creswell & Poth, 2018). Each index participant was encouraged to identify one support person. Identified support persons were defined as significant others, family members, friends, or other individuals the participant deemed supportive of their breastfeeding. Index participants either obtained the support person's permission for the PI to contact them or took an invitational flyer to the support person so that the support person could contact the PI

directly to schedule an interview. Lack of a support person did not lead to exclusion from the study. To generate sufficient knowledge for GT, literature suggests 20 to 60 interviews are needed (Charmaz, 2014). This study had 17 total interviews. We attempted to achieve theoretical saturation with this number of interviews.

The study sample was derived from women with OUD currently being served by an outpatient DRT program, a local high-risk OBGYN office, or a major medical center. Women on methadone are required to go to the treatment facility daily for their doses and must attend a therapeutic group session three times a week, lasting three hours per session. In contrast, women on buprenorphine received a weekly prescription and were required to attend a one-hour therapeutic group session twice monthly. Most of the women from the DRT programs selected for this study have children, but often lack support from family and friends. Hence, treatment requirements and family obligations often conflict with each other. In addition, some women have transportation challenges, which can be difficult for recruitment and research participation. Thus, giving participants reasonable options for interview locations was necessary. Compensation for participant efforts and contributions are suggested for adequate recruitment among vulnerable populations as well (Jessiman, 2013). Funding was obtained to provide educational sessions to key agency gatekeepers and a $20 gift card to participants and support persons for their time and contribution to this study. Gatekeeper educational sessions described the purpose of the study, eligibility criteria, and what assistance was needed from the agency staff. Key agency gatekeepers included nurses, social workers, doctors, and ancillary staff. Food was provided as the information sessions were scheduled during staff breakfast or lunch breaks.

## Data Collection

One to two in-depth semi-structured interviews were conducted separately in a private location with eligible women and their identified support person. Interview questions were developed from the principal investigator's (PI) experience and from the extant literature (Appendices D & F). Faculty with expertise in qualitative methods further assisted in refining the interview questions to ensure appropriateness for GT methodology. Examples of questions for women were: (1) describe your thoughts about breastfeeding with OUD, (2) describe someone that assisted you to breastfeed, and (3) describe someone or something that made it more difficult to breastfeed. Examples of questions for support persons were: (1) describe your thoughts about breastfeeding with OUD, (2) give an example of how you have been helpful when it came to breastfeeding with OUD, and (3) give an example of a time that you felt you could have been more helpful when it came to breastfeeding with OUD. Demographics were obtained for both women and support persons (Appendices E & G). The interviews were audio-recorded and transcribed by the PI. Throughout the interviews, detailed field notes were kept regarding observations of participant behaviors, interactions with participants, and personal thoughts. A local hospital breastfeeding policy and breastfeeding guidelines from the North Carolina Prenatal Opioid Exposure Project (NCPOEP, 2018) were reviewed. Both documents reflected supporting breastfeeding among this population while in treatment. The following organizational position statements were reviewed and found to be supportive of breastfeeding with this population while in treatment: American Academy of Pediatrics (AAP, 2012) *Breastfeeding and the Use of Human Milk,* Academy of Breastfeeding Medicine (ABM) *Clinical Protocol #21: Guidelines for Breastfeeding and Substance Use or Substance Use Disorder, Revised 2015* (Reece-Stremtan, Marinelli, & ABM, 2015), American Colleges of Obstetrics and Gynecology (ACOG, 2015)

*Committee Opinion Number 633: Alcohol Abuse and Other Substance Use Disorders: Ethical Issues in Obstetric and Gynecologic Practice*, and World Health Organization (WHO, 2009) *Acceptable Medical Reasons for Use of Breastmilk Substitutes.*

## Data Management and Analysis

Data analysis was continuous from the first transcript, simultaneous with data collection, and iterative based on information gathered from incoming data (Giles, de Lacey, & Muir-Cochrane, 2016). Incoming data that informed data analysis included the breastfeeding policies and guidelines reviewed, as well as support person interviews. Index person interviews were transcribed using Microsoft Word and then uploaded to NVivo, v12 for data management (QSR International, 2018). Data analysis was conducted through coding and constant comparison (Giles et al., 2016). Coding occurred in three stages, progressing from concrete codes to theoretical codes (Table 1). First, initial coding was completed to find meaning among fragments of the transcripts and identify processes (Charmaz, 2014; Creswell & Poth, 2018). Initial coding was line-by-line in a quick, spontaneous manner assigning action words as codes (Charmaz, 2014). The codes of each interview were compared to codes of the other interviews for similarities between them. Next, focused coding was done to conceptualize the phenomenon by regrouping codes based on patterns between them and across transcriptions (Charmaz, 2014). However, initial and focused coding were not linear, they were often concurrent or iterative based on the findings (Giles et al., 2016). Finally, theoretical coding identified relationships among the focused codes, reconnecting the fragments to develop a theory (Charmaz, 2014). Throughout the analysis, constant comparison was performed using memos to record the researcher's thoughts about codes, patterns, and relationships (Giles et al., 2016). The use of memos in GT is crucial to processing thoughts about codes that progress to a higher level of

abstraction necessary for theory development (Charmaz, 2014). Memos and field notes were analyzed iteratively along with the transcripts as this was helpful for conceptual development and refinement (Charmaz, 2014; Giles et al., 2016).

**Table 1.**

*Grounded Theory Coding Matrix Example*

| Exemplar | Initial Code | Focused Code | Theoretical Code |
|---|---|---|---|
| Like I literally just went back to [intensive program] last week, week before last, Thanksgiving week. And that was my decision because I tested positive for alcohol, and they said either 'I'm cutting your medication down or off and you can stay in the one, once a week program or you can go back to [intensive program] and stay on your meds'. I'm like, 'okay, I'll go back to [intensive program], 'cause I need my medicine'. So umm, its helped a lot, that's for sure. (Kathryn, 31 years old) | Increasing Treatment Intensity | Recovery Maintenance | Recovery-Relapse Cycle |

## Evaluative Criteria for Qualitative Research Trustworthiness

To develop trustworthiness and rigor of this qualitative study, the evaluative criteria of credibility, transferability, dependability, and confirmability are addressed.

**Credibility.** Credibility, or the ability to trust the researcher's work (Polit & Beck, 2017), was maintained in multiple ways. First, theoretical sampling was pursued so that the developed theory would include varying perspectives relevant to the concepts of breastfeeding and OUD (Polit & Beck, 2017). For instance, women with varying numbers of children and amount of breastfeeding experience provide different perspectives. Second, participant confidentiality was ensured for the duration of the study by securely storing de-identified data on an encrypted password protected university drive and in a locked cabinet of a locked office at the university. Participant contact information was stored in a separate, yet similarly protected location. Third, privacy was maintained during interviews by ensuring they were conducted in a private space which prevented the conversation from being overheard. Memos, field notes, and reflexive journals only included pseudonyms to further protect participant privacy. Fourth, interviews were transcribed by the researcher verbatim to stay true to the participant's voice. Accuracy of transcripts were verified by a dissertation committee member. Fifth, following Charmaz's (2014) guidance, data was coded in three progressive stages: initial, focused, and theoretical, to develop a theory explaining the influences of perceived stigma on breastfeeding decision-making among women with OUD. Sixth, the researcher had meetings with the dissertation chair weekly to discuss the progress of the study, allowing for peer-review, debriefing, and reflexivity that ensured representation of participants' voices versus researcher bias. Seventh, data were triangulated through interviewing women, their support persons, and reviewing professional

organization guidelines on breastfeeding. Finally, the researcher had prolonged contact with the agencies and population with persistent observations.

**Transferability.** Transferability was addressed in three ways. First, the context of the researcher's background and experiences was explicitly identified so that readers could make their own judgements about applicability in their area of interest (Charmaz, 2014; Polit & Beck, 2017). Second, thorough description of the recruitment sites was presented when reporting findings so that readers could identify similarities and differences between locations for potential study replication. Third, exemplars of the participant responses with thick description were presented so that comparisons of similar populations in different geographic regions could be identified by the reader (Polit & Beck, 2017).

**Dependability.** Dependability was maintained through various documents such as detailed field notes, memos, and notes from meetings with the dissertation committee. Additionally, member checking was conducted during interviews with probe questions for clarification and a codebook was kept that the expert qualitative researcher reviewed throughout data analysis. The development of visual models and thematic analysis also supported the dependability of the study (Polit & Beck, 2017). A thorough reporting of the methods used to conduct the study allowed others to potentially replicate the research design.

**Confirmability.** Confirmability was supported by three methods. First, explicitly stating the researcher's orientation in relation to the study allowed for reflexivity to ensure that the findings presented were representative of the participant's experiences and the data collected rather than the researcher (Polit & Beck, 2017). Second, keeping detailed memos, an audit trail, and other thorough records provided proof of the process and further removed researcher bias. Third, data triangulation supported confirmability. The researcher obtained data triangulation by

interviewing individuals of the target population from several branches of the outpatient DRT program, the major medical center, and the high risk OBGYN practice (Creswell & Poth, 2018; Polit & Beck, 2017). Additionally, breastfeeding policies were examined along with the transcripts and memos to inform data collection and analysis. By using the above strategies, trustworthiness was addressed throughout this GT study in all phases of the study trajectory.

## Potential Limitations and Alternative Approaches

Although this study was rigorous, there were limitations. The use of one geographical location, a purposive sample, and the homogeneity of the sample limits the transferability of the findings to larger populations. Only one geographical location was utilized for this study, as it was meant to explore the phenomenon and develop a theory that could be used for further research and interventions with this population. The sample was very specific; therefore, women with OUD who have not enrolled in a treatment program may have been missed. Although a proportional number of African American women were present at recruitment sites and invited to participate, many said that their children were older than the inclusion criteria allowed, or they were not able to participate due to other obligations of daily life. Hence, the sample is of all White women. While a quantitative study utilizing a questionnaire might have been an alternative option, the design would lack the richness of the data obtained in this GT study. Nursing science would continue to have a gap in knowledge of why women with OUD make the decisions they do about breastfeeding, even though knowledge of its existence would be improved.

# CHAPTER 4: BREASTFEEDING DECISION-MAKING IN AN ADDICTION TRAJECTORY: A GROUNDED THEORY EXPLORATION


## Abstract

**Objective:** To explore how maternal perceptions of stigma influence breastfeeding decisions.

**Methods:** A Grounded Theory study was conducted with women with opioid use disorder (OUD) using one to two in-depth interviews. Women between 18 and 54 years of age, who breastfed a child in the last three years were recruited from a drug rehabilitation therapy agency, high-risk obstetrical office, and a major medical center. Each woman was asked to identify a support person to interview. Data were coded in three iterative and progressive phases: initial, focused, and theoretical, leading to a theoretical model.

**Results:** Ten women and six support persons participated. The major findings were that these women faced Breastfeeding Decision-Making in an Addiction Trajectory, characterized by the Recovery-Relapse Cycle and Breastworks. Women had multiple Recovery-Relapse Cycle experiences, which involved seeking, initiating, and maintaining recovery and at times falling into relapse, which influenced breastfeeding decisions. Breastworks describes the empowerment of women for maternal breastfeeding decisions with the goal of protecting the infant.

**Conclusion:** This study provides unique theoretical concepts that may be incorporated into the care of women with OUD, from preconception to postpartum, to support breastfeeding decision-making and infant well-being. Implications include development of a mobile application for breastfeeding education, incorporation of breastfeeding guidelines into continuing provider education, and involving successfully recovered women as community health workers.

## Background

Women with substance use disorder are among the nation's most vulnerable populations. Almost 16% of women, ages 18 and older, used illicit drugs in 2016; this percentage continues to trend upward exponentially (Center for Behavioral Health Statistics and Quality, 2017). This means that every 15 minutes a baby is born to an opioid dependent woman (National Institute of Drug Abuse, 2019). Neonatal abstinence syndrome (NAS) is a group of symptoms that infants may experience from prenatal exposure to opioids (Kocherlakota, 2014). These symptoms include mild to severe gastrointestinal, nervous system, and respiratory symptoms that can cause extreme discomfort. Gastrointestinal symptoms may include poor feeding despite hunger, severe abdominal pain, vomiting, and diarrhea (Pritham, 2013). Nervous system involvement can lead to tremors, irritability, convulsions, and seizures (McGlothen, Cleveland, & Gill, 2018). Respiratory symptoms may include tachypnea, making infant feeding unsafe because of respiratory distress (Kocherlakota, 2014). Unlike adult withdrawals, if NAS is not treated it can be fatal (Kocherlakota, 2014). Neonatal withdrawal is typically monitored using the Finnegan scoring tool, which defines mild as a score of less than four, moderate as a score of five to eight, and severe symptoms as greater than eight (Kocherlakota, 2014).

While first line treatment of severe NAS is morphine, mild to moderate symptoms are treated with nonpharmacological interventions. Such interventions include swaddling, providing a pacifier, and decreasing environmental stimulation. Breastfeeding is another effective intervention. Extensive research shows breastfeeding mitigates infant withdrawal symptoms, thus allowing infants to quickly and more easily adjust to extrauterine life (Schiff et al., 2018). Despite current evidence, many women with opioid use disorder (OUD) do not breastfeed,

leaving their infants at a disadvantage (McGlothen & Cleveland, 2018). The reason for the disparity among women with OUD is unclear.

It is known that women with OUD experience stigma related to their substance use and such stigma prevents them from seeking treatment (Stone, 2015). However, literature about how stigma influences breastfeeding decisions among women with OUD is minimal. Most of this literature is retrospective. The few prospective studies focus on the clinicians' perspectives. One qualitative study about how the experiences of pregnant and postpartum women on methadone influence breastfeeding decisions had several methodological flaws (Demirci, Bogen, & Klionsky, 2015). Sensitizing concepts were lactation support, lactation education, and self-efficacy, which came from breastfeeding literature in the general population. Sensitizing concepts are broad terms from researcher knowledge that guide research inquiry (Charmaz, 2014). Despite such research, there is a paucity of theoretically-based research about how stigma influences breastfeeding decisions among women with OUD. Hence, the purpose of this study was to explore maternal perceptions of breastfeeding and how stigma influenced breastfeeding in women with OUD.

## Methods

A Grounded Theory approach was used to meet the purpose of this study. Grounded Theory strives to develop an understanding of a phenomenon that has not previously been described (Charmaz, 2006). Data is coded in three progressive, yet iterative phases, from concrete to more abstract so that a theory or explanation can be developed. First, participants' voices are foregrounded as data is broken into smaller, more manageable parts during initial coding. Second, initial codes are iteratively compared between data sources for similarities that can be used to re-group the data into focused codes. Third, focused codes are organized to

identify themes of the topic being explored. The themes, categories, and subcategories are then organized into a theoretical framework that can be used to compare similar populations and for guidance in their care (Charmaz, 2006; Giles, de Lacey, & Muir- Cochrane, 2016).

Prior to initiation of the study, agency and university IRB approvals were obtained (Appendix A). A waiver of signed informed consent (Appendix B) was acquired to protect the women with OUD because a consent form would be "the only record linking the subject and the research … [meaning] the principal risk would be potential harm resulting from a breach of confidentiality." (Electronic Code of Federal Records, 2018). In contrast, support persons were required to sign an informed consent to participate (Appendix C).

**Researcher Context**

In grounded theory, the researcher's context influences data collection and analysis. The first author and principal investigator (KC) is a current doctoral candidate and registered nurse of 10 years, with experience caring for women with OUD and their infants in a major medical center and is an International-Board Certified Lactation Consultant. Over the years, KC has observed the challenges that many women face during this period in their lives. Hence, the researcher's experiences contribute to the rationale for the study design and methodology.

**Setting and Sample**

This study took place in eastern North Carolina (eNC). Participants were recruited from three separate agencies. First, women were recruited from two sites of an outpatient drug rehabilitation therapy (DRT) agency that serves adults with OUD. Second, recruitment occurred in a high-risk obstetrical office where pregnant women are monitored for prenatal care. Third, women were recruited from a major medical center where they gave birth and received further monitoring for their OUD and its effects on their infants. The participants were women with

OUD who were between 18 and 54 years of age and enrolled in a DRT agency in eNC. Inclusion criteria were that women spoke English and breastfed their child within the last 3 years. The women were asked to identify one support person who could be interviewed, but women were not excluded if no support person was available. The only inclusion criteria for the support person was that the woman identified the individual as supportive of her breastfeeding efforts. Exclusion criteria were women younger than 18 and over 54 years of age, those who did not speak English, women who breastfed their children more than three years ago, and women with OUD obtaining inpatient treatment.

## Data Collection

Women were recruited through individual and face-to-face group sessions where they were introduced to the purpose of the study and invited to participate. During these sessions, KC clarified with potential participants that breastfeeding included any amount of time breastfeeding. An invitational flyer (Appendices I & J) was distributed that asked the women to contact the nurse investigator via phone to schedule an interview. Women who contacted the investigator were reminded of the inclusion criteria before scheduling the interview to affirm their eligibility and the voluntary nature of the research.

**Interviews of Women with OUD and Support Persons.** Prior to beginning the interview, consent was obtained from each participant (Appendices B & C) and demographics were obtained (Appendices E & G). Private semi-structured interviews were conducted by the principal investigator (KC) with the participants, both the women and support persons, at a location of their choice for their comfort. Interview questions included their personal thoughts of breastfeeding with OUD, perceptions of experiences with breastfeeding, and perceptions of assistance with breastfeeding (Appendices D & F). The interviews were audio-recorded.

**Breastfeeding Guidelines from Professional Organizations.** Data from current breastfeeding policies further informed data collection and analysis. Position statements regarding breastfeeding among women with OUD have influenced the development of guidelines and policies at national and state levels. In 2009, the World Health Organization (WHO) released a document on acceptable reasons to provide a breast milk substitute. This document supported breastfeeding with OUD if caution was used. In 2011, the U.S. Surgeon General's call to action on breastfeeding included a need for greater support from family members, the community, and clinicians to decrease disparities in breastfeeding (U.S. Department of Health and Human Services [USDHHS], 2011). The AAP (2012) supported the stance of the WHO and endorsed the opinion that OUD is not a contraindication to breastfeeding if the woman is in a treatment program and has negative HIV and toxicology screens. The American College of Obstetrics and Gynecology (ACOG, 2015) endorsed the view that women with current or past OUD should not be criminalized or excluded from breastfeeding without careful consideration of the individual situation and proper education. The Academy of Breastfeeding Medicine (ABM) endorses multiple criteria for supporting breastfeeding among women with OUD (Reece-Stremtan, Marinelli, & ABM, 2015). These criteria include compliance with prenatal care, active participation in a DRT program, a negative toxicology screening at delivery, and abstinence from illicit substances for at least 90 days prior to delivery (Reece-Stremtan et al., 2015). The North Carolina Perinatal and Maternal Substance Abuse Initiative supported breastfeeding while on medication-assisted therapy for OUD, as well as when to transition medications during breastfeeding (North Carolina Pregnancy and Opioid Exposure Program [NCPOEP], 2018).

## Data Management and Analysis

Audio-recordings were used to transcribe the interviews. Pseudonyms were assigned to all participants to protect their identity. KC then reviewed the transcripts in comparison to the audio recordings for accuracy. Transcripts were saved on a password protected and encrypted drive approved by the university IRB and managed using NVivo, v12 (QSR International, 2018). The second author (KLL) verified transcripts for clarity and accuracy. Field notes were written immediately after each interview with participants, and breastfeeding policies regarding OUD were reviewed from several professional organizations.

Transcripts were read numerous times by both investigators for iterative and constant comparison coding according to Charmaz's (2006) guidance (Table 2). Initial coding of transcripts began as each interview was transcribed and reviewed. This was done line-by-line to identify the unique participant experiences. The initial codes were then compared between the transcripts, leading to recoding of data as appropriate. Focused codes were more conceptual and were informed by the investigator's knowledge of the population through experience caring for women with OUD. Focused codes led to categories necessary for theoretical coding. Theoretical coding allowed the researcher to identify important relationships in the data, thereby developing a theory. Memos were written throughout analysis to help the investigator process all the information gathered during iterative constant comparison.

Table 2.
*Example of Grounded Theory Coding: Raw Data to Theoretical Code*

| Exemplar | Initial Code | Focused Code | Theoretical Code |
|---|---|---|---|
| … The only reason why I know about it this time is 'cause I've had it before with my son, from my last pregnancy. Now with him, I didn't know nothing about it. I was informed that I wasn't allowed to do that. … it was something that was not recommended for me to do. Let me say it like that. Umm, so, but I did research and I looked up and I started finding out that it would actually be better for him if I did do it. You know, and that's why I was so, I tried, then as soon as I was told what I was told, immediately I just, 'No, I'm stopping." … Ya know, but this time around I know better. I know that it is better for her and it needs to be done, period. (Marie, 28 years old) | Knowing nothing about breastfeeding with son | Knowing about Breastfeeding | Breastworks |

## Results

Ten women in treatment for OUD and six support persons participated in the study (Table 3). Although both White and African American women were recruited, only White women agreed to participate. Some African American women had children who were older than the three-year eligibility requirement, others did not breastfeed, and others did not want to participate in the research. Out of almost 200 women invited, half were from the DRT agency, 75 were from the major medical center, and 25 were from the high-risk obstetrical office. Seven participants were recruited from the major medical center, two from the DRT agency, and one from the high-risk obstetrical office. One woman participated in a second interview for clarification of responses from her first interview. Prior to interviews, 10 to 20 minutes were spent building rapport through general conversation about the health of their babies. There was a total of 17 interviews with the women and their support persons lasting 30 to 80 minutes,

producing 218 pages of double-spaced transcripts, 17 pages of field notes, and 21 pages of memos.

Table 3.
*Demographic Characteristics of Women with OUD and Support Persons (N = 16)*

| | Characteristic | Mean | Range | n (%) |
|---|---|---|---|---|
| Women with OUD | Age (years) | 29.7 | 25-36 | 10 (100) |
| | Race/Ethnicity | | | |
| | Caucasian | | | 10 (100) |
| | Education Level | | | |
| | Some HS | | | 1 (10) |
| | HS/GED | | | 2 (20) |
| | Some College | | | 6 (60) |
| | Undergraduate | | | 1 (10) |
| | Occupational Status | | | |
| | Unemployed | | | 8 (80) |
| | Full-Time | | | 2 (20) |
| | Pregnancies | | | |
| | 1 | | | 1 (10) |
| | 2 | | | 2 (20) |
| | 3 | | | 1 (10) |
| | 4 | | | 3 (30) |
| | 5 | | | 1 (10) |
| | 6 | | | 2 (20) |
| Support Persons | Age (years) | 38.7 | 29-57 | 6 (100) |
| | Race/Ethnicity | | | |
| | Caucasian | | | 6 (100) |
| | Education Level | | | |
| | Some College | | | 6 (100) |
| | Occupational Status | | | |
| | Unemployed | | | 2 (33) |
| | Full-Time | | | 4 (67) |

The overarching theme in this study was Breastfeeding Decision-Making in an Addiction Trajectory, which was identified in the two major sub-themes Recovery-Relapse Cycle and Breastworks (Appendix H). The addiction trajectory included symptom management, social and

environmental factors, pain-prescription pathway, street drug pathway, and hitting rock bottom. Some women entered the addiction trajectory in adolescence, but most entered in their twenties.

Women entered the addiction trajectory either through a pain symptom management experience or by way of experiencing social and environmental risk factors. Eight women reported initiating their addiction trajectory beginning with symptom management. These women recounted medical concerns, such as a tooth extraction or back pain, that required prescription medications for pain. At times opioids were prescribed in combination with other potentially addictive medications, such as benzodiazepines. Two of the women from the pain-prescription pathway went directly into recovery. However, six of the women described moving from the pain-prescription pathway to the street drug pathway early in their trajectories through influences from social and environmental risk factors that they encountered over time.

In contrast, four women began their addiction trajectory through social and/or environmental risk factors, such as family instability, living in a risk-prone neighborhood, or access to medication, which led them to the street drug pathway. Family instability was characterized by parental divorce, relocations, personal breakups or divorce, intimate partner violence, loss of custody, death of parents, and stillbirth. Living in a risk-prone neighborhood was characterized by outside influences such as neighbors, peers, and friends who pressured the women into using opioids. Access to medication was characterized by the ability to steal others' medications or the inability to access needed prescription medications. Women who either started in the street drug pathway, or went to this pathway later, described the experience of "hitting rock bottom". Hitting rock bottom was defined as using stronger, more dangerous street drugs like heroin, cocaine, or methamphetamines, as well as becoming involved in the criminal justice system, losing the trust of loved ones, or losing all their possessions.

Genetics can contribute to an addiction trajectory. One participant whose addiction was initiated through the pain-prescription pathway and later went to the street drug pathway, was told by a psychiatrist that she had an "addictive personality":

> … I've just been told by, I guess, my psychiatrist and stuff that I have an addictive personality. Like, just umm, either all or nothing. Like doing too much or nothing at all. I mean I have addictions to food, like it's just not drugs or alcohol necessarily. It can be sex, it can be food, it can be gambling, it can be, you know, anything (Suzy, 36-year-old mother of four).

Genetic predisposition to addiction is associated with dopamine regulation. The $DRD_2A_1$ allele gene causes decreased dopamine levels that contribute to the compulsive behaviors identified in those addicted, while the CYP2D6 gene is specifically linked to OUD and overdose risk (Inaba & Cohen, 2014). Though the opioid epidemic has a 20-year history, the neurobiological science behind its occurrence is in the early stages. According to Agarwal, Udoji, and Trescot (2017), about 10% of White people have a detrimental allele that is associated with OUD, though the prevalence varies among races and ethnicities. Such genetic predispositions likely contributed to hitting rock bottom, which led to the Recovery-Relapse Cycle.

**Recovery-Relapse Cycle**

The Recovery-Relapse Cycle was characterized by three categories, seeking, initiating, and maintaining recovery, and episodic relapse. One woman described the moment she realized that she was addicted after being peer-pressured into using pills by her boyfriend whom she described as having "a whole pharmacy in his house":

> … I never knew what withdrawals were. I didn't know that there was even such a thing. And then, I remember in the morning I woke up and sweat, ya know, I was just sweating. And he was like, 'yeah, you better take some'n, you're gonna be sick today.' And I was like, 'Oh God, what have I done to myself?' (Ginger, 25-year-old, mother of two).

This participant is referring to being "dopesick" (Macy, 2018), the physical illness that people experience during withdrawal. One support person described being dopesick as "the flu times ten" (Adam, 28-year-old, Hannah's fiancé). Symptoms experienced by adults are similar to those of NAS, but they are not fatal.

**Seeking.** Seeking recovery was identified by some women as feigning suicide to get into treatment. One participant who had been prescribed pain medication after being severely beaten by her ex-husband and later gang raped then turned to street drugs, described her experience seeking recovery in the following exemplar:

> … I went to the hospital. Which, I was suicidal, but I wasn't gonna hurt myself. But I told 'em I was going to. And umm, I had just been gang raped prior. That was actually what kind of led up to, like all of, everything. And they had psychiatrists, and everything come in. They told me they could tell I wanted help and that they were gonna make sure I got it (Tara, 31-year-old, mother of one).

Another participant who attempted to initiate recovery on several occasions spoke of her challenges while seeking recovery during one of her attempts:

> … I went to jail one day, for actu-, okay I went to go into detox and the guy that was with me was sitting in the parking lot sniffing pills while I was in there trying to check in. So, they see him on camera, I end up getting arrested there, umm, 'cause I had pills on me

too that I was gonna sneak into the detox so I wouldn't feel as bad, ya know. Just stupid mess! But anyways, got arrested (Ginger, 25-year-old).

Ginger was sneaking pills into detox to avoid being dopesick, even though she really wanted to be free of all substances. Yet another participant who was prescribed narcotics for pain related to endometriosis reported seeking treatment when her doctor stopped prescribing her medicine:

> And then the doctor stopped prescribing and by that time umm I was pretty dependent. Umm, and so, instead of having to go and look elsewhere for, ya know, medicine, I ended up going to treatment … (Ashton, 28-year-old mother of two).

Seeking recovery eventually led to initiation of recovery for these women.

**Initiating.** Initiating recovery was described as difficult for many reasons, but well worth it in the end. Some women were pressured into continuing opioid use by significant others even after reaching out for help. Others spoke of fearing the potential of becoming dopesick with detoxification. Finally, a few women were referred by a physician, as in the case of this woman who realized that she was addicted and needed help during her first visit at the DRT clinic for other reasons:

> …my doctor actually referred me to a facility just to take over my other medication that I was being prescribed. And when I found out that it was at like a treatment facility, I ended up telling 'em about the sub, substance abuse and got help instead of refilling my medicine (Ashton, 28-year-old).

One woman who previously described her unwavering search for help in recovering, reported receiving her phone call of acceptance into a rehabilitation facility:

> … I get a phone call from [inpatient facility] personally to me saying, umm 'We just let them know that we've opened a bed up for you.' And they said 'we could hear it in your voice that you were ready' so. And, now I am here (Tara, 31-year-old).

Another woman who started on pain pills for a tooth extraction described her experience of initiating recovery, stating, "... in that time, you end up doing a lot of soul searching and umm, I felt like I kind of found myself" (Sally, 30-year-old). Another woman also spoke of her experience initiating treatment stating, "… I did a 180 when I got on Subutex, and it's worked for me a lot better than Suboxone did" (Ginger, 25-year-old). Once recovery was initiated, maintaining recovery was a daily challenge for these women.

**Maintaining.** Maintaining recovery was described as continual and arduous. One participant outlined maintaining her recovery in this exemplar:

> … well it started out, when I first began going it was an intensive, every day, group sessions. I had to go every day of the week and they gave me my medicine there. Umm, once you pass drug tests and you go to your groups like you're supposed to daily, and things like that, you can build up enough where you can get, uh, take homes. Like, you start out with just one. You take one dose home and you have to come get the rest there, but now I can take a whole weeks' worth medicine home with me. And umm, I do two groups a month and one one-on-one session with my therapist. But umm, that's as much as you can get it a weeks' worth of the medicine at a time. … But umm, someone just beginning would have to go there daily to be treated-, to get any medicine at all (Sally, 30-year-old).

This woman was proud of her ability to maintain sobriety and being given a weeks' worth of medication, eliminating the daily visits to the DRT center for medication administration. Another woman who started taking unprescribed pain pills after the stillbirth of her son to find comfort spoke matter-of-factly about recovery maintenance stating:

> So, I followed it. Done everything I was supposed to do. Umm, I've had, not had a relapse. Don't plan on having a relapse. Don't have an-, the cravings anymore. Completely despise it (Sarah, 28-year-old, mother of four).

Like Sally and Sarah, many other women reflected a sense of pride for maintaining recovery. In addition to pride, most women reported fearing withdrawal. One participant who struggled to wean from prescription pain medication explained that such fear of being dopesick was her initial reason for maintaining recovery in this exemplar, "… you have like withdrawals if you don't have the medication. … And I have not experienced that with the Suboxone" (Christina, 34-year-old, mother of three). One woman explained the importance of maintaining recovery:

> The stability of the medication and the, uh yeah, the medicine that you're prescribed. And also, being that you're in treatment too, knowing that they're, ya know, constantly drug testing you and all that stuff, it's like, it encourages you to stay clean and just, stay on the medication managed by the doctor (Ashton, 28-year-old).

**Relapse.** Relapse is part of the Recovery-Relapse Cycle that is a constant threat in the lives of these women. One participant described a highly unstable family situation leading to her addiction trajectory and her recent near-relapse event:

> Got into treatment this go ‘round and I’ve been there since December 2015. Like I literally just went back to [intensive program] last week, week before last, Thanksgiving week. And that was my decision because I tested positive for alcohol, and they said either ‘I’m cutting your medication down or off and you can stay in the one, once a week program or you can go back to [intensive program] and stay on your meds’. I’m like, ‘okay, I’ll go back to [intensive program], ‘cause I need my medicine’. So umm, its helped a lot, that’s for sure (Kathryn, 31-year-old, mother of two).

Identifying the need to stay in treatment and alter the intensity of treatment is critical to successful recovery. One participant described the commitment needed for successful recovery and prevention of relapse through her account of attempting recovery on several occasions:

> So, wow, it was a long road. Me and him, we tried to do treatment here or there, but I wasn’t serious about it. Ya know, and every time I would go to treatment and come home, and he would come home, he wanted to go right back to it. And so, I had to leave him. And umm, we ended up splitting up. … I was buying [Suboxone] off the street. And did strictly suboxone and I had smoked some weed here and there for a good while. For about two years then I started with cocaine. And then that was another journey to get clean from that, but umm, ever since I went to jail that day I never touched another pill and it’s been strictly suboxone or Subutex since then (Ginger, 25-year-old).

All aspects of the recovery-relapse cycle influenced personal choices and decisions of these women about breastfeeding.

## Breastworks

While debriefing with a colleague whose brother-in-law is in the military about the results of the pilot study (Cook & Larson, 2019), a quick search of Civil War terms was suggested. The search presented Breastworks, a military term used to describe chest-height man-made walls used for protection against enemy fire. I felt that Breastworks was well represented in the pilot study throughout the subthemes: The Battle, The Lockdown, and The Best Shot. This concept of Breastworks informed the current study (Cook & Larson, 2019) regarding breastfeeding decisions in women with OUD. Breastworks was further identified in this study when women described the power it took to defend their decision regarding breastfeeding while in recovery. Power was gained through Knowing and Learning, but also through their critically conscious evaluation of their role in the current circumstances and the resources necessary to change their infant outcomes. This knowledge gave them power to identify societal and self-stigma influencing their decisions, which empowered them to take action to prevent negative outcomes (Rappaport, 1981). Empowerment to breastfeed was characterized by Knowing and Learning, Good Intentions, and Health Care Provider Sensitivity. Breastworks along with these concepts influenced the newborn's well-being.

**Knowing and Learning.** Breastworks was characterized by "Knowing and Learning", which was how the women knew about breastfeeding benefits with OUD. One woman spoke positively of her breastfeeding experiences with her three previous children, despite comorbidities like gastroschisis and tongue-tie. She also provided her plan to breastfeed her current infant at least two years:

> It's been a good experience. And, I mean, I've done really well with it. It's something that, I guess, I'm proud of I guess. … I was a lot younger [with my first daughter] so I

> breastfed her I think maybe three to six months. Then, my 12-year-old I breastfed him about a year. My six-year-old I breastfed him two years. … my daughter had gastroschisis and they just-, encouraged me to try it and because it was the healthiest option for her, I guess, in her like healing or whatever. So, I just tried it and it worked for me so, and I enjoyed it. … it wasn't a question with my other children. It was just, I knew I was going to breastfeed (Suzy, 36-year-old).

A few had unsuccessfully attempted to breastfeed a previous child and wanted to be successful with their current child, as in Hannah's case who began her trajectory through peer pressure from neighbors: "With [first daughter], it was different with her. I didn't last very long. But with her [second daughter], it's been going pretty good." (Hannah, 26-year-old, mother of two).

**Good Intentions.** Breastworks was also characterized by "Good Intentions" as women described the comments to them by family members, friends, and healthcare providers who were looking out for both the mother's and the infant's well-being. We further analyzed Good Intentions as wither positively or negatively perceived by the women. Positively perceived Good Intentions included instances such as lactation consultants trying to help a novice breastfeeding mother, the nutritionist for the Women, Infant, and Children (WIC) program who provided a breast pump, and family members continually asking about breastfeeding decisions. One participant who was experiencing breastfeeding for the first time stated:

> Just with the lactation specialists here, and people here at the hospital have helped me because I'm really new to it all. ... they supplied a hospital pump for me and the nurses and everybody have just all been really helpful in trying to encourage me and ...kinda telling me little secrets here and there (Sally, 30-year-old).

In contrast, some good intentions were negatively perceived due to the amount of stress they caused. The same participant felt that too much help stressed her and her infant out, which prevented a successful breastfeeding session:

> I found that if there was a lot of people present in the moment, trying to kinda hands-on help, it just kinda stressed me out and it stressed my baby out. Umm, we just, we needed that time just me and her (Sally, 30-year-old).

Though these perceptions were by the same participant, others expressed similar experiences. Another participant gave an example of her mother questioning why she would want to breastfeed:

> [My mom] may not want me to breastfeed because [daughter] will be getting Subutex still, 'cause she did say yesterday, she said, 'see, in my mind, you would want her to go ahead and get off of it while she's there versus giving her little bits at a time. Ya know, when is she ever gonna get off of it?' (Ginger, 25-year-old).

Such positively and negatively perceived good intentions played a vital role in whether these women felt empowered in their decisions to breastfeed.

**Health Care Provider Sensitivity.** Breastworks was characterized by fluctuating levels of Health Care Provider Sensitivity, identified through actions and statements from those caring for the mother or infant. Health Care Provider Sensitivity was described by one participant in regards to care during her most recent stay at the major medical center:

> … the pediatrician, they've recommended here as well, like, 'yes please, we want you to continue to breastfeed.' Ya know, even though we've had the major weight loss, they haven't tried to discourage me at all. They want me to do it. They want me to also just do

the formula as well. Ya know, not take over with formula, she breastfeeds and then after feeding THEN do the formula. (Marie, 28-year-old, mother of five).

In contrast, several women described health care provider insensitivity when actions or statements were not necessarily perceived to be in the interest of the mother-infant dyad. A lack of Health Care Provider Sensitivity was perceived by women and their support persons as stigma against breastfeeding with OUD. Such insensitivity often placed more stress on the mother, who was already concerned about her infant's well-being. One participant reported a scenario where the nurse questioned her adherence to treatment in a vague way:

> ... she kinda asked me if my methadone was prescribed, and kinda [hinted] around that that was why the baby was losing weight, but she never came out directly and said that (Sally, 30-year-old).

Another mother stated that her social worker suggested she stop breastfeeding without providing a rationale: "Yeah, my social worker wanted me to stop breastfeeding altogether, but I told her no, I couldn't do that" (Hannah, 26-year-old). Yet another woman reported the staff being judgmental about her behavior when a medication error caused adverse side effects:

> … So, I had to kick out like, literally, every damn nurse because, just of how they were treating me. But then they called social services on us because I was falling asleep, while I was breastfeeding and because he was extra fussy. Once, my husband had been telling 'em 'give him a paci, give him a paci, give him a paci', they wouldn't, well I mean they did finally, and he was cool. But they took their time, just like they took their time with the epidural and everything else. So, I vaguely remember CPS being in there (Kathryn, 31-year-old).

One woman remarked how a comment by a physician made her decide to give up breastfeeding. Her newborn was losing weight and rather than considering a mutually beneficial solution, the physician gave her this ultimatum:

> … the doctor at that time told me I had one of two choices. Either I can continue to try to breastfeed and I go home and he [the newborn] stays at the hospital *OR* I switch to formula and he can start gaining weight and get healthy and then we can both go home. So, I wound up giving up breastfeeding right then and there and switched over to formula (Marie, 28-year-old).

This participant described another incident of stigma related to her breastfeeding. Staff at one WIC office was perceived as judgmental during her request for a breast pump for use after delivery of a late-preterm infant:

> … the WIC office back home was telling me that I couldn't get a breast pump because I'd have to be going back to work full-time and it would have to be, ya know, 40 hours plus a week, ya know immediately pretty much. And I'm sitting here going, well I couldn't [go back to work] 'til after eight weeks anyway (Marie, 28-year-old).

Another participant perceived a lack of hospital staff willingness to assist her in learning to breastfeed her son, despite this being her first child:

> I felt like, almost in a way, that I was given. Like when it came time for that part [breastfeeding], they handed him over and it was like, 'Alright! Here you go!' (Tara, 31-year-old).

## Newborn Well-Being

The goal of Breastworks was newborn well-being, which involved monitoring the infant's condition and protecting the infant from negative influences. Monitoring the infant's condition was done through a collaborative effort between the mother, family, and health care providers. Protecting the infant from negative influences was also a collaborative effort, with the mother remaining in treatment and breastfeeding while the staff treated the infant for severe NAS and comorbidities, such as gastroschisis and lip or tongue-tie. An infant's medical condition was dependent on his or her tolerance of withdrawal from prenatal exposure. Other conditions may have contributed to NAS scoring, such as gastroschisis and lip or tongue tie, which can alter irritability due to pain or hunger but are required to be scored with the tool most often used (Bagley, Wachman, Holland, & Brogly, 2014).

**Monitoring.** Mothers are often very involved in their infant's NAS scoring as they can provide insight about their sleeping and eating patterns between assessment times. One participant shared her knowledge of the infant monitoring process with her statement, "You know they've got to monitor them at least three days and, ya know, there's certain things they look for…" (Marie, 28-year-old). While Tara did not share what questions the staff asked her about her son's NAS symptoms, she expressed knowledge of monitoring NAS infants:

> [The nurses said,] 'We don't have nurseries no more unless there's like some'n dramatic going on.' And a lot of times now they're using 'em for babies that are coming off of narcotics (Tara, 31-year-old).

Results from NAS monitoring influenced decisions about NAS treatment, which ultimately affected the mother's decision about breastfeeding her infant.

**Protection.** Protection encompasses the balance between emotional and physical needs of the infant. Bonding is an emotional need of infants, suggesting the need for maternal proximity and provision of care. However, the physical needs of the infant are dependent on the social and environmental factors involved regarding the dyad. Treatment of physical needs often centered around the severity of NAS symptoms observed. A few participants mentioned not giving their infants "morphine" and the use of resources, such as nipple shields or breast pumps, to prevent weight loss. The following exemplar describes treatment of infants and how breastfeeding can be integrated into the treatment regimen:

> … when I breastfed them it helped with their withdrawals or whatever … So, I mean, none of them had to be put on morphine or anything like that when they were born. … and I know that, like its common sense that they're gonna get some of it through the breastmilk so, it was just, I knew that would help him calm, you know what I am saying, it would help him calm-, and do the transition easier (Suzy, 36-year-old).

One woman shared resources that she had used to maintain low NAS scores and decrease the amount of weight loss expected for her infant:

> … we're using the [nipple] shield… and then the next thing is pumping. I've been pumping every time afterwards. … at least trying to get her to feed and then if she doesn't really feed from me, I'm pumping it so then I can put that in the bottle for her so that at least she's getting it that way, if not from me (Marie, 28-year-old).

Protection included breastfeeding, which successfully mitigated NAS, to promote the health of the infant. Protection of the infant was the mother's overall goal.

## Discussion

This Grounded Theory study achieved the aims of exploring maternal perceptions of breastfeeding and how stigma influenced breastfeeding with a high-risk group of women in a state that is at the epicenter of the opioid crisis. The findings provide unique theoretical concepts that may be incorporated into the care of women with OUD to support breastfeeding decision-making and infant well-being. This study provided the perspectives of a small sample of White women in a single geographic location, whose perspectives are critical to understanding breastfeeding decision-making in an addiction trajectory. This homogenous sample may be due to African Americans experiencing more stigma and having less trust in the research community from historical events.

This study supports findings of existing literature, though current research is minimal and atheoretical on this topic. Additionally, this study confirms that women with OUD may perceive stigma about breastfeeding from healthcare providers that may not be as sensitive, as well as friends and family members with good intentions, as suggested by Demirci et al. (2015). Furthermore, this study supports the findings of McGlothen, Cleveland, and Gill (2018) regarding mothers with OUD desire to do what is best to protect their infants. This study further conceptualizes a theoretical framework in the Breastfeeding Decision-Making in an Addiction Trajectory Model.

Most women started their addiction trajectories trying to manage pain, then progressed to street drugs to avoid being dopesick when they no longer had access to pain pills. Dopesick is characterized by several symptoms, but these participants described profuse sweating, nausea, vomiting, and severe pain. Previous partners often contributed to women's relapse, while current support persons contributed to their recovery. Some of the women shared that their previous

partners pressured them into using pain pills illicitly and had them easily accessible, as in the case of one couple with a “pharmacy in the house”. Remaining in such environments promotes relapse and prevents recovery. Most women explained that they had to remove themselves from such partners to be successful in recovery.

Addiction coupled with stigma made women reluctant to breastfeed. However, through various forms of knowing and learning, these women came to the realization that breastfeeding was the healthiest choice for their infants’ well-being. Women with OUD who had a greater knowledge of breastfeeding benefits for opioid-exposed infants were able to critically consider their infants’ potential outcomes and their role in protecting the infant, thus empowering them to confidently defend their decisions. Those who lacked such knowledge and confidence to defend their decision, were disempowered by insensitive comments from healthcare providers and good intentions from family and friends that were negatively perceived. The interaction of the woman’s knowledge, good intentions from family and friends, and experience of healthcare provider sensitivity all influenced the level of Breastworks evident in their situations. Women with greater Breastworks, or breastfeeding empowerment, continued breastfeeding despite perceptions of stigma. Continued breastfeeding contributed to the fulfillment of emotional and physical needs of infants, improved their NAS scores, and promoted bonding of the maternal-infant dyad. Thus, Breastworks is the fortress that protects Newborn Well-Being.

This study offers several implications for research and practice. First, to advance the science we should consider the development of a mobile application to reach the highest-risk women and support persons about the benefits of breastfeeding for women with OUD at varying times throughout their addiction trajectory. There should be no uncertainty about the benefits of breastfeeding. Breastfeeding mitigates NAS. Several participants acknowledged that they made

their decision to breastfeed at the last minute. Some said that they were not aware of the benefits of breastfeeding until they were delivering their infants. A few were not ready to hear the benefits when they were initially provided to them but later listened to staff and made their decision. Others initially had no intention of breastfeeding until the infant was delivered. One support person indicated that provision of breastfeeding education through smartphones and/or the internet would be a valuable resource. Mobile applications have been effectively used to provide information, at the individual's convenience, for several other high-risk populations, such as those with alcoholism or suicidal tendencies (Han & Lee, 2018). Second, women who have been successful in recovery could become community health workers or lay health advisors in the community, functioning as a liaison between women with OUD and traditional healthcare providers, thus fostering trust. The implementation of community health workers has been studied and found to decrease healthcare provider distrust and fear of stigma in people who inject drugs (Morgan, Lee, & Sebar, 2015). Community health workers may be the missing link to successful care of women with OUD, especially for those who are pregnant or postpartum. Hodgins, Lang, Malseptic, Melby, and Connolly (2019) discuss a program implementation for integrated care of women with OUD that includes community health workers whose primary role is to build relationships with the women and enroll them in needed services available through the program. Third, a practice implication is to assure current breastfeeding guidelines are part of healthcare policies and procedures through continuing education methods. Most healthcare providers are aware of the risks and benefits of breastfeeding with OUD, but there is still an opportunity to ensure all staff have been exposed to the most current guidelines through annual education modules and/or station check-offs. Lastly, extending this research to diverse populations and geographic locations would broaden the scope of the current theoretical model.

Knowledge gained from a more urban area and with diverse populations would provide unique information to support or suggest revision of Breastfeeding Decision-Making in an Addiction Trajectory.

## Conclusion

This study builds understanding of the Recovery-Relapse Cycle, breastfeeding decision empowerment (Breastworks), and Newborn Well-Being. This study also confirms that responsible prescribing for symptom management that includes SUD screening and opioid risk assessment may help prevent women from entering the recovery-relapse cycle. Continual empowerment is necessary to offset family instability, risk-prone neighborhoods, medication access issues, misperceived good intentions, and lac of healthcare provider sensitivity that women with OUD frequently perceive as stigma. The Breastfeeding Decision-Making in an Addiction Trajectory model can be used beginning with preconception and continuing throughout prenatal care into postpartum to address the various factors that may contribute to perceived stigma among women with OUD and influence newborn well-being.

# CHAPTER 5: "ALWAYS THERE": SUPPORTING BREASTFEEDING AMONG WOMEN WITH OPIOID USE DISORDER


## Abstract

**Objective:** To explore perceptions of support persons of women with opioid use disorder (OUD) that influence the women's breastfeeding decision-making.

**Methods:** A grounded theory study was conducted with women in treatment for OUD who breastfed their child in the last three years, and their support persons. Women were recruited from a drug rehabilitation therapy agency, a high-risk obstetrical office, and a major medical center serving this population. Support persons were identified by the women for participation in separate in-depth interviews. Memos and field notes were documented. Data were coded in three iterative and progressive phases: initial, focused, and theoretical, for the creation of a preliminary theoretical model called Breastfeeding Decision-Making in an Addiction Trajectory.

**Results:** Data from five women and six support persons was analyzed using a dyad profile. One support person in a dyad participated without the index woman because of legal custody involvement that occurred during the study period. Findings indicated that support persons for women with OUD experienced uncertainty about breastfeeding related to potential maternal relapse and infant outcomes. Despite uncertainty, support persons offered physical and emotional breastfeeding support.

**Conclusions:** Findings contributed to development of unique theoretical concepts within the Breastfeeding Decision-Making in an Addiction Trajectory Model. Support person uncertainty can be perceived as stigma by women with OUD which inadvertently disempowers the women regarding breastfeeding and jeopardizes newborn well-being.

## Background

There is a disparity in breastfeeding among women with opioid use disorder (OUD) that affects infant health outcomes (Schiff et al., 2018). Infants exposed to opioids in utero may experience severe gastrointestinal, nervous system, and respiratory symptoms, known as neonatal abstinence syndrome (NAS), that can be fatal if not properly managed (Kocherlakota, 2014; McGlothen, Cleveland, & Gill, 2018). Breastfeeding has been identified as a method of alleviating NAS, potentially preventing the need for pharmacological treatment (Schiff et al., 2018). Breastmilk protects the gastrointestinal tract in newborns and the skin-to skin contact that occurs during breastfeeding helps stabilize neurological symptoms of NAS (Klaman et al., 2017). Furthermore, women with OUD who breastfeed learn their infant's stress cues and build their confidence in caring for their infants quicker than their non-breastfeeding counterparts (Kocherlakota, 2014). Yet in 2016 only 56% of women with OUD initiated breastfeeding, compared to 81.1% of women among the general population (Centers for Disease Control and Prevention, [CDC], 2016; Schiff et al., 2018).

There are many speculations as to why women with OUD do not breastfeed. Several investigators have found that women with OUD have fewer social supports and thus, less breastfeeding support (Demirci, Bogen, & Klionsky, 2015; Stone, 2015). Yet, the general literature on breastfeeding suggests that maternal breastfeeding support by family and friends is necessary for successful breastfeeding (Busch, Logan, & Wilkinson, 2014). Breastfeeding among women with OUD is critical to the health outcomes of infants, and adequate support from their family and friends is necessary to breastfeeding success (Welle-Strand et al., 2013). Therefore, the purpose of this study was to explore perceptions of breastfeeding among support persons that influence women's breastfeeding decision-making.

## Methods

A grounded theory study was conducted using in-depth interviews with women in treatment for OUD and their identified support persons. This study is based on a phenomenon not previously described: how perceived stigma influenced breastfeeding decisions among women with OUD (Charmaz, 2006). Data were coded in three progressive, yet iterative phases: initial, focused, and theoretical coding, as described by Charmaz (2006). Participants' voices were foregrounded through the initial coding phase and were the basis for focused and theoretical coding. The themes, categories, and subcategories were then organized into a theoretical framework referred to as Breastfeeding Decision-Making in an Addiction Trajectory (Appendix H). Data collected from support persons informed the study, and this data is reported in this paper. Agency and university IRB approvals were obtained (Appendix A).

### Setting and Sample

The GT study took place in eastern North Carolina (eNC). Women were recruited from three separate sites: two locations within an outpatient drug rehabilitation therapy (DRT) agency, a high-risk obstetrical office, and a major medical center. During recruitment efforts, the principal investigator (KC) clarified that breastfeeding included any amount of breastfeeding. Support persons were identified by the women being treated for OUD and were invited to participate in the study.

Eligibility criteria for participants in the parent study were that the women spoke English, were between 18 and 54 years of age, were enrolled in a DRT agency in eNC for OUD, and breastfed their child within the last three years. Women were asked to identify a support person that could also be interviewed. The only support person inclusion criteria were identification by the woman as supportive of their breastfeeding.

## Data Collection

Women were recruited face-to-face using flyers (Appendices I & J), whereas support persons were invited by the recruited women. Support persons contacted the principal investigator to schedule an interview. A waiver of signed informed consent (Appendix B) was acquired to protect the women with OUD because a consent form would be "the only record linking the subject and the research … [meaning] the principal risk would be potential harm resulting from a breach of confidentiality" (Electronic Code of Federal Records, 2018, §46.117, section 2i). In contrast, support persons were required to sign an informed consent to participate (Appendix C). Prior to interviews, a demographic profile was obtained from all participants (Appendices E & G). The in-depth semi-structured interviews were conducted at a location of the participant's choice. Interview questions included their personal thoughts of breastfeeding with OUD, perceptions of experiences with breastfeeding, and perceptions of assistance with breastfeeding (Appendices D & F). The interviews were audio-recorded for transcription and accuracy verification.

## Data Management and Analysis

Pseudonyms were assigned to participants during transcription for participant protection. Transcripts and audio files were saved on a password protected and encrypted university hard drive. Audio recordings were deleted after the first author read transcripts a second time. The second author (KLL) verified transcription accuracy. Field notes were written immediately after each interview.

Coding of support person data followed the same process as coding of data from the index women. Data were initially coded line-by-line, then grouped into more abstract categories before being theoretically coded for relationships with the women's data. This allowed support

person data to inform the developed theory of Breastfeeding Decision-Making in an Addiction Trajectory Model that was identified in chapter four (Appendix H). This theory posits that symptom management and social and environmental risk factors contribute to one of two pathways into addiction, pain-prescription or street drug, before entering a recovery-relapse cycle. This cycle then influences a woman's ability to defend her breastfeeding decision based on her knowledge and perceptions of stigma from others through good intentions and healthcare provider sensitivity, thereby influencing newborn well-being. Support persons provided valuable information about perceptions of breastfeeding among women with OUD and the support that women received, which prompted further probe questions with each additional interview. Dyad profiles were developed and reviewed for similarities and relationships, which contributed to the development of the subtheme Breastworks (Appendix H).

## Results

Five out of a total of ten women with OUD and their six support persons were included in the analysis (Table 4). One support person was interviewed prior to the dyad participant's scheduled interview, which subsequently did not occur because of a child custody issue that occurred during the study period. Both White and African American women were invited to participate. However, no African American women participated because either their children were older than three, they did not breastfeed, or they declined to participate in the research. Ten to fifteen minutes was spent in general conversation about the health of the infants to build rapport prior to interviews. There were a total of 11 interviews, five with women who had support person participation and six with the support persons, totaling more than 3 hours, 94 pages of double-spaced transcripts, 11 pages of field notes, and 21 pages of memos.

Table 4.

*Demographic Characteristics of Women with OUD and Their Support Persons (N = 11)*

| | Characteristic | Mean | Range | n (%) |
|---|---|---|---|---|
| Women with OUD | Age (years) | 29.4 | 26-34 | 5 (100) |
| | Race/Ethnicity | | | |
| | Caucasian | | | 5 (100) |
| | Education Level | | | |
| | Some HS | | | 1 (20) |
| | HS/GED | | | 1 (20) |
| | Some College | | | 3 (60) |
| | Occupational Status | | | 3 (60) |
| | Unemployed | | | 2 (40) |
| | Full-Time | | | |
| | Pregnancies | | | |
| | 1 | | | 1 (20) |
| | 2 | | | 2 (40) |
| | 6 | | | 2 (40) |
| Support Persons | Age (years) | 38.7 | 29-57 | 6 (100) |
| | Race/Ethnicity | | | |
| | Caucasian | | | 6 (100) |
| | Education Level | | | |
| | Some College | | | 6 (100) |
| | Occupational Status | | | 2 (33) |
| | Unemployed | | | 4 (67) |
| | Full-Time | | | |

Support person uncertainty informed all three categories of the subtheme Breastworks (Appendix H) but focused mainly on Good Intentions. Breastworks came from a search of military terms after a discussion with a colleague for a pilot study (Cook & Larson, 2019). The military definition of Breastworks was a chest-height man-made wall used for protection of soldiers against enemy fire. In both the pilot and this study, Breastworks depicts the unrelenting fight these women face daily in defense of their decision to breastfeed, which in turn protects their infants. There was a recognized uncertainty among support persons about whether breastfeeding with OUD was a good decision, with four out of six support persons expressing uncertainty (Table 5). Yet, participants described their knowledge of the risks and benefits of breastfeeding from experiences with previous children, conversations with healthcare providers, and finding information for themselves on the internet. Uncertainty from support persons contributed to the uncertainty of the women through support persons' good intentions. Three of the five women expressed uncertainty related to conversations held with support persons, family, and friends. Uncertainty was related to potential relapse risk and effects on infant health. One support person voiced uncertainty about breastfeeding with OUD, but believed that it is the best alternative for their situation:

> … it's hard to say. I know I've worried about it some too, wondering if it was good for her or bad for her. I feel like that, when she [baby] was, ya know, still inside of her, she was kinda getting the same things as the breastmilk's gone give her, ya know. So, I'm trying to-, I feel like it's the best thing for us to do (Adam, 29-year-old, Hannah's fiance).

From prior discussion with her fiancé, one woman said, "I mean, I feel like it's a good thing. I don't know. I don't know. I mean I hate it, 'cause I'm on this medicine. But…" (Hannah, 26-year-old).

This is only one example of uncertainty expressed by a dyad. One woman perceived breastfeeding with OUD positively and felt strongly about it, though her support person (husband) was uncertain:

> I was really wanting to do the breastfeeding this time, so I've done a lot of research and done a lot of things I needed to do in order, so that we could still do this (Marie, 28-year-old).

One support person felt that breastfeeding with OUD was beneficial. She stated, "Uh, if they are clean I think it's great because I think breastfeeding is the best thing for a child." (Gerry, the 57-year-old mother of a woman who could not participate in an interview due to a child custody issue). One other support person echoed this positive outlook on breastfeeding among women with OUD.

In contrast, one index woman explained that breastfeeding with OUD was detrimental to infant health, regardless of being in treatment or using street drugs:

> Oh no, no, no! There's no, there's no difference. Not when it comes to when you're breastfeeding. It doesn't make it any different that you're in treatment for it. It's still there. … Like, if you're meaning, like, you're saying, okay. You got two people using, but since this one's getting help and going to treatment for it, it's okay for her to breastfeed. … No. … I don't. Because the drugs, it's still there. … You can't take the drug out (Tara, 31-year-old).

Table 5.
*Women with OUD- Support Person Dyad Description (N = 11)*

| Dyad | Relationship | Estimated Time Together (years) | Perception of Breastfeeding with OUD | |
|---|---|---|---|---|
| | | | IP | SP |
| Hannah & Adam | Fiancé | 3 | U | U |
| Marie & Linwood | Spouse | 10 | P | U |
| Christina & Gabe | Spouse | 16 | U | P |
| Tara & Lincoln | Fiancé | 3 | N | U |
| Ashton & Carson | Spouse | 2 | U | U |
| Gerry | Mother | 30 | - | P |

Footnotes: Pseudonyms used. IP: Index Participant/Women, SP: Support Person, U: Uncertain, P: Positive Perception, N: Negative Perception

Most dyads ultimately agreed that breastfeeding with OUD in treatment was better than breastfeeding while using street drugs based on education they had received, either independently or from healthcare providers. One woman stated, "Just talking with the doctors and staff…. [they told me] that it's more healthy for the baby. … [buprenorphine will] be in my breastmilk" (Christina, 34-year-old). Christina's husband Gabe talked about his trust in the breastfeeding information that doctors had given them, making him comfortable with the decision to breastfeed. Another woman explained that she searched the internet to find answers:

> … from the research I had done, it seemed like there were benefits, umm, benefits of still breastfeeding, ya know. And also, the fact that according to what kind of medication you're on, umm, some of it can be passed through the breast milk, but not enough for it to have an effect on the baby. So, still the benefits of breastfeeding would outweigh the formula (Ashton, 28-year-old).

Ashton's husband, Carson, discussed his comfort with their daughter being breastfed in retrospect because he can now look back and see that it helped protect the infant.

Even though most participants were uncertain of the benefits, the support persons maintained their support of the women in their decisions. Support persons expressed their support of women through both physical and emotional ways. For example, one support person spoke of physically supporting his wife in pumping for their newborn that remained in the hospital, "Well, I try to help her … just change the bottles out, whatever kind of help [she needs], kind of [a] running person that 'go get' what [she] needs" (Gabe, Christina's husband, 37-year-old). Another support person explained his emotional support for his fiancé, who had previously endured physical and emotional abuse from her ex-husband, during her breastfeeding:

> And she tried, ya know. And then when he was kind of rejecting, ya know, or whatever, and I'm like, 'no, it's not you'. You know what I mean. 'This is a preemie baby, he don't know' (Lincoln, Tara's fiancé, 38-year-old).

Support persons felt that they were as supportive as they could possibly be at the time, but some offered potential improvements in their support in retrospect. One support person stated, "I mean the only [way I could be more supportive] maybe would be try to be more informed the last time, but ya know, normally you typically tend to listen to doctors" (Linwood, Marie's husband, 35-year-old). Two participants felt they needed to be at home to help more but had to be at work to make ends meet. This was best described when one support person that stayed home from his small business for a month stated, "Umm, the only time that I can remember maybe possibly being more helpful was if I could've afforded uh to stay away from work longer" (Carson, Ashton's husband, 36-year-old).

No matter the amount of uncertainty, one participant summed up the overall stance of support persons when he stated, "Uh, just back their play. … Don't never give them a reason to doubt. Ya know what I mean. Support their decision and it shows you support their decision" (Lincoln, Tara's fiancé, 38-year-old).

## Discussion

This analysis of dyad data from a Grounded Theory study of women in treatment for OUD aimed to explore how perceptions of support persons influence women's decisions to breastfeed. This was an educated sample that trusted health care providers and received critically important information that they valued. The findings may provide foundational knowledge for healthcare professionals working with women with OUD and their support persons, serving as a step toward identifying new methods of breastfeeding promotion in this population. This study provided the perspectives of a small sample of White women and their support persons in a single geographic location, whose perspectives are critical to understanding breastfeeding decision-making in an addiction trajectory. This homogenous sample is likely due to African Americans experiencing more stigma and having less trust in the research community secondary to historical events.

While literature suggests that social support networks are minimal for women with OUD, all of the women from this study had a support person to participate (Demirci et al., 2015). A person that expressed uncertainty might be considered unsupportive, yet these individuals were perceived as being highly supportive of breastfeeding by the women participating. When looking at the Breastfeeding Decision-Making in an Addiction Trajectory Model (Appendix H), support person uncertainty is expressed through Good Intentions, while medical staff uncertainty is expressed through a lack of Health Care Provider Sensitivity within Breastworks. Uncertainty is

often perceived by women as stigma, or societal judgement against breastfeeding, which can undermine the effects of Breastworks.

There are research and practice implications from this study. First, development of a mobile application for breastfeeding education to reach women with OUD and their support persons, that can be accessed on demand, with critical benefits. One support person suggested that mobile applications are the best way to reach anyone in today's technologically inclined society. Additionally, numerous mobile applications have been developed and effectively implemented among other high-risk populations, such as those with alcoholism or suicidal tendencies (Han & Lee, 2018). Second, women with OUD who are successful in their recovery could function as community health workers, liaisons between the women, their support persons, and traditional healthcare professionals. The community health worker's primary role would be to enroll women in services available and suggest evidence-based resources for the women to make educated decisions independently (Hodgins, Lang, Malseptic, Melby, & Connolly, 2019; Morgan, Lee, and Sebar, 2015). Lastly, extending this research to diverse populations and geographic locations would broaden the scope of the current theoretical model. Knowledge gained from a more urban area and with diverse populations would provide additional information to support or suggest revision of Breastfeeding Decision-Making in an Addiction Trajectory.

## Conclusion

These findings contribute to the unique theoretical concepts of Breastfeeding Decision-Making in an Addiction Trajectory model. Support persons described uncertainty that may enter the model as Good Intentions, which can be perceived as stigma by women with OUD. Such perceptions place women with OUD at risk of ineffective Breastworks, a form of empowerment,

thereby negatively impacting newborn well-being. Breastworks could be strengthened through use of a mobile application and implementation of community health workers that provide evidence-based information to women with OUD and their support persons.

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# APPENDIX A: IRB APPROVAL LETTER



**EAST CAROLINA UNIVERSITY**
**University & Medical Center Institutional Review Board**
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
www.ecu.edu/ORIC/irb

## Notification of Initial Approval: Expedited

From: Biomedical IRB
To: Kristy Cook
CC: Kim Larson
Date: 10/1/2018
Re: UMCIRB 18-001677
Stigma of Breastfeeding in Substance Use Disorder

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 10/1/2018 to 9/30/2019. The research study is eligible for review under expedited categories #6 and #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

| Name | Description |
|---|---|
| Demographic Profile for Support Persons of Women with SUD_07261018.docx | Data Collection Sheet |
| Demographic Profile for Women with SUD_07261018.docx | Data Collection Sheet |
| Flyer for Support Persons | Recruitment Documents/Scripts |
| Flyer for Women with SUD | Recruitment Documents/Scripts |
| Index Participant Consent Form (Waiver of Signed Informed Consent) | Consent Forms |
| Index Participant Demographic Profile | Interview/Focus Group Scripts/Questions |
| Index Participant Interview Guide | Interview/Focus Group Scripts/Questions |
| Index Participant Interview Guide | Data Collection Sheet |
| Research Protocol | Study Protocol or Grant Application |
| Support Person Demographic Profile | Interview/Focus Group Scripts/Questions |
| Support Person Interview Guide | Interview/Focus Group Scripts/Questions |

| Name | Description |
| --- | --- |
| Support Person Interview Guide | Data Collection Sheet |
| Support Person Signed Informed Consent Form | Consent Forms |

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

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IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: INFORMED CONSENT FOR WOMEN

# Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Understanding Stigma of Breastfeeding Among Women with Substance Use Disorder

Principal Investigator: Kristy Cook, Principal Investigator (Person in Charge of this Study)
Institution, Department or Division: East Carolina University, College of Nursing
Address: Health Sciences Building, East Carolina University
Telephone #: 252-717-3629

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Researchers at East Carolina University (ECU), PORT Human Services, and Vidant Medical Center study issues related to society and health problems. To do this, we need the help of volunteers who are willing to take part in research.

**Why am I being invited to take part in this research?**

The purpose of this research is to understand how stigma influences breastfeeding decisions among women with substance use disorder (SUD). You are being invited to take part in this research because you are a woman between 18 and 54 years old, enrolled in a treatment program, and have recent breastfeeding experience within the last three years. The decision to take part in this research is yours to make. By doing this research, I hope to learn how you perceive stigma related to breastfeeding, how stigma influenced your breastfeeding decisions, how a support person that you identify perceives stigma related to breastfeeding, and how local and national guidelines contribute to your breastfeeding decisions.

If you volunteer to take part in this research, you will be one of about 30 people to do so.

**Are there reasons I should not take part in this research?**

I understand I should not volunteer for this study if:

- I am under 18 years of age or over 54 years of age
- I do not speak English
- I am not enrolled in a drug treatment program
- I do not have a child that I have tried to breastfeed in the last three years
- I cannot sit for at least one hour

## What other choices do I have if I do not take part in this research?

You can choose not to participate.

## Where is the research going to take place and how long will it last?

The research will be conducted at a private location that we agree on, which may include an office in the location you agree to participate from, your home, or another location. You will need to come to the identified location 1-2 times during the study. The maximum amount of time you will be asked to

volunteer for this study is 4 hours over the next year (2 hours maximum per interview, if second interview is needed).

**What will I be asked to do?**
You will be asked to do the following:

- Answer questions about your experience with breastfeeding your child and what influenced your decisions about breastfeeding
- Identify a support person and either get permission for me to contact them or take them a flyer inviting them to contact me to participate
- Allow me to audio-record our conversation so that I can transcribe (type) it, have one of my research mentors review it, and then immediately delete the recording

**What might I experience if I take part in the research?**
I don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. I don't know if you will benefit from taking part in this study. There may not be any personal benefit to you, but the information gained by doing this research may help others in the future.

**Will I be paid for taking part in this research?**
I will be able to pay you for the time you volunteer while being in this study. A $20 gift card will be provided for each interview completed. Since the total of the gift cards will be less than $600 you will not receive an IRS 1099 form.

**Will it cost me to take part in this research?**
It will not cost you any money to be part of the research.

**Who will know that I took part in this research and learn personal information about me?**

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.
- People designated by Vidant Medical Center and Vidant Health, East Carolina University Women's Physicians, and PORT Human Services
- If you are a patient at ECU or Vidant, a copy of this form will be placed in your medical records.

**How will you keep the information you collect about me secure? How long will you keep it?**

- Your name and contact information will be kept on an encrypted research drive through East Carolina University. This file will be kept separate from other study data and will be deleted at the end of the study duration.
- Audio-recordings of the interviews will also be kept on an encrypted research drive through East Carolina University. These files will be deleted immediately after they are transcribed and verified by a research mentor.

- Electronic copies of the transcripts will be kept on an encrypted research drive through East Carolina University and hard copies will be filed in a locked cabinet of a locked office within ECU College of Nursing. All of these files de-identified files may be used for presentations on the study but will be deleted and destroyed after at least three years.

## What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

## Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 252-717-3629 (days, between 9 am and 9 pm).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). You may also call the Vidant Health Center for Research and Grants at 252-847-1177. If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971 and the Vidant Health Risk Management Office at 252-413-4473.

## Is there anything else I should know?

Most people outside the research team will not see your name or your research record. However, one exception is information about child abuse or neglect and harm to yourself or others.

## I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should verbally express agreement:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By verbally agreeing to this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

**Person Obtaining Informed Consent**: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has verbally agreed with the above and answered all of the person's questions about the research.

| **Person Obtaining Consent (PRINT)** | **Signature** | **Date** |
|---|---|---|

APPENDIX C: INFORMED CONSENT FOR SUPPORT PERSONS

# Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Understanding Stigma of Breastfeeding Among Women with Substance Use Disorder

Principal Investigator: Kristy Cook, Principal Investigator (Person in Charge of this Study)
Institution, Department or Division: East Carolina University, College of Nursing
Address: Health Sciences Building, East Carolina University
Telephone #: 252-717-3629

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Researchers at East Carolina University (ECU), PORT Human Services, and Vidant Medical Center study issues related to society and health problems. To do this, we need the help of volunteers who are willing to take part in research.

## Why am I being invited to take part in this research?

The purpose of this research is to understand how stigma influences breastfeeding decisions among women with substance use disorder (SUD). You are being invited to take part in this research because you have been identified, by a previous participant, as someone that is supportive of that person. The decision to take part in this research is yours to make. By doing this research, I hope to learn how women with SUD perceive stigma related to breastfeeding, how stigma influences breastfeeding decisions among women with SUD, how you perceive stigma related to breastfeeding, and how local and national guidelines contribute to such breastfeeding decisions.

If you volunteer to take part in this research, you will be one of about 30 people to do so.

## Are there reasons I should not take part in this research?

I understand I should not volunteer for this study if:

- I am not a support person of a woman with SUD
- I do not speak English
- I cannot sit for at least one hour

## What other choices do I have if I do not take part in this research?

You can choose not to participate.

## Where is the research going to take place and how long will it last?

The research will be conducted at a private location that we agree on, which may include an office, your home, or another location. You will need to come to the identified location 1-2 times during the study. The maximum amount of time you will be asked to volunteer for this study is 4 hours over the next year (2 hours maximum per interview, if a second interview is needed).

**What will I be asked to do?**
You will be asked to do the following:

- Answer questions about your perceptions of stigma related to breastfeeding among women with SUD
- Allow me to audio-record our conversation so that I can transcribe (type) it, have one of my research mentors review it, and then immediately delete the recording

**What might I experience if I take part in the research?**
I don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. I don't know if you will benefit from taking part in this study. There may not be any personal benefit to you, but the information gained by doing this research may help others in the future.

**Will I be paid for taking part in this research?**
I will be able to pay you for the time you volunteer while being in this study. A $20 gift card will be provided for each interview completed. Since the total of the gift cards will be less than $600 you will not receive an IRS 1099 form.

**Will it cost me to take part in this research?**
It will not cost you any money to be part of the research.

**Who will know that I took part in this research and learn personal information about me?**
ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

**How will you keep the information you collect about me secure? How long will you keep it?**

- Your name and contact information will be kept on an encrypted research drive through East Carolina University. This file will be kept separate from other study data and will be deleted at the end of the study duration.
- Audio-recordings of the interviews will also be kept on an encrypted research drive through East Carolina University. These files will be deleted immediately after they are transcribed and verified by a research mentor.
- Electronic copies of the transcripts will be kept on an encrypted research drive through East Carolina University and hard copies will be filed in a locked cabinet of a locked office within ECU College of Nursing. All of these files de-identified files may be used for presentations on the study but will be deleted and destroyed after at least three years.

### What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

### Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 252-717-3629 (days, between 9 am and 9 pm).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971.

### Is there anything else I should know?

Most people outside the research team will not see your name or your research record. However, one exception is information about child abuse or neglect and harm to yourself or others.

### I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

_____ _____

**Participant's Name (PRINT)** **Signature** **Date**

**Person Obtaining Informed Consent**: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has verbally agreed with the above and answered all of the person's questions about the research.

_____

**Person Obtaining Consent (PRINT)** **Signature** **Date**

APPENDIX D: SEMI-STRUCTURED INTERVIEW GUIDE FOR WOMEN

***After verbal informed consent is obtained.***

1. Tell me a little about your family.
    a. Probes: How many children do you have? How old are they?
2. Please tell me about your experience breastfeeding your child(ren).
3. How did you decide to breastfeed?
    a. Probe: Was there something or someone that influenced your decision?
    b. [If not breastfeeding any longer] Please describe the events that led up to your decision to stop breastfeeding?
4. What do you think about breastfeeding with opioid use disorder?
5. Could you describe resources that were available to you that helped you with breastfeeding?
    a. Probes: Lactation Consultants? Educational sessions? Where? When? Self-education through brochures/pamphlets/internet?
6. Could you describe anyone in particular that assisted you to breastfeed?
    a. Please give me an example of a good experience you had with someone.
        i. Probes: Who, What, When, Where?
7. Could you describe someone/something that made it more difficult to breastfeed?
    a. Please give me an example of a bad experience you had with someone.
        i. Probes: Who, What, When, Where?
8. In the hospital setting, were there any rules or procedures discussed about breastfeeding?

    a. Probes: [If infant was separated from mother for procedures, etc.] How long was your baby away from you for [procedure identified]? How did the absence of your infant influence your decisions regarding breastfeeding? Or did it at all?

9. Is there anything that has not been discussed about breastfeeding that you would like to add?

# APPENDIX E: DEMOGRAPHIC FORM FOR WOMEN

Participant #: _____ Pseudonym: _____

Age: _____

Race/Ethnicity: _____

Highest Grade Level Completed: _____

Further Education: _____

Marital Status: _____

Number of Pregnancies: _____

Occupation: _____

Length of time at current job: _____

# APPENDIX F: INTERVIEW GUIDE FOR SUPPORT PERSONS

***Begin after signed informed consent is obtained.***

1. How do you know the person that referred you for this study?
2. What do you think about breastfeeding among women with opioid use disorder?
3. In what ways do you feel that women with OUD are assisted in their decision to breastfeed?
4. In what ways do you feel that women with OUD have difficulty in their decision to breastfeed?
5. Please give me an example of how you have been helpful of [name] when it came to breastfeeding.
6. Please give me an example of a time that you felt you could have been more helpful when it came to breastfeeding.
7. Can you tell me what you have seen about the assistance others have offered her for breastfeeding?
    a. Probes: Who, What, When, Where?
8. Is there anything else that has not been discussed about breastfeeding that you would like to add?

# APPENDIX G: DEMOGRAPHIC FORM FOR SUPPORT PERSONS

Participant #: _____ Pseudonym: _____

Age: _____

Race/Ethnicity: _____

Highest Grade Level Completed: _____

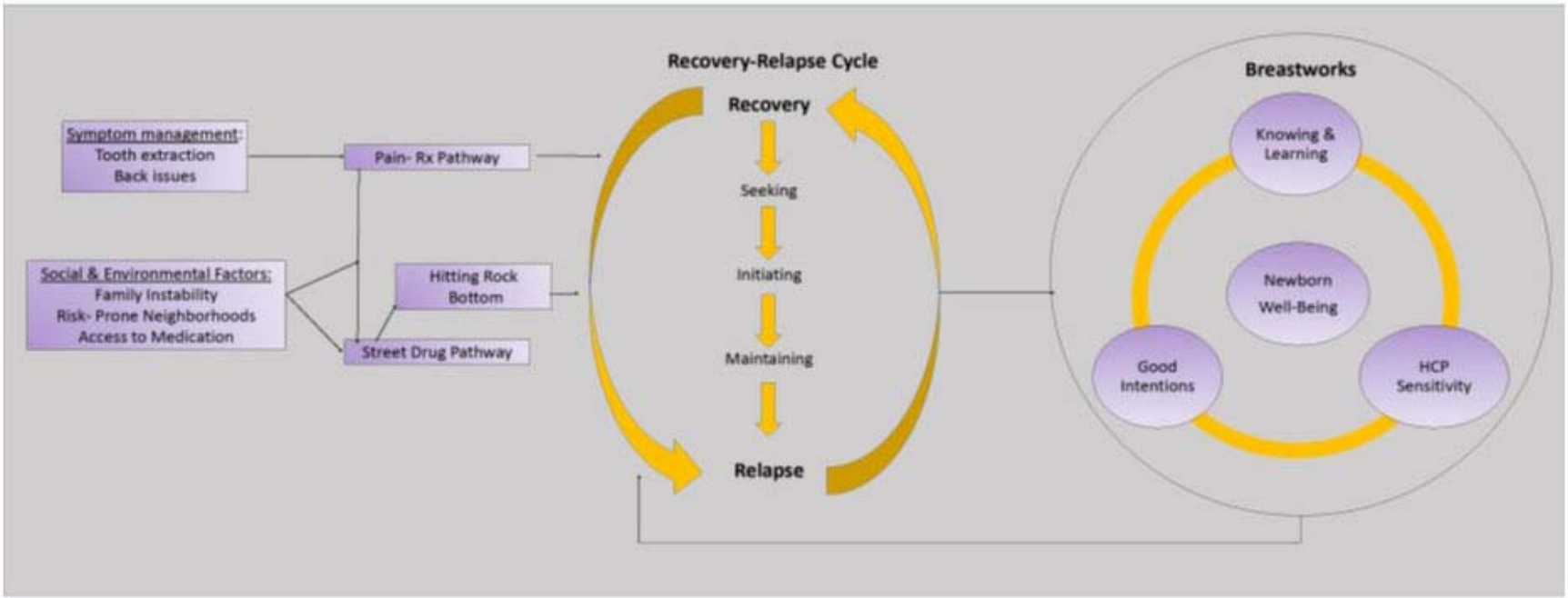
Further Education: _____

Marital Status: _____

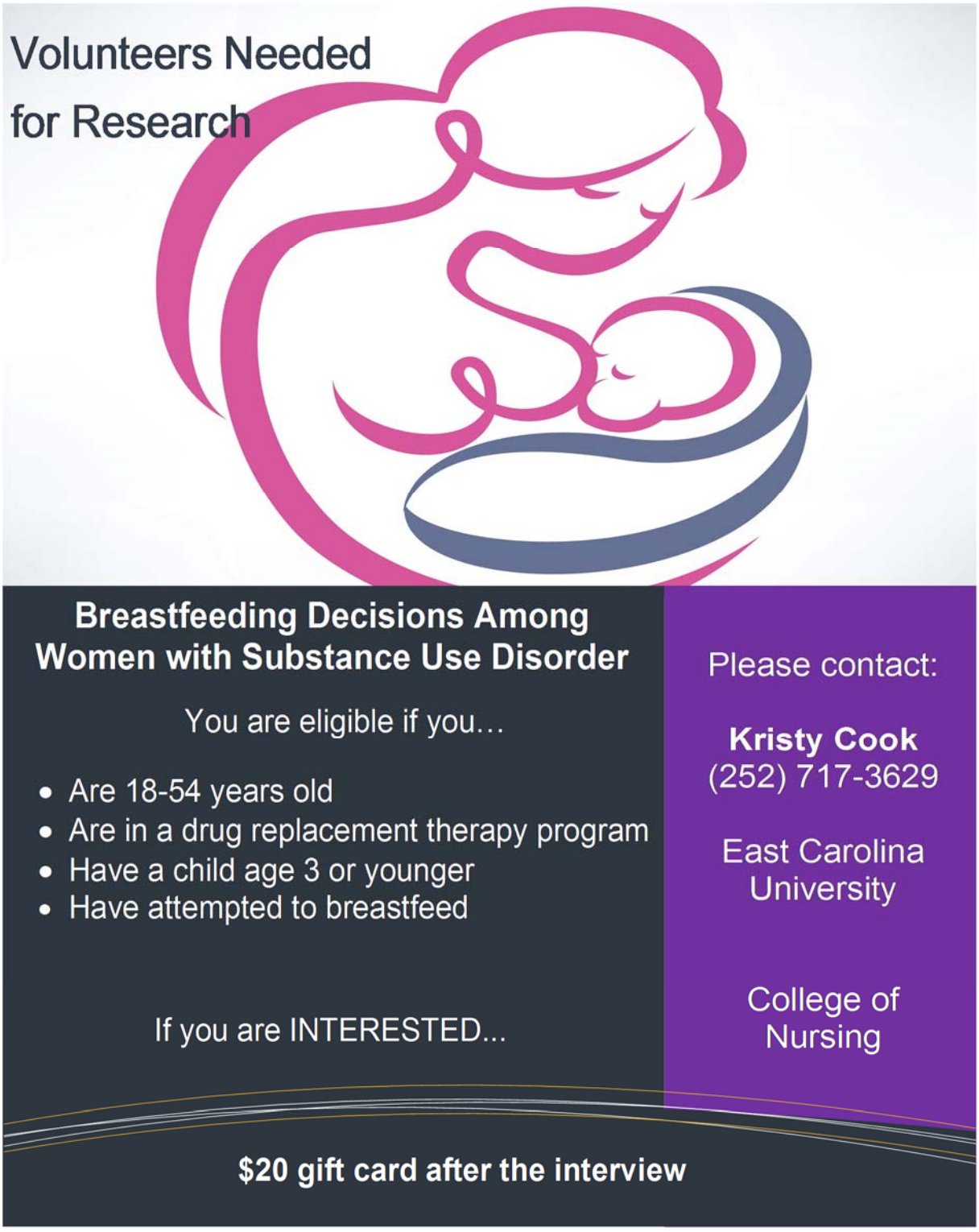
Occupation: _____

Length of time at current job: _____

APPENDIX H: BREASTFEEDING DECISION-MAKING IN AN ADDICTION TRAJECTORY



APPENDIX I: INVITATIONAL FLYER FOR WOMEN WITH OPIOID USE DISORDER



APPENDIX J: INVITATIONAL FLYER FOR SUPPORT PERSONS

# VOLUNTEERS NEEDED

for Research Interviews

## Breastfeeding Decisions Among Women with Substance Use Disorder

SOMEONE FEELS YOU HAVE BEEN SUPPORTIVE OF THEM!

IF INTERESTED PLEASE CONTACT:

**KRISTY COOK**
(252) 717-3629

EAST CAROLINA UNIVERSITY

COLLEGE OF NURSING

$20 gift cards provided after the interview