Experiences and Perceptions of Rural Postpartum Women With Substance Use Disorders Inclusive of Opioids Regarding Their Care

Debra Kramlich

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EXPERIENCES AND PERCEPTIONS OF RURAL POSTPARTUM WOMEN WITH
SUBSTANCE USE DISORDERS INCLUSIVE OF OPIOIDS REGARDING THEIR
CARE

A Dissertation
Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Debra L. Kramlich

August 2017
EXPERIENCES AND PERCEPTIONS OF RURAL POSTPARTUM WOMEN WITH SUBSTANCE USE DISORDERS INCLUSIVE OF OPIOIDS REGARDING THEIR CARE

By
Debra L. Kramlich

Approved May 9, 2017

Dr. Rebecca Kronk
Associate Professor of Nursing
Undergraduate Programs Chair
(Committee Chair)

Dr. Alison Colbert
Associate Professor of Nursing
Associate Dean for Academic Affairs
(Committee Member)

Dr. Karen Jakub
Assistant Professor of Nursing
(Committee Member)

Dr. Lenora Marcellus
Associate Professor of Nursing
(Committee Member)

Dr. Mary Ellen Glasgow
Dean, School of Nursing
Professor of Nursing
ABSTRACT

EXPERIENCES AND PERCEPTIONS OF RURAL POSTPARTUM WOMEN WITH SUBSTANCE USE DISORDERS INCLUSIVE OF OPIOIDS REGARDING THEIR CARE

By
Debra L. Kramlich

August 2017

Dissertation supervised by Rebecca Kronk, PhD, MSN, CRNP

Perinatal opioid use and neonatal withdrawal continue to rise rapidly in the face of the growing epidemic of opioid addiction in the United States, with rural areas more severely impacted. Despite several decades of research and development of practice guidelines, maternal and neonatal outcomes have not improved substantially. This focused ethnography aimed to address that gap by exploring rural women’s experiences and perceptions of care to inform development of efficacious, holistic models of care to improve outcomes for these women and their children. Participant observations, oral accounts and formal interviews, and artifact review (i.e., health records, any print and electronic resources provided to the women to support direct care, and media documentation of the sociopolitical environment influencing the women’s care) were used to seek answers to the following questions: a) What are the experiences and
perceptions of women with substance use disorder regarding the care they received during their pregnancy and through their infants’ hospitalization? and b) How have their experiences supported or inhibited their ability to bond with their baby?

Thirteen participants were recruited through perinatal outpatient practices and hospital social workers. Their personal accounts, reinforced by participant observation and artifact review, uncovered three domains with underlying themes: access (service availability, distance/geographic location, transportation, provider collaboration/coordination, physical and emotional safety), care of the baby (proximity, information), and relationships (respect, empathy, familiarity, inclusion, interactions with care providers). The findings highlight the need for providers and policy makers to reduce barriers to care related to logistics, stigma, judgment, and lack of understanding of perinatal addiction.
DEDICATION

First, this dissertation is dedicated to the courageous women who shared their experiences of pregnancy, birth, and recovery. Their stories revealed pain, gratitude, and hope. I feel honored and humbled that they were willing to open up to me, an outsider dropping into their lives at a vulnerable time for them. I hope I’ve done their stories justice.

I also dedicate this dissertation to my family: my husband, David, my four grown sons and their wives/fiancée, and my seven grandchildren. Their love, support, and belief gave me the strength to persevere in this journey.
ACKNOWLEDGEMENT

First, I thank my dissertation chair, Dr. Rebecca Kronk. I so appreciated her optimism, patience, and kind, gentle spirit. Her guidance helped keep me focused and on track, especially when she would remind me to step back and enjoy the process. I also thank my dissertation committee members: Dr. Karen Jakub, for her invaluable knowledge of focused ethnography; Dr. Alison Colbert, for her practical advice and attention to detail; and Dr. Lenora Marcellus, for her experience, wisdom, and compassion for women and their babies affected by substance use.

I thank the Kappa Zeta-at-Large Chapter, Sigma Theta Tau International Honor Society of Nursing, for their financial support of my dissertation study through the Holly Gimpel Research Grant. I thank the Eastern Maine Medical Center chief pediatrician and perinatal social workers who took time out of their busy schedules to facilitate recruitment and answer many questions. Finally, I am grateful for the kinship of my sisters on this “Gr8 Journey”, my cohort 18 classmates. We did it!
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CHAPTER 1

This document is structured in accordance with the Duquesne University School of Nursing Manuscript Option #2 dissertation format. Chapter 1 provides an overview for this dissertation study, briefly summarizing the background, purpose, and specific aims, as well as definitions of key terms. Chapter 2 is a published systematic review. Chapter 3 is the originally approved proposal for the study and is written in the future tense. Chapter 4 is published manuscript describing methodological challenges encountered during participant recruitment for this study. Chapters 5 and 6 comprise the final study findings and discussion in manuscript form for submission for publication to Qualitative Health Research.

Background

The United States is facing a rapidly growing epidemic of opioid addiction. Since 1999, sales of prescription opioid analgesics and the rate of unintentional opioid-related overdose deaths have more than quadrupled, with women being affected more than men, disrupting the health, social, and economic welfare of the country (American Society of Addiction Medicine [ASAM], 2016; Senate Caucus, 2014; United States Department of Health and Human Services [HHS], 2016). The opioid epidemic has been accompanied by a sharp rise in perinatal exposure to opioids and subsequent increase in the incidence of neonatal abstinence syndrome (NAS), a term applied to a constellation of symptoms characterized by dysregulation and hyperirritability of the central and autonomic nervous, respiratory, and gastrointestinal systems (Ko et al., 2016; Patrick et al., 2015; Pryor et al., 2017; Tolia et al., 2015). Data show disproportionately higher rates of perinatal substance use in rural areas, with three states (Maine, Vermont, and West Virginia) experiencing greater than tenfold increases and NAS incidence rates > 30 per 1,000 hospital births (Ko et al., 2016; Villapiano, Winkelman, Kozhimannil, Davis, & Patrick, 2016).
Women living in rural areas tend to have lower rates of early initiation of prenatal care, higher rates of pregnancy complications, and higher infant mortality rates than their urban counterparts, even when controlling for substance use (American College of Obstetricians and Gynecologists [ACOG], 2014). Additionally, socioeconomic disparities, such as poverty, unemployment, and low education level, which are more prevalent in rural areas, are associated with late or inadequate prenatal care and higher rates of adverse birth outcomes (ACOG, 2014; Blumenshine, Egerter, Barclay, Cubbin, & Braverman, 2010; Phillippi, 2009). Access to prenatal care in rural areas is often hindered by lack of resources (finances, transportation, childcare, availability); in women with substance use disorders, these barriers are compounded by fear of judgment and losing child custody (Phillippi, 2009).

Perinatal substance use directly impacts both the woman and her offspring, and research over the past several decades from a variety of perspectives has attempted to identify modifiable factors associated with negative outcomes, with inconclusive results. Studies have failed to demonstrate a predictable correlation between duration, timing, and total cumulative dose of prescription opioids on incidence or severity of NAS; variability in presentation of NAS symptoms is likely multifactorial (Desai et al., 2015; Kraft, Stover, & Davis, 2016; Stover & Davis, 2015). Studies focusing on care of the newborn with NAS have been equally inconclusive. This is likely due, in part, to wide variations in care of opioid-exposed newborns and lack of standardized NAS treatment (Bogen, Whalen, Kair, Vining, & King, 2016; Kelly et al., 2016).

A growing body of evidence is demonstrating the benefits of early and adequate prenatal care, harm reduction approaches, and promotion of maternal-infant bonding. Pregnancy is often the motivation a woman needs to seek treatment for substance use disorders, which provides an
opportunity for health and social care providers to engage women (Krans, Cochran, & Bogen, 2015). Principles of harm reduction aim to ameliorate the negative impact of substance use and related risks, such as poverty, interpersonal violence, psychiatric comorbidity, nutritional deficiencies, inadequate health care, and stressful life experiences (Sutter, Gopman, & Leeman, 2017). Such a philosophy requires care providers to set aside their own opinions and emotions regarding substance use and instead focus on re-engagement of the woman moving forward (Bartlett et al., 2013). Harm reduction approaches combined with comprehensive care models (antenatal care, social services, and substance use treatment) are showing promising results (Goodman, 2015; Marcellus, MacKinnon, Benoit, Phillips, & Stengel, 2015; Nathoo et al., 2015; Ordean & Kahan, 2011; Ordean, Kahan, Graves, Abrahams, & Boyajian, 2013).

Increased parental presence at the newborn’s bedside has been shown to increase rates of breastfeeding, reduce need for pharmacologic treatment, shorten duration of treatment, and decrease length of hospital stay (Abrahams et al., 2010; Hodgson & Abrahams, 2012; Holmes et al., 2016; Howard et al., 2017; Hünseler, Brückle, Roth, & Kribs, 2013; McKnight et al., 2016; Newman et al., 2015). Historically, opiate-exposed newborns have been admitted for observation, monitoring, and treatment in the neonatal intensive care unit (NICU) (Newman et al., 2015). This environment, while supporting medical management of newborns with NAS, can be stressful due to the increased stimulation and may also discourage parental presence, thus increasing the need for pharmacotherapy (Maguire, 2014; Newman et al., 2015). Infants may be safely observed and cared for in same room with their mothers; these newer rooming-in models can promote maternal-infant bonding and improve outcomes (McKnight et al., 2016). Variation in study designs and models of care, as well as the complex matrix of variables explored in those
studies, obscure efforts to draw conclusions with respect to best practices (Bagley, Wachman, Holland, & Brogly, 2014).

**Purpose**

The problems associated with perinatal substance use disorders persist despite decades of research. The voice of pregnant and parenting women with substance use disorders has been minimally included in prior studies as evidenced by the relatively limited number of qualitative studies. The purpose of this study was to explore rural women’s experiences and perceptions of care they received through their pregnancy and postpartum hospitalization, as well as experiences that may have influenced infant bonding.

**Study Aims**

The specific aim of the current study was to address the identified gaps in knowledge regarding care of this vulnerable population through the personal accounts of the women. Of particular interest was the role of nursing in care delivery. Ethnographic methods (Hammersley & Atkinson, 2007; Spradley, 1979, 1980) were used to seek answers to the following research questions:

1. What are the experiences and perceptions of rural women with substance use disorder regarding the care they received during their pregnancy and through their infants’ hospitalization?
2. How have their experiences supported or inhibited their ability to bond with their baby?

**Definitions of Key Terms**

**Addiction:** Various definitions of addiction are noted in the literature. Maternal addiction, in particular, has been defined as “a complex, progressive behavioral pattern having biological, psychological, medical, sociological, and behavioral components”
(Kaltenbach & Finnegan, 1992, p. 262). The behavioral focus of these definitions has perpetuated the assumption that addiction is a “moral failing or lack of individual self-control” (Bartlett, Brown, Shattell, Wright, & Lewallen, 2013, p. 349). The American Society of Addiction Medicine (2015) defines addiction as “a primary, chronic disease of brain reward, motivation, memory, and related circuitry” (p. 3) with cycles of relapse and remission. This definition emphasizes the bio-psycho-social-spiritual nature of the disease which needs to be addressed within a multifactorial framework and will, therefore, be used for this study.

**Care:** Defined by the mother and included, but was not limited to, access to and coordination and integration of services provided by nurses and other health care professionals, social workers, substance abuse and mental health providers, and other support agencies.

**Opioid use:** Defined for the purpose of this study as use of illegal opioid drugs, such as heroin, misuse of legally available pain relievers such as oxycodone and hydrocodone, and/or use or misuse of medications prescribed for medication-assisted treatment, such as buprenorphine and methadone.

**Rural:** The Federal Office of Rural Health Policy defines rural areas as non-Metropolitan (Metropolitan is defined as a core urban area of 50,000 or more population) and Rural-Urban Commuting Area codes of 4-10 (higher numbers signify lower population density) (Health Resources & Services Administration, 2017).

**Substance use disorder:** The recurrent use of alcohol and/or drugs which causes clinically and functionally significant impairment, such as health problems, disability, and failure to meet major responsibilities at work, school, or home. According to the DSM-5, a diagnosis of substance use disorder is based on evidence of impaired control, social
impairment, risky use, and pharmacological criteria (Substance Abuse and Mental Health Services Administration, 2015).
References


Senate Caucus on International Narcotics Control hearing America’s Addiction to Opioids: Heroin and prescription drug abuse (2014) (Testimony of Nora D. Volkow)


Relational Care for Perinatal Substance Use: A Systematic Review

Debra Kramlich, MSN, RN, CCRN and Rebecca Kronk, PhD, MSN, CRNP

Abstract

Objective: The purpose of this systematic review of the literature is to highlight published studies of perinatal substance use disorder that address relational aspects of various care delivery models to identify opportunities for future studies in this area.

Method: Quantitative, qualitative, and mixed-methods studies that included relational variables, such as health care provider engagement with pregnant women and facilitation of maternal-infant bonding, were identified using PubMed, Scopus, and EBSCO databases. Key words included neonatal abstinence syndrome, drug, opioid, substance, dependence, and pregnancy.

Results: Six studies included in this review identified statistically and/or clinically significant positive maternal and neonatal outcomes thought to be linked to engagement in antenatal care and development of caring relationships with health care providers.

Implications/Conclusion: Comprehensive, integrated multidisciplinary services for pregnant women with substance use disorder aimed at harm reduction show a trend toward positive results. Evidence exists that pregnant women’s engagement with comprehensive services...
facilitated by caring relationships with health care providers may improve perinatal outcomes. Gaps in the literature remain; studies have yet to identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes.
Relational Care for Perinatal Substance Use: A Systematic Review

Recently published data show a nearly threefold increase in the prevalence of perinatal substance use disorders (SUD) and subsequent fetal exposure to addictive substances in the United States in the 10-year span from 2000 to 2009, contributing to poor short-term perinatal and long-term developmental outcomes and creating a significant and costly public health issue (D'Apolito, 2009; McGlone, Mactier, & Weaver, 2009; O'Donnell et al., 2009; Patrick et al., 2012). Women with SUD face numerous impediments to accessing available resources for recovery and parenting support (Fraser, Barnes, Biggs, & Kain, 2007), further complicated by rural healthcare disparities, specifically those related to poverty (Lander et al., 2013). Early and adequate prenatal care has been shown to reduce risks of prematurity and low birthweight, factors known to increase neonatal mortality and morbidity and often related to maternal substance use (Burns, Mattick, Lim, & Wallace, 2007; El-Mohandes et al., 2003; Partridge, Balayla, Holcroft, & Abenhaim, 2012). The level of engagement, defined in part by personalization of care and relationships, rather than access to services may contribute to improved outcomes ( Docherty, Bugge, & Watterson, 2012).

According to the World Health Organization (WHO, 2014), indigenous women such as Native Americans in the United States, or aboriginals in Australia or Canada, in particular, have been exposed to generations of emotional, psychological, and physical trauma related to dislocation and loss of culture, resulting in even higher rates of SUD. These women also experience poorer access to health care. The prevalence of unplanned pregnancies, unemployment, poverty, co-occurring psychiatric disorders, intimate partner violence, co-addicted partners, history of parental abuse and addiction, and rural residence seems to be higher among pregnant women with SUD (Denton, Adinoff, Lewis, Walker, & Winhusen, 2014; Lander
Variables such as lower socioeconomic status, rural isolation, poor nutritional status, environmental pollution, and domestic violence may contribute to negative maternal and fetal outcomes independent of substances used and irrespective of medication-assisted treatment (MAT) (Baldacchino, Arbuckle, Petrie, and McCowan, 2014; Gilligan et al., 2009; Gray, Edwards, Schultz, & Miranda, 2014; Greig, Ash, & Douiri, 2012; Han & Stewart, 2014; Kent, McClure, Zaitchik, & Gohlke, 2013).

Evidence from the above-referenced studies indicates that negative perinatal outcomes involving substance use may be attributable to multiple and interrelated variables. Recently, the WHO (2014) published recommendations for care of pregnant women with SUD based on five overarching principles:

- prioritizing prevention
- ensuring access to prevention and treatment services
- respecting patient autonomy
- providing comprehensive care
- safeguarding against discrimination and stigmatization

Examples of such approaches to address this issue within a context of harm reduction, health promotion, and service coordination, which include the promotion of woman-health care provider (HCP) and mother-infant relationships, are beginning to show some promise (Benoit et al., 2014; Meyer et al., 2012; Wright, Schuetter, Fombonne, Stephenson, & Haning, 2012).

Literature addressing various facets of perinatal SUD has been published in journals targeting distinct yet diverse audiences, such as perinatal, pediatric, substance abuse, psychology, and sociology practitioners, challenging widespread dissemination of study findings. Such diversity and the sheer volume of studies conducted over the past several decades preclude a
comprehensive overview of the literature. The purpose of this systematic review of the literature is to highlight studies of perinatal SUD that included HCP-mother-infant relational perspectives within various care delivery models to identify opportunities for future studies in this area as outlined in the WHO guidelines.

**Methods**

A systematic computer-assisted search of the English-language literature published within the past 10 years was conducted using keyword searches in the PubMed, Scopus, and EBSCO databases. Keyword search terms and Boolean combinations of *neonatal abstinence syndrome, drug, opioid, substance, dependence,* and *pregnancy* were used to identify relevant articles, including primary studies, systematic reviews, general review articles and case studies, and full-text dissertations and theses. Reference lists of each article were then scanned for additional primary sources.

The initial search yielded 305 English-language articles published within the past 10 years. Based on review of abstracts, 88 articles were screened for further review, yielding 38 articles limited to quantitative, qualitative, and mixed-methods studies that included relational variables, such as HCP engagement with pregnant women and facilitation of maternal-infant bonding (see Figure 1). The articles were read in full to evaluate the extent to which relational variables were examined and considered important factors in outcomes. The 32 excluded articles focused primarily on variables such as type and amount of MAT or were secondary analyses of large datasets. The six studies included in this review (summarized in Table 1) identified statistically and clinically significant positive maternal and neonatal outcomes thought to be linked to engagement in antenatal care and development of caring relationships with HCP.
Results and Discussion

Designs

Several of the studies used qualitative methods to explore women’s perspectives of the impact of comprehensive, integrated multidisciplinary services for pregnant women with SUD (Morris, Seibold, & Webber, 2012; Motz, Leslie, Pepler, Moore, & Freeman, 2006; Racine, Motz, Leslie, & Pepler, 2009). Motz et al. (2006) also provided quantitative results of retrospective clinical data collected over a 10-year span to confirm the success of the services as described by the women. Meyer et al. (2012) retrospectively identified their sample and analyzed data extracted from medical records. Buckley, Razaghi, and Haber (2013) stated their cohort was followed prospectively during pregnancy, yet data from hospital records were analyzed retrospectively. Only one of the studies followed and collected data prospectively on a cohort of women using objective clinical data rather than self-report (Wright et al., 2012).

Sample Characteristics

Socioeconomic and demographic characteristics of the samples in the six studies are outlined in Table 1. Demographic data were not quantitatively reported in one study (Morris et al., 2012), and socioeconomic status was missing in another study (Meyer et al., 2012). Three samples reported indigenous status which has been found to contribute independently to substance use and poorer perinatal outcomes (Buckley et al., 2013; Motz et al., 2006; Racine et al., 2009; Wright et al., 2012). Methods of reporting pregnancy status varied from nulliparity to gravidity and parity means and ranges. Such disparate methods of reporting subject characteristics make comparisons across studies challenging.
**Intervention/Program Characteristics**

All six studies described some form of multidisciplinary service provision that the authors identified as contributing to more positive perinatal outcomes; however, the composition and mechanism of delivery of those services varied widely. Buckley et al. (2013) simply stated that a multidisciplinary team of specialist nursing and medical personnel provided comprehensive medical, obstetric, addiction, and psychosocial care. Meyer et al. (2012) described the evolution of their program from community-based services with minimal interaction to a multidisciplinary team that included social work, visiting nurses, physicians (addiction, obstetrics, and neonatology), and child protective services. These services were not center-based but information was freely shared among the providers. Meyer et al. (2012) state that services were coordinated across agencies and that most of the women and newborns received care within a single clinic, yet case management is not explicitly described. Neither program declared a particular guiding model or theoretical framework.

The other three programs were identified as outpatient multidisciplinary clinics with various service provision models. Mothercraft’s Breaking the Cycle (BTC) Pregnancy Outreach Program in Canada was described as a comprehensive, integrated, early intervention program with services delivered collaboratively through a single-access model (Motz et al., 2006; Racine et al., 2009). The services, many described as facilitated or provided by nurses, include individual and group addiction treatment, parenting programs, child care, child developmental services, health/medical services, mental health counseling, case management, parent-infant counseling, home visitation, pregnancy outreach, and support around instrumental needs such as food, clothing, and transportation. The Transitions Clinic (TC), located in a hospital for women in Melbourne, Australia, delivers comprehensive care by a multidisciplinary team, with the first
point of contact being two midwives (Morris et al., 2012). Antenatal and postnatal care, childbirth education, psychosocial and financial support, and addiction treatment is provided, with referral to community agencies as needed. Both programs stage interventions according to the Transtheoretical Model of behavior change (TTM). They use harm reduction principles, which focus on ameliorating the risks associated with SUD through early engagement in prenatal care, encouragement of health-promoting behaviors (improved nutrition, dental care, and physical activity), support for reduction in use of all substances (alcohol, tobacco, and drugs), and promotion of social and community support. The BTC program also identified several theoretical frameworks as key to the success of the program: relational theory, attachment theory, and developmental theory.

These studies described integrated services for SUD and perinatal care with a particular focus on opioid use due to its prevalence in those populations. A comprehensive perinatal, addiction, and social services clinic for pregnant women with SUD in Hawaii, also based on harm reduction principles, was evaluated for the impact on perinatal outcomes in pregnant women using methamphetamines (MA), which is particularly problematic in Hawaii and the western United States (Wright et al., 2012). Unlike MAT for opioid use, there are no approved medications for treatment of MA addiction; therefore, abstinence is the ultimate goal of therapy. This clinic also employed the Transtheoretical Model and Stages of Change Model. Wright et al. (2012) listed the services provided in this freestanding clinic but not the specific providers; therefore, nursing’s role in the model could not be confirmed.

**Program Outcomes**

Due to differences in definition and measurement of outcome variables, it is nearly impossible to compare the results of the six studies. None of the quantitative studies shared
common maternal variables, and those that reported similar neonatal outcome variables used
dissimilar measurement criteria. Pregnancy complications, such as cesarean birth, were reported
in four of the studies (Buckley et al., 2013; Meyer et al., 2012; Motz et al., 2006; Wright et al.,
2012), but no distinctions were made between planned and unplanned cesareans nor comparisons
made with the general obstetric population. Antenatal visits were quantified using a variety of
methods; only one of the studies (Meyer et al., 2012) reported a statistically significant increase
in the number of prenatal visits over the study period ($p = .006$), whereas the other studies only
reported mean numbers of prenatal visits. No description of the quality of those visits was
provided. Neonatal outcomes were typically reported as gestational age at birth, birthweight,
incidence of neonatal abstinence syndrome requiring pharmacologic treatment, length of hospital
stay, and discharge home with mother. The quantitative studies identified that neonatal outcomes
were not independently related to maternal substance use. Other factors, such as treatment
engagement and psychosocial and demographic characteristics, were predictive of improved
outcomes. Table 1 specifically enumerates those reported outcomes.

Perhaps the qualitative data are more indicative of positive program outcomes. Women
engaged in comprehensive, integrated multidisciplinary programs identified the attitudes of the
HCP and the development of collaborative relationships as essential for healing and their
engagement in care. Morris et al. (2012) found that the initial contact between the women and
HCP was crucial to establishment of a collaborative relationship regardless of TTM stage.
Similarly, Motz et al. (2006) noted that respect and empathy shown by the outreach workers
toward the women were foundational to successful relationships, which in turn fostered sustained
positive relationships between the women and their infants, other mothers, friends, and family
members (Racine et al., 2009).
Limitations

Various models of comprehensive programs providing integrated services for SUD and perinatal care have been described in the literature. Differences in service structure and location, modes of care delivery, client demographics, and methods of program evaluation create challenges to comparison of outcomes as well as identification of program components that may have contributed to success. The programs described in this review were structured differently, from a monthly meeting of members of a multidisciplinary needs assessment team of community and hospital-based HCPs following hospitalization for initiation of treatment (Meyer et al., 2012), to single-access community-based programs (Motz et al., 2006; Racine et al., 2009), to specialized multidisciplinary clinics (Buckley et al., 2013; Morris et al., 2012; Wright et al., 2012). The composition of the multidisciplinary teams varied across the studies; one study did not describe specific services or HCPs (Buckley et al., 2013). Support services, such as transportation and child care, were provided by several of the programs (Motz et al., 2006; Racine et al., 2009; Wright et al., 2012), and financial incentives were explicitly described in one study (Wright et al., 2012). Four of the programs were located in major metropolitan areas (Buckley et al., 2013; Morris et al., 2012; Motz et al., 2006; Wright et al., 2012), with three developed in countries with universal health care (Buckley et al., 2013; Morris et al., 2012; Motz et al., 2006). Control groups for comparison were lacking in all the studies.

Implications and Conclusion

Comprehensive, integrated multidisciplinary services for pregnant women with SUD aimed at harm reduction are showing positive results, but gaps in the literature remain. Women living in remote rural geographic areas with fewer resources who may experience greater obstacles to accessing services are grossly underrepresented in the current studies. Research
regarding the impact of marijuana on maternal and neonatal outcomes is inconclusive; as more states legalize marijuana for recreational use, more studies will be needed to accurately inform practice (Miller, 2012). The recent passage of a law in Tennessee explicitly criminalizing drug use during pregnancy is concerning. Prior studies have demonstrated the negative impact of such laws related to the reluctance of women to seek treatment and prenatal care to avoid prosecution without the intended benefits (Lester, Andreozzi, & Appiah, 2004). This resurgence of the “War on Drugs” will need to be followed carefully (Lester et al., 2004, p. 3).

Studies have yet to identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes. The strength of the evidence supporting the WHO recommendations (2014) ranges from conditional to strong, with the quality of the evidence rated as low to very low, indicating substantial gaps in the evidence. World Health Organization research priorities include improved descriptions of current practices, standardized outcomes and measurement of data, qualitative studies on ethical issues, and studies in low-income populations. The WHO recommendations offer a framework for future studies that may strengthen the quality evidence to support comprehensive, integrated, relationship-based care models.

Suggested Clinical Nursing Indications:

1. Nurses caring for pregnant women with SUD should promote and facilitate comprehensive, integrated, multidisciplinary services to reduce barriers to care.
2. Collaborative relationships between nurses and pregnant women with SUD, based on respect and empathy, can promote healing and engagement in care as well as facilitate mother-infant bonding.
3. Harm reduction principles, rather than insistence on abstinence, promote understanding of the context of substance use and can facilitate treatment engagement and reduce barriers to care related to stigma and shame.
Suggested Websites:

World Health Organization Guidelines for the management of substance use and substance use disorders in pregnancy:


Substance Abuse and Mental Health Services Administration TIP 51: Substance Abuse Treatment: Addressing the Specific Needs of Women:


Maine Center for Disease Control and Prevention, Snuggle ME Guidelines for Screening and Treatment of Pregnant Women with Substance Use Disorders:

http://www.maine.gov/dhhs/mecd/population-health/eshn/
References


<table>
<thead>
<tr>
<th>Study</th>
<th>Description of Study &amp; Sample Characteristics</th>
<th>Significant Results &amp; Major Findings</th>
<th>Limitations &amp; Recommendations</th>
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<tbody>
<tr>
<td>Buckley, Razaghi, &amp; Haber (2013)</td>
<td>Retrospective data analysis of a prospective study of pregnant substance-using women to document predictors of neonatal outcomes. Records of 183 methadone or heroin using pregnant women cared for by specialist services in two major teaching hospitals in the Sydney South West Area Health Services area of Australia (107 methadone, 15 heroin, 61 both) Mean age ranged from 25.5 years for heroin-only users to 29 years for methadone-only users; gravidity/parity ranges were reported as 0-21/0-8, with means of 3/1 Nearly¼ of women were of indigenous origin (indigenous population of Australia is 2.5%); less than 10% were employed, and 85% claimed their principle source of income as government benefits or dependent on others</td>
<td>No statistically significant differences in frequency of LBW or prematurity. NAS occurrence comparable across all groups. Methadone only group more likely to retain custody of their newborns at discharge ($p &lt; .001$). Attendance at antenatal visits independently predicted odds of LBW, prematurity, and discharge status; therefore, engagement in antenatal care reduced likelihood of negative outcomes for the mother-infant dyad. Care provided by a multidisciplinary team thought to be crucial to treatment engagement.</td>
<td>Data collected prospectively by clinical staff during routine care, then analyzed retrospectively. Missing data, small sample size, gestational age at first appointment not recorded. Need more research into socioeconomic factors, quality of healthcare interactions, and longer family follow-up.</td>
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<tr>
<td>Meyer et al. (2012)</td>
<td>Retrospective record review of women treated for opioid dependence during pregnancy to determine whether improved access to medication assisted therapy in the general population with improved coordination of ancillary services for pregnant women improved perinatal outcomes 149 women/151 neonates delivered at one tertiary care center acting as a referral hospital for a rural region in Vermont between 2000 &amp; 2006</td>
<td>As access to treatment in the general population expanded, the # of women receiving treatment increased, proportion of women receiving interim substitution therapy decreased ($p &lt; .001$), gestational age at initiation of treatment decreased ($p &lt; .001$), &amp; proportion of women receiving treatment before pregnancy increased ($p &lt; .001$). Infants delivered to mothers in a treatment program had improved birthweight z score compared with those receiving interim substitution therapy ($p = .007$). % of infants requiring pharmacologic therapy for NAS decreased ($p = .03$).</td>
<td>Transition to coordinated services occurred concurrently with expansion of MAT access in the general public. Unable to differentiate between impact of improved access to MAT, improved coordination of services, or effect of buprenorphine as an MAT option.</td>
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<tr>
<td>Author(s)</td>
<td>Study Description</td>
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<td>Morris, Seibold, &amp; Webber (2012)</td>
<td>Critical ethnography to explore extent to which a multidisciplinary specialist clinic focused on harm minimization meets the needs of chemically dependent women. Stage of recovery identified according to the Trans-Theoretical Model (TTM)</td>
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<td>20 chemically dependent pregnant women at a major metropolitan women’s hospital in Australia</td>
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<td>Demographic data not quantitatively reported; women described as experiencing family instability, family history of drug &amp; alcohol abuse, childhood sexual abuse, chemically dependent partners, and dual diagnoses of addiction &amp; mental illness.</td>
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<td>Motz et al. (2006)</td>
<td>Part 3 of this comprehensive report describes the evaluation of the Breaking the Cycle (BTC) program in Toronto, Canada,</td>
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<td>Statistical significance of outcomes was not reported; trends toward improvement in numerous perinatal health indicators and outcomes noted</td>
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**Results:**
- Mean age over the 5 data collection points was 24.7 to 26 years; 5-16% were nulliparous (differences over the data collection periods not statistically significant).
- Demographic data regarding SES not reported.
- Proportion of infants discharged to the care of the mother & remaining in maternal care at 1 year improved both over time ($p = .03; p = .004$) & with treatment within a treatment program ($p < .001; p = .004$).
- No data on women who left treatment before delivery > reasons for premature withdrawal.
- No data on polysubstance use.
- No mention of quality of relationships between HCP & pregnant women.
- Multiple factors influence development & maintenance of chemical dependency: family instability, family history of drug & alcohol abuse, childhood sexual abuse, having a chemically dependent partner, dual diagnosis of substance use and mental illness.
- Attitudes of individual staff members, particularly midwives, were key to the way women responded to care and the evolution of collaborative relationships between HCP & pregnant women.
- Initial contact between women & HCP crucial to establishment of relationship regardless of TTM stage.
- Women sometimes felt secondary to unborn child & resented being seen as “baby incubators”.
- Women felt discounted in decision-making.
- Physical space not facilitative of communication.
- Supportive relationships developed over time; most participants (15/20) reported positive benefits & desire to maintain engagement with the clinic program.
- Some services felt to be lacking: family therapists trained in mental health with drug & alcohol qualifications, and postnatal support for women able to parent children.
- Need quantitative studies to examine perinatal outcomes related to engagement in such care.
<table>
<thead>
<tr>
<th>Racine et al. (2009)</th>
<th>Qualitative study to describe experiences of pregnant substance-involved women engaged in a comprehensive, integrated, single-access early intervention program (Breaking the Cycle Pregnancy Outreach Program - CPNC) based on principles of harm reduction, relational theory, developmental theory, and attachment theory.</th>
<th>Promotion of relational capacity in pregnant &amp; parenting women involved with substance use; non-judgmental, caring attitudes &amp; behaviors of outreach workers; being with other similar women; healing through the power of relationship. Rich data gleaned from the stories of the women engaged in this outreach.</th>
<th>See above; this study gleaned qualitative data regarding aspects of the program likely to engage and retain women in the program. Quantitative studies with control groups in similar populations would use data, no control group.</th>
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<tr>
<td>using quantitative &amp; qualitative methods. BTC is a comprehensive, integrated, single-access early intervention program for pregnant women with substance use disorders based on principles of harm reduction, relational theory, developmental theory, and attachment theory. Approaches &amp; interventions used TTM/Stages of Change model &amp; Motivational Interviewing (MI) Data collected from 160 high-risk women engaged in the BTC Pregnancy Outreach Program (CPNC) April 2001-May 2005; data collected on 1170 mothers accessing BTC 1995-2005 Mean age 28 years; average of one prior pregnancy (range 0-10) Sociodemographic characteristics of participants extensively described: briefly, 13% identified as indigenous (as compared with 4.3% of the general population); 46% experienced homelessness; 37% had no income &amp; 49% were receiving general public assistance; significantly higher rates of food insecurity; 70% had ≤ 10 years of schooling; 60% were single.</td>
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<td>when the Pregnancy Outreach Program was added, including:</td>
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<td>• Lower gestational age at initial engagement in care</td>
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<td>• Greater access to &amp; use of supportive health &amp; treatment services</td>
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<td>• More likely to complete treatment</td>
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<td>• Retained custody of children</td>
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<td>• Maintained substance use recovery at discharge</td>
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<td>• Greater maternal-infant attachment</td>
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<td>• More normal child development</td>
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<td>Respect &amp; empathy shown by Pregnancy Outreach Worker (POW) foundational to successful relationships.</td>
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<tr>
<td>Study</td>
<td>Description</td>
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<td>Three focus groups with total $n = 19$ former high-risk clients of the BTC CPNC program in Toronto, Canada (demographics described above in Motz et al. study); a subset of a larger mixed-methods program evaluation study comparing BTC with CNPC</td>
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<td>strengthen the findings</td>
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<td>Wright et al. (2012)</td>
<td>Examine outcomes of implementation of a harm-reduction model for clinical care of substance using pregnant women; used Stages of Change Model &amp; MI 132 pregnant women (47% indigenous) with past or present history of addiction cared for in a clinic offering comprehensive perinatal &amp; social services in an urban, academic medical center Hawaii, compared with a representative cohort of women (22% indigenous) delivering at the same hospital without the clinic services. Mean age 28.3 years; gravidity 4.5/parity 2.3</td>
<td>Statistically significantly higher rates of gravidity &amp; parity, smoking &amp; methamphetamine use, chronic medical conditions &amp; native Hawaiian in clinic cohort (all $p &lt; .001$); no statistically significant differences in pregnancy complications. Predictors of poor infant outcomes were related to factors other than drug use (parity, history of domestic violence, maternal medical conditions, poor prenatal care). Assumed that comprehensive care delivered using harm-reduction approaches &amp; motivational incentives resulted in relatively normal birth outcomes.</td>
<td>No control group of substance-using pregnant women not engaged in comprehensive services for comparison.</td>
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Figure 1: Flow diagram of article selection

Records identified through search of PubMed, Scopus, and EBSCO databases and scanned reference lists; English-language, years 2004-2014 (n = 305)

Records for further screening (n = 88)

Records excluded (general reports and review articles) (n = 50)

Full-text articles further assessed for eligibility (n = 38)

Full-text articles excluded (primary focus on variables such as type and amount of medication-assisted treatment; secondary analyses of large datasets) (n = 32)

Studies included in synthesis (n = 6)

CHAPTER 3

Chapter 3 is the dissertation proposal in its original form, presented on November 13, 2014.

Experiences and Perceptions of Postpartum Women with Substance Use Disorders Inclusive of Opioids Regarding Their Care

Specific Aims

Data show a rapidly increasing prevalence of substance use disorders during pregnancy and subsequent perinatal exposure to addictive substances, resulting in poor short-term fetal and neonatal and long-term developmental outcomes and creating a significant and costly public health issue worldwide (D’Apolito, 2009; McGlone, Mactier, & Weaver, 2009; O'Donnell et al., 2009; Patrick et al., 2012). Excessive prenatal substance exposure may result in negative birth outcomes, including low birthweight and prematurity, and cause neonatal abstinence syndrome in infants, including respiratory problems, feeding difficulties, and seizures (Walton-Moss, McIntosh, Conrad, & Kiefer, 2009). More is becoming known about the long-term effects of drug exposure, including delayed cognitive and motor development (Mactier, 2013) and increased child protective involvement (Lean, Pritchard, & Woodward, 2013), placing an even greater burden on health care, social welfare, and foster care services.

Maine has the highest rate of prescription opiate drug misuse in the country (Hayes & Brown, 2012); a report published in 2010 by the Substance Abuse and Mental Health Services Administration (SAMHSA) noted Maine’s per capita rate of non-heroin opiate addiction in 2008 was 386 per 100,000, compared to 45 per 100,000 for the Unites States and 131 for New England. The percentage of newborns with neonatal abstinence syndrome discharged from
Maine hospitals rose from 0.1% in 2000 to 2% in 2009 and those numbers continue to increase; 927 babies were born affected by drugs in Maine in 2013, more than 7% of all births (Maine DHHS, 2014). Despite increasing attention on this problem and evidence-based recommendations (Dow et al., 2012; Goettler & Tschudin, 2014; Hudak & Tan, 2012; Jansson, Velez, & Harrow, 2009; Lucas & Knobel, 2012; Queensland & Neonatal Clinical Guidelines, 2010; Winklbaur et al., 2008), management remains inconsistent, hospital length of stay has not declined, and expenditures continue to rise. Quantitative and interventional studies have yet to produce sustained, efficacious improvement in outcomes for these mothers and children (Milligan et al., 2010). Additionally, societal stigma and lack of resources further contribute to the negative outcomes for both mother and child (Lander et al., 2013).

Women with substance use disorders continue to face numerous impediments to accessing available resources for recovery and parenting support (Fraser, Barnes, Biggs, & Kain, 2007). Substance use disorder in women is associated with increased prevalence of mental illness, histories of physical and sexual abuse, and medical and social problems (Milligan et al., 2010). Studies have shown that rural healthcare disparities, specifically those related to poverty, further complicate access to treatment (Lander et al., 2013). This is particularly concerning in light of findings that protective factors, such as caretaker involvement and family resources, may moderate the negative effects of substance use on the developing child (Bada et al., 2012). An exploration of the experiences of women with substance use disorder regarding the care they have received for pregnancy, parenting, recovery, and psychosocial and economic issues is necessary to identify unmet needs and determinants of the problem. Since many of the studies described in the background and significance of the problem have focused on the perinatal impact of opioid use, the population of interest in the proposed study is defined as women with
any form of current opioid use (illicit, misuse of prescription opioid medications, medication assisted treatment) and not excluding use of other substances. The long-term objective, future development of efficacious interventions to promote successful parenting and decrease the risk of further trauma to the mother-infant dyad, is contingent upon such understanding.

The specific aim of this study is to begin to bridge the current gap in knowledge regarding care of this vulnerable population. “Care” will be defined by the mother and may include, but not be limited to, access to and coordination and integration of services provided by nurses and other health care professionals, social workers, substance abuse and mental health providers, and other support agencies. Of particular interest will be the role of nursing in care delivery. This may be achieved through a qualitative exploration of the following questions:

1. What are the experiences and perceptions of women with substance use disorder, defined for the purpose of this study as any form of current opioid use while not precluding use of other substances, regarding the care they received during their pregnancy and through their infants’ hospitalization?

2. How have their experiences supported or inhibited their ability to bond with their baby?

**Background and Significance**

Results from the 2013 National Survey on Drug Use and Health found that among pregnant women aged 15 to 44, 5.4% were current illicit drug users (SAMHSA, 2014). Current illicit drug use was lower among pregnant women aged 15 to 44 during the third trimester than during the first and second trimesters (2.4% vs. 9.0% and 4.8%). When stratified by age, the rate of current illicit drug use was 14.6% among pregnant women aged 15 to 17, 8.6% among women aged 18 to 25, and 3.2% among women aged 26 to 44. According to data from the Treatment Episode Data Set (TEDS), while the proportion of substance abuse treatment admissions in
females aged 15 to 44 years who were pregnant at treatment entry has remained stable between 2000 and 2010, the percentage reporting drug abuse but not alcohol abuse has increased from 51.1% to 63.8% (SAMHSA, 2013).

Of drug exposed newborns, 50% to 90% will experience some degree of neonatal abstinence syndrome, a term applied to a constellation of symptoms characterized by dysregulation and hyperirritability of the central and autonomic nervous, respiratory, and gastrointestinal systems (Sublett, 2013). Symptoms are treated with a combination of pharmacologic and non-pharmacologic therapies typically requiring specialized care in the neonatal intensive care unit (NICU) with an average length of hospital stay of 25 days.

A retrospective study conducted by Patrick et al. (2012) found that between 2000 and 2009 the incidence of neonatal abstinence syndrome among newborns in the U.S. increased from 1.20 to 3.39 per 1000 hospital births per year while antepartum maternal opiate use increased from 1.19 to 5.63 per 1000 hospital births per year. In 2009, newborns with neonatal abstinence syndrome were more likely than all other hospital births to have low birthweight, have respiratory complications, and be covered by Medicaid. Mean hospital charges for discharges with neonatal abstinence syndrome increased from $39,400 in 2000 to $53,400 in 2009. By 2009, 77.6% of charges for neonatal abstinence syndrome were attributed to state Medicaid programs (Patrick et al., 2012).

Concerns regarding perinatal substance use are not new; literature regarding physician interest in the effects of drugs and alcohol on women and children dates back nearly three centuries (Boyd & Marcellus, 2007). Attitudes toward therapeutic and illicit use of substances, particularly opioids, and approaches to addiction treatment have been shaped by various social, moral, political, economic, and legal influences. The development of practices and policies
specifically addressing perinatal substance use has paralleled the evolution of the rights of women and children, including the unborn fetus. Generally, the women affected by such decisions have been excluded in the process.

Pregnant and parenting women with substance use disorders present a particular challenge with regard to problem identification and outcome measurement. Pregnancy and childbirth are considered normal physiological processes, yet framed by the disease of addiction, these processes tend to be pathologized and used to punish women for their addictive behaviors (Boyd & Marcellus, 2007). Salmon (2010) advanced the term reproductive citizenship to describe the assumption that women have both the ability and responsibility to minimize risk in their lives during pregnancy and birth. Pregnant and parenting women who use substances have been thought to be deviant; such moral judgments, stigmatization, and subsequent punitive policies have resulted in challenges to engagement of these women in the treatment process.

The disease of addiction, particularly maternal addiction, has been defined as “a complex, progressive behavioral pattern having biological, psychological, medical, sociological, and behavioral components” (Kaltenbach & Finnegan, 1992, p. 262) and, therefore, needs to be addressed within a multifactorial framework. Maternal substance use disorder does not occur in a vacuum, and it would be a disservice to describe and explain addictive behaviors solely on the basis of individual factors. One study found multiple biopsychosocial predictors of treatment outcomes in women with substance use disorders and identified the importance of careful assessment of these factors when designing outpatient and residential treatment programs for these women (Comfort, Sockloff, Loverro, & Kaltenbach, 2003). As noted by Suchman, Pajulo, and Mayes, (2013), “pregnant and parenting women who suffer from substance use disorders present a very complex and difficult challenge to those concerned with improving the
environment of care for their children” (p. 185). These women often report family histories of substance abuse which suggests both genetic and environmental determinants of substance misuse. They also experience higher rates of violence, trauma, and subsequent post-traumatic stress disorder, as well as psychiatric comorbidity. Native American women, in particular, have been exposed to generations of emotional, psychological, and physical trauma related to dislocation and loss of culture, resulting in even higher rates of substance use disorder (Bohn, 2003; SAMHSA, n.d.). The lack of positive role models and personal coping skills further contribute to substance use disorders in women with these multiple, complex challenges. It seems a majority of the published studies of antenatal substance use disorders and the impact on the women and infants have failed to account for this complexity and have targeted limited aspects of the problem.

**Maternal Medication-Assisted Treatment and Neonatal Outcomes**

Perinatal substance use directly impacts two constituencies, the woman and her offspring, and therefore the problem has been examined from a variety of perspectives. Numerous quantitative studies have been conducted to identify factors regarding maternal drug use which may be predictive of neonatal outcomes, such as the type and amount of medication-assisted treatment for opioid use. Several retrospective studies associated higher doses of maternal methadone dose with higher incidence of neonatal abstinence syndrome as well as duration of neonatal abstinence syndrome treatment (Dryden, Young, Hepburn, & Mactier, 2009; Lim, Prasad, Samuels, Gardner, & Cordero, 2009). These findings contradicted those of other studies, which reported no such correlation (Berghella et al., 2003; McCarthy, Leamon, Parr, & Anania, 2005; Pizarro et al., 2011; Seligman et al., 2008). One prospective cohort study also concluded that the incidence and duration of neonatal abstinence syndrome was not affected by methadone
dose (Cleary et al., 2012). McCarthy, Leamon, Stenson, and Biles (2008) noted that infants of women who began methadone treatment prior to conception had better outcomes compared with those whose mothers began treatment mid-pregnancy.

Similar conflicting results have been noted in studies comparing maternal methadone and buprenorphine medication-assisted treatment. Several studies suggested improved neonatal outcomes, such as lower incidence and severity of neonatal abstinence syndrome, in infants exposed to buprenorphine as compared with methadone exposure (Binder & Vavrinkova, 2008; Coyle et al., 2012; Gaalema et al., 2012; Kakko, Heilig, & Sarman, 2008; Salisbury et al., 2012). Other studies found no such differences (Jones et al., 2010; Lejeune, Simmat-Durand, Gourarier, & Aubisson, 2006; Welle-Strand et al., 2013). Patel and colleagues (2013) noted no difference in neonatal abstinence syndrome expression when comparing infants exposed to buprenorphine to those exposed to illicit opiates. The concomitant use of illicit substance, as well as alcohol and tobacco, with medication-assisted treatment seems to confound the results of these studies (Blandthorn, Forster, & Love, 2011; Kaltenbach et al., 2012).

Many of the aforementioned studies have been retrospective reviews of clinical data or secondary analyses of data from larger studies. Two multicenter prospective studies from which much data have been drawn, the Maternal Lifestyle Study (Bauer et al., 2002) and the Maternal Opioid Treatment: Human Experimental Research (MOTHER) study (Jones et al., 2010), have generated a great deal of discussion and debate among the scientific and practice communities. Findings of these studies regarding severity of neonatal abstinence syndrome relative to type and dose of maternal substance or medication-assisted treatment have been conflicting. In fact, Winklbaur-Hausknost and colleagues (2013) found that maternal treatment resulting in reduced illicit drug use throughout pregnancy had no influence on neonatal outcomes in two separate
studies. In a systematic review and meta-analysis, Cleary and colleagues (2010) found no clear link between neonatal abstinence syndrome severity and methadone dose. Similarly, Thajam, Atkinson, Sibley, and Lavender (2010) found no correlation between amount and type of fetal opioid exposure and neonatal abstinence syndrome expression in eight of the 10 studies they reviewed. It may be concluded that a singular focus on drug type and dose fails to account for the complex array of factors contributing to neonatal outcomes.

Maternal-Infant Bonding

Literature regarding neonatal abstinence syndrome care has been equally inconclusive. Sublett (2013) noted that, despite extensive research on pharmacologic therapy and recommendations by the American Academy of Pediatrics, no clear answer to standardized neonatal abstinence syndrome treatment has been established. This is likely due, in part, to failure to establish a definite relationship between maternal drug type and dose and severity of neonatal withdrawal symptoms (Dryden et al., 2009; Sublett, 2013; Velez, Jansson, Schroeder, & Williams, 2009). It appears that factors other than maternal medication-assisted treatment, such as maternal-infant bonding, have greater influence on neonatal outcomes. One study conducted by Saiki, Lee, Hannam, and Greenough (2010) showed that care of neonatal abstinence syndrome infants on the postpartum unit with their mothers, rather than in the NICU, resulted in shorter duration of treatment and hospital stay.

Backes and colleagues (2012) found that infants discharged home on a methadone weaning protocol with support from a multidisciplinary team, as opposed to a traditional inpatient methadone wean, resulted in shorter hospital stays and reduced cost. A retrospective review conducted in the United Kingdom yielded similar findings (Smirk, Bowman, Doyle, & Kamlin, 2014). Investigators in both studies noted that breastfeeding rates were significantly
higher in the home detoxification groups which may have accounted for perceived benefits. Several studies found that substantial breast milk intake significantly reduced severity of neonatal abstinence syndrome symptoms, delayed the onset of symptoms, and decreased the need for pharmacologic treatment (Abdel-Latif et al., 2006; Dryden et al., 2009). These studies seem to support the conclusion that treatment of the neonatal abstinence syndrome baby should be provided with the participation of the mother to promote maternal-infant bonding and breastfeeding (Sublett, 2013). As will be noted, however, engagement of the mothers to establish a foundation for this bonding has proven challenging.

**Maternal Substance Use and Child Maltreatment**

According to Smarsh Hogan and Myers (2006), it is commonly believed that mothers with substance use disorders may place their children at higher risk of maltreatment. While data suggest an association between maternal substance use disorders and child maltreatment (Walsh, MacMillan, & Jamieson, 2003), other studies have noted that environmental risks, such as depression, psychiatric disorders, domestic violence, and lower socioeconomic status may contribute more significantly to child maltreatment (Nair, Schuler, Black, Kettinger, & Harrington, 2003; Smarsh Hogan & Myers, 2006). Unfortunately, pregnant women with substance use disorders tend to face those same problems; studies have shown a higher prevalence of unplanned pregnancies, unemployment, poverty, co-occurring psychiatric disorders, intimate partner violence, co-addicted partners, history of parental abuse and addiction, and rural residence among this population (Denton, Adinoff, Lewis, Walker, & Winhusen, 2014; Lander et al., 2013; Unger, Metz, & Fischer, 2012).

**Early Identification, Engagement, and Treatment Retention**
Early and adequate prenatal care has been shown to mitigate the negative effects of substance use disorders during pregnancy (Wright, Schuetter, Fombonne, Stephenson, & Haning, 2012). Unfortunately, pregnant women with substance use disorders may delay or completely avoid seeking care due to fears of judgmental or uncivil care provider reactions (Metz, Kochl, & Fischer, 2012). These fears are not unfounded; evidence has shown continued misunderstanding and negative attitudes of healthcare providers toward pregnant women with substance use disorders (Benoit et al., 2014; Fraser et al., 2007; Maguire et al., 2012; Murphy-Oikonen, Brownlee, Montelpare, & Gerlach, 2010). Socioeconomic constraints and low literacy levels are additional barriers to treatment engagement (Alto & O'Connor, 2011). While attrition rates for women who do engage in treatment are reported to be high (Sharon M. Mullins, Suarez, Ondersma, & Page, 2004), engagement is the first step toward treatment and recovery. Ideally, comprehensive care for these women would include treatment for the substance use to promote abstinence and ease withdrawal symptoms, combined with antenatal care and social services to support parenting success. Pregnancy is often the impetus a woman needs to seek treatment for substance use disorder, providing an opportunity for health and social care providers to engage these women.

Studies of early identification, engagement, and treatment retention of pregnant women using integrated substance abuse and perinatal services are showing potential benefits in the promotion of maternal-infant bonding (Burns, Mattick, Lim, & Wallace, 2007; Kissin, Svikis, Moylan, Haug, & Stitzer, 2004; Mayet, Groshkova, Morgan, MacCormack, & Strang, 2008; Meyer et al., 2012; Mullins, Bard, & Ondersma, 2005; Racine, Motz, Leslie, & Pepler, 2009; Suchman, Mayes, Conti, Slade, & Rounsaville, 2004; Suchman, Pajulo, DeCoste, & Mayes, 2006; Taylor et al., 2012). Identification of maternal substance use has been challenging. Some
studies have indicated that universal screening of all women for drugs and alcohol may reduce socioeconomic and racial disparities, resulting in improved identification (Casper & Arbour, 2013; Eichel & Johannemann, 2014; Roberts & Nuru-Jeter, 2011). Others have questioned the wisdom of this approach, suggesting that fear of negative consequences may preclude women from seeking prenatal care (Roberts & Nuru-Jeter, 2010).

A variety of strategies for engagement of pregnant women with substance use disorders in prenatal care and treatment have been explored. Motivational interviewing (MI) and motivational enhancement therapy (MET) have been included in studies of prenatal alcohol use (Osterman & Dyehouse, 2012), treatment utilization in pregnant substance users (Winhusen et al., 2008), and treatment retention of women with substance use disorders involved with child welfare (Mullins et al., 2004). Both MI and MET interventions have shown mixed results in pregnant women. According to Jones and Kaltenbach (2013), MI appears to hold some promise as part of a comprehensive approach, but more studies are needed to determine if and how it facilitates behavior change in this population.

Use of behavioral incentives has been explored as a means for engaging and retaining pregnant women in substance-abuse treatment (Brigham, Winhusen, Lewis, & Kropp, 2010; Comfort, Loverro, & Kaltenbach, 2000; Hutchinson, Chisholm, Tuten, Leoutsakos, & Jones, 2012; Jones, Svikis, Rosado, Tuten, & Kulstad, 2004; Schottenfeld, Moore, & Pantalon, 2011; Svikis, Silverman, Haug, Stitzer, & Keyser-Marcus, 2007). Results have been mixed, but it seems that efficacy is related to the type, amount, timing, and frequency of the incentives as well as the mechanism of treatment entry (coerced versus voluntary). Trust-building was also found to be an important component of the intervention.

Harm-Reduction Philosophy
Decades of failed attempts to require and achieve abstinence in addictive behaviors has led to development of a harm-reduction philosophy (Boyd & Marcellus, 2007). Harm-reduction recognizes the relapsing characteristic of substance-misuse, not unlike other chronic diseases, and is “based on the premise that alcohol and drug addiction and the associated risks can be placed on a continuum, with the goal being to help the client move along this continuum from excess to moderation” (Suchman et al., 2013, p. 375). Such a philosophy requires care providers to set aside their own opinions and emotions regarding relapse and instead focus on re-engagement of the woman moving forward. Studies of harm-reduction approaches in Britain, the Netherlands, and Canada have shown positive outcomes in terms of lower rates of child protective involvement and withdrawal symptoms in infants (Boyd & Marcellus, 2007). Pilot studies in the U.S. have shown similar results (Wright et al., 2012). The programs described in the literature have used a variety of interventions, including integrated prenatal and substance abuse services and motivational incentives, so it is unclear which aspects of a harm-reduction approach contribute to outcomes.

**Literature Synthesis and Identified Gap**

As the literature shows, the problem of maternal substance use and its negative impact on both the mother and the infant persists despite numerous quantitative studies from multiple perspectives. Recent studies continue to demonstrate a lack of provider understanding of the disease of maternal addiction (Benoit et al., 2014). It would seem from this review of the literature that the voice of pregnant and parenting women with substance use disorders has been minimally included in prior studies as evidenced by the relatively limited number of qualitative studies. A more focused review of the literature, highlighting studies of perinatal substance use disorders that included health care provider-mother-infant relational perspectives within various
care delivery models, was conducted by this researcher and submitted for publication (Chapter 2). Published studies have yet to identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes. The proposed study aims to address that gap by exploring the women’s experiences and perceptions of care. Nurses and other health care professionals may then be better able to provide efficacious, holistic care to improve outcomes for these women and their children.

**Preliminary Work**

Preliminary explorations have provided background information to guide this study. Telephone conversations and personal meetings with various providers of care for these women as well as attendance at conferences and meetings where these individuals have spoken have contributed to a greater awareness of the problem. These care providers identified potential sites for observation and processes for gaining access to informants in addition to anticipated challenges. The relationships cultivated with these professionals will enhance this researcher’s ability to conduct the proposed study. This pre-fieldwork yielded what Hammersley and Atkinson (2007) termed a *foreshadowed problem*, the starting point for an investigation that will evolve as knowledge is gained through inquiry and observation.

**Research Design and Methods**

**Research Design**

In the proposed study, ethnographic methods (Hammersley & Atkinson, 2007; Spradley, 1979, 1980) will be used to better understand: (1) the experiences and perceptions of postpartum women with substance use disorders regarding the care they received during their pregnancy and through their infants’ hospitalization; and (2) how have their experiences supported or inhibited their ability to bond with their baby. These methods will include: participant observation of
postpartum women with substance use disorders at Eastern Maine Medical Center; oral accounts and formal interviews; and artifact review, such health records and print and electronic resources provided to the women to support direct care.

Ethnographic studies are designed to understand a culture by learning from the people within that culture through contextualized examination of their speech, behavior, and artifacts (Spradley, 1979). A focused ethnography, defined by Munhall (2012) as “the study of small elements of one society, group, or culture; focus on [a] distinct problem within a specific context among a small group of people” (p. 291) is particularly suitable for the proposed study. The topics of inquiry for a focused ethnography are pre-selected, and the short-term yet time-intensive nature of observations are conducive to the study of sensitive topics and complex issues such as substance use disorders in women during the postpartum period within the limitations imposed by dissertation studies.

The exploratory nature of ethnographic research requires a focused yet flexible approach to sampling and data gathering and analysis (Maxwell, 2013). The anticipated population and study methods described as follows are tentative; the design will emerge as the study progresses.

Setting

This study will be conducted at Eastern Maine Medical Center in Bangor, Maine, which serves Washington and Penobscot Counties in northern Maine. According to the Maine Office of Substance Abuse and Mental Health Services (2012) these counties have the highest rates of opiate addiction in Maine. The 927 drug-affected births reported in Maine in 2013 represent about 7% of live births (Maine DHHS, 2014). At Eastern Maine Medical Center there were 308 substance-exposed infant reports in 2011, approximately 19% of live births at Eastern Maine
Medical Center that year; nearly 60% of the mothers of those infants lived in Washington or Penobscot counties.

Poverty, rural isolation, and Native American culture have been noted to contribute to poor perinatal outcomes and challenges to access to care (Bohn, 2003; Kent, McClure, Zaitchik, & Gohlke, 2013). Penobscot and Washington Counties have the highest rates of poverty (Maine State Planning Office, 2012) and lowest population density in the state (Maine DHHS, 2008). Nearly 20% of the total population of Washington County is reported to live below the poverty level; the highest rate of child poverty (nearly 31%) is in Washington County. Maine is one of the least densely populated states in the country, and both counties include a large number of unorganized territories (an area having no local, incorporated municipal government). While less than 1% of the population (0.9% U.S., 0.6% Maine) is identified as Native American, 4.9% of the population of Washington County is identified as such (Maine CDC, 2103). All of which underscore the importance of research in this setting.

The majority of pregnant women with substance use disorders in both counties deliver their babies at Eastern Maine Medical Center (located in Bangor in Penobscot County), the state’s second largest hospital which serves the northern two-thirds of the state and delivers an average of 1,600 babies annually. This encompasses a relatively large geographic area, with towns located in the farthest reaches of Washington and Penobscot Counties situated over 100 miles from the hospital. Three smaller hospitals located 50 to 100 miles from Bangor provide obstetric services but do not provide care for newborns with neonatal abstinence syndrome requiring treatment. Newborns delivered at one of those small hospitals, either anticipated or unplanned, who show signs of neonatal abstinence syndrome in need of treatment are transferred to Eastern Maine Medical Center. Depending on the circumstances, the mother may or may not
be transferred with the newborn; typically, the mother has been discharged from the hospital and must travel to visit the hospitalized newborn.

Access to treatment for substance use disorders is limited, with one outpatient practice in Washington County and two in Penobscot County, none of which are designed specifically to address the unique needs of pregnant and parenting women. In contrast, comprehensive integrated outpatient services for pregnant and parenting women with substance use disorders, including medical, behavioral, and mental health services, are available in the more densely populated southern areas of the state.

Women living in Washington County receive a flexible, individualized, strength-based, integrated, collaborative, wrap-around model of care delivery linking them with various services, while those in Penobscot County must access those services with limited case management and without the characteristics of the Washington County model. It has been identified that women living in remote rural geographic areas with fewer resources who may experience greater obstacles to accessing services are underrepresented in current studies. The barriers to accessing adequate resources for substance use disorder recovery, pregnancy, and parenting support, addressed earlier in this proposal, are clearly present in this setting. Such a setting provides the opportunity to further explore the factors contributing to unmet needs and potential determinants of the problem.

Population

The general target population identified for this study will broadly include women living in Washington and Penobscot Counties identified with a substance use disorder inclusive of opioid use who deliver their babies at Eastern Maine Medical Center. Clinically important neonatal withdrawal most commonly results from intrauterine opioid exposure (Hudak & Tan,
2012), and 56% of substance-exposed infants born at Eastern Maine Medical Center in 2011 were identified as being opiate-exposed. This is a heterogeneous population with respect to substances used and stage of recovery in addition to the complex array of biopsychosocial, environmental, and economic variables influencing substance use disorder and recovery (M. Brown, M. Moran., & M. Withers, personal communication, August 5, 2014).

Sample and Sampling Procedures

The sample will be purposefully selected using maximum variation sampling strategies to observe a range of informants and activities in a variety of contexts according to demographic, phenomenal, and theoretical categories (Sandelowski, 1995b). Participants may be of any race/ethnicity, social class, relationship status, pregnancy status, child custody status, and stage of recovery. Inclusion criteria for all participants are: (a) have a newborn hospitalized at Eastern Maine Medical Center, either from birth or through transfer from a smaller facility; (b) have an identified substance use disorder that includes current use of an opioid (legally prescribed medication assisted treatment, misuse of prescription opioid medications, or illicit opioids); and (c) live within Washington or Penobscot County. Participants must be English-speaking and able to give informed consent.

Sample selection. Sample selection will be dictated by availability and willingness of participants meeting inclusion criteria as well as establishment of trust with potential informants. Sampling decisions are dictated by the emergence of data with the intention of including units of observation (settings, individuals, and activities) representative of pre-selected variables as well as typical or unusual cases (Sandelowski, 2000).

Sample size. Sample size will be determined as the study evolves; as noted by Sandelowski (1995b), sample size is a matter of judgment and depends on breadth and depth of
the data that emerge. Distinction is made between informational redundancy (no new information is available from newly sampled units) and theoretical saturation (data has been gathered and analyzed from all theoretical categories) (Coyne, 1997; Sandelowski, 1995b). Data collected and analyzed concurrently will inform sample configuration and size decisions based on the richness and variation found in the data. In the proposed study, participants will be selected that vary as much as possible according to various demographic characteristics based on literature and personal communication with expert practitioners (Gilligan et al., 2009; Gray, Edwards, Schultz, & Miranda, 2014; M. Brown, M. Moran., & M. Withers, personal communication, August 5, 2014): (a) race/ethnicity, (b) social class, (c) relationship status, (d) pregnancy status, (e) child custody status, (f) stage of recovery, and (g) county of origin (see Appendix A). This information will be gleaned from the health care record and informant self-disclosure and recorded by the researcher on a demographic data form. The researcher will aim for a sample size of 20 to 30 informants to achieve the goal of maximum variation.

Data Collection Procedures

Institutional review board (IRB) approval will be sought from Duquesne University and Eastern Maine Medical Center; data collection will commence upon these approvals as well as permission received from physician and nursing leadership at Eastern Maine Medical Center. Data will be collected primarily through participant observation, oral accounts and formal interviews, and artifact review. It is anticipated that data will be collected over several months. A reflective journal will be maintained by the researcher throughout the data collection, preparation, organization, and analysis process to record memos regarding methodological issues and decisions and personal impressions as well as to facilitate thinking and stimulate insight (Maxwell, 2013).
**Participant recruitment.** A letter explaining the study and inviting eligible women to participate will be drafted by the researcher for distribution by providers of care for the women. Such providers will include but not be limited to prenatal care practices and substance use services. Included with the letter will be a postcard with a self-addressed, stamped envelope which a woman can return to the provider if interested in being contacted post-delivery by the researcher during the mother’s and/or baby’s hospitalization at Eastern Maine Medical Center. This information will be shared only with the primary team responsible for care of the women and infants at Eastern Maine Medical Center; the researcher will have no prior knowledge of the women’s identities. The letter will explain that the researcher will be notified by the perinatal health care team when she has delivered her baby; only then will the participant be contacted by the researcher for informed consent, Health Insurance Portability and Accountability Act (HIPAA) Privacy release, and data collection.

Due to the vulnerability of this population, it is important to maintain the privacy of potential informants until they have agreed to be contacted. Contacts have been made with several prominent practice directors (Marjorie Withers, LCPC, Director, Community Caring Collaborative; Mark Brown, MD, Chief of Pediatrics & Neonatology, Eastern Maine Medical Center), and through meetings, e-mail, and telephone communication the researcher has delineated the research purpose and plan to conduct the study with women in their service areas. They have given support for the study and have arranged contacts with professionals working in the field who will be instrumental as gatekeepers in identifying potential informants and facilitating recruitment as previously outlined.

Potential informants will be approached inconspicuously at the hospital as facilitated by the gatekeepers and permission will be requested to discuss the study. Care will be taken to
assure privacy during this discussion. Discussions and subsequent interviews will take place in the woman’s private hospital room or in a private office designated by the gatekeepers, depending on the woman’s preference and comfort. The presence of family members and friends will influence the discussion timing and location. The study aim will be explained to the informant as follows: “I am interested in learning more about how women who have infants and are also dealing with substance use feel about the care they received during their pregnancy and since the baby was born. I am also hoping to learn more about how this care has affected mothers bonding with their babies. I want to learn all this so nurses can take better care of women and their babies”. The details of data collection and management will be discussed and questions will be answered, followed by written consent and HIPAA release. Women consenting to participate in the study will be offered a gift card to a local merchant.

**Participant observation.** Participant observations occur in social situations identified by places, people, and activities (Spradley, 1980). As noted by Hammersley and Atkinson (2007), selection of settings and cases in ethnographic research often occurs on the basis of foreshadowed problems and pre-fieldwork, and the researcher may not be able to stipulate these details in advance. Observations will take place in the perinatal units at Eastern Maine Medical Center facilitated by the providers with whom the researcher communicated during pre-fieldwork, specifically the neonatologist and social worker who care for the women and their babies at Eastern Maine Medical Center.

Participation may occur on a spectrum from non-involvement to complete involvement as an ordinary participant (Spradley, 1980). It is anticipated that participation in the settings described would be passive to moderately engaged, depending on the comfort and trust of the participants and the researcher’s familiarity with the activities. The researcher understands that
practitioners and staff may have concerns about inclusion in these observations. The cultivation of good field relations includes impression management and addressing concerns of those working in the field (Hammersley & Atkinson, 2007). A fact sheet about the study will be drafted by the researcher for distribution to staff and the researcher will be available to answer questions and concerns (Appendix B1). Family and friends may express similar concerns; a fact sheet will be available for them, as well (Appendix B2).

As noted by several authors, pregnant and parenting women with substance use disorders have been reported to experience stigma, fear, shame, and guilt, as well as high rates of co-occurring mental health problems, trauma, and post-traumatic stress disorder (Brandon, 2014; Haug, Duffy, & McCaul, 2014). Therefore, it is important to begin any field observation as unobtrusively yet transparently as possible to cultivate trust. Informal questions may be asked of practitioners and staff prior to approaching potential participants to understand and clarify observed behaviors and practices.

Observations also range from broadly descriptive to more narrowly focused and selective. Observations may occur over the span of several days while the woman and/or her baby are hospitalized and will be centered on: (a) participant behavior and demeanor during interviews and in the hospital environment; (b) interactions between participants and others in the environment; (c) behavior and demeanor of others in the environment during interactions with the participants; and (d) the environment and context of care. The purpose of such observations will be to enhance the researcher’s understanding of informant reports. An observation guide will be used to focus attention on only the most salient observations (see Appendix C). Observations will be recorded through handwritten jottings and detailed field notes while in the practice settings if this can be accomplished discreetly. Descriptions may also be spoken into a digital
recorder when no participants are present and then transcribed into written fieldnotes for analysis. Jottings and fieldnotes will be reviewed immediately following each observation and amended as needed to ensure completeness and accuracy and to facilitate validation of findings (Maxwell, 2013).

**Oral accounts and formal interviews.** Spradley (1979) defines speech events as casual conversations and formal interviews which may serve to validate observations. In this study, the purpose of oral accounts and formal interviews will be to glean the women’s accounts of their experiences and perceptions of the care they received during their pregnancy and throughout their hospitalization as well as what factors of that care may affect their ability to bond with their infant.

Three main types of interview questions (descriptive, structural, and contrast) will be used and will be structured as suggested by Spradley (1979). Descriptive grand tour questions are loosely structured and allow the informants freedom of expression; an example would be: “Can you tell me about the care you received during your pregnancy?” Grand tour questions may then lead to mini-tour, example, experience, and native-language questions. Examples include: “Can you describe the process of making that appointment?” “Can you give me an example of a time you felt accepted/judged?”, “What are some of the experiences you’ve had trying to make appointments?”, and “How would you refer to someone who made you feel that way?” Structural and contrast questions are more directive and may be used for additional clarification; examples of such questions may include: “What is the process for scheduling appointments?” and “How was that experience different from the one you described previously?” An interview guide will be used to frame the more general research questions; more specific questions will evolve as the oral accounts and interviews progress (Appendix D).
Oral accounts and formal interviews will be recorded through handwritten notes and digital recorder, depending on the comfort of the informant. Interviews will likely vary greatly in length, depending on informant comfort and any time constraints. Digital recordings will be transcribed verbatim by an experienced professional transcriptionist as soon as possible after each interview. Additionally, all recordings, the transcripts, and the fieldnotes will be reviewed by the principal investigator as soon as is feasible to ensure completeness and accuracy. Process notes will be written following interviews to record observations such as body language, facial expressions, and general impressions.

**Artifact review.** Data in the form of documents and material artifacts may provide additional information about study settings and serve to either corroborate or challenge information from observations or informants (Hammersley & Atkinson, 2007). These material goods may take the form of agency records, informational literature, educational brochures, and aesthetic features of settings. After consent, pertinent demographic data and relevant health and social information, such as pregnancy status, self-reported/laboratory confirmed substance use, and child custody, will be accessed from agency records (Appendix E). Samples of publicly available information relevant to the study, such as pamphlets and brochures, may be gathered. Details of aesthetic characteristics of the setting, such as posters, signage, and artwork, may be recorded through handwritten notes or digital audio or video recording depending on the propriety to the situation.

**Plans for Data Analysis**

Analysis of ethnographic data is an evolving and iterative process, occurring concomitantly with data collection, preparation, and organization to make meaning and search for patterns (Hammersley & Atkinson, 2007; Spradley, 1979). Fieldnotes and transcriptions will
be reviewed and proofed against recorded data for accuracy and to serve as preliminary analysis
to guide subsequent data collection (Sandelowski, 1995a). All data will be entered into the
current version of NVivo computer-assisted qualitative data analysis software (CAQDAS) for
organization and assistance with analysis.

Once entered, data will be coded, or categorized, according to the process described by
Maxwell (2013). Coding labels are applied to units or segments of data that appear significant or
relevant in some way and are then explored and compared both within and between cases and
categories. Organizational categorization is the broadest level of ordering the data and may be
established prior to observations and interviews. The participant characteristic matrix (Appendix
A) will facilitate organization of cases for later comparison. As data collection progresses,
constant comparison will be used to create substantive (descriptive) and theoretical (abstract)
categories; annotations and analytic memos will be written to assist with this process and
subsequent comparison within and between cases. Substantive categories reflect the “emic”
view, informant perspectives in their own words taken from recorded data. Theoretical categories
emerge from the researcher’s “etic” interpretation of the data. Data matrices will be developed
from the coding schema to organize and display categories and establish emerging themes.

Validity is related to the accuracy of interpretation of the data and is an important step in
analysis. Creswell (2009) proposed the terms trustworthiness, authenticity, and credibility to
describe validity and suggested a number of validation strategies which are reiterated by
Maxwell (2013). Triangulation involves collection of information from a variety of information
sources to build justification of themes, which are enumerated in the procedures for data
collection. Documentation and analysis of observations, interviews, and artifacts will contain
thick, rich description of data. Feedback, also known as respondent validation or member
checking, will be solicited from informants to determine accuracy of conclusions. Reflective journaling will serve to both document analytic decisions and identify possible personal biases. Although this researcher has some experience with this population, a relatively unfamiliar study setting has been chosen to promote a more objective stance. A search for negative or discrepant information adds to the credibility of the findings and will be addressed through discussion of impressions with dissertation committee members. Additionally, notes, transcripts, and access to CAQDAS files will be shared with dissertation committee members to facilitate review and recommendations.

**Study Limitations**

An ethnographic study of this population may pose certain limitations related to the reliability and authenticity of information obtained from the informants. The participant pool may be skewed by gatekeeper bias toward informants deemed more reliable or favored in some way. Reactivity, or observer effect, may influence how forthright the women might be. Additionally, the sample size may be restricted due to fluctuations in women meeting inclusion criteria, their availability and willingness to participate, and attrition. Such limitations will be addressed by the researcher remaining flexible and opportunistic in observations. Casual conversations and formal interviews will be augmented with observational and artifact data. Interviews questions will be varied and structured to encourage honesty while remaining sensitive to the informants’ vulnerability.

**Potential Procedural Problems and Strategies to Address**

A number of constraints may be anticipated when conducting fieldwork with a vulnerable population, particularly within the limitations posed by doctoral dissertation work. Given the complex challenges of this population, recruitment and retention may be difficult, which is
closely aligned with development of rapport and establishing trust with both service providers and prospective informants. Prospective informants will be identified on the advice of those gatekeepers.

Informants who have consented to participate in the study may experience barriers to completing the study. The mothers who did not deliver their babies at Eastern Maine Medical Center or who have already been discharged without their babies may experience logistical challenges, such as undependable transportation and child care for other children. Women may also be dealing with challenges such as postpartum discomfort and fatigue, distressing family and social circumstances, and child protective services involvement. The researcher must be compassionate and flexible in the scheduling of appointments for formal interviews.

The researcher must be prepared to address disclosure of sensitive information or potentially illegal activities, particularly if such disclosure suggests child maltreatment. The informed consent process will include a discussion of mandated reporting. Additionally, the researcher will collaborate with the hospital social worker to anticipate potential disclosure. In cases that may not be straightforward, the researcher will consult with her dissertation committee chair.

**Timeline**

It is anticipated that once this proposal has been successfully defended and the study is approved, IRB approval will be sought by November 2014 and the study site secured by December 2014. Recruitment activities will commence and data collection will begin. Data collection will continue until data saturation or informational redundancy is recognized. Data analysis will begin immediately and continue throughout the project. Dissertation defense will occur once the final analysis has been completed. Final results of the study will be disseminated
through manuscript submission in a peer-reviewed journal upon successful defense. Due to the evolving nature of qualitative studies, the exact timeframe for dissertation defense and dissemination of results cannot be predetermined.

**Protection of Research Participants**

IRB approval will be obtained from Duquesne University and Eastern Maine Medical Center, Bangor, Maine. Directors of agencies and practices where potential informants will be recruited will be approached to obtain permission for letters to be drafted to be given to prospective informants. The issue of informed consent in qualitative research, particularly ethnographic studies where interaction with informants may vary over time, has been debated by a number of researchers (Munhall, 2012). The emergent nature of ethnographic research and the spectrum of researcher participation from passive observation to active involvement raise the questions of who must give written informed consent and when that consent is obtained. Munhall (2012) proposed the concept of *process consent* whereby permission is renegotiated with each interaction. Written informed consent will be obtained from informants upon initial contact and reaffirmed verbally with any subsequent interaction. HIPAA release will also be obtained prior to review of any agency records. Information sheets explaining the study will be distributed to all staff involved in the care of the prospective informants. Verbal consent will be obtained from persons not directly involved in the study but who may become part of the data collection through their interaction with prospective informants (such as friends and family members).

Potential risks to informants and participants include breach of anonymity and confidentiality. To minimize these risks, permission will be requested prior to any dialogue, and conversations and interviews will be conducted privately. All protected health information will be de-identified and each case will be assigned a number which will be used on all digital files,
transcripts, fieldnotes, and journal notes. All forms of data will be stored in a locked file cabinet accessible only to the principal investigator. Electronic files will be preserved on a secure password protected computer, and electronic transfer of data to the researcher’s dissertation chair will be accomplished through encrypted files. Digitally recorded data will be retained until analysis is completed; following completion of dissertation research, data will remain secure at Duquesne University School of Nursing for five years.

Registered nurses in the state of Maine are mandated to report to the Department of Health and Human Services any suspicion of child abuse, neglect, or exploitation. This places a limit on the assurance of confidentiality, which will be outlined in the informed consent process. The researcher acknowledges that such a justifiable breach of confidentiality may affect recruitment and retention of participants; however, it is imperative that child welfare take precedence over potential harm to participants (Fisher, 2009).

Informants may also be at risk for emotional distress by discussing their experiences. Informants will be reminded that any sharing of information is completely voluntary, that they can choose to withhold information or withdraw from the study at any time, that admission of use of illegal substances will not be revealed to anyone, and that any information shared will not influence their care. Should informants express any distress, referral will be made to the appropriate service provider.
References


## Appendix A: Potential participant characteristics

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A. Race/ethnicity
   1. White
   2. Native American
   3. Other

B. Social class
   1. Income
   2. Education
   3. Employment

C. Relationship status (includes all combinations of sexual preferences and partnership arrangements)
   1. Single, never married
   2. Single but previously married
   3. Married
   4. Committed but unmarried
   5. Other

D. Pregnancy status (gravidity/parity)
   1. Primiparous
   2. Multiparous

E. Child custody status (includes family and non-family custody arrangements)
   1. Fully retained custody
   2. Fully relinquished custody
   3. Shared custody

F. Stage of recovery
   1. Active recovery (adherent to MAT, no illicit substance use)
   2. Relapse (on MAT with continued illicit substance use)
   3. Pre-recovery (illicit substance use, no MAT)

G. County of origin
   1. Washington
   2. Penobscot
   3. Other
Appendix B1

Fact Sheet
(Postpartum and neonatal care - Hospital Personnel)

Duquesne University School of Nursing
Information about a Research Study

<table>
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<tr>
<th>IRB Study #</th>
<th>Consent Form Version Date:</th>
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**Title of Study:** Experiences and Perceptions of Postpartum Women with Substance Use Disorders Inclusive of Opioids Regarding Their Care

**Principal Investigator:** Debra Kramlich, MSN, RN, CCRN

**Duquesne University Department:** School of Nursing

**Study Contact Telephone Number:** xxx-xxx-xxxx

**Study Contact Email:** kramlichd@duq.edu

**Faculty Advisor:** Rebecca Kronk, PhD, MSN, CRNP

**Duquesne University Telephone Number:** xxx-xxx-xxxx

**Email:** kronkr@duq.edu

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**What are some general things you should know about research studies?**
You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

**What is the purpose of this study?**
The purpose of this research study is to better understand the experiences and perceptions of postpartum women with substance use disorders inclusive of opioids regarding their care.

**How many people will take part in this study?**
There will be approximately 20 to 30 women asked to participate in this study. Hospital personnel may also be observed. These personnel may be asked questions to help the researcher understand what is going on.

**How long will your part in this study last?**
You may be observed while engaging in normal activities and routines in the setting. You may be asked some informal questions to clarify information and help the researcher understand what is going on. Time spent to answer some questions should be approximately 10-20 minutes.
What will happen if you take part in the study
I will observe the women in the neonatal care area as they interact with their babies, family members, other mothers, and hospital staff. The focus of the observations will be on the women. I will not interfere in the women’s care in any way. I will take notes about the physical setting and what is happening during care.

I may ask you questions about your work with women who have experienced substance use disorders and their babies. I may also ask you to clarify activities that were seen or heard during my observations. This will be done only after the observations are completed. I will take notes about what you say. You do not have to answer any questions that you do not wish to answer, for any reason.

What are the possible benefits from being in this study?
Research is designed to benefit society by gaining new knowledge. Your participation is important to help healthcare providers learn about the experiences and perceptions of postpartum women with substance use disorders regarding the care they receive. You will not likely benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?
I do not anticipate you will experience any discomfort or risk from being observed or asked some informal questions.

How will your privacy be protected?
I will not use your name in any handwritten notes or audio recorded notes. Your name will not be used when presenting this research to others. You will only be identified in the researcher’s notes by your profession (e.g., nurse, physician, aide, social worker).

Will you receive anything for being in this study?
You will not receive anything for being in the study.

Will it cost you anything to be in this study?
There are no costs to you for being in the study.

What if you have questions about this study?
You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact me or my academic advisor using the contact information listed at the beginning of this form.

What if you have questions about your rights as a research participant?
All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at __________ or by email to ____________.

Thank you for helping me with this study.
Appendix B2

Fact Sheet
(Postpartum and neonatal care - Family)

Duquesne University School of Nursing
Information about a Research Study

IRB Study # Consent Form Version Date:

**Title of Study:** Experiences and Perceptions of Postpartum Women with Substance Use Disorders Inclusive of Opioids Regarding Their Care

**Principal Investigator:** Debra Kramlich, MSN, RN, CCRN
**Duquesne University Department:** School of Nursing
**Study Contact Telephone Number:** xxx-xxx-xxxx
**Study Contact Email:** kramlichd@duq.edu

**Faculty Advisor:** Rebecca Kronk, PhD, MSN, CRNP
**Duquesne University Telephone Number:** xxx-xxx-xxxx
**Email:** kronkr@duq.edu

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**What are some general things you should know about research studies?**
You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

**What is the purpose of this study?**
The purpose of this research study is to better understand the experiences and perceptions of postpartum women with substance use disorders inclusive of opioids regarding their care.

**How many people will take part in this study?**
There will be approximately 20 to 30 women asked to participate in this study. Hospital personnel and family members may also be observed in the hospital setting.
How long will your part in this study last?
You may be observed while in the hospital setting (most likely your family member’s hospital room or in the common family area). You will only be observed when with your family member.

What will happen if you take part in the study
I will observe the women in the neonatal care area as they interact with their babies, family members, other mothers, and hospital staff. The focus of the observations will be on the women. I will not interfere in the women’s care in any way. I will take notes about the physical setting and what is happening during care.

What are the possible benefits from being in this study?
Research is designed to benefit society by gaining new knowledge. Your participation is important to help healthcare providers learn about the experiences and perceptions of postpartum women with substance use disorders regarding the care they receive. You will not likely benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?
I do not anticipate you will experience any discomfort or risk from being observed.

How will your privacy be protected?
I will not use your name in any handwritten notes or audio recorded notes. Your name will not be used when presenting this research to others. You will only be identified in the researcher’s notes by your relationship to the patient (e.g., husband, sister, friend).

Will you receive anything for being in this study?
You will not receive anything for being in the study.

Will it cost you anything to be in this study?
There are no costs to you for being in the study.

What if you have questions about this study?
You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact me or my academic advisor using the contact information listed at the beginning of this form.

What if you have questions about your rights as a research participant?
All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at __________ or by email to __________.

Thank you for helping me with this study.
Appendix C: Observation guide (adapted from Spradley, 1980)

Focus areas for observations:

1. Participant behavior/demeanor during interviews
2. Participant behavior/demeanor in the hospital environment
3. Participant interactions with staff
4. Participant interactions with newborn
5. Participant interactions with friends/family members
6. Participant interactions with other patients (if appropriate – as an example, if several consenting participants happen to be interacting in common areas on the unit, this interaction would be observed)
7. Staff interactions specifically involving consenting participants (as an example, change of shift report, interdisciplinary report)
8. Behavior/demeanor of others in the environment during interactions with participants
9. Contextual/environmental factors impacting behavior and interaction
Appendix D: Interview guide (adapted from Spradley, 1979)

Interviews will start with broad, open-ended grand tour questions; subsequent questions will be based on the answers to the grand tour questions.

Topic areas to be covered:

1. Care received during pregnancy
   a. Experiences of making appointments
   b. Experiences of getting to appointments
   c. Interactions with care providers

2. Hospital experiences
   a. Experiences of being in the hospital
   b. Experiences of getting to the hospital (if mother discharged and baby still there)
   c. Interactions with care providers
   d. Preparation for discharge
Appendix E

*Medical Record Data Extraction Guide*

Demographics:

- Age ______
- Race/ethnicity _________________
- County of origin _________________
- Education ______________________
- Employment status ______________________
- Income level (may be deduced from public assistance status) _______________
- Marital status ______________________
  - Others in Household
    - None ______
    - Partner ______
    - Children ______
    - Others ______
- Child custody status ______________________

Medical Information:

- Pregnancy status _________________
- Substance(s) used __________
- Stage of substance use recovery _______________
Chapter 4 is the final peer-reviewed manuscript as published in *The Qualitative Report*:


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**Challenges and Facilitators of Recruitment: Lessons Learned from Conducting a Focused Ethnography in a Vulnerable Rural Population**

Debra Kramlich, Rebecca Kronk, and Karen Jakub

Duquesne University

**Abstract**

The purpose of this article is to describe the challenges and facilitators of recruitment encountered in an ethnographic dissertation study of rural women with substance use disorders during the perinatal period. While the study is being conducted in the hospital setting post-delivery, potential participants who meet inclusion criteria are identified by practitioners through a number of perinatal practices within a wide geographic area as well as by inpatient social workers. Recruitment in this vulnerable and often socially disadvantaged population has been found to be challenging with regard to ethical approval, participant eligibility
Background

The first author (herein referred to in the first person) lives in a rural area in the northeastern United States identified as having one of the highest rates of prescription opiate drug misuse and neonatal abstinence syndrome (NAS) in the country (Hayes & Brown, 2012; Ko et al., 2016). As a registered nurse caring for newborns with NAS, I was concerned with this trend and sought to better understand the determinants of the issue. This interest led to a search of the evidence and subsequent focus of the current dissertation study. The second and third authors serve as my advisor/dissertation committee chair and methods expert, respectively, providing continuous consultation throughout the process.

Women with substance use disorders continue to face numerous impediments to accessing available resources for recovery and parenting support (Fraser, Barnes, Biggs, & Kain, 2007). Substance use disorder in women is associated with increased prevalence of mental illness, histories of physical and sexual abuse, and medical and social problems (Milligan et al., 2010). Pregnant and parenting women with substance use disorders have been reported to experience stigma, fear, shame, and guilt, as well as high rates of co-occurring mental health problems, trauma, and post-traumatic stress disorder (Brandon, 2014; Haug, Duffy, & McCaul, 2014). Studies have shown that rural healthcare disparities, specifically those related to poverty,
further complicate access to treatment, and societal stigma and lack of resources further contribute to the negative outcomes for both mother and child (Lander et al., 2013). This is particularly concerning in light of findings that protective factors, such as caretaker involvement and family resources, may moderate the negative effects of substance use on the developing child (Bada et al., 2012).

Of newborns prenatally exposed to addictive substances, 50% to 90% will experience some degree of neonatal abstinence syndrome (NAS), a term applied to a constellation of symptoms characterized by dysregulation and hyperirritability of the central and autonomic nervous, respiratory, and gastrointestinal systems (Sublett, 2013). Symptoms are treated with a combination of pharmacologic and non-pharmacologic therapies typically requiring specialized neonatal care with an overall mean length of hospital stay of 16 days, increasing to 23 days for newborns requiring pharmacologic treatment (Patrick, Davis, Lehman, & Cooper, 2015). Despite increasing attention on this problem and evidence-based recommendations (Dow et al., 2012; Goettler & Tschudin, 2014; Hudak & Tan, 2012; Jansson, Velez, & Harrow, 2009; Lucas & Knobel, 2012; Queensland & Neonatal Clinical Guidelines, 2010; Winklbaur et al., 2008), management remains inconsistent, hospital length of stay has not declined, and expenditures continue to rise (Patrick et al., 2015).

Perinatal substance use directly impacts two constituencies, the woman and her offspring, and therefore the problem has been examined from a variety of perspectives. Numerous quantitative studies have been conducted to identify factors regarding maternal drug use which may be predictive of neonatal outcomes, such as the type and amount of medication-assisted treatment for opioid use. Several retrospective studies associated higher doses of maternal methadone dose with higher incidence of neonatal abstinence syndrome as well as duration of
neonatal abstinence syndrome treatment (Dryden, Young, Hepburn, & Mactier, 2009; Lim, Prasad, Samuels, Gardner, & Cordero, 2009). These findings contradicted those of other studies, which reported no such correlation (Pizarro et al., 2011; Seligman et al., 2008). One prospective cohort study also concluded that the incidence and duration of neonatal abstinence syndrome was not affected by methadone dose (Cleary et al., 2012). McCarthy, Leamon, Stenson, and Biles (2008) noted that infants of women who began methadone treatment prior to conception had better outcomes compared with those whose mothers began treatment mid-pregnancy.

Similar conflicting results have been noted in studies comparing maternal methadone and buprenorphine medication-assisted treatment. Several studies suggested improved neonatal outcomes, such as lower incidence and severity of neonatal abstinence syndrome, in infants exposed to buprenorphine as compared with methadone exposure (Binder & Vavrinkova, 2008; Coyle et al., 2012; Gaalema et al., 2012; Kakko, Heilig, & Sarman, 2008; Salisbury et al., 2012). Other studies found no such differences (Jones et al., 2010; Welle-Strand et al., 2013). Patel and colleagues (2013) noted no difference in neonatal abstinence syndrome expression when comparing infants exposed to buprenorphine to those exposed to illicit opiates. The concomitant use of illicit substance, as well as alcohol and tobacco, with medication-assisted treatment seems to confound the results of these studies (Blandthorn, Forster, & Love, 2011; Kaltenbach et al., 2012).

Many of the aforementioned studies have been retrospective reviews of clinical data or secondary analyses of data from larger studies. Findings of several prospective studies regarding severity of neonatal abstinence syndrome relative to type and dose of maternal substance or medication-assisted treatment have been equally conflicting. Winklbaur-Hausknost and colleagues (2013) found that maternal treatment resulting in reduced illicit drug use throughout
pregnancy had no influence on neonatal outcomes in two separate studies. In a systematic review and meta-analysis, Cleary and colleagues (2010) found no clear link between neonatal abstinence syndrome severity and methadone dose. Similarly, Thajam, Atkinson, Sibley, and Lavender (2010) found no correlation between amount and type of fetal opioid exposure and neonatal abstinence syndrome expression in eight of the 10 studies they reviewed. In a systematic review of the literature, Milligan and colleagues (2010) noted that quantitative and interventional studies have yet to produce sustained, efficacious improvement in outcomes for these mothers and children. It may be concluded that a singular focus on drug type and dose fails to account for the complex array of factors contributing to neonatal outcomes.

Literature regarding care of the newborn with neonatal abstinence syndrome has been equally inconclusive (Dryden, Young, Hepburn, & Mactier, 2009; Sublett, 2013; Velez, Jansson, Schroeder, & Williams, 2009). It appears that factors other than maternal medication-assisted treatment, such as maternal-infant bonding, have greater influence on neonatal outcomes:

- Care of neonatal abstinence syndrome infants on the postpartum unit with their mothers, rather than in the NICU, resulted in shorter duration of treatment and hospital stay (Saiki, Lee, Hannam, & Greenough, 2010).
- Infants discharged home on a methadone weaning protocol with support from a multidisciplinary team, as opposed to a traditional inpatient methadone wean, resulted in shorter hospital stays and reduced cost (Backes et al., 2012; Smirk, Bowman, Doyle, & Kamlin, 2014).
- Substantial breast milk intake significantly reduced severity of neonatal abstinence syndrome symptoms, delayed the onset of symptoms, and decreased
the need for pharmacologic treatment (Abdel-Latif et al., 2006; Dryden et al., 2009).

Early and adequate prenatal care has been shown to mitigate the negative effects of substance use disorders during pregnancy (Wright, Schuetter, Fombonne, Stephenson, & Haning, 2012). Studies of early identification, engagement, and treatment retention of pregnant women using integrated substance abuse and perinatal services are showing potential benefits in the promotion of maternal-infant bonding (Burns, Mattick, Lim, & Wallace, 2007; Mayet, Groshkova, Morgan, MacCormack, & Strang, 2008; Meyer et al., 2012; Racine, Motz, Leslie, & Pepler, 2009; Suchman, Pajulo, DeCoste, & Mayes, 2006; Taylor et al., 2012). In a recently published systematic review, Jumah (2016) identified location as a major factor in accessibility to treatment for rural, opioid-dependent pregnant women, yet she also noted that gender issues and stigma remain largely unaddressed in the literature. Studies of harm-reduction approaches in Britain, the Netherlands, and Canada have shown positive outcomes in terms of lower rates of child protective involvement and withdrawal symptoms in infants (Boyd & Marcellus, 2007). Pilot studies in the U.S. have shown similar results (Wright et al., 2012). The programs described in the literature have used a variety of interventions, including integrated prenatal and substance abuse services and motivational incentives, so it is unclear which aspects of a harm-reduction approach contribute to outcomes. A focused review of the literature, highlighting studies of perinatal substance use disorders that included health care provider-mother-infant relational perspectives within various care delivery models, concluded that published studies have yet to identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes (Kramlich & Kronk, 2015).
It would seem from this review of the literature that the voice of pregnant and parenting women with substance use disorders has been minimally included in prior studies as evidenced by the relatively limited number of qualitative studies. Woodley and Lockard (2016) noted that qualitative research methods may provide more opportunities to engage with marginalized groups through personal connections as compared to quantitative methods, therefore informing my choice of study design. My dissertation study aims to address the gaps in the literature by exploring the women’s experiences and perceptions of care, leading me to ask several questions: a) What are the experiences and perceptions of women with substance use disorder regarding the care they received during their pregnancy and through their infants’ hospitalization? and b) How have their experiences supported or inhibited their ability to bond with their baby? For research purposes, pregnant women, human fetuses, and neonates are identified as vulnerable populations and are afforded additional protection (Protection of Human Research Subjects, 2001). Additionally, Flaskerud and Winslow (1998) suggest that persons who are poor, subjected to discrimination, intolerance, subordination, stigma, politically marginalized, disenfranchised, and denied human rights may be considered vulnerable. Studies have shown that women with substance use disorder, particularly those who are poor, indigenous, and members of racial minorities, “are the most vulnerable to arrest, child apprehension, and poor health outcomes” (Boyd & Marcellus, 2007, p. 14). Access to and engagement of participants from vulnerable, socially disadvantaged populations have been found to be challenging due to mistrust of research/researchers and fear of authority, public exposure, and potential harm, stigma, mistreatment, or exploitation (Bonevski et al., 2014). For the reasons noted above, pregnant and parenting women with substance use disorder may be reluctant to participate in research studies due to the perceived and real risk of prosecution and incarceration, particularly in light of the
criminalization of drug use during pregnancy in several states (Miranda, Dixon, & Reyes, 2015). Gatekeepers may serve as both barriers to and facilitators of participant recruitment; the relationship between vulnerable individuals and the health professionals caring for them may potentially inhibit the recruitment process (Bonevski et al., 2014; Namageyo-Funa et al., 2014).

**Study Purpose and Design**

Women living in remote rural geographic areas with fewer resources who may experience greater obstacles to accessing services have been underrepresented in prior studies. An exploration of the experiences of women with substance use disorder regarding the care they received for pregnancy, parenting, recovery, and psychosocial and economic issues is being undertaken to identify unmet needs. It is hoped that results of the study may contribute to a better understanding of the determinants of the problems associated with perinatal substance use to inform development of efficacious models of care. These findings may be of particular interest to the health care and psychosocial support services professionals who care for these women, as well as policymakers tasked with addressing issues related to substance use disorders.

Ethnographic studies are designed to understand a culture by learning from the people within that culture through contextualized examination of their speech, behavior, and artifacts (Spradley, 1979). Focused ethnography, defined by Munhall (2012) as “the study of small elements of one society, group, or culture; focus on [a] distinct problem within a specific context among a small group of people” (p. 291), may be particularly suitable for the study of vulnerable, stigmatized groups and sensitive issues (Li, 2008; Stahler & Cohen, 2000). The topics of inquiry for a focused ethnography are pre-selected, and the short-term yet time-intensive nature of observations are conducive to the study of sensitive topics and complex issues
such as substance use disorders in women during the perinatal period within the limitations imposed by dissertation studies.

This study is being conducted at a large tertiary care hospital serving the northern two-thirds of a state in the northeastern United States. This encompasses a relatively large geographic range, with towns located in the farthest reaches of the service region situated well over 100 miles from the hospital. The area is also identified as having the lowest population density and highest rates of poverty in the state, one of the highest rates of opiate addiction in the country, and a Native American population greater than five times the national average. These variables have previously been noted to be barriers to access to adequate resources for substance use disorder recovery, pregnancy, and parenting support. The majority of pregnant women with substance use disorders in the area deliver their babies at this hospital. Three smaller hospitals located 50 to 100 miles from the hospital provide obstetric services but do not provide care for unstable substance-exposed newborns; newborns delivered at one of those small hospitals, either anticipated or unplanned, who show signs of neonatal abstinence syndrome in need of escalating medication-assisted treatment are transferred. Depending on the circumstances, the mother may or may not be transferred with the newborn; typically, the mother has been discharged from the hospital and must travel to visit the hospitalized newborn.

I engaged in preliminary exploration which provided background information to guide this study. Telephone conversations and personal meetings with various providers of care for these women as well as attendance at conferences and meetings where these individuals have spoken contributed to a greater awareness of the problem. These care providers identified potential sites for observation and processes for gaining access to informants in addition to anticipated challenges. The relationships cultivated with these professionals has enhanced my
ability to conduct the proposed study. This pre-fieldwork yielded what Hammersley and Atkinson (2007) termed a *foreshadowed problem*, the starting point for an investigation that will evolve as knowledge is gained through inquiry and observation.

This study is currently in progress; to date, primarily due to the recruitment challenges, only 13 participants have consented to interviews, observations, and data collection. The original prenatal recruitment method, as outlined below, yielded less than half of these participants; the remainder have been recruited postpartum through the hospital social worker subsequent to protocol amendment. Data in the form of transcribed interviews, participant observation, field notes, demographic data, and artifact reviews has undergone preliminary analysis and initial coding. Deeper analysis is currently underway and will involve constant comparison to create substantive (descriptive) and theoretical (abstract) categories. Data matrices will be developed from the coding schema to organize and display categories and establish emerging themes.

**Recruitment Challenges**

**Multiple Processes for Ethical Approval**

To conduct this study, ethical approval from several Institutional Review Boards (IRBs) was required, a process that took nearly eight months. IRB members, particularly at the study hospital, were concerned about maintaining privacy of the women during prenatal recruitment since special protection is required for research involving pregnant women, fetuses, and neonates (Protection of Human Research Subjects, 2001). After multiple protocol revisions and two full hospital IRB reviews, it was agreed that a researcher-designed informational flyer would be made available to eligible women in the perinatal practices. Women interested in the study would give permission for me to be contacted by the hospital social worker after delivery.
to initiate informed consent, Health Insurance Portability and Accountability Act (HIPAA) Privacy release, and subsequent data collection.

The ethical approval process itself required a certain degree of gatekeeping, consistent with the findings of Walker and Reed (2011). The university IRB requested letters of agreement from the four perinatal practices to allow and participate in recruitment; the hospital also needed to provide a letter of agreement for the study to be conducted, separate from their own IRB approval process. For a variety of reasons, it took over three months to receive the letters.

As noted by Walker and Reed (2011), gatekeepers of ethical approval for research in vulnerable populations and sensitive subjects can serve as facilitators and barriers for the protection of their organizations and participants. Reviewers of the original study protocol requested that researcher-developed fact sheets for gaining verbal consent by hospital personnel and participants’ family and friends for observation during data collection be eliminated, deeming them confusing and unnecessary. The hospital’s IRB, however, expressed concern with the absence of a verbal consent process for non-participant observations, so the fact sheets were reinstated. Additionally, the method of distribution of the research information flyer at the perinatal practices evolved with each IRB review. The first reviewers were uneasy with the idea that eligible participants would be identified and given a flyer by practitioners due to negative experiences reported during previous full IRB protocol reviews, the details of which were not disclosed. They suggested instead that recruitment materials with researcher contact information be placed in waiting areas and examination rooms. The hospital IRB, on the other hand, disliked that procedure and asked that practitioners hand-deliver to eligible women the recruitment flyer with a pre-addressed stamped envelope for return to me. The recruitment process, therefore, came full circle.
The extended process for ethical approval as well as the time lapse between perinatal practice site commitment, subsequent initiation of recruitment, and postpartum data collection appear to have negatively impacted recruitment. As will be noted, practitioners seemed to forget recruitment procedures, eligibility criteria, or the study itself, or lose the recruitment materials. Additionally, the reliance on busy practitioners to facilitate recruitment due to privacy concerns, rather than direct recruitment by the researcher, may also reduce the potential participant pool. Lack of time and gatekeeper bias toward participants deemed more reliable or favored in some way may also skew the participant pool. My experience is consistent with challenges noted by Bonevski et al. (2014) and Namageyo-Funa et al. (2014).

Ineligibility

One inclusion criterion for the study is a personal substance use history inclusive of opioids, whether that be past or current use of illicit substances, misuse of prescription opioids, or engagement in opioid-replacement therapy, in recovery or relapsing. Several of the women who returned flyers early in the process did not in fact have a personal substance use history. They indicated that they misread or misunderstood the criteria for inclusion in the study and thought having a friend or relative with a substance use history would qualify them.

Women to be considered for the study also need to be currently pregnant since informed consent and data collection commences once the woman delivers her baby. Several women returning flyers, when asked about their expected due dates, responded that they had delivered a number of months prior. This discovery illuminated a limitation of the study which did not allow access to women once they and their baby were discharged from the hospital.
Unavailability

Given the demographic profile of the women most likely eligible for the study (rural, higher rates of poverty, relapsing nature of substance use disorder), it was not surprising that I was never able to reach three of the women who returned flyers despite multiple attempts. This is not an unusual phenomenon (van Wijk, 2014). Wireless coverage in the northern part of the state is often unreliable. Residents turn to web-based service and prepaid phones for numerous reasons. Economic instability may cause unpaid bills and disconnected service. Lapses in judgment and avoidance of law enforcement also may result in full voice mailboxes and unreturned calls. In one case, the message on every attempt was “number unreachable.” Multiple voice messages left over a period of weeks, with the other two potential participants, were never returned.

Practice Change

When the study was initially proposed, all babies born with any addictive substance exposure in the northern part of the state were automatically transferred to the large hospital where the study was approved. In the time between study proposal, IRB approval, and commencement of recruitment, practices at the smaller hospitals evolved. Substance-exposed babies not requiring pharmacologic treatment were being retained for observation at the small hospitals. One of the earliest flyers I received was returned by a woman whose first baby required transfer for observation and treatment; she was hopeful that this delivery would be different. Indeed, as it turned out, she and her baby were able to stay in their local community hospital, which was a positive outcome for them but the loss of a study participant.
Observed Anomalies

The recruitment flyers were color-coded by perinatal practice site to facilitate data collection and organization. I supplied what should have been sufficient numbers of flyers and pre-addressed stamped envelopes to each practice with the promise of more as needed. I maintained close contact with each practice to check on the status of the supply of flyers. Several months into recruitment, white flyers in envelopes not provided by me began to appear, some with stamps that had not been cancelled and appeared to have been left in my mailbox without going through the postal service. This was a bit unsettling, as I live well over 100 miles from the hospital and nearest perinatal practices. Coincidentally, all but one of those irregular returns were also from women with whom I could not connect. I again contacted the practitioners to reinforce the recruitment process, and the anomalies ceased.

Questionable Leadership Approval

After months of recruitment, I noticed that one of the recruitment sites had not yet yielded a returned flyer. This might not be unusual given that it is a small rural perinatal practice; however, the rate of perinatal substance use disorder in that county is among the highest in the state. Additionally, the senior administrator who had granted permission for recruitment was no longer at the hospital and the remaining administrators were unaware of the study, a finding that was revealed when I sought an amendment to the original study proposal. Unfortunately, this experience seemed to create enough uncertainty that the new senior administration elected to prohibit further recruitment efforts.

Recruitment Facilitators

I initially contacted perinatal practice leadership to delineate the research purpose and plan to conduct the study with women in their service area. Hammersley and Atkinson (2007)
identify individuals with control over access to key informants or potential participants as gatekeepers and suggest that “identifying the relevant gatekeepers is not always straightforward” (p. 49). It has been noted that most health-related research studies of human participants involve collaboration with other health care professionals, and cultivating relationships with key administrative, clinical, and support staff is crucial to successful recruitment at the practice sites (Patel, Doku, & Tennakoon, 2003; van Wijk, 2014). I connected with the practice leaders through the process of community networking as described during preliminary work; often the support staff facilitated introductions with practice leaders. Leadership positions ranged from practice manager to hospital senior administration to health care practitioner. I then arranged initial meetings with the practitioners designated to identify potential informants and facilitate recruitment. I have attempted to maintain ongoing dialogue with these practices through personal meetings, e-mail, and telephone communication to further cultivate the relationships. This relationship-building has proven to be beneficial to the recruitment and data collection process.

I was aware of the potential constraints and limitations posed by study of a vulnerable rural population, including distance, time constraints, fluctuations in women meeting inclusion criteria, their availability and willingness to participate, and attrition. The relationships fostered with perinatal practitioners have mitigated the challenges, but my willingness to remain flexible, sensitive, and responsive to practitioner and participant needs has been equally important.

**Conclusions and Lessons Learned**

Conversations about the recruitment challenges with my advisor and the hospital social workers led to possible strategies to improve the recruitment process. The hospital social workers suspected many eligible participants were not being identified through the perinatal practices due to practitioner time constraints and confusion regarding the process, which is consistent with
other reports in the literature (Namageyo-Funa et al., 2014). They suggested direct recruitment in
the hospital and were willing to act as facilitators since they were already familiar with the study
and the population. Subsequently, amendments to the original study proposal were approved by
the IRB, and two participants have been recruited into the study.

Qualitative research takes time which can result in changes in practice patterns
(Hammersley & Atkinson, 2007) and which was certainly the case in the present study. The
revelation that the small rural hospitals were changing practice and beginning to retain
substance-exposed newborns for observation unless pharmacologic treatment was needed
motivated me to seek an additional protocol amendment to allow direct recruitment and data
collection at those rural hospitals. The IRB has approved the amendment and I have met with
senior hospital leadership and the perinatal unit nursing staff to initiate the process. A parallel
process was advancing slowly through the other rural hospital where a complete senior
leadership turnover has occurred and the original administrative approval was in question. I have
spent countless hours meeting in person and by conference calls with the current administration
to establish legitimacy and regain trust so the study may advance, to no avail.

A prior study by Namageyo-Funa et al. (2014) identified recruitment challenges,
including access to participants with the use of one recruitment strategy and limited interview
locations. These issues have become evident in the current study. The distribution of flyers
through gatekeepers at multiple sites, with diverse practices and processes, and the restriction of
data collection to the inpatient postpartum setting, seem to have undermined recruitment rather
than enhanced it. I anticipate that expansion of the study to the small rural hospitals may mitigate
some of those constraints. I did contact a number of substance use disorder treatment practices in
the service area on the advice of the social workers; they hypothesized that, although pregnant
women may receive integrated services for pregnancy and substance use, some women may slip through the cracks and be more easily recruited through a substance abuse program. Those practitioners politely declined to participate, indicating that they did not feel they could add to the current recruitment efforts. In consideration of the potential participants excluded due to lack of personal substance use history but who had friends or relatives with substance use disorders, I am now offering additional flyers and envelopes to study participants to share with contacts who may be interested. As indicated by several potential participants who were excluded due to remote delivery and hospital discharge dates, the ability to collect data in the postpartum period following hospital discharge may have further augmented informant recruitment. Although this strategy was considered in the original study proposal development, it was rejected for consideration of my safety. In hindsight, I would have contemplated other creative solutions, such as data collection at the same perinatal practices in the postpartum period rather than at private homes or other public places.

As noted by Maxwell (2013), the exploratory nature of ethnographic research requires a focused yet flexible approach to sampling and data gathering, which extends to participant recruitment and negotiating of relationships. Maxwell further asserts that “research relationships…can facilitate or hinder other aspects of the research design” (p. 91), and gatekeepers are included in the established relationships. Despite careful forethought and planning, I encountered numerous challenges in the recruitment process alone. It is hoped that through this reflection and reconsideration of methodological decisions, other qualitative researchers might avoid and be prepared for similar challenges. Persistence in overcoming barriers to inclusion of already marginalized and underrepresented populations in research studies may significantly impact their outcomes.
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CHAPTERS 5 AND 6

Chapters 5 and 6 comprise the final study findings and discussion in manuscript form for submission for publication to *Qualitative Health Research*.

Experiences and Perceptions of Rural Postpartum Women with Substance Use Disorders

Inclusive of Opioids Regarding Their Care

Debra Kramlich
Duquesne University

Keywords: Substance use disorder, rural women, pregnancy, neonatal abstinence syndrome

Abstract

Perinatal opioid use and neonatal withdrawal continue to rise rapidly in the face of the growing epidemic of opioid addiction in the United States, with rural areas more severely impacted. Despite several decades of research and development of practice guidelines, maternal and neonatal outcomes have not improved substantially. Through the voices of 13 rural women, this focused ethnography sought to better understand the experience of accessing treatment and care necessary for substance use disorder recovery, pregnancy, and parenting. Their personal accounts, reinforced by participant observation and artifact review, uncovered three domains with underlying themes: challenges of getting treatment and care (service availability, distance/geographic location, transportation, provider collaboration/coordination, physical and emotional safety), opportunities to bond (proximity, information), and relationships (respect, empathy, familiarity, inclusion, interactions with care providers). The findings highlight the need
for providers and policy makers to reduce barriers to treatment and care related to logistics, stigma, judgment, and lack of understanding of perinatal addiction.

**Background**

The United States is facing an escalating epidemic of opioid addiction. Since 1999, sales of prescription opioid analgesics and the rate of unintentional opioid-related overdose deaths have more than quadrupled, with women being affected more than men, disrupting the health, social, and economic welfare of the country (American Society of Addiction Medicine [ASAM], 2016; Senate Caucus, 2014; United States Department of Health and Human Services [HHS], 2016). Additionally, emergency room visits for nonmedical prescription opioid use increased by 183% from 2004 to 2011, and there was a 900% increase in individuals seeking treatment for prescription opioid addiction from 1997 to 2011 (Kolodny et al., 2015; Substance Abuse and Mental Health Services Administration [SAMHSA], 2013). The opioid epidemic has been accompanied by a sharp rise in perinatal exposure to opioids and subsequent increase in the incidence of neonatal abstinence syndrome from 1.5 to 6.0 cases per 1000 hospital births from 1999 to 2013 (Ko et al., 2016; Patrick et al., 2015; Pryor et al., 2017; Tolia et al., 2015). Data show disproportionately higher rates of perinatal substance use in rural areas, with three states (Maine, Vermont, and West Virginia) experiencing greater than tenfold increases and NAS incidence rates > 30 per 1,000 hospital births (Ko et al., 2016; Villapiano, Winkelman, Kozhimannil, Davis, & Patrick, 2016).

Neonatal abstinence syndrome (NAS) is a term used to describe the postnatal opioid withdrawal that may occur in up to 94% of newborns prenatally exposed to prescription or illicit opioids used by a woman during pregnancy (McQueen & Murphy-Oikonen, 2016). This statistic has been questioned due to the variability in identification of NAS as well as the influence of
factors such as polysubstance exposure, timing and level of exposure, and social determinants of maternal health (Clark & Rohan, 2015; Tolia et al., 2015). Clinical manifestation of NAS are related to dysregulation and hyperirritability of the central and autonomic nervous, respiratory, and gastrointestinal systems and can range from mild tremors and irritability to excessive weight loss and seizures (McQueen & Murphy-Oikonen, 2016; Sublett, 2013). Symptoms, which generally appear within the first five days of life, are treated with a combination of pharmacologic and non-pharmacologic therapies (swaddling, rocking, dark quiet room, pacifier) which have historically required specialized care in the neonatal intensive care unit (NICU). In one large national data set, the median length of hospital stay for NAS was reported to be 19 days (Tolia et al., 2015). Studies have suggested that excessive prenatal substance exposure may result in negative birth outcomes, including low birthweight and prematurity (Walton-Moss, McIntosh, Conrad, & Kiefer, 2009), delayed cognitive and motor development (Mactier, 2013), and increased child protective involvement (Lean, Pritchard, & Woodward, 2013), placing an even greater burden on health care, social welfare, and foster care services. In short, perinatal opioid use is a significant and costly public health issue (Patrick et al., 2012).

Perinatal substance use directly impacts both the woman and her developing child, and attempts to identify variables that may be predictive of neonatal outcomes have produced conflicting results. Studies have failed to demonstrate a predictable correlation between duration, timing, and total cumulative dose of prescription opioids on incidence or severity of NAS (Desai et al., 2015; Kraft, Stover, & Davis, 2016; Stover & Davis, 2015). A singular focus on drug type and dose seems unable to account for the complex array of factors contributing to neonatal outcomes. Additionally, no definitive evidence exists that opioid exposure alone results in negative long-term developmental outcomes in children; adverse childhood experiences and
toxic stress, which includes health disparities related to poverty and rurality, contribute to poor outcomes and may be mitigated by access to treatment and care (Holbrook & Nguyen, 2015; Shonkoff & Garner, 2012; Sword et al., 2009).

Studies focusing on care of the newborn with neonatal abstinence syndrome have been equally inconclusive. This is likely due, in part, to wide variations in care of opioid-exposed newborns and lack of standardized NAS treatment (Bogen, Whalen, Kair, Vining, & King, 2016; Kelly et al., 2016). Factors other than maternal medication-assisted treatment, such as maternal-infant bonding, seem to influence neonatal outcomes. Maternal-infant bonding has been described as an affective process with behavioral and biological indicators (Altaweli & Roberts, 2010; Bicking Kinsey & Hupcey, 2013). Breastfeeding and rooming-in during the immediate postpartum period has been found to promote bonding (Altaweli & Roberts, 2010), while physical or emotional separation of the mother from the newborn can inhibit bonding (Bicking Kinsey & Hupcey, 2013). Increased parental presence at the newborn’s bedside has been shown to increase rates of breastfeeding, reduce need for pharmacologic treatment, shorten duration of treatment, and decrease length of hospital stay (Cirillo & Francis, 2016; Hodgson & Abrahams, 2012; Hünseler, Brückle, Roth, & Kribs, 2013; Newman et al., 2015).

Early and adequate prenatal care has been shown to alleviate negative effects of substance use disorders during pregnancy (Wright, Schuetter, Fombonne, Stephenson, & Haning, 2012). Reduction of physical and psychological barriers to women’s access to adequate care is necessary to promote engagement (Lefebvre et al., 2010; Saia et al., 2016). Studies of early identification, engagement, and treatment retention of pregnant women using integrated substance abuse and perinatal services are demonstrating potential benefits in the promotion of maternal-infant bonding (Meyer et al., 2012; Taylor et al., 2012). Harm reduction approaches
combined with comprehensive care models (antenatal care, social services, and substance use treatment) are also showing promising results, such as increased prenatal care visits and patient satisfaction, improved coordination of care, and decreased drug and alcohol use (Goodman, 2015; Lander, Marshalek, & Sullivan, 2016; Marcellus, MacKinnon, Benoit, Phillips, & Stengel, 2015; Nathoo et al., 2015; Ordean & Kahan, 2011; Ordean, Kahan, Graves, Abrahams, & Boyajian, 2013). These programs have been found to be feasible, yet they are resource-intensive and are often located in urban academic medical settings (Mittal & Suzuki, 2015). While access to integrated care models may be limited in rural areas, coordination of community-based services is possible with careful planning (Jumah, Graves, & Kahan, 2015; Meyer & Phillips, 2015). The principles of harm reduction include strategies for reduction of the negative impact of substance use as well as advancement of the rights of people who use substances (Harm Reduction Coalition, n.d.). Such a philosophy requires care providers to set aside their own opinions and emotions regarding substance use and instead focus on re-engagement of the woman moving forward (Bartlett, Brown, Shattell, Wright, & Lewallen, 2013).

Programs for perinatal substance use disorders described in the literature have used a variety of interventions, including integrated prenatal and substance abuse services and motivational incentives (Ordean & Kahan, 2011; Ordean, Kahan, Graves, Abrahams, & Boyajian, 2013). Additionally, women and providers may perceive effectiveness of program components differently, so it is unclear which aspects of a harm-reduction approach contribute to outcomes (Kruk & Sandberg, 2013). A focused review of the literature, highlighting studies of perinatal substance use disorders that included health care provider-mother-infant relational perspectives within various care delivery models, concluded that published studies have yet to
identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes (Kramlich & Kronk, 2015).

Pregnancy is often the impetus a woman needs to seek treatment for substance use disorder, providing an opportunity for health and social care providers to engage these women (Krans, Cochran, & Bogen, 2015). Covington (2008) suggested that women-centered approaches to addiction and recovery should be gender-responsive, focusing on fostering connection between healthcare providers and the women. She described a model of integrated care for women framed in part by relational-cultural theory, which emerged from the work of Jean Baker Miller in the 1970s (Comstock et al., 2008). Relational-cultural theory posits that healing relationships are contextual, grounded in cultural and social identity, and that fear, shame, and mistrust challenge the development of connection (Comstock et al., 2008).

Identification of maternal substance use and engagement in treatment have been found to be challenging. Research has shown continued misunderstanding and negative attitudes of healthcare providers toward pregnant women with substance use disorders (Benoit et al., 2014; Maguire, Webb, Passmore, & Cline, 2012; Murphy-Oikonen, Brownlee, Montelpare, & Gerlach, 2010). Pregnant women with substance use disorders may delay or completely avoid seeking substance use treatment due to fears of judgmental or uncivil care provider reactions (Metz, Kochl, & Fischer, 2012). Some studies have indicated that universal screening of all women for drugs and alcohol may reduce socioeconomic and racial disparities, resulting in improved identification (Casper & Arbour, 2013; Eichel & Johannemann, 2014; Roberts & Nuru-Jeter, 2011), while others have suggested that fear of negative consequences related to discovery may preclude women from seeking prenatal care (Roberts & Nuru-Jeter, 2010). Societal stigma, low literacy levels, socioeconomic constraints, lack of resources, and rural healthcare disparities,
specifically those related to poverty, further complicate engagement and access to treatment and contribute to the negative outcomes for both mother and child (Alto & O'Connor, 2011; Jumah, 2016; Lander et al., 2013).

Social determinants of health, defined by the World Health Organization (WHO) as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” (WHO, 2017, para. 1), have been shown to impact both substance use and perinatal outcomes (Centers for Disease Control and Prevention [CDC], 2011; Kim & Saada, 2013). Women living in rural areas tend to have lower rates of early initiation of prenatal care, higher rates of pregnancy complications, and higher infant mortality rates than their urban counterparts, even when controlling for substance use (American College of Obstetricians and Gynecologists [ACOG], 2014). Additionally, socioeconomic disparities, such as poverty, unemployment, and low education level, which are more prevalent in rural areas, are associated with late or inadequate prenatal care and higher rates of adverse birth outcomes (ACOG, 2014; Blumenshine, Egerter, Barclay, Cubbin, & Braverman, 2010; Phillippi, 2009). Access to prenatal care in rural areas is often hindered by lack of resources (finances, transportation, childcare, availability); in women with substance use disorders, these barriers are compounded by fear of judgment and losing child custody (Phillippi, 2009). Rural areas are also much less likely to have adequate outpatient substance use disorder treatment services (Cummings et al., 2014). Such barriers to treatment for pregnant women related to limited accessibility and availability have been identified nationally (Jumah, 2016; Krans & Patrick, 2016).

The issue of maternal substance use and its negative impact on both the mother and the infant persists despite numerous studies from multiple perspectives. Published studies have yet to
identify the relative contribution of multiple risk factors to adverse outcomes as well as program components most likely to improve outcomes. The voice of pregnant and parenting women with substance use disorders seems to be largely missing in the literature as evidenced by the comparatively limited number of qualitative studies. This focused ethnography aimed to address that gap by exploring rural women’s experiences and perceptions of care to inform development of efficacious, holistic models of care to improve outcomes for these women and their children.

**Design and Method**

As noted by Woodley and Lockard (2016), qualitative research methods may provide more opportunities to engage with marginalized groups through personal connections as compared to quantitative methods, therefore informing the choice of study design. Focused ethnography, defined by Munhall (2012) as “the study of small elements of one society, group, or culture; focus on [a] distinct problem within a specific context among a small group of people” (p. 291), was particularly suitable for this study. The topics of inquiry for a focused ethnography are pre-selected, and the short-term yet time-intensive nature of observations are conducive to the study of sensitive topics and complex issues such as substance use disorders in women during the postpartum period. Participant observations, oral accounts, and formal interviews were used, with artifact review (media documentation of the sociopolitical environment influencing the women’s care) woven into this data, to better understand: (1) the experiences and perceptions of postpartum women with substance use disorders regarding the care they received during their pregnancy and through their infants’ hospitalization; and (2) how have their experiences supported or inhibited their ability to bond with their baby.

This study was conducted at a large tertiary care hospital serving the northern two-thirds of a state in the northeastern United States, an area encompassing seven counties and nearly
25,000 square miles. The majority of these counties are identified as rural as defined by the Federal Office of Rural Health Policy (Health Resources & Services Administration, 2017). Towns located in the farthest reaches of the service region are situated nearly 200 miles from the hospital. This area is known to have one of the highest rates of opiate addiction in the country, with over 12% of live births identified as substance-exposed (Hayes & Brown, 2012; Ko et al., 2016). The area is also identified as having the lowest population density and highest rates of poverty in the state and a Native American population greater than five times the national average (Maine Center for Disease Control and Prevention, 2103; Maine Department of Health and Human Services, 2008; Maine State Planning Office, 2012), factors noted to be barriers to access to adequate resources for substance use disorder recovery, pregnancy, and parenting support (Center for Substance Abuse Treatment [CSAT], 2009).

Institutional Review Board (IRB) approval was granted by the hospital to conduct formal interviews with participants, informal conversations with non-participants, and observations of the care environment and processes. Letters of agreement for participant recruitment were obtained from directors of agencies and practices where potential informants were to be recruited. Women were recruited for study participation in two ways, either through informational flyers shared by their prenatal providers or by the inpatient perinatal social workers after delivery. Women were offered a $25 gift card to a local department store to participate in the study, received upon completion of the formal interview and data collection. Written informed consent was obtained from participants upon initial contact and reaffirmed verbally with any subsequent interaction. Health Insurance Portability and Accountability Act (HIPAA) release was also obtained prior to review of any agency records. Information sheets explaining the study were distributed to all staff involved in the care of the prospective
informants. Verbal consent, supplemented with information sheets, was obtained from persons not directly involved in the study but who became part of the data collection through their interaction with prospective informants (such as friends and family members).

Women to be included in the study must have been pregnant (if recruited through prenatal practices) or have recently given birth (if recruited through inpatient perinatal social workers); English-speaking; at least 18 years of age and able to give informed consent; and had an identified substance use disorder that included current use of an opioid (legally prescribed medication assisted treatment, misuse of prescription opioid medications, or illicit opioids). A total of 22 referrals were received over a 10-month period; of those potential participants, five were deemed ineligible due to lack of personal history of substance use or already having delivered their baby. Four other women were never successfully contacted due to unreachable phone numbers, unreturned messages, or full voice mail-boxes despite multiple attempts. One potential participant, whose first baby was transferred to the tertiary care hospital from a small rural hospital, anticipated transfer of her second baby after delivery, as well. The practice changed, however, and her baby was retained for observation at the small hospital, therefore exempting her from participation.

Thirteen women were subsequently consented and interviewed, ranging in age from 22 to 40 years, with diverse demographics in terms of race/ethnicity, relationship status, child custody, and stage of addiction recovery (Table 1). Nine of the interviews were conducted shortly after delivery, during the five-day NAS observation period, with the remainder conducted nine days to five weeks postpartum while the infants were receiving pharmacologic therapy for NAS. Only about half of the women described living in stable housing with their partner and any other children. Five of the women were living with extended family or friends, one temporarily. Six of
the state’s 16 counties were represented, covering a geographic area of approximately 20,000 square miles, more than half of the state. Ten of the 13 women were multiparous and were therefore able to compare their current experiences with those of previous pregnancies. Five women had one or more psychiatric diagnoses that included depression (5), anxiety (4), bipolar disorder (4), and post-traumatic stress disorder (2); three of those women had also been diagnosed with attention-deficit/hyperactivity disorder.

Semi-structured interviews were conducted by the principal investigator in the mother’s or baby’s hospital room and typically lasted 30 to 40 minutes. An interview guide, adapted from Spradley (1979), was used to start with broad, open-ended grand tour questions focusing on treatment and care received during pregnancy and eventual hospital experiences; subsequent questions were based on answers to the grand tour questions. Interviews were digitally audio-recorded and transcribed verbatim by the researcher. Observations ranged from broadly descriptive of the general hospital environment to more narrowly focused and selective during participant interviews and were recorded through handwritten fieldnotes. The researcher was denied access to the full electronic health record, so limited demographic data were gathered from existing paper records. Other material artifacts, such as informational literature and educational brochures that may have been relevant to the study, were not found in public areas. Visual media reporting on the impact of perinatal substance use was collected and served to augment the formal interviews and observations. All protected health information was de-identified and each case was assigned a computer-generated random code which was used on all digital files, transcripts, fieldnotes, and journal notes to maintain participant confidentiality. Informed consent and HIPAA forms were stored separately from interview transcripts and all other forms of data.
Framework analysis was used to analyze all data, including transcripts, typed fieldnotes, and material artifacts, using various functions in Microsoft® Word, aided by NVivo 11® computer-assisted qualitative data analysis software. Data analysis proceeded according to the stages of framework analysis as described by Ritchie and Spencer (1994).

**Stage 1: Familiarization through immersion in the data**

Prior to transcription, recorded interviews were listened to for elements of speech, such as intonation, stress, tempo, rhythm, pause, pitch, and register. Typed fieldnotes and transcriptions were reviewed and proofed against handwritten and recorded data for accuracy and served as preliminary analysis to guide subsequent data collection and analysis. Transcripts and fieldnotes were read completely several times to get a sense of the whole (Sandelowski, 1995). Digital and material artifacts, such as news accounts, were also gathered and reviewed for relevance to the study. Jottings in margins served to create initial potential codes.

During this stage of familiarization, initial random coding of the interview transcripts revealed 25 emerging concepts. Phrases exemplifying the concepts were extracted from the transcripts and served as a catalyst for identification of a thematic framework. A key word count was conducted using the “find” function in Microsoft® Word; dictionary definitions aided in identification of synonyms and reduced the list from 25 to 13 concepts. Eighteen theoretical and philosophical approaches to care in this population, informed by the literature review, pre-fieldwork conducted by the researcher, and consultation with the dissertation committee chair and external member topic expert, were considered in the development of the thematic framework (Stage 2).
Stage 2: Identification of a thematic framework

As noted by Pope, Ziebland, and Mays (2000), “key issues, concepts, and themes by which the data can be examined and referenced [are identified] …by drawing on a priori issues” (p. 116). In this stage, findings from the literature and pre-fieldwork conducted by this researcher guided development of a thematic framework. Theoretical constructs and themes identified in previous studies were used to develop labels for subsequent data categorization, the researcher’s “etic” interpretation of the data.

Five theoretical and philosophical approaches were culled from the initial list based on the congruence of the theoretical constructs with the emerging concepts. Through an iterative process of comparing the terminology between the theoretical constructs and the emerging concepts, three of the approaches, harm reduction, relational-cultural theory, and maternal-infant bonding, surfaced as a sufficient thematic framework to categorize the data. Subsequently, a codebook was created to begin Stage 3, the process of indexing the data.

Stage 3: Indexing – thematic framework applied to the data in text

Index headings were created from the thematic framework and then applied to units or segments of data that appeared significant or relevant. Passages of data were highlighted and color-coded notes were made in the margins of transcripts, fieldnotes, and print artifacts. Annotations and analytic memos assisted with this process and subsequent comparison within and between cases.

Stage 4: Charting through data matrices

Data matrices were developed from the coding schema to organize and display categories. Substantive categories reflect the “emic” view, informant perspectives in their own words taken from recorded data. Abstraction and synthesis of verbatim text was then
summarized and passages were entered into charts to assist with subsequent mapping and interpretation.

Stages 3 and 4 (Indexing and Charting) proceeded almost simultaneously; as the transcribed and artifact data were reexamined through the lens of the coding themes, data matrices and summary charts were developed. Concurrently, a list of initial impressions was developed to solicit feedback from the ten participants who consented to being contacted after the culmination of data collection. From that list, a feedback letter to participants was created in a more readable and welcoming format. This process assisted in further refinement of the themes, as it became apparent that both facilitators and barriers or challenges existed within each of the themes.

**Stage 5: Mapping and interpretation to find patterns, relationships, and explanations**

The data matrices were further reviewed for themes and searched for patterns and possible explanations for barriers to and facilitators of care in this population. The original aims of the study and concepts generated from the data influenced this process, as suggested by Heath et al. (2012).

Validity of the data, also known as trustworthiness, authenticity, and credibility, was addressed through strategies described by Maxwell (2013). The principal investigator has experience with the population of interest but was relatively unfamiliar with the study setting, which may have reduced any researcher bias. Additionally, a reflective journal served to both document analytic decisions and identify possible personal biases. Data was collected from a variety of information sources (interviews, observations, artifacts) to build justification of themes; documentation and analysis of that data contained thick, rich description. Data matrices developed for data retrieved from all sources were shared with the dissertation committee chair,
and discussions with the chair and methods expert assisted in validation of impressions and search for any negative or discrepant information. Ten of the 13 women consented to follow-up after discharge; a member checking letter was sent to those 10 women, with only one response, and she concurred with the findings. Informational redundancy was recognized by the tenth interview; three additional interviews produced no new themes, and therefore data saturation was reached.

Findings

Participants described both supportive and challenging care experiences they encountered for their substance use disorder, their pregnancy, and their subsequent delivery and participation in their baby’s care. Their experiences and perceptions of care uncovered three domains with underlying themes: challenges of getting treatment and care (i.e., service availability, distance and geographic location, transportation, collaboration and coordination among providers, physical and emotional safety), opportunities to bond (i.e., proximity, information), and relationships (i.e., respect, empathy, familiarity, inclusion, interactions with care providers).

Challenges of Getting Treatment and Care

This domain focuses on the women’s narratives of the challenges they encountered in seeking substance use disorder treatment and pregnancy care; arranging and getting to appointments once they did find treatment and care; and dealing with multiple providers, often in separate locations. The women also recounted situations that helped them overcome any personal and logistical challenges they might have faced. The harm reduction literature provided a framework for themes that emerged within this domain.

Waiting to get treatment. The 13 women interviewed shared numerous challenges to accessing treatment, most notably with respect to availability of providers, compounded by
distance, transportation, and coordination of services. Five of the 13 women spoke of the challenges to access to treatment related to the lack of available services, insurance issues, and long waitlists. Three of these women had been trying to get into substance use disorder treatment for months; they gained immediate access once they became pregnant because they were then Medicaid eligible. As one woman noted, “you had to wait”; another stated, “it was impossible to get anywhere, and as soon as I got pregnant I got everything I possibly could need.” The third woman became incarcerated during a six-month waiting period; she did not discover her pregnancy until several months into her incarceration, and then she could not receive treatment until she was released several weeks later. The three other women sought treatment early in their pregnancies, and their access was expedited, as exemplified by the comment “I was the first one they called because I was pregnant.” Expedited access due to pregnancy, however, did not mitigate the lack of available treatment options; neither the one inpatient facility nor the handful of outpatient services in the northern part of the state offered women-specific therapy. Only one integrated program for pregnant and parenting women, with specialized substance use disorder treatment, mental health, and social services co-located within a perinatal care practice, was available in this area.

**Geographic location is hard.** Six of the 13 women lived in the county where the hospital and most services are located; the remainder traveled up to three hours for their appointments. Barriers presented by distance and geography (remote rural areas, only 10% of the state’s public roads are major roads, many in poor condition) are illustrated by the comment “living an hour away is definitely hard.” Women who received separate substance use disorder treatment and perinatal care services in different locations faced additional challenges, regardless of where they lived. One woman living in a different county stated that she received her services in “two
separate places…it was hard.” Another woman traveled 40 minutes to receive treatment and care in two different offices but stated, “it worked out pretty well ‘cause they’re not that far away from each other.” The women’s perceptions of any barriers related to distance and location seemed to be influenced by other factors, such as transportation and relationships with care providers. One woman noted, “I live in [hometown], so it was 45 minutes away, which made it a little difficult, but definitely worth it”, while another woman who lived two hours away offered, “I do have the option to go somewhere closer to home, but I don’t want to, I really like where I am.” Three other women traveled long distances for treatment and care by choice due to lack of confidence in providers close to their homes. One woman described feeling “like you’re going back 30 years”, while the other two perceived a lack of adequate knowledge and technology.

**Transportation is a struggle.** Ten of the 13 women talked specifically about transportation issues, such as limited options and variable quality. Due to its rural nature, the state’s public transportation system consists of unlinked transit services, a centralized non-emergency transportation scheduling system for persons with disabilities or low income, and reliance on volunteers. Public transportation for these women is typically coordinated by two non-profit social service agencies with mixed reliability and convenience. Four of the women stated they had no public transportation options, while four others described it as “unreliable.” Women described a variety of transportation challenges irrespective of geographic proximity to care providers: delays in receiving approval for free transportation and filling the gaps with rides from family and friends; arranged transportation that arrived too early, too late, or not at all; weather-related transportation cancellations; refusal of city buses to go to one of the substance abuse service agencies due to safety concerns; navigating public transportation with small children and their gear in tow; and having to pay cab fare home because appointments ran late.
As one woman plainly stated, “it’s been a struggle with transportation, especially not having a license..., having anxiety and PTSD (post-traumatic stress disorder) not able to take the bus...some days, like snowstorms or whatever, they cancel...the bus stops at 6:00...and I would have to take a cab home.” Her experience was echoed by another woman who stated, “for somebody that couldn’t handle for whatever reason doing [public transportation], what, a cab? For me, that’s $3 every time...unfortunately, a lot of my family doesn’t know, so my option is taxi.” Two women who were new to the area weren’t aware of available options; one stated she didn’t know about [non-emergency transport service], while the other (who lived almost an hour away from the hospital and received treatment and care from two practices 40 miles apart) wasn’t aware of bus transportation. Since the two women had not established social contacts in the area and did not have cars or driver’s licenses, private transportation was extremely limited. Despite the challenges, three women expressed relief that they had some form of transportation, as conveyed by the statement, “I didn’t have to worry about rides, and [non-emergency transport service] was helpful, too, because they made it so I could actually get there.”

**Collaboration and coordination among providers.** Six women who received treatment and care in separate practices for their substance use disorder and their pregnancy encountered varying levels of collaboration and coordination among care providers. Two of the women expressed satisfaction with the level of collaboration and coordination between their providers. As one stated, “they seemed to coordinate very well”, while another noted that both practices worked together to accommodate her schedule. One woman who was told by her long-time provider that “if I got pregnant again he couldn’t see me anymore” described being pleasantly surprised to discover that he facilitated transfer of her treatment and care to two new providers, one with whom she was already familiar; as she said, “I didn’t have to do anything, like he made
all the appointments for me, he did all the referrals, he took care of everything…that was awesome.”

Even women who expressed satisfaction with their providers found mixed collaboration. For example, one woman indicated that her obstetrician and substance use disorder provider did not discuss adjustments of her buprenorphine dosing. She found that her dose had been increased due to reported hip discomfort, without her or her obstetrician’s knowledge, stating that her provider “just wanted to make sure she was getting through the night OK.” Subsequently, her obstetrician would ask “she didn’t change you again, right?” Another woman had a similar experience in a different location, where decisions to increase her buprenorphine dose were not discussed with her or between her prescriber and her obstetrician, and both providers relied on her to relay information between them. One woman described a lack of communication and collaboration among obstetric providers within the same practice, noting that lab tests were repeated or omitted and the tubal ligation for which she consented with her elective repeat Caesarean section was overlooked. A third woman simply stated, “they didn’t really communicate (with one another).”

Coordination of appointments at separate practices was also variable. One woman stated that “they seemed to coordinate very well” in scheduling her appointments and found “it wasn’t that big of an inconvenience.” Another woman noted that while attempts were made to schedule her appointments on the same day, “sometimes that didn’t happen”, while a third woman asserted “basically I did it by myself.”

Seven women received integrated care through a program where specialized substance use disorder treatment, mental health, and social services are co-located within a perinatal care practice. Care is coordinated by a core group of physicians and an advanced practice nurse.
These women expressed great satisfaction with their care, all using words such as “easy” and “convenient.” One woman stated that “it made it so much easier, you know, to be able to just go, and the same doctor I was seeing for my pregnancy was the same doctor that was prescribing me the Subutex.” None of these seven women had previously received both substance use treatment and prenatal care where services were not integrated; one woman received prenatal care for two prior pregnancies in another state and had not sought substance use treatment, instead actively using illicit substances throughout those pregnancies. She did not elaborate on her reasons for not previously seeking substance use treatment other than to say it was “different” where she came from, that she felt “looked down on” there. She talked about how being able to get her treatment and care in the same place where she also felt no judgment facilitated honesty and attendance at her appointments.

**Fears for physical and emotional safety.** Women shared some of the fears they overcame to seek treatment. Two of the women described a specific substance abuse treatment facility where they felt unsafe due to the mixed population and fights among the clients, further complicated by the refusal of the city buses to transport clients to that location. One woman spoke of feeling grateful that she was not referred to that facility and instead was in a practice where she felt safe, “‘cause that was my biggest fear of getting help.” Another woman contrasted her experiences between that facility and where she received substance use treatment during her pregnancy, a place she stated she knew was safe. Her ability to change practices was unusual as few treatment options for substance use disorder are available in this area, and due to limited capacity, it is nearly impossible to transfer to a different practice once treatment has been established. She talked about her fear related to interaction with the clients at the former facility; she described them as “enemies” and “triggers” for her. She attributed her ability to resist relapse
to the physical and emotional safety she felt with her current provider. In contrast, and despite
the physical safety challenges, another woman continued treatment for her substance use
disorder at that facility through two pregnancies. Her emotional safety seemed to outweigh any
physical threats she felt; as she stated, “they worked around my schedule; it made it easier, and
not one of the doctors judged me, and that absolutely helps.”

Five women suggested that the emotional safety and trust they felt allowed them to be
honest, which, as one woman noted, “got me better help.” Women with multiple pregnancies
described contrasting experiences with respect to emotional safety. For example, one woman
talked about not being honest about her substance use to providers in another state because “I
was looked down on, I was talked about, I was treated differently, which makes you really not
want to say anything.” During her most recent pregnancy, she stated she was honest because
“nobody ever treated me different…even when I did slip, I did fall, I did use, I never was looked
at weird or talked down to.” Another woman reported numerous instances of feeling judged and
dismissed, false reports, gaps in care, and miscommunication that left her feeling mistrustful of
her providers with both of her pregnancies (one out of state, the current pregnancy in Maine).
She talked about wanting to stay clean and stated, “if I wasn’t thinking right I would have gone
back to drugs because that (mistrust) was a trigger for me.” She stated she didn’t like the prenatal
practice for those reasons but she stayed “because it was already too late for me to just go to
another one.” Despite those experiences, she talked about being positive and not changing
practices because “I don’t want to start all over again because I’m scared that I go back, that I
don’t have that strength to just express myself again from the start.” She spoke most positively
about her substance use treatment provider as she stated, “I can be open and talk to him about
anything and trust him a lot...he’s doing a good job ‘cause I been clean for a year.”
Opportunities to Bond

This domain speaks to the women’s descriptions of aspects of care that either supported or inhibited opportunities to bond with their babies, themes which are also found in the maternal-infant bonding literature. Proximity was contingent upon factors such as distance from hospital, physical environment, and resource availability. Women sought complete and accurate information to prepare for immediate newborn care and transfer home. They reported varying degrees of self-efficacy and participation in their baby’s care.

Being with the baby. Twelve of the 13 women were with their babies during the interviews; seven of those 12 were rooming in, while space and double occupancy allowed for only visitation for the other five. Observed interactions with their babies varied; one woman breastfed her baby through the entire interview, three provided basic care (diaper change, swaddling), two held and rocked their babies during the interviews, and the remainder allowed their babies to sleep in open cribs but stopped to check on them frequently during the interviews. Four women indicated that their presence and active participation in their baby’s care seemed to alleviate their baby’s distress as exemplified by the comment, “the longer I would be away from him, he would start showing more agitation and irritability.” Another woman noted that her baby seemed to feed better for her than for the staff when she left for the night; as she stated, “when I’m here during the day he holds all his bottles down… he really doesn’t puke besides when he's with them.” The woman who lived three hours away described cutting short a necessary trip home because her baby’s withdrawal symptoms were escalating; she believed her baby’s condition improved as soon as she returned and assumed care.

Distance between home and the hospital proved to be challenging for the seven women from other counties. As an example, one single mother with a school-aged daughter described
the difficulty of being away from home for a month, stating, “I haven’t left her (her new baby), you know, I’ve been here for God knows how many days, 30 something days.” Three women expressed fear that they might have had to deliver their babies at their local hospitals, which were not equipped to care for substance-exposed newborns. In such cases, their newborns would have been transferred to the larger hospital without them. As one woman noted, “I didn't honestly think I was going to make it. I thought I would have to go to [small hospital closer to home], and you know I wouldn't be able to be with him. It was hard.” The other two women offered similar concerns that their babies would have been transferred without them; one stated, “I’m not OK with that.”

Options allowing parent cohabitation with their babies, known as rooming-in, became more available with the opening of the new NICU at the large hospital. The new NICU was built with all private rooms, pull-out cots, private bathrooms and showers, individual breast pumps, and breast milk refrigerator/freezers. The five women interviewed on this unit described the comfort and ability to stay with their babies; three of those five women were multiparous and could compare the improvements with their prior experiences. In contrast, the eight women interviewed prior to the opening of the new NICU were limited in their ability to room in with their babies due to space constraints and transfer to semi-private rooms. As one woman noted, “it’s uncomfortable and difficult to stay here with your baby.” Another stated, there's no room upstairs so he had to stay here and I can't be here with him so I try to be here with him during the day and go home at night and sleep and, you know, which stinks really bad because I hate leaving him.
One multiparous woman was interviewed in the old continuing care nursery (lower-acuity intermediate care unit) just prior to the opening of the new NICU; she observed and commented on the construction, stating,

Do I think that these rooms are set up to have families room in with them? No. I really think you guys have it right on point that their new wing or development, what they're doing so that it is comfortable for people to stay right there with them is the most important.

**Not always feeling prepared.** Eight of the women described gaps in their knowledge and understanding of the impact of their substance use on their babies. Even women with prior experience seemed unprepared for their babies’ withdrawal symptoms and possible need for pharmacologic therapy. Women offered comments such as “nobody really prepared me for this”, “I didn’t know what to expect”, “they didn’t tell me how bad it could get”, and “getting that phone call saying we’d like to start methadone was still a shock to me.” One of those women said she was told that “within 5 to 7 days she’d be home and she’d be fine”; her baby required pharmacologic therapy and an extended hospital stay. Two women described getting information from friends or online searches. Only two of the eight women stated they felt well-informed and prepared for the required observation period and the potential for their babies to withdraw.

Information, education, and communication regarding newborn care seemed variable. Although the four first-time mothers expressed feeling well-informed and prepared for discharge (“they definitely go through and cover everything before they let you go home”), two of the women with other children were feeling ill-prepared for the challenges they were facing, such as how to console their child. The one woman whose baby was not present during the interview felt she had to send her baby to the nursery because she “didn’t know what to do with him, they’re
not really helping me.” Two women spoke specifically about not being informed about key aspects of their baby’s care, such as time and amount of prior feeding. Observations conducted in the inpatient care settings seemed to validate the women’s impressions. Dry erase boards commonly used in patient rooms for communication were noted to be blank or not updated, and these study interviews were frequently delayed or interrupted because the women were trying to track down information necessary for their baby’s care. Three women suggested that information was readily available if needed, although one woman felt that unless education was mandatory, most women would not take the time to ask. One woman stated, “whether you choose to know, if there’s a question you have, I pretty much feel I could ask.” Another advised health care providers to

Just try to be understanding as far as the parents' concerns and their questions and try not to be judgmental. Um, 'cause then that makes the parents feel awkward and then they're not going to ask what they need to. And it's important that they can feel comfortable to be able to ask what they need to, 'cause otherwise they don't know what they're doing when they go home.

Relationships

The relationship domain encompasses the women’s accounts of respect, empathy, and inclusion (or lack thereof) as well the importance of familiarity with care providers, which exemplifies relational-cultural theory. They all shared examples of interactions with providers that exemplified respect for their choices, personal respect, understanding of how hard addiction and recovery are, and inclusion in decisions regarding their own care and care of their baby. This theme spans both prenatal care and postpartum hospital experiences.
Respect and judgment. Relationships with health care providers that included respect and understanding seemed to be most important to the women and often mitigated burdens such as distance and transportation. All the women manifested signs of internal stigma, referring to themselves as “addicts” and speaking of feeling guilt, shame, and embarrassment. As one woman stated about her previous experience, “people were very judgmental…that’s a big thing, you know, the stereotype, and you already feel shitty enough.” Despite transportation challenges, she continued with her current providers because none of the providers judged her; “it’s challenging, but we made it work.” Another woman described her challenges regarding distance, transportation, and substance use treatment and prenatal care in separate practices, and yet she persisted because of her relationships with her providers, stating, “times I thought I would relapse, I talked to my clinician and she’s amazing, I love her to death.” As noted by a third woman, “I do have the option to go somewhere closer to home, but I don’t want to, I really like where I am, I like the people that take care of us.” She added, “they don’t look at me and go ‘oh, she’s a drug addict’…this place, I’ve never felt more like a human being in my life…I matter to them.” Three women specifically mentioned feeling respected by the advanced practice nurse at the integrated care program; one woman described her as “awesome, very awesome, she’s fantastic”, noting that she lived 45 minutes away, “which made it a little difficult, but definitely worth it.” As another expressed, “it was really hard to stay clean, but there was no judgment…people who have been pregnant with substance abuse, everybody goes there because it’s really good care.” The third woman stated, “she’s made a big difference in my life…she doesn’t treat me like an addict.” Conversations between the principal investigator and the advanced practice nurse corroborated the women’s impressions; she conveyed a sense of genuine respect and empathy for the women for whom she cared.
Women in the current study anticipated judgment by caregivers, and, in many cases, their fears were not unfounded, as they recounted situations where they felt disrespected. One woman recounted “rude” behavior by a nurse caring for both her baby and the other baby in the room (who also had NAS), noting a contrast with how other women (whose babies did not have NAS) were treated. She stated, “I left a couple of times in tears.” A woman who described particularly traumatic prenatal and birth experiences said she was told “we don’t want to do a C-section because you were a junkie and we don’t want to give you drugs” even though she had been in recovery for over three years. She went on to say that it “made my first experience having a baby miserable.” She contrasted her prenatal experience with her inpatient interactions; she noted “I felt like people were gonna judge me because I put her here…but this place is amazing.” Another woman stated that “having NAS on my file and stuff, I felt not as well treated” on the labor and delivery unit. She described feeling “so guilty and so horrified, I felt like a horrible person, I felt like a horrible mother.” Two other women described similar experiences of feeling “looked down on” and “talked down to” because of their substance use; as one woman stated, “if I give respect, I should get respect back, and I don’t think nobody should talk me down, talk to me like I was a nobody.” She implied a willingness to endure less respectful behavior if her baby was well cared for, indicating that she overlooked some of the hurtful comments (“I just put my head down and I just walked away”). She stated several times that she was trying to focus more on the positive than the negative and was grateful for nurses and volunteers “taking their time to just care about the baby.”

One specific NICU nurse was referred to by two women as caring and taking the time to talk with them; as one woman noted, “we felt very comfortable with him, he lightened the mood by joking, I mean, it just really raised our spirits.” During observations, this nurse seemed to take
an active interest in the study and spent time to converse with the principal investigator on several occasions, always speaking respectfully about the women. His observed interactions with the women were patient and kind, and the women appeared comfortable with him. This contrasted with other observations where staff interactions with the women seemed brief and limited to necessary tasks. No conclusions could be drawn from these limited observations as the environment did not allow for general observation of interactions with women not included in the study.

Three women spoke positively about the chief pediatrician’s influence on the care they received. One woman described his advocacy for her to stay with her baby and relieving her guilt. Multiple discussions with this pediatrician by the principal investigator seemed to reinforce the women’s accounts. His regard for the women has been well-captured in a video documentary (YoungParentsLearnTogether, 2011).

**Understanding the challenges.** Five women offered their opinions that providers and caregivers need to understand how hard addiction is and that women are doing their best to stay in recovery although they sometimes make mistakes. They shared that they already feel guilt and shame, and they asked that they not be criticized or judged, noting that such attitudes would discourage women from being open and honest. One woman admitted to “having slips” and described her prenatal providers as “understanding about everything”; as she stated, “when I did slip, I did fall, I did use, I never was talked down to.” Another woman attributed her ability to avoid relapse to the support of her provider.

Four of the women described the challenges of having other children to care for and the lack of family accommodations. Two women specifically spoke to a lack of understanding about limitations in their presence at their baby’s bedside due to responsibilities for their other
children. As one woman stated, “she complained I wasn’t here early enough, she’s like ‘all I’ve been doing is changing his diapers all morning’…I’ve got other kids, I have to take care of them too.” During one observation, a nurse was heard to exclaim loudly that “she had four NAS babies screaming their heads off and their mothers aren’t here”, the reasons for which were not divulged. Conversations between the principal investigator and the two social workers revealed the challenges faced by the women and their impression was that it takes great courage for the women to overcome barriers in order to be present and care for themselves and their babies.

**Seeing different providers.** One woman who was required to change practices with her third pregnancy expressed concern about having to establish new relationships and described her relief and gratitude that her previous provider facilitated transfer to a new practice that included familiar and trusted providers. Another woman who was also required leave a familiar practice upon becoming pregnant spoke of the initial adjustment and “getting used to the new providers.” A woman with three children who had been in recovery for over 10 years and had maintained the same providers recounted being “shuffled around and bounced around” initially, which made her feel uncomfortable due to the “stigma that comes with being an addict.” She was “pretty adamant that I see the same three people”, including one advanced practice nurse who “doesn’t treat me like I’m an addict…there’s been some trust built up and I’m open with her about things.” Two women described a level of discomfort with frequent changes in health care professionals both in their prenatal practices and in the hospital setting. As one woman noted, “having different nurses constantly is kind of a pain in the butt because you’ve gotta get to know someone new every shift.” This sentiment was echoed by another woman when she said, “each day there’s a different doctor, and two different nurses for each shift…that’s four nurses a day, and every one of them has a different way of doing things.”
**Feeling included.** Two women related specific instances where they felt included in decisions about their own treatment and care. As one noted, “they don’t try to pressure you into doing anything…they’ll sit there and talk to you, and if it’s something you don’t agree with, they won’t push it.” One woman noted that her substance use disorder treatment provider adjusted her medication doses only after discussing it with her; another woman found that her doses had been adjusted without her knowledge, which “kind of bothered” her. Five women described inclusion in choices regarding where they would deliver their babies, frequency of visits for substance use disorder treatment, and aspects of the baby’s care regarding medication-assisted withdrawal.

Women described contrasting experiences in regard to feeling included in their baby’s care. As one woman stated:

I definitely feel included, I definitely feel welcomed, I feel like when we're here they basically, you know, "do you need anything? no, OK, we're gonna let you do it". And that's what I want, I mean, I want the offer of help and know that it's there if we need them. But I also want to be a parent to my child.

Another woman described a different impression; she spoke of feeling that her choices were not respected, saying, “every nurse and doctor is different…and every one of them has a way of doing things, and then there’s your way of doing things. I’ve tried to learn their ways…if you don’t, it comes back at you.” She added that “if you don't do it their way, there is a couple that, you know, aren't so nice.”

Inclusion in neonatal withdrawal scoring was variable. As noted by one woman, “I’ve been right here with her and I do pretty much all of her care”, answering affirmatively when asked if she was encouraged to participate in the NAS scoring. Another woman, whose baby was born at a small hospital and had been transferred numerous times among three different units due
to acuity and space issues, recounted her attempts to participate in withdrawal scoring being largely ignored on several of the units. She felt this lack of inclusion contributed to at least one of the transfers. She noted that nurses on one of the units did take the time to listen, stating, “they respect me, make me feel comfortable.” A third woman wasn’t sure if her reports of her baby’s symptoms were considered in the scoring.

**Discussion**

The purpose of this study was to add personal accounts to the literature regarding care of rural women with substance use disorders through their pregnancy and early postpartum period to address this gap in research. Formal interviews of the 13 rural women in this study revealed experiences and perceptions of the care they received during their pregnancy and through their infants’ hospitalization as both supportive and challenging. The women’s personal accounts were supported by conversations by the principal investigator with health care providers; observations of care environments and participant interactions with others in the context of care; and review of artifacts, such as publicly available information.

The women in this study encountered limits in access for both their substance use disorder treatment and pregnancy care, most notably regarding availability and insurance coverage for services, often having to wait to get treatment. While these challenges may not be unique to rural women, they are intensified by the lack of capacity related to too few willing and/or knowledgeable providers in rural areas (Bishop et al., 2017; Rosenblatt, Andrilla, Catlin, & Larson, 2015). This was demonstrated by the women’s descriptions of having to travel long distances using sometimes unreliable transportation to access services or encountering perceived knowledge deficits in their local care providers. These women all relied on public assistance for their health care; specialty services for substance use disorders have been found to be more
heavily financed by public sources, such as Medicaid (Cummings, Wen, Ko, & Druss, 2014). The state where this study was conducted is one of the 19 states that did not expand Medicaid coverage to low-income adults, which directly impacted three of the women in this study as they described the long wait for treatment for their substance use disorder until they became pregnant. Public assistance also impacts transportation options for these women. These challenges have been outlined in numerous articles in the major local news media over the past six years as funding has been cut and restrictions placed on eligibility and treatment duration (Appendix F).

In general, the women described gaps in information and their understanding of available resources and the impact of their substance use on their babies. Paired with this lack of information were variable degrees of inclusion in decision-making and the care of their newborns. Women in a study conducted by Howard (2016) likewise noted a wide range of information and inclusion with respect to their options. Evidence exists that maternal presence and active involvement in decision-making and care result in improved maternal and newborn outcomes (American Academy of Pediatrics [AAP], 2016; Boucher, 2016; Edwards & Brown, 2016; Holmes et al., 2016; McKnight et al., 2016). Six of the babies in this study required pharmacologic therapy for NAS; three were deemed eligible for earlier discharge home on a methadone weaning protocol, as opposed to a traditional inpatient methadone wean. The woman’s active involvement in her baby’s care, with support from a multidisciplinary team, is required for this outpatient treatment.

The women’s experiences and interpretations of how they were perceived by both outpatient and inpatient care providers seemed to dominate the interviews. The women revealed a willingness to accept inconvenience and logistical challenges to receive care where they felt respected and understood. As noted by Marcellus and Poag (2016), these women “typically face
significant negative attitudes, judgment, and stigma” (p. 327). Additionally, women chose to travel longer distances from their homes to access treatment and care by providers they perceived as more competent. Oser and Harp (2015) suggested that while stigma and rural cultural values may inhibit utilization of substance abuse treatment and support resources, rural clients with SUD may prefer treatment in a more urban setting for the perceived practice expertise, relative obscurity, and reduced stigma. They used the term geographic discordance to describe the phenomenon of “traveling from one’s home residence to a county with a different socio-cultural context” to receive treatment and care (Oser & Harp, 2015, p. 77).

The women in the present study expressed feelings of guilt, shame, and embarrassment, particularly when they talked about the effect of their substance use on their babies and the rest of their families. Similar feelings were described by women in a recent study conducted by Cleveland, Bonugli, and McGlothen (2016). In that study, as in the present study, the women felt their presence and active participation in their baby’s care alleviated their baby’s distress. Findings of new research suggests that newborns whose parents spent more time at their bedside have less severe withdrawal symptoms and shorter hospital stays during treatment for NAS (AAP, 2016). Women in the present study expressed fear of being judged by health care providers based on their prior experiences or those of their acquaintances. Such fear and stigma have been shown to be barriers to treatment and care, discouraging women from seeking and engaging in substance use treatment and prenatal care, potentially increasing the risk of harm to the mother and baby (CSAT, 2009; Stone, 2015). Judgment of pregnant women with SUD by rural practitioners due to a lack of knowledge and experience regarding perinatal substance use may be reduced through targeted education (Seybold et al., 2014).
The personal accounts shared by the women were consistent with concepts gleaned from
the harm reduction, maternal-infant bonding, and relational-cultural literature. The women
touched upon elements of harm reduction strategies, including information and understanding of
available resources, access to services, collaboration among providers, transportation assistance,
and integrated care models, as they related both supportive and challenging care experiences. As
noted, 12 of the 13 women were with their babies during the interviews, whether they could
room in or not. They spoke of some of the challenges they encountered to be with their babies
and their belief that their involvement in their baby’s care was important. A qualitative study
conducted by Atwood et al. (2016) revealed similar themes, such as parental education and
preparation for NAS, parents as partners in care, interpersonal interactions and communication
with the health care team, and the hospital environment and transitions in care. The women
interviewed in the present study conveyed a need for connection, a basic tenet of relational-
cultural theory, whether that be with providers and caregivers, other women in similar
circumstances, or their babies and other family members. They all expressed gratitude for the
opportunity to tell their stories and hoped the information they shared would be helpful to others.
They were emotional and often shed tears when they related episodes that seemed painful to
them. They wanted people to understand that addiction and recovery were hard; they were doing
their best despite the barriers; they took responsibility for their choices; sometimes other
responsibilities kept them from being with their babies; and judgment and disrespect were
triggers to relapse that also discouraged them from being honest. Five of the women had
diagnosed mental health disorders, including post-traumatic stress disorder; six others described
traumatic events that they felt contributed to their substance use disorders and relapses. Research
has shown that interactions not grounded in respect and empathy can retraumatize women,
triggering relapse and impeding access to care (Boyd & Marcellus, 2007; Covington, 2008; SAMHSA, 2014b).

**Implications**

The results of this study add the voices of rural women in the development of practices and policies regarding access to substance use treatment, care provider education and training, non-punitive approaches to substance use during pregnancy, and models of both prenatal and postpartum care of the mother-infant dyad. As the rates of perinatal substance use disorders and NAS continue to rise, nurses, other health care providers, and social and mental health professionals need to be mindful of the unique challenges and complex needs of this population, particularly in rural areas where services are limited. Legislation, such as the Drug Addiction Treatment Act of 2000 (DATA2000), the Office of National Drug Control Policy Reauthorization Act of 2006, the 2010 Affordable Care Act (ACA), and the 2016 Comprehensive Addiction and Recovery Act (CARA), has expanded substance use treatment options that may benefit areas with limited substance use treatment providers. Office-based physicians who have completed approved courses or have board certification in addiction medicine (called “waivered physicians”) may prescribe buprenorphine maintenance therapy, with patient limits recently increased from 30 to 100 per waivered physician (DeFlavio, Rolin, Nordstrom, & Kazal, 2015; Stein et al., 2015). Section 303 of CARA extended buprenorphine prescribing privileges to nurse practitioners and physician assistants who have completed 24 hours of required training, thereby increasing the number of providers and filling practice gaps in rural areas (ASAM, 2017). Despite this expansion, providers have cited inadequate training as the biggest barrier to adoption (DeFlavio et al., 2015). Learning collaboratives, utilizing
teleconferencing across a wide rural geographic area, may provide a solution to that challenge (Nordstrom et al., 2016).

While availability, accessibility, and affordability may impede substance use treatment in rural areas, acceptability related to guilt, shame, and fear of stigma has been found to be a greater barrier (Jackson & Shannon, 2012). The women in the present study demonstrated a willingness to sacrifice convenience of services closer to home for substance use treatment and prenatal care that was felt to be respectful and inclusive. Compassionate, women-centered approaches that incorporate a harm reduction philosophy are key to successful care of these women (Sutter, Gopman, & Leeman, 2017). The CSAT (2009) and other agencies (SAMHSA, 2016; WHO, 2014) have identified strategies to engage women with substance use disorders through development of personal connections and trusting relationships. Additionally, several published local, national, and international guidelines encourage parent education, anticipatory guidance, and collaborative decision-making to improve care and outcomes for the mother-infant dyad (Maine Chapter AAP, n.d.; O’Connor & Alto, n.d.; SAMHSA, 2016; WHO, 2014). Further, programs for outpatient pharmacologic therapy for newborns withdrawing from opioid exposure are showing promising outcomes with respect to length of stay and expenditures (Lee, Hulman, Musci, & Stang, 2015); such a program has been available since 2014 in the area where the current study was conducted, and three of the women’s babies were being discharged home through this program.

More research is needed to explore the uptake of the new SAMHSA (2016) guidelines and their subsequent effects on maternal and infant outcomes. Women in the present study, particularly the six who received their substance use treatment and prenatal care through separate practices, described their experiences of provider practices and interactions that were
inconsistent with recommendations of the SAMHSA guidelines, such as lack of collaboration and standardization of care. The comprehensive guideline promotes collaborative policies and practices to “support the health, safety, well-being, and recovery of pregnant women with opioid use disorders and their infants” (SAMHSA, 2016, p. 8), focusing on interventions that may reduce the harm of perinatal substance use. The nurse’s role in the care of the woman and her newborn in outpatient, acute care, and community-based settings is delineated in the guidelines.

Nursing research should focus on the most effective strategies in overcoming the well-documented barriers to substance use treatment and prenatal care in rural areas, such as lack of resources. The women in this study offered their perspective on their unique challenges as well as suggestions for mitigating those barriers, specifically in regard to collaboration, communication, and relationships. Further studies are essential to identify effective care delivery models and best practices for staff training regarding perinatal substance use and care that is nonjudgmental, standardized, and collaborative. Longitudinal studies would provide evidence of factors that contribute to engagement in treatment and care, sustained recovery, and child development. Research into the impact of changing public policy on women’s access to treatment and care is also necessary.

Knowledge translation, defined as a “dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system” (Straus, Tetroe, & Graham, 2011, pp. 6-7), provides a framework to support improvement of care based on the research findings. The Rural Health Research Gateway (https://www.ruralhealthresearch.org/), an online library of research and expertise supported by the Federal Office of Rural Health Policy, Health Resources and Services Administration, U.S.
Department of Health and Human Services, includes a toolkit for dissemination of rural health research (Schroeder, 2015). The toolkit proposes guidelines for various modes of dissemination and provides examples of effective use of products (e.g., policy briefs, fact sheets, publications, and presentations) through social media, press releases, and media interviews. As noted by Boydell, Stasiulis, Barwick, Greenberg, and Pong (2008), it is important that dissemination strategies are adapted to the audience and specific community. This toolkit can be a valuable resource for moving the findings of the present study into practice.

**Study Limitations**

Recruitment in this population was found to be challenging with respect to ethical approval, participant eligibility and availability, practice changes, and discrepancies in the recruitment process. To conduct this study, ethical approval from two Institutional Review Boards (IRBs) was required, a process that involved two full board reviews and took nearly eight months. Recruitment procedures seemed inconsistent for unclear reasons, and potential participants were found to be ineligible or unavailable in nine of the 22 referrals. Despite several amendments to the research protocol and expansion of recruitment methods and locations, participant recruitment was limited to the tertiary care hospital and two local perinatal practices. No participants were recruited for the present study from the rural county where community-based services are coordinated to compensate for the lack of an integrated care model. Early successes of the program, such as increased prenatal care visits and decreased hospital length of stay for babies with NAS, have been reported (Morton, Withers, Konrad, Buterbaugh, & Spence, 2015), and the local hospital also expanded care for infants with NAS, both of which may have accounted for the lack of participants from that county.
Visits and frequent telephone and e-mail contact with key personnel by the principal investigator did not seem to increase the potential participant pool. Conversations with outpatient providers and inpatient social workers revealed potential challenges to recruitment, including the women feeling overwhelmed with information about programs and services, multiple other studies being conducted in this population, and women often not being present due to transportation and/or other family obligations. Staff conceded that they often forgot to introduce the study to eligible women due to workload issues, indicating that a number of potential participants were likely missed.

Opportunities for substantial observation periods were limited due to hospital renovation and new construction. The units lacked common public areas and family waiting rooms, and prior to the opening of the new NICU, many patient rooms were semi-private. Hospital staff requested that the principal investigator not linger in hallways or outside patient rooms to respect the privacy of other families, so opportunities for observation of the general care environment were confined to the nurses’ stations or chart rooms during collection of demographic data. Additionally, as anticipated, the women were often fatigued, entertaining visitors, or had other commitments that shortened the interviews and observations.

Data collection was limited to the inpatient setting, and therefore the women’s accounts of their prenatal experiences were retrieved from memory and may have been influenced by their current postpartum experience. Although women were given the researcher’s contact information, and ten of the 13 women consented to follow-up, only one woman responded to the member checking letter. Sequential interviews and observations over time, to include the prenatal and post-discharge period, may have contributed valuable insights into the women’s experiences.
Selection bias may have been present due to the vulnerability of this population. Women who consented to participate in this study either retained full custody of their newborns, had relinquished custody to a family member, or were working on reunification. All participants were aware of the state mandated reporting to the Department of Health and Human Services of infants identified as being prenatally substance exposed (Child and Family Services and Protection Act, 2003). Women who did not volunteer for participation in the study may have feared child protective services investigation; therefore, results of the present study may not represent the views of such women.

Conclusions

Substance misuse persists, and pregnant and parenting women with substance use disorders continue to face stigma and barriers to treatment and care despite the mounting evidence that addiction is a chronic relapsing medical condition (Terplan et al., 2015). Nursing is the largest of the health care professions in the U.S., and nurses comprise the largest single component of hospital staff (American Association of Colleges of Nursing [AACN], 2011). Nurses’ scope of practice includes comprehensive assessment, collaboration with other members of the health care team, development of patient-centered health care plans, and evaluation of nursing interventions, all important components of care for women with substance use disorder and their babies (Russell, 2012). Nurses connect with women in both community-based and inpatient settings and, as such, can positively impact the care of these women and their babies through provision of skilled, nonjudgmental care (Chu & Galang, 2013; McKeever, Spaeth-Brayton, & Sheerin, 2014; Shaw et al., 2016). Evidence and resources are available to provide compassionate care. It is imperative that nurses become actively involved in development of public policies to support collaborative, integrated models of care, reduce rural and poverty-
related health disparities, and discourage punitive treatment of women that only serves to impede their access to treatment and care.
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http://hsrc.himmelfarb.gwu.edu/sphhs_centers_jacobs/5


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<td>Single</td>
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<td><strong>Child custody</strong></td>
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<tr>
<td>Relinquished</td>
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<tr>
<td>Unclear</td>
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<td><strong>Pregnancy</strong></td>
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<td>Multiparous</td>
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<td><strong>Delivery</strong></td>
<td>SVD - term</td>
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<tr>
<td>SVD - preterm</td>
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<td>Unplanned home delivery</td>
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<td>Induced (IUGR)</td>
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<td>Planned repeat CS</td>
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<td><strong>NAS Rx</strong></td>
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<td>Pharmacologic (outpatient)</td>
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<td>Uncertain (still under observation)</td>
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<tr>
<td><strong>Stage of recovery</strong></td>
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<tr>
<td>Relapsing</td>
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<td>Court-ordered residential treatment</td>
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<td><strong>Location in hospital</strong></td>
<td>NICU (old)</td>
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<tr>
<td>NICU (new)</td>
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<td>CCN</td>
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<td>MBU</td>
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<td>Pediatrics</td>
<td>1 (external transfer)</td>
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<td><strong>Prenatal Care</strong></td>
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<td>WCHM</td>
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<tr>
<td>A………. County</td>
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Table 1 Legend:

1. Marital status:
   a. Partner: women referring to a partner, boyfriend, or fiancé; Maine does not have common law marriage
   b. Single: women stating they were single or divorced and not with the father of the baby
2. Child custody:
   a. Visitation: previous child in relative care with visitation rights
   b. Relinquished: Previous children had been relinquished to child protective services, working on reunification
   c. Unclear: Custody of previous children relinquished to their fathers, custody status of current baby undetermined/undocumented
3. Stage of recovery:
   a. Adherent: Evidence of consistent use of medication-assisted therapy (methadone or buprenorphine) in narrative documentation and toxicology screening
   b. Relapsing: Evidence of use of illicit substances in addition to medication-assisted therapy (methadone or buprenorphine) in narrative documentation and toxicology screening
4. Definitions of acronyms:
   a. SVD: spontaneous vaginal delivery
   b. IUGR: intrauterine growth retardation
   c. CS: Cesarean section
   d. NICU: neonatal intensive care unit
   e. CCN: continuing care nursery
   f. MBU: postpartum mother-baby unit
   g. FMRP: integrated care program where specialized substance use disorder treatment, mental health, and social services are co-located within a perinatal care practice
   h. WCHM: prenatal practice that does not include specialized substance use disorder treatment, mental health, and social services
Appendix F

Media Artifact References


Appendix G: Data Analysis Process Flowchart

**Familiarization**
- Listened to recorded interviews for elements of speech
- Transcription of recorded data & fieldnotes
- Reviewed all transcribed data
- Reviewed artifacts
- Initial random coding

**Thematic framework**
- Theoretical constructs extracted from literature
- Pre-fieldwork information considered

**Indexing**
- Coding themes created
- Transcribed & artifact data color-coded, placed within themes
- Annotations & analytic memos

**Charting**
- Matrices developed for data retrieved from interview transcripts, observational notes, & artifacts
- Verbatim text abstracted, synthesized, & summarized

**Mapping & interpreting**
- Data matrices reviewed for themes & patterns
- Generated possible explanations, influenced by study aims
Appendix H: MCN Permission to Reuse Published Article

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Kathleen

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Cc: dkramlich@une.edu
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Kindest regards,

Debra Kramlich, PhD(c), RN, CCRN, CNE