2024

"Why Does This Have to be So Hard?": Perinatal Experiences from an Ecological Systems Approach

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Recommended Citation

Senk, C. (2024). "Why Does This Have to be So Hard?": Perinatal Experiences from an Ecological Systems Approach. https://aura.antioch.edu/etds/1016

“WHY DOES THIS HAVE TO BE SO HARD?”: PERINATAL EXPERIENCES FROM AN ECOLOGICAL SYSTEMS APPROACH

A Dissertation

Presented to the Faculty of

Antioch University Seattle

In partial fulfillment for the degree of

DOCTOR OF PHILOSOPHY

by

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May 2024

“WHY DOES THIS HAVE TO BE SO HARD?”: PERINATAL EXPERIENCES FROM AN ECOLOGICAL SYSTEMS APPROACH

This dissertation, by Caitlin Senk, has
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Antioch University Seattle
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DOCTOR OF PHILOSOPHY

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ABSTRACT

“WHY DOES THIS HAVE TO BE SO HARD?”: PERINATAL EXPERIENCES FROM AN ECOLOGICAL SYSTEMS APPROACH

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This study examines the lived experience of the perinatal population to understand how they can be supported from the lens of different ecological systems and what counselors can do to better serve people with uteruses during their perinatal experience. Furthermore, this study aims to utilize an inclusive framework for capturing the perinatal experience of people with uteruses and to explore barriers and facilitators to care through an ecological systems framework. Fifteen participants who have experienced infertility, conception, pregnancy, miscarriage, childbirth, stillbirth, and postpartum were recruited through various means throughout the United States. Thematic analysis was used, with semi-structured interviews and photovoice, to gather and analyze participant narratives through oral and visual means in two phases. The first phase resulted in eight themes: (1) social and cultural influences, (2) navigating transitions and changes, (3) support networks and resources, (4) discrimination and stigma, (5) advocacy and empowerment, (6) mental health and well-being, (7) interactions with medical systems, and (8) impact of systems and policies. The themes identified in phase two were: (1) meaning making, (2) the emotional impact of perinatal experiences, (3) navigating roles and identities, (4) pressure and expectations, (5) advocacy and empowerment, (6) social support and community, (7) prevalence of infertility and miscarriage, and (8) challenges in healthcare. Implications of this study indicate a need for collaborative, interdisciplinary communication among providers interacting with the perinatal population and perinatal mental health competency training. This dissertation is available in open access at AURA (https://aura.antioch.edu) and OhioLINK ETD Center (https://etd.ohiolink.edu).

Keywords: perinatal mental health, perinatal care, thematic analysis, ecological systems, photovoice

Acknowledgements

I would like to thank the following people who contributed in a myriad of ways to the completion and success of my doctoral program.

I am beyond grateful for the Director of Doctoral Research, Dr. Stephanie Thorson-Olesen. You guided me through this process every step of the way and offered support and motivation that helped build my confidence to complete this project. I am deeply thankful for Dr. Katherine Fort. You have been instrumental in my process through this program by offering reflections that open up my perspective. Your feedback truly expanded this dissertation. Thanks to Dr. Angela Mensink for your time and invaluable feedback. I’ve said it once and I’ll say it again, you are a wizard with editing! A big shout out to the data analysis team. I would not have been able to complete this project without your feedback, insight, and perspective. Thank you to soon-to-be Dr. Dana Trottier, my cohort colleague and dear friend. We were with each other every step of the way and I am grateful for your support. We did it! Thank you to the participants who contributed their time and shared their beautiful perinatal stories. Your strength and vulnerability gives voice to those who are not heard during their perinatal journeys and will continue to build this community of support.

I wish to thank my friends for sharing their perinatal stories with me over the years. You all have reminded me of the importance of this work. I have thought of you every step of the way. To my husband, Jamie. I love you so much. It is no mystery how I was able to complete my doctoral journey. Your unwavering support, encouragement, patience, and cooking kept me fed and energized to keep going. Finally, I would like to thank my son, Henry. You have moved me

to this work in more ways than you know. I am so grateful we got to have you. You are amazing and I love you.

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CHAPTER I: INTRODUCTION

Statement of the Problem

As of 2021, there are 3.6 million live births per year in the United States (Centers for Disease Control and Prevention [CDC], 2022). According to the World Health Organization (WHO, 2023), perinatal mental health disorders affect approximately 10% of pregnant women and 13% of women who have recently given birth worldwide. In the United States, the most common reproductive complication is developing a mental health condition like depression (14%), anxiety (6–8%), PTSD (9%), OCD (4%), and psychosis (1–2 women per 1,000 births) (Maternal Mental Health Leadership Alliance [MMHLA], 2023). The treatment gap for perinatal mental health disorders is substantial, with many individuals not receiving the necessary support and interventions. According to the Centers for Disease Control and Prevention (CDC, 2021), about 50% of perinatal mental health disorders go undetected and untreated in high-income countries, while the figure rises to around 85% in low-and middle-income countries. In the United States, 75% of individuals impacted by perinatal mental health conditions are untreated with suicide and overdose being the leading cause of maternal deaths in the first year postpartum (MMHLA, 2023).

Disparities in access to perinatal mental health care exist across racial, ethnic, and LGBTQIIA+ communities with additional barriers such as lack of culturally competent care, language barriers, discrimination, and limited access to healthcare services (Abelsohn et al., 2013; CDC, 2021; Huggins et al., 2020; Light et al., 2014; Maccio & Pangburn, 2011; Ross, 2005). Many healthcare professionals, including obstetricians, midwives, primary care physicians, and mental health counselors, may have limited training and knowledge in identifying and managing perinatal mental health disorders. The lack of training can result in missed diagnoses, inadequate support, and delayed access to appropriate treatment. Perinatal problems frequently go undiagnosed and untreated due to the parallel symptoms that coincide with hormonal changes, as well as the fear and stigma of seeking help (Tripathy, 2020). This study focused on the perinatal experiences of people with uteruses which encompasses physical, environmental, and medical aspects of their experience. All of these aspects interact with mental health and therefore, take priority throughout this study as it relates to the perinatal experience.

Furthermore, the narrative around perinatal mental health seems to be focused on hetero- and cis-normative experiences (Kirubarajan et al., 2022), and the language that is often used in the research is “mother,” which is not gender expansive or inclusive such as person with uterus or birthing person which would be more inclusive. According to the 2015 U.S. Transgender Survey, 8.7 million sexually and gender-diverse parents gestated their children in the United States (James et al., 2016). Additionally, the focus on the impact that culture has on perinatal experiences in the current literature is fragmented. Given that current research highlights the disparities in perinatal care (Abelsohn et al., 2013; Alio et al., 2010; Barnett et al., 2022; Carter et al., 2021; Copeland et al., 2023; Darling et al., 2019; Declerq et al., 2022; Helm et al., 2023; Huggins et al., 2020; Khan et al., 2021; Kirubarajan et al., 2022; Losada, 2022; Panko et al., 2023; Pilav et al., 2022; Ross et al., 2012; Salm Ward et al., 2013; Smeltzer et al., 2016; Soled et al., 2023; Tarasoff, 2017), there is a call to know more about the lived experience of the perinatal population to gain insight into what can be done from an ecological systems model and what counselors can do to support this population. Therefore, this study aims to utilize an inclusive framework for capturing the perinatal experience of people with uteruses and to explore barriers and facilitators to care through an ecological systems framework.

Theoretical or Conceptual Framework

Liberation psychology is utilized to develop a more inclusive framework for recruiting participants and capturing demographic information. Liberation psychology was developed by Ignacio Martín-Baró (1994) in an effort to support marginalized and oppressed individuals to reclaim their history and culture. Martín-Baró (1994) identified the main tenets of liberation psychology as *realismo-crítico* or focusing on solutions rather than problems, recovering historical memory, *concientización* or consciousness-raising (meaning a collaboration with the client regarding sociohistorical contexts influencing their situation), and *deideologized reality* or empowering the client to re-author their narrative. This study focuses on the perinatal experience of people with uteruses to have a gender-expansive approach. In addition, demographic information includes race, ethnicity, socio-economic status, disability, and mental health.

Torres Rivera and Comas-Díaz (2020) stated that liberation psychology and decolonization should focus on turning outward to consider how liberation psychology can continue being effective, commit to reworking theoretical concepts from the unique perspectives of the oppressed, and constantly reflect and evaluate the development of theory to avoid becoming repetitive and colonized. With this foundational understanding, incorporating photovoice into this study is an important component that involves feedback from the community and population this study aims to serve and support. Liberation psychology also embodies the work of Bronfenbrenner's (1994) ecological model of human development to consider the individual, microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The ecological model of human development is tied to the tenants of liberation psychology in the sense that oppression and marginalization occurs at different systemic levels and therefore, liberation also needs to occur at these different levels.

The ecological systems approach is utilized to understand the barriers and facilitators to care. Bronfenbrenner (1979) stated, “knowledge and analysis of social policy are essential for progress in developmental research because they alert the investigator to those aspects of the environment … that are most critical for the cognitive, emotional, and social development of the person” (p. 8). This model of human development is a framework that describes how individuals develop within the context of their environment and consists of several interconnected systems, each influencing an individual’s growth and development (Bronfenbrenner, 1994). The microsystem is the closest and most immediate environment impacting an individual, such as family, friends, school, or neighborhood. The mesosystem is defined by the interactions and connections between microsystems, such as the impact that family interactions may have on work performance. The exosystem is the external setting that indirectly impacts an individual. An example of an exosystem would be how government policies impact an individual’s access to education or healthcare. Next, the macro system involves the broader society and cultural forces such as cultural norms, values, and customs that shape a person’s development. And finally, the chronosystem encompasses the dimension of time, such as historical events or personal life changes. The ecological systems theory emphasizes the importance of understanding the complex interactions between these systems to comprehend an individual’s experience and development more fully. This theory highlights that development is not solely determined by genetics or individual factors but is shaped by the dynamic interplay between various environmental influences (Bronfenbrenner, 1979). The perinatal experience is woven into these systems as it interacts with family, community, mental health, healthcare systems, governmental policies, and cultural norms and values. Therefore, this study incorporates both liberation psychology and the ecological systems framework to deepen understanding of the perinatal experience.

Statement of Purpose

This study specifically utilizes liberation psychology to develop an inclusive framework for capturing the perinatal experience of people with uteruses. More specifically, liberation psychology provided perspective on the demographic questions, as well as the way in which data was collected. Focusing on liberation psychology when gathering demographic information enables the study to expand from previous research that does not include this framework or address inclusivity. Considering inclusivity in this research through a liberation psychology perspective is vital to understanding the perinatal experience of people with uteruses because they have not been historically included in the literature related to perinatal care. The purpose is to understand barriers and facilitators to perinatal care from an ecological systems framework using interviews and photovoice.

Research Questions

The primary research question is, “What is the perinatal experience of people with uteruses?” The secondary research question that connects the photovoice aspects of the study is “What are the perceptions of people with uteruses regarding barriers and facilitators of perinatal care?”

Significance of the Study

Much of the research dedicated to perinatal care comes from medical journals, and there is a lack of counseling and mental health journals that focus on perinatal mental health (Akhter et al., 2020; Barnett et al., 2022; Carter et al., 2021; Charter et al., 2018; Copeland et al., 2023; Darling et al., 2019; Helm et al., 2023; Khan et al., 2021; King, 2014; Light et al., 2014; Panko et al., 2023; Saeed et al., 2022; Salm Ward et al., 2013; Soled et al., 2023; Smeltzer et al., 2016; Tarasoff, 2017). While having robust medical research around perinatal experiences, it is important to highlight the ways in which counselors can contribute to supporting the perinatal community. While the medical profession is separate from mental health counseling, the collaboration between the two would encourage greater outcomes for people with uteruses to have better support. Hartling (2008) discusses the importance of counselors creating communities of allies and advocates to dismantle oppressive systems. By focusing on strengths and resources, liberation psychology advocates for community involvement in social change (Chávez et al., 2016).

McNab et al. (2022) highlighted that perinatal health is an issue that impacts the well-being of society and requires a collaborative response from the government, health sector, social development systems, academia, and families. Therefore, this study aims to understand different aspects of the perinatal experience while using an inclusive framework for participant recruitment. With this information, counselors and counselor educators can better understand ways to support the perinatal population.

Atif et al. (2015) investigated the magnitude, impact, and interventions used for common maternal mental health problems, especially depression, in Chile, Jamaica, South Africa, and Pakistan and found that the physical health of women and children is prioritized over their mental health, which is ignored in low- and middle-income countries (LMIC). The studies that were reviewed reveal that psychosocial, education, and supportive interventions effectively improve mental health. Some contributing factors related to maternal depression in LMIC are poor socio-economic conditions, interpersonal problems, and adverse life events. Conversely, protective factors included education, having a permanent job, being the ethnic majority, and support from an intimate partner. Maternal mental health is also linked to the impact on the infant’s growth and development. Atif et al. (2015) asserted that the priority is to make policymakers, planners, and politicians integrate maternal and child health interventions to facilitate more research and funds to face these challenges. These tasks include international recognition and policy forums, enhanced training and supervision of the perinatal mental health community, adaptation of effective interventions, including systems, and investment in research and implementation of programs.

Keefe et al. (2016) aimed to identify variables at the micro, mezzo, and macro levels that inhibit mothers at risk for perinatal mood disorders from accessing health and mental health care services and how to intervene to remove the barriers to care. The barriers at the individual level included pragmatic issues, fear and stigma, and culture. At the family level, a lack of support leads to a significantly higher risk for postpartum depression. From the healthcare system level, mental health treatment is inaccessible and unaffordable to some. Keefe et al. (2016) added that individual healthcare providers are often unprepared to screen and treat mothers with perinatal mood disorders or symptoms that are dismissed as a typical hormonal response.

Howard and Khalifeh (2020) highlighted that “models of collaborative care in psychiatric settings liaising between maternity, primary care, generic community psychiatric care and specialist perinatal mental health care need to be developed and evaluated for women with perinatal mental disorders” (p. 322). In addition, many countries, including the United States, do not have specific perinatal training for practitioners, and it has been found that continued generic services are unhelpful (Howard & Khalifeh, 2020).

Definition of Terms and Operationalized Constructs

Perinatal is a term with varying definitions, perhaps due to the legal variations around reproductive health in different countries (Nguyen & Wilcox, 2005). Additionally, there seems to be a lack of agreement on the term depending on the discipline in which it is being used. For the purpose of this study, *perinatal* is defined as “occurring in, concerned with, or being in the period around the time of birth” (Merriam-Webster, n.d.). This includes infertility, conception, pregnancy, miscarriage, childbirth, stillbirth, and up to one year postpartum. People with uteruses is used rather than “mothers” to be gender expansive. This term includes LGBTQIA+ individuals, as it recognizes anyone with the biological means to be pregnant.

In addition, demographic questions and prompts consider cultural factors, which represent intersectionality, including race, ethnicity, gender identity, sexuality, socioeconomic status, age, among other identities and social locators. It is important to note that much of the literature uses gendered terms such as “mom,” “mother,” and “women,” and while this study aims to be gender expansive, these terms are maintained in the literature review. Additionally, the language that the study participants use in Chapter IV will also be maintained.

Assumptions and Limitations

It was assumed that this study would identify perinatal experiences and barriers and facilitators to care will be revealed which can inform counselors and other providers. Results could be useful for interdisciplinary practice and advocacy for improved perinatal care. In addition, this study uses gender-expansive language and recognizes that many diverse cultural influences can impact the perinatal experience. In addition, there could be similarities and differences across cultures that can be useful for counselors to consider.

Literature frequently refers to mothers in a gender-reductive manner. Chapter II represents the language the literature used while recognizing that this study aims to be more gender expansive. Other limitations include a lack of focus on non-gestational partners or other parenting experiences such as adoption, fostering, or surrogacy. Additionally, the study does not focus on the experience of abortion. Further, as society evolves and may attempt to be more inclusive, this study may eventually be outdated, so the time period in which data is collected ought to be noted by the reader.

Table 1.1

Glossary of Terms

Term	Definition
Chestfeeding	An alternative and more inclusive term for breastfeeding; the act of feeding a baby with milk from the body.
Dilation and curettage (D&C)	A surgical procedure in which the cervix is dilated so that the uterine lining can be scraped with a curette to remove abnormal tissues (Johns Hopkins Medicine, n.d.-a).
Doctor of Obstetrics and Gynecology (OB/GYN)	An OB/GYN, meaning obstetrician gynecologist, is a medical doctor who combines two disciplines: obstetrics and gynecology. Gynecology is the care of a woman's reproductive organs and health. Obstetrics involves the treatment of pregnant women, including the delivery of babies (American University of the Caribbean School and Medicine, 2021).
Doula	A trained professional who provides continuous physical, emotional and informational support to their client before, during and shortly after childbirth to help them achieve the healthiest, most satisfying experience possible (DONA International, n.d.).
Infertility	Not being able to get pregnant (conceive) after one year (or longer) of unprotected sex (CDC, 2023).
Intrauterine insemination (IUI)	During an intrauterine insemination (IUI) procedure, sperm is placed directly into the uterus using a small catheter. The goal of this treatment is to improve the chances of fertilization by increasing the number of healthy sperm that reach the fallopian tubes when the woman is most fertile (Johns Hopkins Medicine, n.d.-b).
Midwifery	Midwifery as practiced by certified nurse-midwives (CNMs) and certified midwives (CMs) encompasses the independent provision of care during pregnancy, childbirth, and the postpartum period; sexual and reproductive health; gynecologic health; and family planning services, including preconception care (American College of Nurse-Midwives, 2021).
Miscarriage	The spontaneously loss of a fetus before the 20th week of pregnancy (Medline Plus, 2022).
Pelvic Floor Physical Therapy	A specialized kind of physical therapy to relieve the symptoms of pelvic floor dysfunction and help the muscles work the way they should (WebMD, 2023).
People with Uteruses	Gender inclusive term to refer to birthing people rather than "women".
Perinatal	Occurring in, concerned with, or being in the period around the time of birth" (Merriam-Webster, n.d.).

Postpartum Mood and Anxiety Disorders (PMADs)	A commonly used term to refer to a mental health disorder experienced during pregnancy, after having a new baby, adopting, or experiencing pregnancy/infant loss (Minnesota Department of Health, 2023).

CHAPTER II: LITERATURE REVIEW

Introduction to the Literature Review

The literature review starts by introducing the theoretical orientation of this study and its use in previous research. This is followed by a review of the literature highlighting mental health aspects such as perinatal mood and anxiety disorders, grief and loss, and trauma, LGBTQIA+ experiences, race and ethnicity, socioeconomic influences, disability, and policy. Each of these topics is covered in a separate section. However, it should be noted that each of these themes have significant overlap as they are not mutually exclusive. This section ends with a rationale and implications for the current study. The search terms listed below were used to capture expansive experiences through different cultural lenses to understand the needs around perinatal mental health in the United States. Although the current study focuses on perinatal experiences in the United States, the review includes current research in different countries and cultural experiences to acknowledge the work being done internationally and to highlight how this research informs research in the United States.

Keywords searched include perinatal mental health, perinatal experiences, perinatal mental health and culture, perinatal mental health and race, perinatal mental health and LGBTQ, perinatal mental health and socioeconomic status, disability and perinatal mental health, cultural experiences of perinatal mental health, deafness and perinatal mental health, and neurodivergence and perinatal mental health.

Theoretical Orientation

The ecological systems approach emphasizes the impact that the environment has on an individual's development and their perceptions of their experiences (Bronfenbrenner, 1994). This approach has been used in existing perinatal research to understand birthing outcomes, health disparities, and barriers to care (Alio et al., 2010; Guilfoyle et al., 2014; Tyokighir et al., 2022). Guilfoyle et al. (2014) applied ecological systems theory to their study, which sought to gain an understanding of refugee women's experiences around perinatal mental health issues in Australia. Participants engaged in focus groups and follow-up interviews to share narratives about their experiences, and data was studied through an interpretative phenomenological methodology. The study intended to introduce group-based informal support for refugee women by offering playgroups. Through an ecological systems-informed lens, qualitative findings indicated "women's microsystems were lost in resettlement, and they experienced feelings of shame and stigma around perinatal mental health issues through macrosystem influences" (Guilfoyle et al., 2014, p. 51).

Another study that utilized an ecological model was conducted by Alio et al. (2010) and focused on the factors that contribute to racial health disparities through a socioecological framework and the impact on birthing outcomes of Black women. Alio et al. (2010) shared that the missing piece in current research is understanding the historical context of the Black woman in the United States. More specifically, "The ecological model suggests that birth outcomes are impacted by maternal and family characteristics, which are in turn strongly influenced by the larger community and society" (Alio et al., 2010, p. 557).

A qualitative study focused on understanding the knowledge of and barriers to mental health services for women in the perinatal period (Tyokighir et al., 2022). The aim was to triangulate themes from pregnant women, healthcare providers, and mental health providers, which had not been conducted in prior research. Pregnant or postpartum participants were recruited from maternal and child health programs in Kansas. Healthcare providers were recruited from the University of Kansas School of Medicine, and mental health providers were recruited through the same school in the behavioral science department and Postpartum Support International, internet searches, and professional societies. Structured interviews were conducted with participants and lasted about 20 minutes, and the themes were found using grounded theory and organized using a social-ecological model. A total of 33 interviews were included, which encompassed 12 pregnant or postpartum women, 15 primary care providers, and six mental health providers. Interpersonally, social support was important, and a lack of this was identified as a barrier to care. Organizationally, a lack of communication between providers was identified as a barrier across all three groups. At the community level, stigma was a theme that emerged from all providers but was not discussed by the pregnant or postpartum group. Finally, at the public policy level, providers stated that being underinsured was a barrier for people receiving care. This study concluded that there is a need for interventions at different systemic levels to improve access to care for lower income women in the perinatal period (Tyokighir et al., 2022).

Review of Research Literature and Synthesis of the Research Findings

Mental Health

Perinatal experiences may often result in the development perinatal mood and anxiety disorders (Atif et al., 2015; Goodman, 2009; Law et al., 2021), grief (Armstrong, 2004; Berry et al., 2021; Christiansen, 2017; Dube et al., 2021; Herbert et al., 2022; Hutti et al., 2011), and trauma (Lai et al., 2023; Reed et al., 2017; Simpson & Catling, 2016). Additionally, current research has shown that perceived support can influence the outcome of perinatal experiences (Bedaso et al., 2021; Bhamani et al., 2023; Nagle & Farrelly, 2018; Stewart et al., 2022). Each of these components will be discussed in the following section.

Perinatal Mood and Anxiety Disorders (PMADs)

In an effort to understand perinatal mood disorders, Goodman (2009) conducted a study to examine pregnant women's preferences and attitudes about treatment for depression and perceived barriers to accessing treatment. Participants (*N* = 509) were given a questionnaire about the modes of treatment they would most likely participate in if they wanted help with depression and their attitude toward receiving treatment. The participants were primarily well-educated, high-income, married, and in the United States during the last trimester of pregnancy. Over half of the women were White, followed by 26.5% Latina. The study found that the most significant barriers to treatment were time, stigma, and childcare issues. Additionally, many of the participants noted that they preferred to receive mental health services at the clinic where they were receiving obstetric care perhaps due to the increased convenience considering that a lack of time was also considered a major barrier (Goodman, 2009).

In Ontario and Quebec Canadian provinces, Law et al. (2021) conducted a study to gather personal narratives of women experiencing postpartum depression, as the current research seemed to be lacking a wider-ranging self-report of perinatal mental health issues. Email invitations to established mental health programs and support groups in Ontario and Quebec were sent to recruit participants. There were 21 semi-structured interviews conducted regarding participants' perinatal mental health to better understand cultural narratives of motherhood connected to perinatal mental health and the influence of shame, guilt, suffering, healing, and recovery. The study revealed four themes from the collective narrative after conducting a thematic analysis using the constant comparative method, which included feeling like a failed mother, societal silencing of negative experiences of motherhood, coming to terms with a new sense of self, and finding solace in shared experiences. These interviews were turned into a short film with consent from the participants so that others would feel supported and connected. Cultural representation is difficult to ascertain from the study as many participants did not respond to the ethical and cultural background questions. Additionally, most of the participants were employed, aside from three who did not answer the occupation question, which may limit the experience of those who are also not employed in the perinatal period. Overall, there was limited diversity in income, race, education, socio-cultural background, sexual orientation, and gender identity (Law et al., 2021).

Support

A systematic review and meta-analysis was conducted by Lai et al. (2023) to connect the incidences of postpartum post-traumatic stress disorder (PTSD) in women who experienced traumatic childbirth. In this meta-analysis, traumatic childbirth was defined as “birth in which a mother has a sense of damage, serious harm, or life-threatening conditions to herself or her baby during childbirth and it can result in overwhelming distressing emotions and reactions” (Lai et al., 2023, p. 212). Six databases were reviewed using key terms and nine studies were included in the final review and included Asia, Europe, Oceania, and North America regions. Roughly 19.4% of pregnant women studied in the articles were diagnosed with PTSD after a traumatic childbirth experience and this rate is higher than the general obstetric population, which is 4%. These findings suggest that trauma-related care for women who have experienced traumatic childbirth should be considered and this can be incorporated through professional training (Lai et al., 2023). In addition to trauma, grief and loss bring a myriad of difficulties.

From an ecological systems perspective, perinatal support may look like a friend or family member attending appointments (microsystem), a hospital policy that an interpreter is always offered (exosystem), or validation from society that experiencing depression after a perinatal experience is not just the ‘baby blues’ (macrosystem). One study explored perinatal support by focusing on women’s views and experiences of having their mental health needs considered in the perinatal period in an Irish maternity hospital setting (Nagle & Farrelly, 2018). The main research question focused on women’s views and experiences of having mental health needs considered in the perinatal period. The study used a qualitative design using semi-structured interviews and the data was analyzed using thematic analysis. Inclusion criteria for the study participants were: postnatal women who delivered a baby within the last three months, were physically and mentally well after birth, were receiving routine standard postnatal care by midwives, and over 18 years old. There were 10 participants identified and two were unable to make the time to be interviewed. The interviews were made up of nine main questions. One theme highlighted the experience of mental distress (an emotional time, you are supposed to be happy, confidence in managing mental health). A second theme was telling and disclosing (talking to healthcare professionals, screening tools -ticking the box, stigma/shame). A third theme was the experience of obtaining help (attitudes of healthcare professionals, baby as a motivator, getting help). One of the main contributing barriers to seeking help was not knowing what “normal” or “abnormal” emotions in the perinatal period are and many professionals asked about the physical body rather than emotionally or mentally. The limitations were that it was in one small town in Ireland, and all the participants were White. This research can contribute to developing standardized local and national clinical practice guidelines and procedures in focusing on perinatal mental health issues specifically (Nagle & Farrelly, 2018).

In 2021, Bedaso et al. conducted a meta-analysis to systemically review the current research on the importance of social support during pregnancy to reduce the risk of anxiety, depression, and self-harm. Articles on the topic were reduced from 3,760 to 67, which included

64,449 pregnant women. The results indicated that low social support is significantly associated with the risk of perinatal mood and anxiety disorders (PMADs) during pregnancy. These findings show that maternal health professionals need to interact more with their patients regarding the source and level of social support they have. Additionally, there is a call for policymakers and other stakeholders to develop and build community-based social support programs for pregnant people to lean on during their pregnancy and as mental health issues arise (Bedaso et al., 2021).

In a more recent study, Stewart et al. (2022) argued that art practices to support health mainly apply to Westernized contexts and overlook other cultural healing traditions. The study introduced the Community Health Intervention through Musical Engagement (CHIME) project for perinatal mental health, focusing on The Gambia and Kanyeleng groups (female fertility societies) that evaluate maternal mental health through social singing. The Kanyeleng group consists of women who have experienced infertility or child mortality and have begun to assume prominent roles as health communicators. They often use collective music creation as a healing intervention. The goal of the project was to develop a universal intervention that targets all intensity levels of depression and anxiety in the postpartum period. The study used ethnographic research through interviews and focus group discussions with pregnant women, midwives, community birth companions, Kanyelengs, and griots (hereditary musicians). To avoid stigma and assumptions, the study aimed to understand perinatal mental health in the Gambian context as well as the language used to describe mental distress. The intervention was co-designed and informed by the participatory ethnography, which included a combination of singing, dancing, joking, and praising. The trial was conducted in a stepped wedge design where pregnant women were recruited from local clinics and assigned to the intervention group (*n* =29) or control groups (*n* = 60). Those in the intervention group attended six weekly sessions led by the Kanyeleng group, and depression and anxiety scores were collected before and after using the Self-Reporting Questionnaire (SRQ-20). Additionally, 36 participants were interviewed, and thematic analysis was used. The findings were that the intervention group had a significant reduction of systems, and the emerging themes were social relationships, peaceful mind, learning, evaluations, and suggestions for the future. They involved the National Centre of Arts and Culture to ensure the translations were accurate and captured the participants' experiences. The study design intentionally involved the community in the research process and focused on co-creating with the Kanyeleng (Stewart et al., 2022).

A different study aimed to develop and validate the cultural appropriateness of the Safe-Motherhood-Accessible Resilience Training (SM-ART) intervention with pregnant women in Pakistan (Bhamani et al., 2023). A three-phase approach was used to develop and validate an intervention that promotes resilience in pregnant women. The first phase was a needs assessment with pregnant women to gather their opinions, followed by the second phase, which included the development of an intervention to build resilience based on a literature review. Lastly, phase three validated the intervention by eight mental health experts. The needs assessment included a literature review and interviewing (semi-structured) 17 pregnant women and eight key informants (KI) such as psychologists, psychiatrists, and nurses. All interviewees were women, married, and at least 18 years old. The interview asked open-ended questions about daily experiences managing everyday challenges and their views on the role of resilience-building skills in their mental health. The informants were asked questions geared toward opinions of the module content and approach within Pakistani culture. In phase two, they created six modules that came from the six themes uncovered in phase one, and the interventions were flexible to engage different learning styles and also considered cultural factors such as domestic responsibilities, academic difficulties, husband approval, and lack of enthusiasm toward learning. The six themes were finding the purpose in life, dealing with emotions, believing in yourself, adopting an optimistic approach, strengthening support systems and relationships, and internalizing spirituality and humanity. Findings suggested that after six weeks of training, the entire house or family was more empowered with resilience through the women's education (Bhamani et al., 2023).

Trauma

Another important aspect to consider consists of the experience of trauma. A study by Simpson and Catling (2016) focused on gaining a better understanding of factors that contribute to birth trauma and the efficacy of interventions that currently exist in the literature. In this article, birth trauma was defined as subjective and also related to the birth process and outcome. They reported that birth experiences are "multidimensional" (Simpson & Catling, 2016, p. 204) and can be impacted by many factors such as fear for self and the infant, medical interference, type of delivery, cultural expectations, and environmental factors (Simpson & Catling, 2016). The authors also noted that the birth experience is significantly affected by the quality of interactions that patients have with providers. They gathered 21 articles that were either original research or had high scientific quality and found that women with previous mental health disorders were more likely to experience giving birth as traumatic. From the review, it was found that midwifery care during the antenatal and postnatal period provides benefit especially when early identification of risk factors such as development of mental health disorders, obstetric emergencies, and neonatal complications and postnatal counseling is prioritized (Simpson & Catling, 2016).

A mixed-method study conducted by Reed et al. (2017) aimed to understand how interpersonal factors influence women's experience of traumatic birth to inform the development of care that promotes optimal psychosocial outcomes. The participants (N = 748) were recruited through social media platforms and completed an online survey in which they were prompted to describe birth trauma experience and share what they specifically thought was traumatizing about it. The results were analyzed using an inductive thematic analysis that specifically looked at the actions and interactions of care providers. Four themes were identified: prioritizing the care provider's agenda, disregarding embodied knowledge, lies and threats, and violation. These findings were consistent across different birth settings and cultural contexts. The authors noted that while non-interpersonal factors can contribute to birth trauma, many of the descriptions of the trauma was related to healthcare provider interactions and therefore, continued training and education is needed (Reed et al., 2017).

Grief and Loss

Approximately one in four pregnancies end in loss from conception to 28 days of life and may lead to parental depression and anxiety (Armstrong, 2004; Christiansen, 2017; Hutti et al., 2011). Herbert et al. (2022) conducted a large systematic review and meta-analysis to identity the association between perinatal loss and anxiety, depression, and post-traumatic symptoms. Experimental studies from January 1995 to March 2020 were included in the review and emphasized perinatal mental health outcomes after a perinatal loss. The review included 29 studies from 17 countries and had a perinatal loss sample of 31,072 women and a control group of 1,261,517 women who did not experience loss. Through random-effects modeling and when compared to the control group, women who experienced perinatal loss were more likely to experience depression and anxiety. The study found little significance for post-traumatic stress outcomes. Overall, the study was consistent with other findings from previous studies and highlights the need for timely mental health education and care. Additionally, this study emphasized the need for “a more nuanced understanding of the associated social and cultural risk and protective factors for common mental health disorders following loss could also support planning and implementation of health policies that enable equitable access to maternal mental health care” (Herbert et al., 2022, p. 127).

Berry et al. (2021) identified five articles through a metasynthesis of qualitative publications from the last 10 years that specifically focused on the perspectives of the parents who experienced perinatal loss. The term perinatal loss was defined as “the unintentional loss of a pregnancy via miscarriage, stillbirth, or neonatal death” (Berry et al., 2021, p. 20). The findings from the review were linked to one theme which was the paradox of perinatal loss and the four subthemes were complex emotional responses, prenatal bonding-acknowledging personhood, interactions with health care professionals, and traversing the social sphere. These themes were strongly connected to the relational influence that healthcare professionals have regarding perinatal loss. The article states the critical nature of equipping health care professionals with theory-based models to care for parents as they grieve the loss of their child. The authors go on to claim that perinatal bereavement is a unique experience that requires attention through evidence-based practices considering the complexity of the loss experience that challenges traditional grief paradigms (Berry et al., 2021).

Another study conducted by Dube et al. (2021) aimed to identity the specific psychological components of infertility-related distress to help the development of targeted and effective therapeutic interventions. In this article, infertility is defined as “the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (Dube et al., 2021, p. 1). While the rate of infertility affects 15% of couples globally, the interventions to treat this population are usually expanded versions of existing interventions to treat depression and anxiety and are not significantly effective (Dube et al., 2021). Twenty-one women struggling with infertility were interviewed as well as 14 mental health professionals who specialize in infertility regarding the psychological challenges to infertility. There were two focus groups of four women each, seven face to face interviews, and six individual telephone interviews. Additionally, there were 16 mental health professionals who participated in a phone interview. The data from the interviews with the women and mental health professionals were combined and revealed five major themes including anxiety, mood disturbance, threat to self-esteem, identity, and purpose, deterioration of the couple, and weakened support network. The mental health professionals used a variety of theoretical approaches when working with their clients including cognitive behavioral therapy, acceptance and commitment therapy, and mindfulness. The study highlights the themes of this population as well as the importance of interventions that are more specific to their needs in counseling (Dube et al., 2021). Future research could include theoretical approaches that focus on re-building self-concept such as feminist or strengths-based theories.

Gender Diverse Experiences

It is essential for research to also consider LGBTQIA+ experiences. A study from 2008 aimed to describe the mental health services used by lesbian, gay, and bisexual (LGB) women in the perinatal period to identify potential correlates of mental health service use through a cross-sectional approach (Steele et al., 2008). Participants were recruited through email and paper flyers to LGB and parenting community listservs. Eligibility included identifying other than heterosexual, trying to conceive a child or currently pregnant or biological mothers of children less than one-year-old, or non-biological mothers of children less than one-year-old. Seventy-three participants were given a mailed survey that included questions related to their depression level, quality of life, social support, outness, discrimination, and use of mental health services. Of the 73 participants that were mailed surveys, 64 responded and were mostly white, urban, educated, and partnered. The findings of the study were that financial barriers were the indicator of women not seeking out mental health services (Steele et al., 2008).

In 2012, Ross et al. (2012) explored the mental health, social support, and other variables related to the experiences of sexual minority women who were trying to conceive, are pregnant, or are parenting an infant (Ross et al., 2012). The study found that of the 64 participants, those who identified as bisexual reported poorer scores on mental health, substance use, social support, and perceived discrimination experiences. The participants were recruited through email and flyers distributed in discussion boards of the gay, lesbian, and bisexual parenting communities in Toronto, Ontario. Participants were also given $25 upon receipt of the questionnaire. Participants were given the option to interview and an additional $25. Thirteen participants opted to be interviewed. The findings indicated that bisexual mothers and prospective mothers are not the same as women of other sexual identities, resulting in significant differences in quantitative mental health, stress, and social support-related outcomes. The study showed that "bisexual individuals can experience exclusion not only from the heterosexual community but also from lesbian/gay communities, particularly on the basis of stereotypes about bisexuality (Ross et al., 2012, p. 149). This study belies the idea of privilege as a bisexual woman being able to "pass" as heterosexual as this study found it is actually a source of significant discomfort and can further isolation.

Another study sought to explore the factors that affect mental health and wellness in Lesbian, Bisexual, and Queer (LBQ) non-birthing parents during pregnancy (Abelsohn et al., 2013). The study used an intersectional theoretical framework acknowledging the multiplicity of communities' identities. It was part of a more extensive study examining postpartum depression and social exclusion in LBQ mothers, and the participants were asked if they had a partner eligible. Eligibility included being over 16 years old, living in Toronto, Canada, English speaking and self-identified as a lesbian, bisexual, or queer woman (or a related term). Eight participants were in semi-structured qualitative interviews analyzed using grounded theory. The results showed four major themes: (a) biology, connectedness, and relatedness, (b) social recognition, (c) social support, and (d) changes during pregnancy. Many themes were connected to policy and law that do not support the non-birthing parent as a "legal" parent and the related fear. This study aimed to capture the experiences of non-birthing people which is significantly underrepresented in the research. The participants noted the need for educational resources and programs that address the experiences of expecting non-birthing parents throughout pregnancy and new support needs that emerge postpartum (Abelsohn et al., 2013). Implications of this study include the importance of professionals interacting with LBQ people and, treating them as equal partners to understand what factors contribute to mental health and wellness in order to provide support for the unique needs of this population.

A cross-sectional study of transgender men who had been pregnant and delivered after transitioning from female to male was conducted to guide and improve health and healthcare experiences for transgender men (Light et al., 2014). Participants were older than 18, self-identified as male before pregnancy, had a pregnancy within the last 10 years, and could fill out a survey in English. Medical or surgical transition was not required to participate.

Participants were recruited through distribution to key stakeholders in LGBTQ health centers, community groups, and social networking pages. The study had 41 participants after some were excluded due to a lack of responses for analysis or did not meet study criteria. Most of the participants were White and attended some college. A cross-sectional survey from March to December 2013 was sent through REDCap. It contained 47 multiple-choice questions and 24 questions addressing demographics, hormone use, fertility, pregnancy experience, birth experience, and fetal outcomes. There were also four open-ended questions: (a) What was the experience of being pregnant like for you? (b) What was the experience of giving birth like for you? (c) What was the postpartum experience like for you? and (d) Is there anything you would like medical providers to know about transgender men and pregnancy? The themes from the open-ended questions were the effect of pregnancy on concepts of family structure, isolation, gender dysphoria and pregnancy, and interactions with healthcare providers. Many of the participants desired more information about fertility options and access to providers who respect, support, and understand their gender identity (Light et al., 2014).

Charter et al. (2018) aimed to fill in the gap of literature regarding the lived experience of transgender (trans) men in Australia around their desire for parenthood and experiences of pregnancy. This study is also a subset of a larger study that was open to any transgender person in Australia who was also a parent. The participants were 25 trans men whose ages ranged from 26–46 years and who had experienced gestational pregnancy. This was a mixed methods design which included the use of online survey data and one-to-one interviews and was analyzed using thematic analysis. Participants were recruited by a distribution sheet given to transgender support groups, posted on social media, and community organizations. Participants were then asked to fill out an online survey that collected demographic information and asked open-ended questions regarding the transition experience, family history, relationship history, support, and other experiences of parenthood. The participants were then asked if they would be open to a semi-structured interview, in which 16 participants agreed. The opening question was, "think back to when you first had children, what was life like for you then" (Charter et al., 2018, p. 67) and the individual survey responses informed the rest of the interview questions. One theme was perspectives on parenting, with subthemes of growing up female, the assumption of motherhood, orienting toward fatherhood and parenting on my own terms. Another theme was pursuing pregnancy, with subthemes including a functional sacrifice, the struggle, living without T (testosterone), and accessing reproductive assistance. Finally, the last theme was the pregnant man with subthemes of inhabiting the pregnant body, chest distress, and the isolation of exclusion. The findings also showed that heteronormativity in parenting contributes to isolation and exclusion for trans men who decide to carry a child. The report also stated the harm from woman and mother being synonymous terms and does not necessarily capture the experience of trans gestational men. Through the process of transition, trans men can construct their sense of self and what it means to be a parent that challenges the dominant cultural narrative. Another finding is that hormone therapy can be essential to combating gender dysphoria, and ceasing this treatment in order to conceive is distressing and troubling as they notice their bodies change. A limitation is that while it set out to be gender-diverse, due to its recruitment strategies, it mostly had trans men and not those who may identify in other gender-diverse ways (Charter et al., 2018).

Kirubarajan et al. (2022) conducted a study to synthesize, through a systematic review, the literature on the LGBTQ2S+ experiences of childbearing individuals regarding perinatal mental health that includes symptomatology, access to care, as well as care-seeking behaviors.

Eight databases were reviewed using PRISMA guidelines and included peer-reviewed articles that were related to LGBTQ2S+ and specific to the perinatal period. A qualitative review using the JBI SUMARI and ConQual approach was utilized for analysis. Twenty-six articles met the requirements encompassing 1,199 LGBT2S+ childbearing participants. The findings from the articles were coded as being relevant to sexual orientation, gender identity, or both, and of seventeen categories, they synthesized into six "themes" with subcategories. The first theme was difficulties of the perinatal period (low mood, anxiety and trauma, and challenges related to gender identity). The second theme was swimming upstream (community-based risk factors, individual-based risk factors, relationship-based risk factors, and context of perinatal period). The third theme was barriers to seeking mental healthcare (stigma, system-based barriers, and individual barriers). The fourth theme was mental healthcare experiences (experiences with treatment, and exclusion within mental healthcare). The fifth theme was resilience beyond traditional care (community-based strategies, cognitive and spiritual strategies, boundary setting and self-empowerment). Finally, the sixth theme was steps forward (combating heteronormativity and cisnormativity, safe(r) care, and healthcare provider training). Overall, the themes seemed to highlight exclusion and stigma for the LGBTQ2S+ childbearing population. This study attempts to uplift the voices of a marginalized population under-researched, especially around perinatal experiences (Kirubarajan et al., 2022).

A systematic meta-synthesis of sexual and gender-diverse childbearing experiences (SGD) was conducted to improve perinatal health care for this population to reduce disparities (Soled et al., 2023). Four databases were searched from 2011 to 2021, and studies focusing on perinatal or childbearing experiences were included. Data was extracted and inductively coded using content analysis, revealing 25 articles through Sandelowski and Barroso's six-step meta-synthesis. Thematic analysis identified the following themes: systematic invisibility (erasure, structural exclusion, discrimination), creating personhood through parenthood (journey to parenthood, grappling with gender, when creating is losing, climbing mental mountains), and resilient narratives of childbearing (strategies for emotional and social safety, communities of support, from the margins to the center, queering childbearing narratives). Participants (*N* = 297) were mostly White, highly educated, and partnered. The findings implied that training and clinical education around competent care to SGD individuals during the perinatal period is essential (Soled et al., 2023).

Copeland et al. (2023) set out to understand more deeply the transgender and nonbinary person's pregnancy and birth experience to inform professionals of inclusive care practices. The sample consisted of two transgender and nonbinary people who have their pregnancy and perinatal care through a Midwifery Group Practice in Australia. The data was collected using open-ended questions in semi-structured, face-to-face interviews. The interviews were done by the professional the participants were in contact with during perinatal care at the midwifery. The first question to start the conversation asked participants to describe their experiences as gender-diverse people in the perinatal period. These transcripts were reviewed using content analysis to identify patterns, themes, and word groupings. The themes found were: anticipation of pregnancy care communication from staff (brace themselves-misgendered, feeling feminized), education for staff (gaps in the system), gender-inclusive literature, and continuity of care. The limitation and strength of this study is that there were two participants. The strength is that the participant narrative is robust and impactful. However, the findings seem congruent with other research that calls for systemic change and paradigm shifts in perinatal care, including professional training (Copeland et al., 2023).

Race and Ethnicity

In addition to LGBTQIA+, race and ethnicity are important to consider. In the United States, Black women are twice as likely as white women to experience perinatal mental health conditions and half as likely to receive care (MMHLA, 2023). Additionally, Black women are two to three times more likely to experience maternal death than white women (MMHLA, 2023). A study conducted by Barnett et al. (2020) aimed to examine and understand the experiences of BIPOC women as they relate to pregnancy and birth complications to inform policy to decrease racial and ethnic health disparities. The participants were (*n* = 31) women who identified as women of color, English-speaking, 18 years and older, and had experienced pregnancy or birth complications in the state of Ohio during their pregnancy. This study had six, 90-minute focus groups in which a guide was created to elicit discussions that focused on barriers, successes, and opportunities to have equitable care throughout the perinatal period. Additionally, each participant was given a $50 gift card for their time. The study then used an inductive and iterative thematic analysis approach to disseminate the themes from the focus group discussions. The study's results showed seven key themes: lack of knowledge, mental health, communication with providers, support systems, representation, social determinants of health, and discrimination and stigma. These findings indicated that there is a need for change at multiple levels of the health care system (Barnett et al., 2022).

Health equality will remain elusive if we do not name the racism, classism, and power divide between patients and the people embedded in systems, structures, and policies (Carter et al., 2021). To further illuminate this point, a case study was introduced to highlight how group prenatal care can support Black women, which also involves clinicians to decrease bias and increase contact time between the two individuals. Previous studies in group prenatal care have shown that participation in these groups improves patient knowledge, behavior change, social support, clinician contact, and reduced stress and depression (Herberlein et al., 2016; Ickovics et al., 2003). The case study discussed was a group of clinicians, health center representatives, patients, and community organizations that developed and introduced an intervention and racial equity framework into the group process, which increased the likelihood of diagnosing unmet mental health needs. The group process highlighted that clinicians should slow down and listen to the community that they are there to support and advocate for change at the systems level to which they have access. Ultimately, focusing on the interventions for the patient alone misses the mark, and the focus should shift to the clinician and the systems. Carter et al. (2021) call for expanding research to practitioners and institutions to explicitly address social determinants of health. In addition, it is essential to recognize the past and present impact of racism. The study illuminated that answers are often found in the community, so involving the community in research is essential. Involving the community could develop policy and reimbursement structures to support equitable outcomes (Carter et al., 2021).

Another study focused on inspecting the factors that are associated with the lack of women receiving perinatal mental health counseling services, especially inequities in race and ethnicity (Declercq et al., 2022). The study looked at data from the Listening to Mothers in California survey, which captured 2,539 women who gave birth in 2016 and was pulled from a representative sample of birth certificate files. The survey included the PHQ-4, questions on the receipt of counseling, whether a practitioner asked about their mental health, and if they were taking any medications for anxiety or depression. The results found that non-Latina Black women experienced higher rates of prenatal depressive symptoms and significantly lower use of counseling services or medications than White women. Of the women with depressive symptoms reported, 46% were asked about counseling services, and 20% were not asked. In the multivariate analysis, those who were asked about counseling services were six times more likely to report counseling. These findings indicated that there is a need for universal, required screening for depressive symptoms in the perinatal period to reduce inequities and increase counseling services for support (Declercq et al., 2022).

Socioeconomic Experiences

In looking at both ethnicity and socioeconomic status, one study examined the experiences of racial discrimination during perinatal care from the perspectives of African-American women in a low-income neighborhood in Milwaukee, Wisconsin (Salm Ward et al., 2013). This qualitative study used six focus groups of 29 women and two individual interviews to identify themes of their experiences. The sample intended to focus on women who were at the highest risk for poor birth outcomes and chosen if they were African American, at least 18 years old, with a child younger than one year, and who had at least one perinatal care visit. The findings showed that there were experiences of discrimination based on insurance or income status, race, and lifetime experiences of racial discrimination. Some women reported receiving a lower quality of care if they were using public insurance and had limited access to care given this. This study's limitations are that each woman interacted with a different healthcare provider (midwife, OBGYN, RN), and the provider's race was not collected (Salm Ward et al., 2013).

Another study intended to identify similarities and differences in perinatal experiences between women with low socioeconomic status by race, ethnicity, and nativity to understand the sociocultural and environmental contexts of perinatal experiences (King, 2014). The study used a purposive stratified sampling method to represent diversity in race, ethnicity, and perinatal development among women with low socioeconomic status who were likely to be screened for perinatal depression. These women were recruited from health and social service providers at pre-selected community-based organizations in two of the largest cities of a midwestern state. Inclusion criteria included being 18–45 years old, pregnant or up to one year postpartum, self-identified as African American, White, Latina, or Hmong and spoke English, Spanish, or Hmong. Women ($N = 32$) were recruited and participated in four focus groups that were moderately structured and lasted between 75 and 120 minutes. The questions were open-ended about perinatal experiences as well as more specific questions relating to depression symptoms. Each focus group was split up by racial and ethnic background. The data was analyzed using content analysis and showed that women primarily understood their perinatal experience through the stressors in their environment, including financial, insufficient partner support, and lack of community. The study identified environmental factors such as limited income, inconsistent access to resources, and insufficient social support, which are pervasive in the experiences of women with low socioeconomic status. These results show the need for understanding the environmental context of perinatal people to accurately identify depression and the implications of adverse perinatal experiences (King, 2014).

It is also important to understand the barriers and facilitators of people with low socioeconomic status accessing midwifery care (Darling et al., 2019). Participants were eligible if they were pregnant or had given birth within the last year and were of low socioeconomic status. Recruitment occurred through social media and posters at health care and social services sites in Hamilton, Canada from January to May 2018. Low socioeconomic status was determined by income, occupation, and educational attainment. This was a qualitative descriptive study design in which semi-structured interviews were conducted with 30 pregnant and postpartum people. Of the 30 participants, 13 received care at a midwifery and 17 had never received care from a midwife. The themes that emerged were: (a) I have no idea…, (b) babies are born in hospitals, (c) physicians as gateways to prenatal care and, (d) why change a good thing? The results indicate that those who had not interacted with or received care from a midwifery had misconceptions about their scope of practice and saw physicians as the only entry into care. The participants who experienced care from a midwife stated that it was an appropriate match for the needs of people with low socioeconomic status. These findings emphasize that the lack of awareness about midwives limits the approachability of these services that can benefit people from low socioeconomic status. Pregnant people impacted by low socioeconomic status can tend to move passively through healthcare networks without being presented with options for their perinatal experiences and care. This study contributed to the literature by supporting inclusivity through the use of "people" or "pregnant people;" however, they did not gather the gender identity of the participants, which limits the intersectionality of marginalized identities that influence this population (Darling et al., 2019).

Another vital population to consider is the perinatal mental health experiences of migrant women from ethnic minority backgrounds during COVID-19 in London, England (Pilav et al., 2022). Eighteen women from ethnic minority backgrounds were interviewed, and the data was analyzed using thematic analysis. Results revealed three main themes with each having two subthemes. The first was difficulties and disruptions to access (access to appointments, pandemic restrictions and disruption). The second was experiences of remote delivery (preference for face-to-face contact, advantages of remote support). The third was psychosocial experiences linked to COVID-19 (heightened anxiety, social isolation). These findings indicate that ethnic minority women experienced disrupted perinatal mental health care which compounded their mental health difficulties. This study highlights the necessity to take women's circumstances and external systems into account in order to provide unique and flexible care based on their specific needs. Additionally, this study sheds light on the increased isolation women experienced during the pandemic on top of the isolation that pregnancy can cause. A limitation is the small sample area (Bromley, Bexley, Greenwich) all of which are boroughs of South London. The participants were recruited if they were already seeking services from a specific community perinatal mental health organization during COVID-19. A strength of the study was the intentionality about using the language that participants used when defining ethnicity (Pilav et al., 2022).

Another study sought to understand what prevents poor women in Dhaka, Bangladesh from seeking free or low-cost government-provided healthcare (Akhter et al., 2020). The sample included 34 women who already had a child or were pregnant within the last five years. These women were interviewed to understand perceptions and experiences of using maternal health care for childbirth. The women reported experiencing deep-rooted fear of using such services, which included having to make undocumented payments, unfamiliarity with the institutional processes, lack of social and family network support within their neighborhoods, concept of honor and shame [sharam], a culture of silence and inadequate spousal communication regarding health issues. So, although there are resources that are cost-effective and nearby, they would choose not to give birth at such facilities. The study shows that it is crucial to meet the needs of these women by understanding their fears and providing them with factual information and culturally sensitive counseling (Akhter et al., 2020).

Disability Experiences

In understanding perinatal needs, the experiences of those with disabilities must also be considered. Khan et al. (2021) conducted a study that sought to use the socio-ecological model to explore the barriers and facilitators that impact the perinatal care experiences of people with intellectual and/or developmental disabilities (IDD). The participants included 10 individuals with IDD in Ontario, Canada, who had given birth in the last five years. Convenience and purposeful sampling methods were used to recruit participants. Semi-structured interviews were conducted and focused on the participants' experiences before, during, and after pregnancy. The data was analyzed using directed content analysis and the socio-ecological systems model as a guide. Barriers were identified at each level: societal (cultural norms of motherhood), policy/institutional (child protection policies and practices), interpersonal (inadequate formal and informal support), and intrapersonal (internalized stigma), all of which contributed to negative perinatal care experiences. Conversely, the study found that there were interpersonal facilitator factors: positive interactions with perinatal care providers and familial and social service supports. The findings indicate that change regarding perinatal care for individuals with IDD should occur at multiple levels which includes policy change at institutional levels and training of care providers to facilitate the institutional change as well as their interpersonal dynamics working with this population. A point of interest to consider is the overall support of healthcare in Canada and the disconnect between training and supportive providers. Given the demographics of the study, there is a wide range of experiences captured (socioeconomic status, age, race, education) while limitations around gender identity and sexual orientation which is cis-normative. This study highlights the aspects of systems at many different levels in for a paradigm shift to occur realistically (Khan et al., 2021).

It is also important to understand the communication experiences of birthing people with intellectual and developmental disabilities (IDD) and/or sensory disabilities in perinatal care (Saeed et al., 2022). This study presented effective provider-patient communication as a critical element of quality health care and is often one of the barriers to perinatal care, especially for patients with IDD. The participants included 17 people with IDD in Ontario, Canada, and were recruited through convenience and purposeful sampling methods. The participants were interviewed using a semi-structured format, and the data was analyzed using both deductive and inductive thematic analysis. Interviews were conducted via Zoom or in-person based on the participant's needs. Results showed that birthing people with IDD experienced many barriers to perinatal care around lack of policy and guidelines, lack of provider experience, lack of provider effort, ableism, and provider assumptions. Factors that contribute to a positive experience were knowledgeable, aware, and supportive providers, access to communication aids and services, tailoring information to patient's disability-related needs, empathic communication, and interdisciplinary communication. These findings support the need for accessibility policy implementation and practice changes to meet the diverse needs of the perinatal population. The study intentionally chose to use "birthing people" to acknowledge that not all birthing individuals identify as cisgender women (Saeed et al., 2022).

To further explore the perinatal experiences of women with physical disabilities (WWPD), a study was developed to gather recommendations for clinicians to improve care (Smeltzer et al., 2016). The participants were 25 WWPD who gave birth in the last 10 years and were 21–55 years old. This study was a qualitative descriptive mixed methods design with a semi-structured interview to identify the experiences of WWPD, which was part of a larger study of the barriers and unmet needs to perinatal care experienced by WWPD. The interviews were conducted by telephone, and participants were asked about intersections with clinicians during the perinatal experience and how their care could have been improved. Content analysis was used to transcribe the interviews and Kurasaki's coding was used to establish themes and reliability of the coding. The study found three themes: (a) clinicians' lack of knowledge about pregnancy-related needs of WWPD, (b) clinicians' failure to consider women's knowledge, experience, and expertise about their disabilities, and (c) clinicians' lack of awareness of the reproductive concerns of WWPD. The language used to define this population was gender-limiting, and convenience sampling was done mainly via the Internet and social media, which not everyone can access (Smeltzer et al., 2016).

A different study aimed to understand the perinatal experiences and outcomes of women with physical disabilities in a Canadian province in order to identify barriers to perinatal care (Tarasoff, 2017). The participants were 13 women with physical disabilities who had given birth in the last five years, and the phone interviews were analyzed using a constructivist grounded theory approach. The recruitment was through the use of convenience sampling, word of mouth, and flyers to groups that serve pregnant women. Data analysis identified five themes around barriers to care which included inaccessible care settings, negative attitudes, lack of knowledge and experience, lack of communication and collaboration among providers, and misunderstandings of disability and disability-related needs. These barriers may contribute to poor outcomes for the birthing person and their newborn. The findings indicate that the perinatal care system is not set up to care for women with physical disabilities and that more research and training is needed in this field. Additionally, there is a call for interdisciplinary collaboration and inclusion needed to improve the perinatal care experiences for women with disabilities. The limitations of this study include only capturing those who identify as a woman and the limitation of generalizability that only Ontario residents could participate (Tarasoff, 2017).

The purpose of this next study was to explore the perinatal experience of Black and deaf and hard of hearing (DHH) women to understand the factors that influence their pregnancy outcomes (Helm et al., 2023). Between 2018 and 2019, 67 DHH women who gave birth in the last five years were interviewed, and this study represented a subgroup of eight women from the 67 who self-identified as Black. The participants were recruited from two research sites in Chicago, New York, and online. The sample was limited to women between 21 and 50 years old, with an average age of 35. Five of the eight participants attained some college and five reported an annual household income of less than $20,000. The interview questions focused on pregnancy and birthing experiences, previous healthcare experiences during and after live birth. They were also asked about barriers and facilitators to care as well as support. The interviews were either in spoken English or ASL based on the participant's preferred language to increase their sense of belonging during the interview process. To analyze the data, the researchers used Dedoose to manage the coding of each interview. The emerging themes were cultural and familial support, knowledge and educational opportunities, and communication accessibility with subthemes of unmet needs, barriers, and facilitators. Black DHH women experience perinatal challenges related to inaccessible healthcare communication, low health knowledge, decreased communication satisfaction, and ineffective healthcare provider and team support. They are also met with racial and cultural biases from healthcare providers. The findings show the importance of providers and practices to have access to communication accommodations, information, and cultural competency training. This study could expand to examine the intersection of mental health resources to support this population (Helm et al., 2023).

Another study compared the lived perinatal experiences of women who are deaf and their peers who can hear in order to understand the barriers and facilitators of optimal pregnancy- related healthcare (Panko et al., 2023). The participants were 45 women who are deaf and communicate using American Sign Language (ASL) and gave birth in the United States within the past five years. This qualitative study used semi-structured, individual interviews that were either in-person or remote. The open-ended questions of the 90-minute interviews explored how deaf mothers experienced the perinatal period, including access to information and resources, relationships with healthcare providers, and communication accessibility. Three major themes emerged from a thematic analysis: communication accessibility, communication satisfaction, and healthcare provider and team support. Each theme included both a barrier and a facilitator to the perinatal experience. The barriers were related to choosing a healthcare provider, inconsistent communication access, and access to health information. The facilitators were mainly related to what the system can do to provide access to care and communication. When women had access to ASL interpreters, their experiences were more positive. A limitation is that this study does not disclose the recruitment strategy or other demographic information of the sample. While the study does not share the specific demographics, they share in the limitations section that most of the participants were White and well-educated, which can contribute to the high level of self-advocacy that was reported (Panko et al., 2023).

Policy Change

In 2009, Section 2952 of the Patient Protection and Affordable Care Act (2010) aimed to expand the research for postpartum depression and evaluate current service and screening models, similar to the MOTHERS Act, which was the first federal legislation on perinatal depression in 2003 (Rhodes & Segre, 2013). The second provision of Section 2952 "authorizes grants to support the establishment, operation, and delivery of effective and cost-efficient systems for providing clinical services to women with, or at risk for, postpartum depression or psychosis (Rhodes & Segre, 2013, p. 6), however, it only recommends research on the development of screening and diagnostic tools, but "does not recommend screening per se"

(Rhodes & Segre, 2013, p. 6). United States and British organizations conducted studies that found that the current screening for perinatal women is not an effective protocol (American College of Obstetricians and Gynecologists, 2010). Without training, “a federal or state screening mandate does not guarantee that perinatal depression screening will be successfully implemented” (Rhodes & Segre, 2013, p. 12).

It is important to highlight the impact structural racism and gendered oppression have on the well-being of birthing people and attempts to challenge assumptions about the psychosocial aspects of the perinatal experience and discuss a way to encourage well-being in the perinatal period (Foster et al., 2021). To reimagine what holistic well-being could look like, Foster et al. (2021) conducted focus groups and interviews with advocates, clinicians, creatives, educators, researchers, students, and people with lived experience of pregnancy, birth, miscarriage, abortion, infertility, and childlessness. The goals of the interviews and focus groups were to disrupt underlying assumptions about the perinatal experience’s psychosocial aspects and think of a way forward to foster inclusivity and access to care that includes perinatal mental health. The group members were found through the authors’ networks and an electronic Black Mamas Matter Alliance (BMMA) discussion board to center Black, Indigenous, and People of Color (BIPOC) voices. The questions asked in the focus group included the current structure of perinatal mental health care, recommendations for changes to perinatal mental health care, experience with perinatal mental health diagnostics and treatment, BIPOC intersections and distinctions in perinatal mental health care, people with disabilities, LGBTIA+, and barriers to thriving for pregnant people and their families. Fifteen themes fell into three categories: people, systems, and structures. Themes were connected to policy gaps, including the obligation to fulfill human rights through policy change efforts. There is a call for a paradigm shift as the definition and concepts of perinatal mental health were built within an existing system of care that upholds oppressive structures (Foster et al., 2021).

Rationale

Based on existing research, disparities in perinatal mental health are abundant (Abelsohn et al., 2013; Alio et al., 2010; Barnett et al., 2022; Carter et al., 2021; Copeland et al., 2023; Darling et al., 2019; Declercq et al., 2022; Helm et al., 2023; Huggins et al., 2020; Khan et al., 2021; Kirubarajan et al., 2022; Losada et al., 2022; Panko et al., 2022; Pilav et al., 2022; Ross et al., 2012; Salm Ward et al., 2012; Smeltzer et al., 2016; Soled et al., 2022; Tarasoff et al., 2017). The understanding of the impact that culture has on perinatal experiences is fragmented as the research stands. Therefore, this study aims to explore all cultural aspects of an individual's experience and how those intersecting identities influence the barriers and facilitators to the perinatal care experience. This study focuses on using inclusive language by moving away from hetero- and cis-normative assumptions and embracing the complexities of the participant's cultural diversity. By looking at this data through an ecological systems framework, healthcare professionals and policymakers may be able to better influence change so that the perinatal population can have access to care and meet unique needs given their circumstances. This study aims to use qualitative methods and photovoice to support the existing quantitative literature for a more robust and impactful call to action. Additionally, the use of photovoice allows participants to engage in research differently and uplift their perspectives.

CHAPTER III: METHOD

Introduction to the Method

A Qualitative Approach

The philosophical foundation of constructivism informs this study. Crotty (1998) suggested constructivism points out the unique experience of each of us. Every person’s way of making sense of the world is as valid and worthy of respect as any other. This is to say that each perinatal experience is different from the next, and that experience should be honored and heard. Additionally, this study aims to capture the cultural influence of one’s perinatal experience, which may be seen as a social constructionist approach that “emphasizes the hold our culture has on us: it shapes the way in which we see things” (Crotty, 1998, p. 58). A tenant of constructivism is that individuals develop subjective meanings of their experience, and therefore, multiple meanings may exist, and qualitative research is flexible enough to hold these complexities (Creswell & Creswell, 2023).

While qualitative methodologies have been used for centuries, the term qualitative research is a young field of inquiry that began in the 20th century (Leavy, 2020). Qualitative research focuses on exploring and understanding the meaning individuals or groups ascribe to a social or human problem (Creswell & Creswell, 2023, p. 4). Qualitative research supports the study’s aim of capturing the perinatal experience of people with uteruses. This study also includes a feminist perspective due to the “intricate and implicate relationships between language, voice, and consciousness” (Patton, 2015, p. 73). A feminist perspective uplifts historically marginalized voices, and people with uteruses are often in this category. Considering that each individual’s perinatal experience is unique, qualitative research supports the personal nature of understanding an individual’s perspective through storytelling (Patton, 2015). The primary research question asks, what is the perinatal experience of people with uteruses? The sub-question asks, what are the perceptions of people with uteruses regarding barriers and facilitators of perinatal care?

Photovoice

Photovoice can be used to support previous quantitative studies for policy change as an opportunity, and can complement or enhance data collection visually and narratively (Wang & Pies, 2004, p. 100). Photovoice is a participatory research method that utilizes feminist theory and engages with participants as co-researchers (Breny & McMorrow, 2021). By combining interviews with photovoice, participants can expand on their narratives and not feel limited by the framing of interview questions. Additionally, this combination helps researchers check their assumptions, biases, and judgments by having participants share their photovoice narratives rather than leaving it up to the researcher for interpretation. Wang and Pies (2004) claimed, “photovoice may also serve to foster a sense of community and place among participants” (p. 100). Leavy (2020) added that participants take more of an active role by taking photos for research as they are able to discuss what is meaningful or important to them. A few photovoice studies in the current research are discussed below.

Carlson et al. (2006) conducted a study to determine how using photovoice research in a lower-income, African American, urban community facilitated authentic engagement and participation. The reluctance of communities to engage in research, and the researchers’ lack of penetration into a community are significant barriers to community-based research approaches. The study’s purpose was to report on a retrospective ethnographic analysis of a photovoice project and the events that occurred afterward. The project took place for five weeks during August 2000, where members of an African American community took photographs of what they were proud of about their neighborhood, and photographs of what they would like to see changed and to tell the story of why these pieces are important. These photos aimed to document the community health concerns through storytelling and photography. Additionally, the first author was part of this community, holding many roles, and therefore could offer a different perspective from a different level of influence. There were two 8-hour workshops, and participants received $100. The first workshop had 45 participants, and 24 returned for the second workshop. The data that was collected included 54 photographs and stories that the community participants generated, and due to the multimedia data, it was analyzed using ethnography and visual anthropology. The themes, or “levels of cognitive-emotional interpretations that moved participants from passive adaptation to higher levels of critical consciousness” (Carson et al., 2006, p. 843), were emotional engagement, cognitive awakening, and intentions to act. The authors found that by using photographs and stories, a social process took place that resulted in higher levels of critical consciousness and is necessary to engage and maintain participation in historically marginalized communities (Carlson et al., 2006).

Musoke et al. (2015) used photovoice to generate evidence by community members “in ways that articulate their perspectives, support local action and allow direct communication with stakeholders” (p. 136). Participants were allowed to take as many photos as they wanted over a five-month period related to aspects and situations in their community to maternal health. Monthly meetings were conducted so participants could share how the pictures were related to their lives and those of the community, and what they meant for the study. Guided questions in the monthly meetings included: 1. What was happening in the photo? 2. How it related to the photographer’s lives and what could be done about it. The guided questions offered an opportunity for the participants to expand on their process and what their experiences are in their community.

Losada (2022) completed their dissertation research around traumatic birth, breastfeeding, caregiving, and bonding using an interpretive phenomenological methodology through use of diary-interview, photovoice, and research journaling. The researcher used purposeful sampling and had 13 participants that were located in the Midwest and Southwest regions of the United States. The study found nine themes that were related to traumatic birth experiences. Losada (2022) had participants capture photographs and a brief written summary of the significance of the photos, followed by a discussion that "moved participants out of helplessness toward authentic engagement and participation" (Carlson et al., 2006, p. 836). They state that using photovoice allowed for multiple forms of expression, especially for those who prefer non-writing forms of expression.

Study Design

This study included a two-phase design. During Phase One, participants were recruited through the researcher's network through convenience and snowball sampling. The recruitment email included participation criteria, details, and a link to fill out the consent and demographic survey information. Participants were asked to share their email for scheduling purposes only. The researcher emailed participants who filled out the consent form and demographic survey to schedule an individual one-on-one interview.

Phase One of the study included a semi-structured interview to capture participants' personal perinatal experiences. The data gathered from the interview was coded and themed using thematic analysis. Given that the goal of the study was to uncover lived experiences to determine how to better support the perinatal community, a semi-structured interview for Phase

One allows for the freedom for participants to tell their stories. Thematic Analysis (TA) is a flexible analytical method that enables the researcher to construct themes. TA allows the researcher to report their interpretation of a qualitative data set and honors the participants and their stories. TA consists of six steps utilized for this study: (a) become familiar with the data, (b) generate initial codes, (c) search for themes, (d) review themes, (e) define themes, and (f) write the report (Terry & Hayfield, 2021). After the theming from Phase One was completed, those themes informed the photovoice prompts for Phase Two. Participants from Phase One were emailed the photovoice instructions, which included a link to sign up for a focus group and a link to upload their photos and narratives. Participants who attended the focus group received a $25 Amazon gift card stipend for their time.

Phase Two consisted of participants uploading their photos related to the themes from Phase One. The prompts for the photovoice were: (a) grief, (b) support, (c) pressure and expectations, (d) identity transformation and shifting roles, and (e) advocacy and empowerment. Participants were given a link to upload their photos and share the narrative for each photo. Participants then had the opportunity to join a focus group to discuss their perinatal experiences through their photos. The focus group allowed participants to engage in theming and a member check given the themes from Phase One. Photovoice, used in Phase Two, aligns with thematic analysis in that it also prioritizes the stories of the community in their own words (Breny & McMorrow, 2021). Together, these methodologies complement one another and give voice to the population reflected in the research.

Study Context

An electronic survey was used to capture participant consent and demographic information. The end of the survey included a place for participants to share their email so the researcher could schedule an interview time with each participant. Another electronic survey was used in Phase Two where participants could upload their photos and narrative descriptions. Zoom was used to conduct the semi-structured interviews and focus groups. The interviews were HIPAA-compliant and password-protected. These Zoom meetings were also recorded, and audio was saved. This study had no manipulation or intervention of variables. Using electronic means to interact with participants allowed the study to be accessible regardless of location in the United States and was most cost-effective.

Participants

The population consisted of people with uteruses who have a biological means of getting pregnant and giving birth. Participants were recruited using convenience sampling as well as snowball sampling. Purposeful sampling was used to capture a diverse range of experiences. Inclusion criteria consisted of the following experiences: infertility, conception, pregnancy, miscarriage, childbirth, stillbirth, and postpartum. Participants could participate after the experience (i.e., a person with a uterus with a 6-year-old reflecting on their perinatal experience). Exclusion criteria included adoption (PADS- post-adoption depression syndrome), third-party reproduction (surrogacy), non-gestational partners, and abortion, as these go beyond the context of this study.

Data Sources

Demographic

After reviewing the consent form, participants were prompted to complete an electronic demographic survey. Many questions were open-ended to capture the language each participant identifies as part of their unique identity. The demographic survey's open-ended nature aligns with liberation psychology's premise that oppressed populations are often subject to colonization by having their history written through the colonizer’s lens (Martín-Baró, 1994). Previous studies such as Charter et al. (2018) and Barnett et al. (2022) also informed the demographic questions. Additionally, aspects of Hays (2016) ADDRESSING Model are included. Descriptive statistics were used to interpret the demographic survey data.

Phase One Interview Questions

The interview was semi-structured, with the first question being, “Tell me about your perinatal experience.” Based on where the interview went, other questions were in place that are specifically related to the ecological systems theory, such as cultural norms and what roles counseling, government, and community play in the perinatal experience (Bronfenbrenner, 1994). Leavy (2020) stated, “ Compared to structured interviews, semi structured interviews can make better use of the knowledge-producing potentials of dialogues by allowing much more leeway for following up on whatever angles are deemed important by the interviewee” (p. 437).

Phase Two Focus Group Questions

The questions asked in the focus group were also semi-structured with the opening question encouraging participants to share the narrative of their photos. From a Feminist perspective, focus groups “afford women safer and more supportive contexts within which to explore their lived experiences with other women who will understand what they are saying intellectually, emotionally, and viscerally … mitigate alienation, create solidarity, and enhance community building” (Leavy, 2020, p. 488). Additionally, the focus group community can lessen the power dynamics between the interviewer/researcher and interviewees.

Phase One

Phase One included demographic questions on the following: age, sex assigned at birth (male or female), gender identity, sexual orientation, racial identity, ethnicity/cultural background, employment status, education, disability, religion or spiritual orientation, region, household income, health insurance, number of pregnancies, number of live births, perinatal status, postpartum diagnosis (PMADs)- optional, relationship status, and other pieces of identity wanting to disclose. The semi-structure interview questions included:

- Tell me about your perinatal experience.
- How do you imagine bringing a person into the world?
- How do cultural norms and values influence your perinatal experience?
- Was there anything about society that impacted your perinatal experience?
- How do your intersecting identities impact the perinatal experience?
- How did you feel during the perinatal period?
- What was your experience of being asked about your mental health during the perinatal period?
- How did you feel talking about your mental health with professionals?
    - Were there any barriers to disclosing?
- If you mentioned mental health issues, how did the health professional respond?
- What kind of support were you needing during that time?
- What barriers to your perinatal care were there?
- What role can counseling play in supporting perinatal care?
- What role can the government play in supporting perinatal care?
- From your perspective, how have perinatal experiences been viewed historically and shifted over time?
- What else would have been helpful during your perinatal experience?

Phase Two

As part of Phase Two, with photovoice, participants were instructed to take five photos to share their perinatal experience around the some of the themes in Phase One which were: (a) grief, (b) support, (c) pressure and expectations, (d) identity transformation and shifting roles, and (e) advocacy and empowerment. In addition, focus groups included the following prompts:

- Tell us about what these photos mean to you?
- What is the story that is connected to these photos?
- What feels most important about your story that you want to share in community?
- Did the prompt words feel connected to your own story from the first interview?
- What themes are you noticing from today's conversation?

Data Collection

Institutional Review Board approval and informed consent were obtained before the start of the demographic survey. During Phase One, SurveyMonkey was used to gather participant consent, demographics and schedule time to meet for the interview. The semi-structured interview was conducted via Zoom with each participant and was approximately 45–60 minutes. Once theming from Phase One was completed, participants were given the photovoice instructions for Phase Two.

Phase Two consisted of participants taking photos given the photovoice instructions. After taking photos, participants upload their photos and narrative descriptions to an electronic survey and participate in a 60–90-minute focus group to discuss the photos. Participants who attended the focus group received a $25 Amazon gift card stipend for their time.

Data Analysis

Demographic data was analyzed with descriptive statistics. The interviews and photovoice transcripts and descriptions were analyzed with six-phase Thematic Analysis (Braun & Clarke, 2006; Terry & Hayfield, 2021) by a data analysis team. Phase One involved becoming familiar with the data by reading and re-reading the interviews and taking notes on initial thoughts. The second phase included the generation of initial codes, and data that is relevant to each code is gathered. Phase three was categorizing each code into initial themes. In phase four, the themes were reviewed to ensure they were consistent with the codes across all the interview data. Phase five required that the themes are defined and named using words or phrases. Finally, phase six involved writing the report by highlighting examples from the data that are relevant to the research question and the literature review. Throughout the data analysis process, bracketing occurred to consider how bias and personal experience may be influencing the themes.

Ethical Considerations

The American Counseling Association (ACA, 2014) *Code of Ethics* has been utilized in all phases of data collection (Section G.1.a.). This includes confidentiality in research (ACA, 2014, Section G.1.b.), precautions to avoid injury (ACA, 2014, Section G.1.e.), informed consent in research (ACA, 2014, Section G.2.a.), and commitments to participants (ACA, 2014, Section G.2.f.). Furthermore, accurate results (ACA, 2014, Section G.4.a.) has been of utmost importance during data analysis and dissemination of the results.

Research Team Positionality

The primary researcher is a white, cis-gender, heterosexual woman, is the parent of a child who is approximately two years old, struggled with infertility and experienced birth trauma. Additionally, the primary researcher is a licensed professional counselor who is seeking certification in perinatal mental health. During the interviews, the researcher would share their role as a counselor in order to be clear that the interview was not a counseling session and would offer a list of national support resources to each participant. Being both a person with a uterus and a mental health counselor, the primary researcher was able to navigate the border between these roles throughout the interviews by being emotionally connected to each participant's story and utilizing foundational counseling skills. The data analysis team of two additional individuals. The first is a counselor educator who is the parent of three biological children, has expertise with both thematic analysis and photovoice and identifies as a Norwegian/American, cis-gender woman. The second is a counselor, supervisor, and counselor educator who is soon to be a parent and identifies as White Northern European American and nonbinary.

CHAPTER IV: RESULTS

The purpose of this study was to utilize an inclusive framework for capturing the perinatal experience of people with uteruses and to explore barriers and facilitators to care through an ecological systems framework. Using thematic analysis and photovoice, two primary questions were explored: (a) What is the perinatal experience of people with uteruses? and (b) What are the perceptions of people with uteruses regarding barriers and facilitators of perinatal care? To ensure the trustworthiness of the process, there were multiple people involved in the analysis of the data. Three analysts engaged in a team approach that included bracketing or reflexivity and met to discuss findings. Additionally, the quotes captured to reflect the codes and themes were crosschecked to ensure the representation of race.

Demographic Information

Twenty-two people responded to the consent form and demographic survey; however, only 21 completed the survey. Of the 21 respondents, 15 participants were interviewed, and only their demographic information was included in the study. Participants were asked about their age, sex assigned at birth, gender identity, sexual orientation, racial identity, ethnicity of cultural background, relationship status, employment status, education, disability, religion or spiritual orientation, region, household income, if they had health insurance during the perinatal period, number of pregnancies, number of live births, current perinatal status, and postpartum diagnosis. All of the questions were open-ended so that participants could use language that they were comfortable with, aside from the region of residence question in which they were able to choose urban (population more than 2,500) or rural (population less than 2,500). A detailed table of the demographic information of participants can be found in Appendix A.

Factual Reporting of the Project Results

Thematic analysis was conducted at two different intervals after data collection was completed for each phase of the study. This study consisted of two phases which included semi-structured interviews and photovoice with focus groups, respectively. Each phase and the results are described below.

Phase One

During Phase One, 15 participants completed the demographic survey and were interviewed. Data from the interviews were analyzed using thematic analysis (Braun & Clarke, 2006; Terry & Hayfield, 2021) with a trained team of three researchers. Each team member received raw data transcripts from the interviews. From this data, each team member highlighted meaning units, or words and phrases that were deemed significant. After each team member completed their independent analysis, they met to share their findings. Curiosities and biases were discussed and noted. All of the coded data was then organized into themes and subthemes and categorized based on an ecological framework.

Theme One: Social and Cultural Influences

There were three subthemes identified: pressure and expectations, cultural components of perinatal experiences and family dynamics.

Table 4.1

Theme One Subthemes and Related Codes

Subtheme	Codes	Quotes
Pressure and Expectations	Pressure to conform to gender roles and societal norms regarding pregnancy, childbirth, and parenting	*Back then, women didn't get a break anyway, because there was nowhere to go and not a lot to do. And I'm just speaking from a Black woman perspective. But now,*

Subtheme	**Codes**	**Quotes**
	Pressure to know everything, expectation to be perfect Societal pressure to fulfill multiple roles Challenging societal narratives and expectations surrounding parenthood and productivity Choices are charged with values; no neutral decisions Historical expectations that Black women are fertile/lack of representation Choosing time off to bond or getting paid to support growing family: expectation to do both and no support for doing both	*you know, we travel, we have passports, we go places. And even that's still frowned upon by people because the roles. Because the cultural roles, that women just stay home and just care for the man, and whatever the case. It's not about really being a unit. It's not about love* *My own culture or family pressure where it's the norm for the mom to be the stay-at-home mom and to take care of the kids. That for the man to go to work. And that's very opposite in my house* *I feel like there's a lot of pressure for moms to like feel like they're the best first-time mom that they can be* *Well, if your baby won't take a bottle, you just need to quit working* *I remember one time in one day, four professionals asked me if I considered leaving my job while my husband's sitting next to me and nobody has asked him* *I think there's also just like a lot of pressure around the idea of like being like a quote unquote good mom or a good parent or not* *There was a lot of like, you know, why aren't you happy? Like, you know, children are a blessing. You should be happy* *But I expected, because I was a black woman, I expected myself to be able to bear children. The fact that I was having problems or it wasn't happening or I was having miscarriages really made me question what was wrong with me or what was so different with me*

Subtheme	**Codes**	**Quotes**
		And it was like a choice I'm supposed to have to make between having that time, which should have been a minimum of six months, or having my job
Cultural Components of Care	Desire for a great conception story	
	Importance of naming a child	*It was important to me for her to have a Muslim name*
	Honoring faith as support	
	Honoring native experiences	*I think I lean a lot on my own spirituality because I am white and I'm also [native tribe]*
	Lack of representation and support for diverse experiences, including those of Black women	*The mothers come out. The babies don't come out. And I'm just like, it's so dangerous*
	Little representation of loss in mass media	*Seeing other friends who seem to conceive without problem and have a baby. And like, that started to get really triggering for me to be on social media*
	Social media creates support and fear	
	Perinatal experiences are discussed more and supported less over time	
Family Dynamics	Navigating family dynamics and expectations	*And even though I felt like I was still young, I was an older mom. So, for my family, that's older, and generally, you know, among young black women, that's older*
	Differentiating from family norms and facing challenges due to it	
	Desire to give their children what they did not receive as children themselves	*Fighting back a little bit of the perception or how we were raised in regards to our own parents being like, 'it's your right and duty'*
	Intergenerational patterns of care within the family	*I breastfed, but that wasn't always welcomed. I don't know if it's all black families, but it's a lot that I have dealt*

Subtheme	Codes	Quotes
	Chestfeeding in black families not supported	*with where it's like, oh, give that baby some formula* *That was difficult to constantly have to fight to breastfeed. And so, it kind of made you feel a little inadequate at times*

Theme Two: Navigating Transitions and Changes

There were three subthemes identified: identity shift/transformation, multiple roles, and self-exploration.

Table 4.2

Theme Two Subthemes and Related Codes

Subtheme	Codes	Quotes
Identity Shift/Transformation	Shifting expectations (desire v. reality) Flexibility Mourning past self Acceptance of new role Developing an identity other than being a parent	*The hardest part has just been the adjustment of not being at work, not being in those roles that I know that I'm quote unquote good at* *One of the biggest things that I'm starting to learn is that I need time to be a human outside of being a mom* *I'm still at home full time, but it's like I'm playing dress up when I go to teach that one day a week and I'm [name], I'm not just mommy. So, it was quite an expansion of identity* *It feels like I'm not doing a good job in my spousal role, or in my work role sometimes. It still feels like I'm like not performing at the level I was before*
Multiple Roles	Loss of roles Overlapping roles	*But I remember thinking, gosh, who was I before? What did I like to do before? And it still happens to this day where I'll give*

Subtheme	Codes	Quotes
	Navigating roles of being a mother and pursuing education or work Delays in education and career aspirations due to becoming a parent Stigma and judgment are faced in academia and the workforce Questioning ability in multiple roles	*myself permission to put on music that I listened to when I was in my twenties and I'll pop it on in the car without my daughter and be like, oh, yeah, I remember that girl.* *I don't know that I've totally reemerged with all of my old identities* *I felt like in academia, my advisor didn't think I was serious about finishing my degree because I would show up to my doctoral meetings with a baby and stroller*
Self-Exploration	Getting to know self again Process Prioritizing self during postpartum	*It just feels like you're just supposed to be you but now you have like this little baby accessory. And it's like no, my brain doesn't work in the same way* *I just wish I would have been more secure in who I was because, at 21, still really understanding who I am and practicing my religion*

Theme Three: Support Networks and Resources

There were four subthemes identified: community, mental health, challenges with support, and comprehensive and collaborative care.

Table 4.3

Theme Three Subthemes and Related Codes

Subtheme	Codes	Quotes
Community	Importance of supportive partners, parents, extended family, work, school, and friends	*There's comfort in knowing I'm not the only one* *I wasn't having a crisis that needed addressing. I just needed community*

Subtheme	Codes	Quotes
	Recognition of privilege in having supportive environments and access to resources Support groups of individuals experiencing similar challenges without shame or guilt Social Media Desire for validation and understanding	*Having access to healthcare, having a partner, and having a stable job is definitely such a blessing during this experience because I had people, I had resources, and I had the ability to reach out* *And it was like when I finally started confiding in people about how I was really doing that solidarity and the validation of, you know, other people who had experienced similar things was really helpful*
Mental Health	Emotional support and guidance More accessible and culturally competent mental health resources Counseling to be a place to not be okay Lack of miscarriage and infertility mental health support Support around changing relationship with partner and what happens during postpartum	*I think that was a piece that was missing, like more professional mental health support immediate postpartum* *Other women sharing their stories, whether it be with me or on social media, also gave me tools and awareness of steps to take during the experience and then also just feeling supported* *And so that's one of the things that I find that I am frequently reinforcing with my clients. That everyone needs help. And we can make help seeking the superpower that it is* *That's the only thing that I would have liked is more on what to do after, how to work together after, especially if one or both have little to no experience. And navigating that as a team, because I could definitely see how marriages or relationships really struggle right now*
Challenges with Support	Lack of microsystem support and isolation, resources, information around process and expectations	*Having more information and discussion about supports like certified chiropractors, pelvic floor physical*

Subtheme	Codes	Quotes
	Limitations of insurance coverage creating emotional pain and stress Difficulty in accessing care due to insurance complexities Desire for more support throughout the perinatal period Lack of specialists Job flexibility	*therapists, having doulas being covered by insurance, both pregnancy as well as postpartum doulas, having the access to having the birth you would like, regardless of where that is, being covered by insurance*
Comprehensive and Collaborative Care	Transformative experiences with supportive professionals, such as midwives and doulas The desire for comprehensive, collaborative care across different professions Emphasizing the importance of holistic support, empathy, and empowerment	*Having those resources to be able to provide them that are specific to their needs, whether it's a lactation consultant, or physicians, or a mommy group, or an exercise club, yoga, and having online resources as well* *I ended up finding a doula, which I think was extremely transformative in my perinatal journey and then my birth experience, as well as support and postpartum*

Theme Four: Discrimination and Stigma

Table 4.4

Theme Four and Related Codes

Theme	Codes	Quotes
Discrimination and Stigma	Racial; Anti-Blackness Fear with black infant and mother mortality rates Age	*The fear for me was always, the mortality rate for black mothers is very concerning to me* *And I was like, no, thanks. I don't want a caesarean. Because I knew the mortality rate*

Theme	Codes	Quotes
	Weight; Sizeism Gender roles Silence around mental health Education as burden and benefit; supported having language and access to get help Microaggressions Assumptions of support, education SES Chestfeeding stigma Bias Staying home with child is a choice Getting pregnant is easy Neurodivergence	*for black mothers. I knew that it increased if you had a caesarean, and so I declined* *During one of those monthly visits, she made a comment, "you're picking up a lot of weight, you need to stop eating so much fried chicken"* *I'm still breastfeeding my son. He's going to be two…I went from being proud that I could breastfeed my son up until he was a year old. And now it's almost like an embarrassment to say that I still breastfeed him* *I'm still breastfeeding my son and he's 19 months old. And I've started to get some messaging from like people like, when are you going to wean?* *I think in black families, sometimes we don't talk about our health conditions* *You envision something and you see everybody else doing it. And it's so biological. Where you think, oh yeah, it's going to be that easy* *Being a person with an advanced degree meant that I maybe understood some things differently, read and researched things at a different level* *I think being an educated black woman and having that doctor in front of my title probably supported medical professionals to talk to me in a different way* *There was like kind of an assumption of larger support and structures of care that like we might have that we didn't*

Theme Five: Advocacy and Empowerment

There were three subthemes identified: lived experience fueling advocacy efforts, resilient narratives, and self-advocacy as need.

Table 4.5

Theme Five Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Lived Experience Fueling Advocacy Efforts	Striving to help others and create positive change Giving what needed in own experience Giving to a child what didn't get as a child Advocacy for policy changes regarding paid leave, reproductive choice, holistic perinatal care, and to prioritize mental health	*I feel like my experience has led me to be more of like, has let me feel more of an advocate and try to do more* *That fueled me to want to do more, because I realized that not only were there not enough people to help these parents cope with parenthood or miscarriage or infertility, there weren't any resources* *We're making big policy changes to how we support lactating employees to make sure that all of the rooms are accessible* *I'm starting to think, what did I need and how can I be that? So, we're starting up a postpartum support group in one of the counties that's very rural and affected by a lot of the maternity ward closures* *I get to give her the things that I never received. And it's been tough. It's been really tough. I hope that I'm modeling to her to choose herself first*
Resilient Narratives	Building community by sharing experiences Resilience in the face of adversity	*I ended up doing a prenatal yoga class where I met a good group of other women* *I actually helped co -found a group for postpartum at my work. And since I've*

Subtheme	Codes	Quotes
		started talking about this stuff really openly, almost everybody I talk to says back, "oh, me too"
Self-Advocacy as Need	Advocacy for oneself in healthcare settings and seeking out supportive communities and resources Hard to advocate when you don't know what to advocate for or what needs will be Importance of consent, autonomy, and choice in medical decision-making Resource-seeking	*I'm quite honestly not even sure if my community has any of those resources either. And so, I would maybe like to dive into some of those if I can, you know, find the research and do the time to do that* *They kind of relied on me to ask what I needed and advocate for myself, which would be great if I knew what to advocate for* *Having two recurrent miscarriages we're thinking that something is wrong. And so, we're going into our doctor and trying to advocate for both of us to get tested* *I didn't have the best experience when I was having those miscarriages. So, I actually ended up switching providers because I felt as though they weren't listening to me and my concern*

Theme Six: Mental Health and Well Being

There were three subthemes identified: emotional, psychological, and physical impact; counseling; and questioning/mental load.

Table 4.6

Theme Six Subthemes and Related Codes

Subtheme	Codes	Quotes
Emotional, Psychological, and Physical Impact	Postpartum anxiety and depression (PMADs), traumatic birth experiences,	

Subtheme	**Codes**	**Quotes**
	stress, fear, anxiety, vulnerable, shame, guilt Anxiety and fear of getting pregnant after loss taking away from other emotions during pregnancy	*I really didn't realize how you can get such anxiety and PTSD from miscarriages. And that was something that was really shocking to me. And I grappled with that a lot. And it was just a pretty dark time*
	Embarrassed of losses, miscarriages Empowerment	*I really do think about my birth experience a lot. I like telling it. I like reliving it. I feel strong. I feel powerful*
	Isolation Impact of COVID on mental health	*I was also like dying because I was struggling so much. Like I couldn't even really like try to connect with people and it was just really hard.*
	Impact on non-gestational partners Focus on child milestones; person with uterus forgotten, abandoned	*My first IUI procedure was actually canceled right before it was supposed to happen because all of those procedures were considered nonessential*
	Grief Taboo Invisibility Self-blame	*I wish I could have just let myself enjoy that period of time. And I think that's the grief that comes up, is I wish I could have just settled and enjoyed it and created those memories rather than feeling like a ball and chain to the postpartum anxiety*
	Ambiguous loss	*I feel like my body had failed me*
	Feeling like a failure, inadequate	*But it's just really, really strange. I didn't give myself a chance to grieve really. I just was like, I'm going to just go and get pregnant again. And I didn't really have the support to actually process it either*
Counseling	Need for comprehensive, inclusive mental health care	*It was refreshing. She was awesome. I tell her all the time. I*

Subtheme	Codes	Quotes
	and support options, including counseling and validation of feelings Coping mechanisms and strategies for navigating emotional challenges Stigma and shame surrounding mental health issues lead to hesitation in seeking help Counselors to offer space to be heard without judgment, normalizing and validating experiences Counselors who specialize in perinatal mental health are able to understand the system of perinatal care and how to work within it Counselors to be space of what to expect, exploration, connect to resources, honor individual experience, impact of relationships Relationship to counselors more critical than their specializing in perinatal care	*still see her now. That she talked me off the ledge because I was so low that I was getting tunnel vision and I can only see all things that were bad. And so, it was nice to have a space for somebody who actually listened to what I was saying* *Therapy was absolutely my main source of support* *I think that if he had more of a fertility specialty, he might be able to walk me through all of the existential pieces that I'm feeling, you know, all of the grief* *It would have just been nice to touch base with someone who could hold the emotional experience, but also understand the biological, this is what's happening to your body, because I had no idea* *She gave me the space to kind of work out my thoughts just out loud. This is what's going on. I don't understand this. This is what I feel. She allowed me to have that space without shame or guilt*
Questioning/Mental Load	Number of choices and decisions Burden of choice Overwhelm of the unknowns Comparing to others leads to self-judgment	*How warm is the bottle supposed to be? Is it supposed to be cold? Is it supposed to be hot? Like no one tells you that, you don't know* *Do we use those? Do we not use those? Why do they exist if people don't use them?*

Subtheme	Codes	Quotes
		And then the next visit, the doctor said it was an early miscarriage. And so, lots of curiosity. Was it the missed shot? Was it flying on an airplane during the super early time period? Was it just not supposed to be? *Am I doing the same thing that happened in May? Am I going to somehow lose this baby because I'm not resting?* *What am I doing? What can I do differently? What did I do wrong? How can I fix this?* *Am I a good mom? Am I a good person? Should I have waited to get my PhD when she was older? Should I have done this? Maybe I shouldn't have done that* *Am I pregnant? Am I not pregnant? Am I having a miscarriage?*

Theme Seven: Interactions with Medical Systems

There were three subthemes identified: relationship with provider, mental health screening, and challenges within healthcare systems.

Table 4.7

Theme Seven Subthemes and Related Codes

Subtheme	Codes	Quotes
Relationship with Provider	Lack of communication, empathy, and warmth from medical professionals leading to disappointment	*We had a relationship where I could call in and she trusted my judgment on things*

Subtheme	Codes	Quotes
	Knowledgeable/unknowledgeable providers	*The power dynamic is so strong there. You're in the bed. You're wearing footy socks with a gown; you have no control*
	Power dynamics in medical settings and feeling unheard or pressured into decisions Dismissal or invalidation of concerns by medical professionals Negative, fear-based communication causing lack of agency and pressure Need for supportive relationships with healthcare providers	*I ended up seeking midwifery care instead. And I got in like the next week with her and that felt just night and day from my experience with an OB. Once I established care with her, I just felt so much more cared for. And she really addressed all of my needs, like the spiritual aspect of acknowledging the miscarriage. And she gave me some really tangible things that I could do to aid in my grief process and I just loved their model*
	Communication challenges with healthcare providers and the importance of feeling heard and understood	*Something about the communication was challenging and I felt like I was always like trying to get myself like truly understood*
	Providers not taking time to understand perspective Positive experience when listened to	*When I had another miscarriage, which was viable, nobody would really listen to me and they would just say, 'this is normal'*
	Lack of trust established with providers as barrier to discussing concerns Harmful and neglectful care Need to give patients autonomy through education, information	*I felt kind of like a disappointment initially because I wasn't getting a lot of like, this is what's happening in your body, this is what's normal, this is what you can expect, this is what we're thinking of doing, you know. Talking about like more informed consent, what are my options. I wasn't getting that from my care team*
Mental Health Screening	Honesty depends on the relationship with the provider	*It felt like that was just something on their checklist*
	Lack of resources shared regarding mental health, support groups, etc.	*Even with the screening, it's just a questionnaire, you know, like no one's actually sitting you down in a close physical space and looking at you in the face to ask you, how are you?*

Subtheme	Codes	Quotes
	Mental health was not prioritized or dismissed; checked-box, "quick glance," surface level Mental health screening but no conversation Mental health assumptions based on appearance Stigma surrounding mental health and reluctance to discuss it with medical professionals Dismissive attitude from providers More inclusive screening tools and options	*Nobody at any time really checked on me. Like they gave a survey…after I had my son, but while I was actively having miscarriages, nobody at any point checked to see how are you mentally* *It was very surface level. My OB did an amazing job with me physically, sure. Mentally, it was the postpartum depression check. I passed that because I didn't have postpartum depression. And that was it. So, you don't have postpartum depression. You're good. I'll see you in a year*
Challenges within Healthcare Systems	Challenges with accessing healthcare Lack of support and understanding from healthcare providers Disparities in healthcare access and treatment based on factors like race, socioeconomic status, and location Need for more inclusive and personalized care plans Charts not reflective or accurate of actual experience Impact of education and medical literacy on the perinatal experience Lack of agency; loss of control, power	*It wasn't fully dismissive, but it kind of felt like a, like not like that much gravity was given to it* *When I was told that I was having a miscarriage, there was no suggestion of some services or are you okay? They kind of just told me, we don't hear a heartbeat and then they just left. It was very medical, that's it. Not even like a pat on the shoulder or anything. It's just like I just kind of had to sit there and cry and then get myself together and then leave* *And I read her notes and it was like patient reports satisfaction with her birth experience. I was like, none of this conversation happened. She didn't even ask me how I felt about my birth experience* *There is definitely a loss of control that happens when you get into that environment*

Theme Eight: Impact of Systems and Policies

There were four subthemes identified: access as privilege, financial burden, lack of support, disparities of care.

Table 4.8

Theme Eight Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Access as Privilege	Geographic location influences access and race of providers Privilege around choice, access, and support More accessible support options	*I wish I would have fought a little harder, but again, you know, at the time, 21, in a rural state, Republican state, my medical providers are white, and I am like lost and scared* *I was aware that there was a privilege moving from the hospital environment to the midwifery system*
Financial Burden	The financial burden of care and choosing perinatal experience outside of the Westernized medical system for more holistic care Childcare Insurance	*One thing that I wish would be different just overall for my perinatal journey that I know I could make happen, but just financially there's a lot of additional implications, is the access to midwifery care or birth care outside of a hospital setting*
Lack of Support	Lack of paid leave and supportive workplace policies for perinatal care Need for government policies to support reproductive choice, perinatal care, healing and bonding time Insurance to cover all aspects of perinatal experience	*In other cultures, the mom is allowed to heal . And here in the US, that just doesn't happen, where the structures are not built to support that. And if you choose that, well, then there's a consequence, usually financial or a long-term consequence, that the family has to endure. And that's a lot to have to weigh out as a new parent. And in the pregnancy period, if it's your first child, you have no clue what it's going to be like* *When I was expecting with my daughter, it was like the big slap in the face about what*

Subtheme	**Codes**	**Quotes**
		that meant for me and my postpartum journey and my time off to be home with her. Because there was zero paid parental leave. And it was, you know, FMLA, the standard, we won't fire you for 12 weeks. But there was no... Hey, we're going to support you, and we're going to give you the time that you need
Disparities of Care	Health insurance, disparities in coverage and parental leave Employment status	*In my state, insurance does not cover fertility treatments. We are paying out of pocket. I have to use my PTO. I'm doing everything I can to make it work. But this is the same thing that I believe about childcare. Childcare workers need to be paid more than a living wage. Childcare also needs to be affordable.* *When I got pregnant with my older son, I had just gotten a job and he was considered a preexisting condition. So, he was not covered, which meant I had to pay out of pocket to have him and also meant that I went back to work four weeks after having him.*

Phase Two

During Phase Two, all 15 participants from Phase One were given instructions to take photos and schedule a focus group time. Out of the 15 participants, 12 participants responded with their availability to attend a focus group. Based on availability, seven participants were able to join a focus group session and eight participants uploaded their photos and photo narratives. There were two focus groups with three participants in each and one focus group with one participant. During the focus groups, participants shared their photos and narratives around their perinatal experiences. The data from the focus groups were analyzed using thematic analysis (Braun & Clarke, 2006; Terry & Hayfield, 2021) with a trained team of two researchers. Each team member received raw data transcripts from the focus group sessions. From this data, each team member highlighted meaning units or words and phrases that were deemed significant. After each team member completed their independent analysis, they met to share their findings. Curiosities and biases were discussed and noted. All of the coded data was then organized into themes and subthemes and categorized.

Theme One: Meaning Making

There were two subthemes identified: impact of expression, and meaning through community.

Table 4.9

Theme One Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Impact of Expression	Solace in creative outlets such as art and storytelling Opportunity to process experiences differently Tattoo as part of grief process and transformation in grief	*Keep it external and let it sit in in the representation of artwork on me rather than having to carry it and be heavy, and take that time and attention away from my children who were here and who deserve that, and myself, who deserve that* *I appreciated being able to put pictures to it because there are so many words that I don't have that the picture can just say for me or feel for me because that was my experience* *I don't always have the words to describe it and that description might change based on where I'm at my own journey* *Meaningful activity to like see words and put a picture to it* *I was able to like work my grief and put in my hopes and my desperation into things that I would create for myself*

Subtheme	Codes	Quotes
Meaning through Community	Meaning and purpose in sharing experiences with others	*And it just felt like there was meaning behind sharing our story and help*
	Less isolation in shared experiences	*I haven't heard anybody else in my circles have their spouse have that surgery. So, it feels really validating to me to be like, Oh yeah, that was a thing. And it was like really helpful; that was our experience too.*

Theme Two: Emotional Impact of Perinatal Experiences

There were four subthemes identified: complex emotional responses, grief as all encompassing, desperation, and emotional rollercoaster.

Table 4.10

Theme Two Subthemes and Related Codes

Subtheme	Codes	Quotes
Complex Emotional Responses	Hope Amid Grief	*Our grief holds a lot of hope too*
	Desire to be happy, enjoy pregnancy and "scared to death" of losing again	*Grief isn't just grief. It's also desperation and sadness and scared and hope and all of these things*
	Happiness met with grief after loss	*It is true that you can be anxious but happy at the same time, or hopeful*
	Dialectic of being happy for others and sad for self	
	Expressions of hope and desire for a positive outcome despite losses	
Grief as all Encompassing	Grief around not being comfortable to share experiences with others	*I didn't know the grief was going to hit that hard, if that makes sense. It was really overwhelming. And it felt like it was from all areas at one time*

Subtheme	Codes	Quotes
	Grief from isolation when others don't understand Layered grief and fear of pregnancy after miscarriage No photos when grieving after miscarriage Sadness to not have anything to remember miscarriage babies	*Grief is a constant companion* *When I was looking for photos of a picture for grief, it was actually an emotional experience for me because I couldn't find any photos from that time. I understand why I didn't take any photos, but it made me feel sad that I didn't have, in a way, anything to remember that child*
Desperation	Longing to stay pregnant Wanting body to "cooperate" Anxiety	*I remember finding out and I remember just like, oh god, just please stay, just hang on just a little while longer*
Emotional Rollercoaster	Jealousy Self- Judgment Hopeful Perseverance Resilience Anger and Rage Isolation Guilt	*There was like a grief in that relationship and a jealousy* *I recognize throughout my grief process that I kind of went through a phase as if I if I'm not sad about this, if I'm not continuing to be sad about this, somehow, that means I don't care* *I've always been transparent that I'm a mom, but it's still like, it's still isolating, very isolating*

Figure 4.1

Participant Photo Resembling Grief in the Perinatal Experience

Note. “I found out on this trip that I was pregnant with my first baby. That I would miscarry 3 days later.”

Figure 4.2

Participant Photo Resembling Grief in the Perinatal Experience

Note. “I remember the process of meeting with the reproductive endocrinologist and various nurses to learn various things throughout the process ... that we’d need to conceive with medical assistance due to chemo, that we had to wait another cycle to proceed, that we weren’t pregnant, that we’d experienced an early pregnancy loss, that I had a short cervix and needed a cerclage, and so much more. This image captures the grief of all of those medical moments mostly feeling surrounded by imagery of ‘happy’, ‘successful’, ‘easy’ pregnancy.”

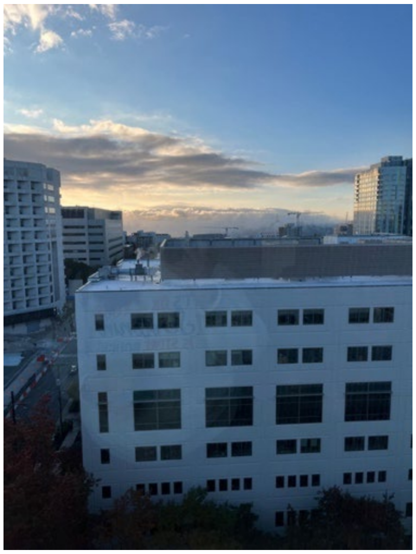
Figure 4.3

Participant Photo Resembling Grief in the Perinatal Experience

Note. “I initially was very anxious and worried about breastfeeding—our first few nights were rough and I felt easily panicked that my son or husband was going to get emotionally dysregulated and I would be helpless to soothe either. This photo is a snapshot of my son feeding to soothe as I most likely wasn’t producing much in the first 72 hours.”

Figure 4.4

Participant Photo Resembling Grief in the Perinatal Experience



Note. “The sunrise from the fertility office on the morning we found out we were pregnant, only to lose them the next day. A brief moment in time where our dreams had been realized.”

Figure 4.5

Participant Photo Resembling Grief in the Perinatal Experience

Note. “I keep this photo at my desk. It was the first picture that I received of the child I nicknamed ‘popcorn’. This was my second miscarriage and the furthest along that I was prior to miscarrying. ‘Popcorn’ was also my first dilation and curettage (D&C) where I felt as though I was getting rid of something that I wanted and loved.”

Figure 4.6

Participant Photo Resembling Grief in the Perinatal Experience

Note. “I had started showing and I was so excited. When I see this photo, it breaks my heart because it didn’t last long.”

Figure 4.7

Participant Photo Resembling Grief in the Perinatal Experience

Note. “This is a ‘heartbeat’ animal. There is an ultrasound company in my area that records the heartbeat of your child and puts the recording in an animal for you to push and listen to whenever you want. This one is my living daughter’s heartbeat animal. While we love and cherish this, we wish we would have been able to get these for the children we lost.”

Figure 4.8

Participant Photo Resembling Grief in the Perinatal Experience

Note. “The last two photos, the one with me holding [child] in the orange dress and her sleeping on the bed represents grief. Again, grieving having to leave her behind to pursue my educational studies. She had been through both Bachelor’s degrees and my Master’s degree so it did not feel right that she would not be joining me on my journey to get my PhD degree.”

Theme Three: Navigating Roles and Identities

There were four subthemes identified: cultural identity and healing, narrative shifts, identity transformation, and navigating multiple roles.

Table 4.11

Theme Three Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Cultural Identity and Healing	Honoring heritage, heritage preservation Connected to environment, nature through native heritage Hope to continue traditions for own family of creation	*Because of my cultural background, I find a lot of like signs and spirituality in nature* *Crack open part of my identity and really explore what does being [native tribe name] mean to me. What does it mean to carry on our language, customs? What does it mean to share culture? What does it mean to have a child to me?* *Because the cultural implication of beading also is that you put into what you create, what you're experiencing* *It feels like my journey was laid out in this way of like, I need to return to my own identity, my own self, my own culture, explore what it means to me to be able to move forward in a way that feels really healthy.*
Narrative Shifts	Process of telling stories Focal point and salience shifts over time Reminder that story will shift again Impact of time on emotion of perinatal experience	*Our brain, let's go of things when we don't need to be storing them anymore* *I feel like I used to be talking about that all the time. And then I had not talked about it in so long. That's just a little bit of an awareness about how life progresses and we sort of shift in terms of what feels most salient or most important to us*

Subtheme	**Codes**	**Quotes**
Identity Transformation	Recognizing miles travelled Graduating from MA program with a child Physical transformation Life and relationships are different Impact of miscarriages on identity Self-discovery, exploration and reflection	*Explore what I want this journey to be for me and what it holds for me and kind of bringing back to kind of rediscovering this part of my identity that I had maybe forgotten or let go of.* *She was in my stomach and now she's out. And so now she's like growing and she's out in the world. She has her own thoughts. She has her own opinions* *Seeing her in my car and it's just like, oh wow, like she's a big girl* *And sometimes I still have that like, oh my gosh, I can't believe I'm a mom but I have the scar to prove it right.*
Navigating Multiple Roles	Grief of leaving child to finish education Balancing Navigating the roles of being parent, partner, academic, professional Expectation as counselor to manage emotions, difficult when going through own experience	*I had another child to take care of. I had things to work to do* *I remember that whole process of trying to balance everything and working full time and being a single mother* *My department chair was just like my first priority is to my university. And I said, actually my first priority is to be a mom* *I'm also a counselor, a school counselor and a licensed professional counselor. And you think that you're able to manage emotions and all the things. And it's weird when you can't describe or can't manage your own*

Figure 4.9

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “I remember this being one of the first times I felt like a mom. I really struggled to identify with my ‘motherly’ role while pregnant. Partially due to fear and anxiety.”

Figure 4.10

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “I felt and still feel the challenge of balancing my intersecting identities ... as a mother who works as well as a professor who parents.”

Figure 4.11

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “This photo is roughly 2-3 minutes post-birth. I felt so many emotions in this moment; relief, euphoria, appreciation, gratitude, fear, anxiety, exhaustion, and love. While I looked at this little being that I helped bring into the world, I recall sitting in the feelings and growing awareness that nothing was going to be the same from the moment on … my life had irrevocably changed, my roles would never be simple nor independent again.”

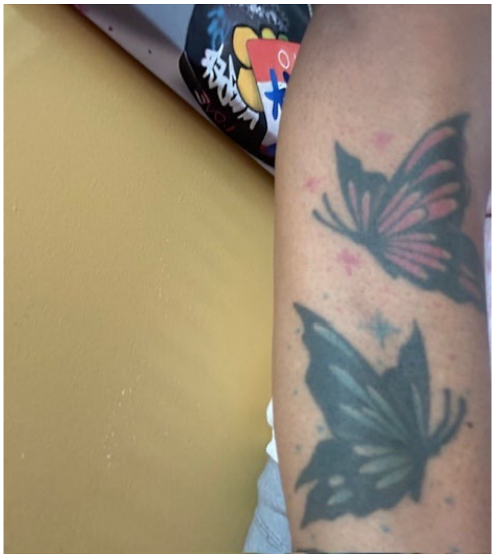
Figure 4.12

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “To quell the anxiety attacks, I began beading. This practice was new to me, but I’ve watched family bead my whole life. Not only did beading give me confidence and a space all for myself, to create, it also provided me with a greater sense of my own identity.”

Figure 4.13

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience



Note. “This is a butterfly tattoo that I got to remember my angels. I created a blue one for the boys and a pink one for the girls. I began to realize that walking around with my grief, shame, and pretending to be okay was getting heavy. I wanted to show my love through art that I could see daily but I also wanted to put down the emotions that were weighing me down to focus on what I could control moving forward.”

Figure 4.14

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “I felt that I had reverted back to who I was, but I was still unhealed.”

Figure 4.15

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “This photo is from my maternity shoot. It is the time I actually started to believe in my identity as a mom, even though I already was one to 2 angel babies.”

Figure 4.16

Participant Photo Resembling Identity Shift and Transformation in the Perinatal Experience

Note. “The picture with [child] sitting in the driver’s seat and her holding my hand with my degree in my hand represents identity transformation and shifting roles. One day my daughter will be in the driver’s seat and it made me realize like I’m a mom. I have a kid and I will do life with her. Also, the picture with the degree was like another degree with her by my side. My educational experiences have made me a better person overall and has shifted my identity of what it means to be a mother.”

Theme Four: Pressure and Expectations

There were two subthemes identified: external and internal.

Table 4.12

Theme Four Subthemes and Related Codes

Subtheme	Codes	Quotes
External	Societal pressure around norms Follow IVF protocol, medications, and timeline Desire to make family happy Pressure to choose between education/work and being a parent Stigma surrounding infertility, miscarriages, and mental health challenges	*A lot of pressure about making sure that I finished school. A lot of expectation about, you know, feeling like we needed to get married. We needed to figure things out where we were going to live and all that stuff* *I had a million medications and a schedule to take. And if you don't know anything about IVF, it is very time focused. If you like miss a minute or an hour or a day, you kind of messed yourself up for months.* *I need to give my in -laws a grand kid, you know, because we had seen how happy they were and the other pregnancies where we were further along*
Internal	Having child while in school: questioning, worrying Pressure to advocate and take care of child Pressure to be successful Pressure and fear to have viable pregnancy Expectations of body: guilt that "something is wrong" with self, failing Emotional weight	*Not only the pressure on the outside is making sure that I did what I was supposed to do according to my IVF protocol, but my internal pressure that I was not like I'm not going to lose this baby.* *Because I was really focused on, I'm supposed to have a baby. There's something wrong with me. Let me figure out what I can do to fix it so that I can get this goal. And that was kind of that pressure as to I'm going to succeed at this because I failed at this four times. And, you know, the fifth time I'm not going to fail.*

Figure 4.17

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience

Note. “My partner and I did not intentionally get pregnant. When I found out, I cried as I was not done with school, we didn’t have a house yet and we were not married at the time. I remember wondering if we were going to be judged for our situation.”

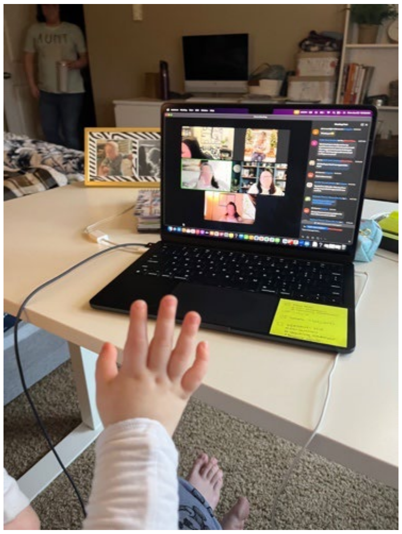
Figure 4.18

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience

Note. “As an ‘academic’ and a person deemed an ‘expert’ on children and childhood I felt lots of pressure to know everything there was to know about every phase of the process (conception, pregnancy, childbirth, parenting, etc.). I felt like I needed to read every book and had both internal and (perceived) external expectations to ‘know it all’.”

Figure 4.19

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience



Note. “This photo captures an image of a common staple of work-mom-life balance, and that is my son wanting to take a peek at my computer screen and see faces while I participate in required classes. I have and will continue to feel pressured to engage in school, academia, and professional settings at a high level, and while that’s fine, occasionally I take advantage of the spaces where the expectations are more welcoming and tend to let both realms cross over.”

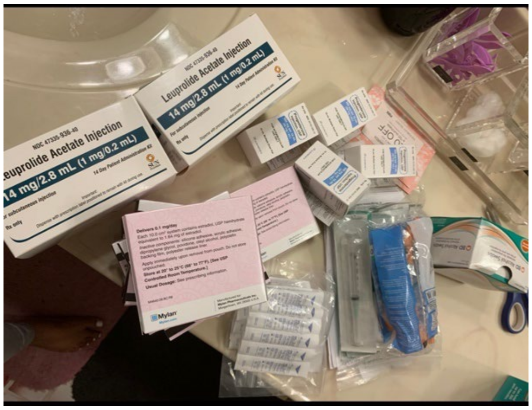
Figure 4.20

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience

Note. “The first fertility clinic we tried and were met with judgement. As we were unsure of what the process would hold with us, we decided against using this facility and, instead, chose our agency.”

Figure 4.21

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience



Note. "Feeling as though something was wrong with my body. I was determined to make sure that I had a baby that lived. This picture represents the start of my IVF journey which was filled with many medications, shots, calls to insurance companies, and doctor's visits. I had pressure on myself with expectations to succeed and pressure from deadlines and costs to go through the IVF process."

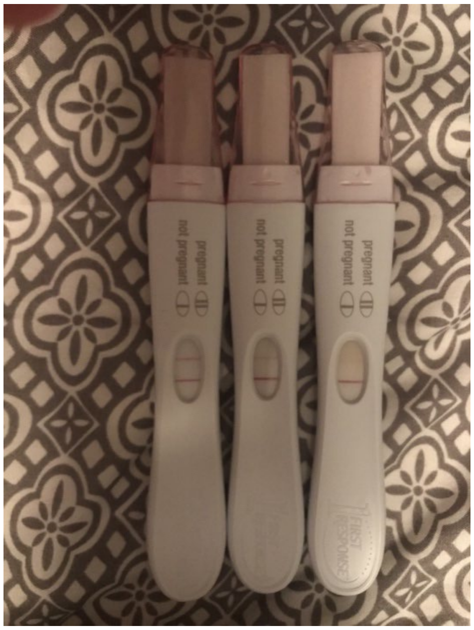
Figure 4.22

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience

Note. "I just felt compelled to drink, the reality was that although I had not miscarried, the pregnancy was no longer viable."

Figure 4.23

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience



Note. “This is a picture of the line progression of our pregnancy tests. After 2 losses, seeing there was a lot of pressure to see the lines ‘get darker,’ or doubling HCG levels from blood tests.”

Figure 4.24

Participant Photo Resembling Pressure and Expectations in the Perinatal Experience

Note. “The picture with me holding [child] and kissing her forehead represents pressure and expectations. I had her in my last year of my undergraduate program and I was wondering what kind of life we would have or would I be able to give her the life that she is worthy of.”

Theme Five: Advocacy and Empowerment

Table 4.13

Theme Five and Related Codes

Theme	Codes	Quotes
Advocacy and Empowerment	Advocacy for the sake of children Modeling advocacy for child to be supported and be in relationships and communities that serve Advocating for students due to own experiences Advocating for self and making changes if not supported Advocacy to connect with others Education of perinatal health with counselors	*My advocacy in trying and turning what I had experienced and how isolated I felt into another experience where I could try to connect with other people and potentially give some support* *I do hope that she doesn't stay stuck anywhere or stay in relationships or in communities that are no longer serving her* *My husband's scar is just the proof, the evidence of how hard we had to advocate to get our kids here* *I've been able to try and put myself in a position to where I can feel comfortable because I was uncomfortable or I did have those situations where I was worried and I didn't like feeling that way. So, I personally made sure that I could do what was ever in my power to put myself in a space where I didn't have to be in those positions*

Figure 4.25

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. “I felt unheard by my doctors at times due to being so sick. I remember wondering if I was going to survive let alone my baby.”

Figure 4.26

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. “I wasn’t completely sure about this picture going here ... but I wanted it to go somewhere. I appreciate the optimism and hope it conveys. I think that can be empowering for individuals in the process.”

Figure 4.27

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. “This is my view while sitting in the gallery of my state’s congressional session of this year. It was taken after I had attending and participated in a lobbying experience for my state’s regional branch of American Mental Health Counselor’s Association. I was able to attend and advocate AND bring a student of mine to co-experience the event, and was fortunate to have support and childcare that gave me the opportunity to participate in this.”

Figure 4.28

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. “My mother shared with me my baby mocs, which had a small, pink beading pattern on them. As this was part of my self-nurturing practice (beading), she shared how my identity has always been with me.”

Figure 4.29

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

African American Women and Fertility Challenges

[redacted] I'm interested in learning more about the stories of African American women who have experienced challenges conceiving, carrying children to term, or conditions that have impacted the ability to have children for a year or longer.

BRIEF INTERVIEW

Your participation is confidential. It will include a 60 min interview via Zoom

COMPENSATION

Participants will receive an Amazon gift card for their time and consideration

SUPPORT FOR WOMEN

Findings from this study will be used to better support the counseling needs of African American women with challenges

Contact via DM or [redacted]

Note. "After my experience, I wanted learn more about others who had gone through similar experiences. So, I decided to do research on Black women with Infertility diagnoses. It helped me to find a network of others just like me but also to share the needs of women when it involved counseling support."

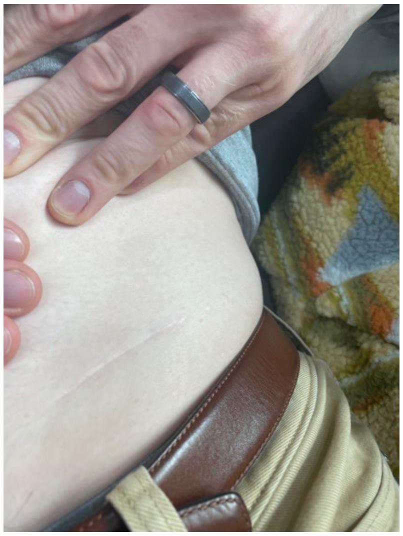
Figure 4.30

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. "It's a photo of a double rainbow, before I had my rainbow baby."

Figure 4.31

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience



Note. "This is a photo of my husband's scar from surgery. After 2 pregnancy losses, we had to fiercely advocate for us BOTH of us to get tested. My husband had a varicocele vein in his testicle which was impacting his sperm quality. After this surgery we have had 2 successful pregnancies and birth!"

Figure 4.32

Participant Photo Resembling Advocacy and Empowerment in the Perinatal Experience

Note. "The photo with my daughter holding my niece and holding hands with her in the field represents advocacy and empowerment. I would say the pictures involving my niece represent more of the advocacy piece. We need more women to advocate for each other as well as others. The photo with her sitting on the stump represents empowerment. I hope my daughter feels empowered or that I have given her the skills to feel empowered, especially as a Black girl."

Theme Six: Social Support and Community

There were two subthemes identified: seeking community and supportive environments, and navigating support systems.

Table 4.14

Theme Six Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Seeking Community and Supportive Environments	Support from animals, partners, friendship, family Social media as place to feel supported and offer support Connecting with people throughout the world having infertility issues Validation in shared experiences and sharing stories Support is healing, comforting, empowering	*These are my brothers, my sister, my mom and my dad. They've always been there to support me* *Holding hope is I think the biggest thing for me because I don't always know how.* *My family is very central to me. So, me and my sister, we kind of co -parent* *I looked to social media and with some of these hashtags, I was able to find other people who were documenting their stories about miscarriages, or stories about having other children, or working to have other children, through IVF or the fertility process* *I didn't necessarily have people around me that understood what I was doing and understood what kind of support I needed*
Navigating Support Systems	Support shifted over time and can be isolating/lonely Not sharing out of fear of pushback and judgment Engaging in creative outlets as support and control	*And I was able to offer support and get support at the same time from people who understood what I was going through* *I haven't told a single person on my dissertation committee that I had a baby because I knew there was going to be pushback of me like focusing on*

Subtheme	Codes	Quotes
	Difficulty offering support when struggling with fertility and loss Continue education to support child, have power, impact others	*my kid and not allowing me to pursue my education* *I don't think that I would have been able to like give support, and like good support, until I had my own children here. Because before I had children, I was pretty resentful, I think, of other people who had children, which is really sad*

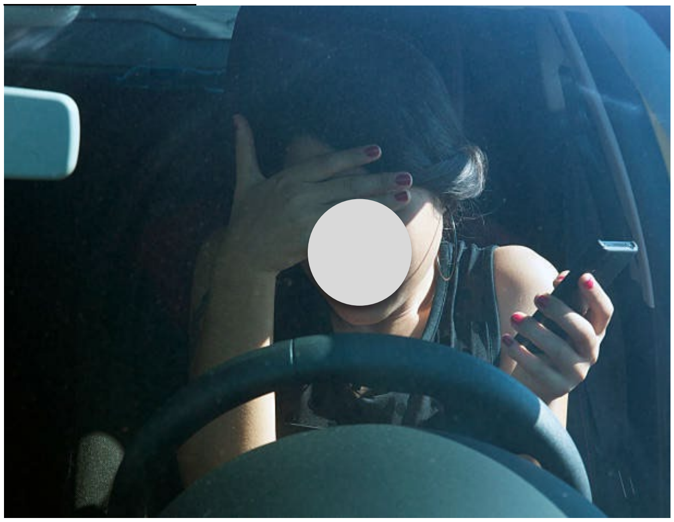
Figure 4.33

Participant Photo Resembling Support in the Perinatal Experience

Note. "I truly do not know how I could have made it without my support team. Cat, Dog and my human."

Figure 4.34

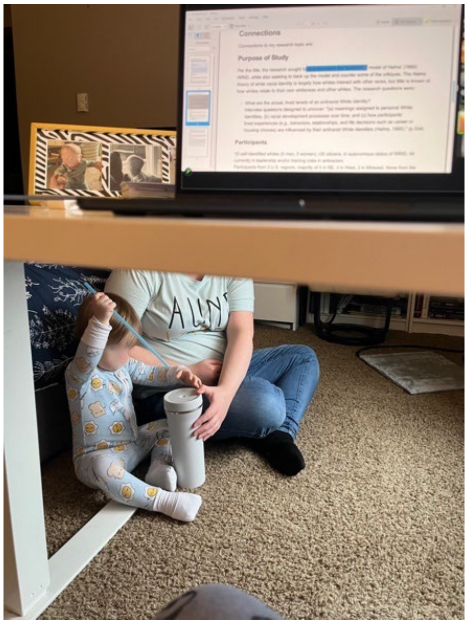
Participant Photo Resembling Support in the Perinatal Experience



Note. “This one just reminds me of sitting in my car talking to my friends when I wanted to protect my partner from my sadness, frustration, etc. during the process or when I thought he might not understand. I’m grateful for friends who were always available for those calls!”

Figure 4.35

Participant Photo Resembling Support in the Perinatal Experience



Note. “This photo shows me working on my doctoral studies while my son is being entertained/occupied by my primary childcare provider, his aunt. During informal meetings I tend to leave my door open to them both and it shows a two parts of my identity co-existing.”

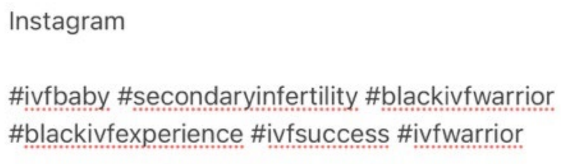
Figure 4.36

Participant Photo Resembling Support in the Perinatal Experience

Note. "Shortly after finding out about our infertility, this visitor appeared on our door. Much like our family and friends, it showed up and offered its beauty and comfort. We took solace in the meaning of the moth."

Figure 4.37

Participant Photo Resembling Support in the Perinatal Experience



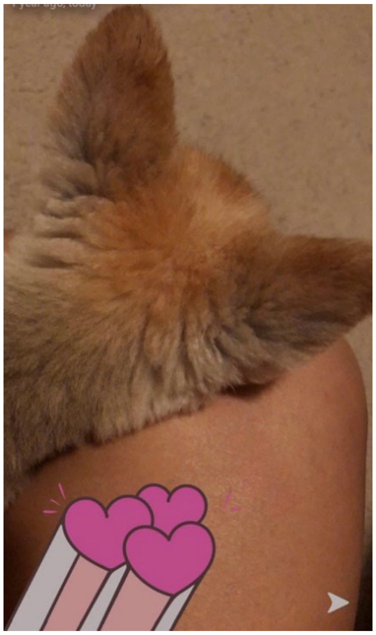
Instagram

#ivfbaby #secondaryinfertility #blackivfwarrior
#blackivfexperience #ivfsuccess #ivfwarrior

Note. "I found a network of people who understood my fears, anxiety, sadness, and anger through social media. When I decided to document my IVF journey and I was ashamed of my infertility struggles, I connected with people who had similar stories and who supported me without personally knowing who I was."

Figure 4.38

Participant Photo Resembling Support in the Perinatal Experience



Note. “My Pomeranian curled up in my lap and it gave me strength because he felt seen.”

Figure 4.39

Participant Photo Resembling Support in the Perinatal Experience

Note. “This is the picture we shared on Facebook when we told our story of pregnancy loss. We wanted to be able to share what we learned from our experience to help others, and it did! At the same time, I remember the response of the post feeling healing for me with the amount of supportive words we received.”

Figure 4.40

Participant Photo Resembling Support in the Perinatal Experience

Note. "The photos of my sister, niece, and [child] as well as the family photo at the restaurant represents support. My family has always been my biggest supporters throughout this journey. I couldn't be the mother I am without them. They have been there since day 1."

Theme Seven: Prevalence of Infertility and Miscarriage

There were four subthemes identified: emotional impact of infertility, intersectionality and representation, challenges with infertility, evidence of loss.

Table 4.15

Theme Seven Subthemes and Related Codes

Subtheme	Codes	Quotes
Emotional Impact of Infertility	Emotional pain of miscarriage Pain having to try before testing Comforted to not feel alone in infertility Isolation: Difficult for family to know what to say or how to talk about miscarriages	*I did not know that I would have trouble getting pregnant. I did not know that I would have trouble carrying a child to term.* *It was really hurtful and embarrassing because I felt like my child was already not alive, but I felt like, you know, I was removing my child and I was doing stuff to something that was a part of me*

Subtheme	Codes	Quotes
	Struggle to enjoy pregnancy after miscarriage	*I really struggled to connect to her when she was in my belly, because I think it was out of fear, out of anxiety, that something was going to go wrong, and so not to get my hopes up*
Intersectionality and Representation	Representation of seeing black women talking about miscarriages/infertility	*I saw mostly white women who were documenting their self, white women with means. And I was like, OK, I can't really relate to that*
Challenges with Infertility	Time/schedule focus of IVF process Work flexibility to get treatments Harmful Assumptions	*I spent my whole life trying to avoid pregnancy only for everything to turn when I got married. And it was like, oh, just kidding, you can't get pregnant* *I assumed it would be easy. And this kind of showed me that it was not*
Evidence of Loss	Physical changes Honoring miscarriages	*I wonder who that baby would have been because that was to me evidence that there was a baby. Even though I have another baby sometimes I just I feel conflicted like, you know, I feel that had that baby lived I wouldn't know her. But then sometimes I'm still like, I still wonder who that baby would have been* *I feel like I just repressed that part so much. And I'm just trying to find ways to honor those two babies*

Theme Eight: Challenges in Healthcare

There were three subthemes identified: stigma in healthcare, navigating healthcare, challenges in advocacy and communication.

Table 4.16

Theme Eight Subthemes and Related Codes

Subtheme	**Codes**	**Quotes**
Stigma in Healthcare	Met with stigma around mental health and medication when trying to get pregnant Expectation that it is the person with uterus problem and not non-gestational partner No mental health assessment or screenings after traumatic experiences (miscarriage, traumatic birth) Medication to help with depression and anxiety during pregnancy	*And we were advocating for both of us to get tested. And they were like, I remember one of the doctors saying like, no, no, it's normally a problem with the woman* *When we were diagnosed with infertility or like it was confirmed that we had infertility, I had a lot of panic attacks and anxiety attacks. I had to be put on a medication* *Sometimes you try medication and it doesn't really help, but it helped. It helped a lot and was a saving grace* *The first thing that this fertility doctor said to me was he saw that I was allergic to an anti-anxiety medication. And he said, oh, you must be really moody*
Navigating Healthcare	Treated poorly by OBGYN and sought out other care Advocate to see fertility specialist Advocate to get testing sooner Roadblocks within the system	*We had to advocate and, you know, harass the doctors as well to get tested before three losses. And I was like, no, thank you. Two is enough. Let's get tested* *I reached out to a fertility clinic myself. So, I wasn't getting the support that I needed from my OBGYN*
Challenges in Advocacy and Communication	Importance of agency and choice Providers to trust what patients know about themselves Frustration, defeat	*I don't know that I trust this doctor. I don't know that I feel comfortable here* *I felt like my doctors didn't hear me and didn't understand my experience of what I was going through. And it was really very frustrating for me. And I really had to advocate for myself a lot, trying to get the care that I needed*

Subtheme	Codes	Quotes
	Dependent on providers; only hope Unheard and dismissed Lack of contact Lack of empathy and support from providers Advocacy as need to receive proper care and support	*I switched doctors because I didn't feel like I was being heard, and luckily I did work with people, I moved to people who actually listened to me. But I think that's a common theme too, where there's a frustration of, this is my body and I know something's going on with my body, I just don't know what it is, and this is causing added stress and anxiety because nobody's listening to me* *I would go in and they would just stand at the computer and I'd be like, I'm struggling and they'd be like, oh, that's normal. And it just felt kind of cold* *Why does this have to be so hard? Like it's already hard enough? Like why does every single part of it have to be so challenging? Like why do I have to advocate for myself in this space where I feel really defeated?*

CHAPTER V: CONCLUSIONS

> No pregnancy exists in a vacuum—pregnant and birthing people experience and make sense of the perinatal period as it coexists with other parts of their lives. Importantly, physical, emotional, and social processes are co-constitutive (Foster et al., 2021, p. 1592).

Interpretation of Data

This chapter examines the themes and subthemes from Phase One and Two through an ecological systems perspective. Phase One themes and subthemes were: (a) Social and Cultural Influences (pressure and expectations, cultural components of care, and family dynamics), (b) Navigating Transitions and Changes (identity shift/transformation, multiple roles, and self-exploration), (c) Support Networks and Resources (community, mental health, challenges with support, and comprehensive and collaborative care), (d) Discrimination and Stigma, (e) Advocacy and Empowerment (lived experience fueling advocacy efforts, resilient narratives, and self-advocacy as need), (f) Mental Health and Well Being (emotional, psychological, and physical impact; counseling, and questioning/mental load), (g) Interactions with Medical Systems (relationship with provider, mental health screening, and challenges with healthcare systems), and (h) Impact of Systems and Policies (access as privilege, financial burden, lack of support, and disparities of care).

Phase Two themes and subthemes were: (a) Meaning Making (impact of expression, and meaning through community), (b) Emotional Impact of Perinatal Experiences (complex emotional responses, grief as all-encompassing, desperation, and emotional rollercoaster), (c) Navigating Roles and Identities (cultural identity and healing, narrative shifts, identity transformation, and navigating multiple roles), (d) Pressure and Expectations (external, and internal), (e) Advocacy and Empowerment, (f) Social Support and Community (seeking community and supportive environments,, and navigating support systems), (g) Prevalence of Infertility and Miscarriage (emotional impact of infertility, intersectionality and representation, challenges with infertility, and evidence of loss), and (h) Challenges in Healthcare (stigma in healthcare, navigating healthcare, and challenges in advocacy and communication).

There was considerable overlap with the themes and subthemes for Phases One and Two, which may conclude a point of saturation was met as well as the recursive process of phase one informing the photovoice prompts for phase two. Additionally, many subthemes are connected to multiple ecological levels which speaks to another layer of overlap. This may also be indicative of the impact each theme has on other themes. For example, stigma may impact specific medical care needs being unmet as well as feelings of isolation, lack of support, and the development of perinatal mood and anxiety disorders.

The themes from Phase One that informed the photovoice prompts for Phase Two were: support, grief, pressure and expectations, identity shift and transformation, advocacy and empowerment. Participants were asked to capture a photo that connected to the themes from their perinatal experience and share the narrative around these photos in the focus group. In this way, Phase One created a foundation of themes and Phase Two deepened and solidified the themes.

Theory and Research

This chapter examines the findings of the study through an ecological system framework. The findings are organized by themes and subthemes (see Table 5.1, Table 5.2) and are extrapolated further below. The chapter ends with a discussion of the findings that pertain to the implications for the counseling profession, limitations, and recommendations.

Phase One

Table 5.1

Phase One Themes, Subthemes, and Ecological Levels

Theme	Subthemes	Ecological Systems
Social and Cultural Influences	Pressure and Expectations	Macrosystem, Chronosystem
	Cultural Components of Care	Macrosystem, Chronosystem
	Family Dynamics	Microsystem, Chronosystem
Navigating Transitions and Changes	Identity Shift/Transformation	Microsystem
	Multiple Roles	Exosystem
	Self-Exploration	Microsystem
Support Networks and Resources	Community	Microsystem
	Mental Health	Microsystem, Exosystem
	Challenges with Support	Microsystem, Exosystem
	Comprehensive and Collaborative Care	Mesosystem
Discrimination and Stigma		Macrosystem
Advocacy and Empowerment	Lived Experiences Fueling Advocacy Efforts	Microsystem, Mesosystem Exosystem
	Resilient Narratives	Microsystem, Mesosystem
	Self-Advocacy as Need	Microsystem
Mental Health and Well Being	Emotional, Psychological, and Physical Impact	Microsystem, Chronosystem
	Counseling	Microsystem, Macrosystem
	Questioning/Mental Load	Microsystem, Macrosystem
Interactions with Medical Systems	Relationship with Provider	Microsystem
	Mental Health Screening	Exosystem, Macrosystem
	Challenges within Healthcare Systems	Exosystem, Macrosystem
Impact of Systems and Policies	Access as Privilege	Exosystem
	Financial Burden	Exosystem
	Lack of Support	Exosystem
	Disparities of Care	Exosystem

Theme One: Social and Cultural Influences

Participants reported social and cultural influences impacting their perinatal experience and focused specifically on pressure and expectations, cultural components of care, and family dynamics. From a macrosystem perspective (Bronfenbrenner, 1994), participants stated that they felt pressure to conform to gender roles and societal norms regarding pregnancy, childbirth, and parenting. They also discussed the societal pressure to fulfill multiple roles, such as being a parent, partner, student, and professional, without faltering. Some participants of color stated that they also felt pressure from a historical expectation that Black women are fertile and should not struggle to conceive, leading to isolation and embarrassment when struggling with infertility. This is a similar finding to Harrison and Pinkney (2024) study on the infertility experiences of Black women and their perinatal journey. The lack of representation highlights the dimension of time, or the chronosystem (Bronfenbrenner, 1994), and that the narrative of fertility is inaccurate around the lived experience of Black people with uteruses. Barnett et al. (2020) also found that representation is lacking when exploring the lived experience of BIPOC women, which instigates the racial and ethnic health disparities.

The cultural components of care participants discussed were connected to their own narratives and culture through a macrosystem and chronosystem lens (Bronfenbrenner, 1994). Participants discussed their desire to have a great conception story and the importance of naming their child that has meaning and is connected to their family of origin. In addition, participants found that honoring their faith and cultural history was an important aspect of their perinatal experience. Some participants also noted the juxtaposition of perinatal experience being discussed more through social media and yet still supported less over time, which emphasizes how the chronosystem (Bronfenbrenner, 1994) impacts the perinatal experience. These findings of cultural influences are reminiscent of the tenets of liberation psychology (Martín-Baró, 1994) as the narratives focus on history and empowerment within family culture.

Focusing on the microsystem, family dynamics were also a topic of focus when participants shared about social and cultural influences on their perinatal experience. Current research often discusses the context of family impact on perinatal experiences from the lens of support (Akhter et al., 2020; Bhamani et al., 2023; Keefe et al., 2016) rather than on the expectations and values that families hold and how that creates challenges. Participants reported that they had to navigate their family of origin's expectations of the perinatal experience, including infertility, birth, chestfeeding, and parenting style. Participants stated that when they differentiated from what their caregivers did, they were faced with challenges within the family system. Some Black participants reported that their family did not support their desire to chestfeed, which led to feelings of inadequacy as a new parent. Black women breastfeed less frequently compared to White women due to the fact that societal, political, personal, and community factors discourage breastfeeding among Black women (Alio et al., 2010). Petit et al. (2021) stated that Black women continually experience institutionalized racism, which directly impacts their experiences of chestfeeding. The intergenerational patterns of perinatal care in the family are indicative of the chronosystem as well as microsystem of direct impact (Bronfenbrenner, 1994). Participants discussed the desire to disrupt these patterns in order to give their children something that they did not receive themselves as children.

Theme Two: Navigating Transitions and Changes

Participants highlighted identity shifts and transformation, holding multiple roles, and self-exploration as influencing their perinatal experience. At the micro level, participants shared that being flexible and shifting their expectations of the perinatal experience contributed to feeling more at ease with different outcomes. Participants also reported the need to mourn their past selves, either before they began trying to get pregnant or after birth and accepting their new role as a parent. Similarly, some participants discussed the need to develop an identity other than being a parent, such as being a partner, professional, or friend. Law et al. (2021) also found that individuals who were diagnosed with postpartum depression were learning to come to terms with a new sense of self during their perinatal experience.

Bronfenbrenner (1994) characterizes the exosystem as indirect influences to the individual. An example of the exosystem in the perinatal experience is related to participants navigating many different roles simultaneously. Participants shared that they experienced a loss of some roles, overlapping roles, and experiencing delays in pursuing education and career aspirations as well as stigma and judgment for being a parent in academia and the workforce. Due to this stigma, participants found themselves questioning their ability in these roles. One participant stated that they got the sense their academic advisor did not think she was serious about completing her degree because she had a child while in the program. The societal expectation of “idealized mothering” (Springer et al., 2009, p. 436) and being “100% academic” (Springer et al., 2009, p. 436) is unrealistic, unsupportive, and setting up people with uteruses to fail.

Participants acknowledged that the theme of navigating transition and change also comes with self-exploration; another microsystem influence of their perinatal experience. Participants reported going through a process of getting to know themselves again postpartum and attempting to prioritize themselves. Some participants even noted that after several years postpartum, they are still trying to re-engage with old identities while developing new ones. Participants who struggled with infertility also reported a need to know themselves during their infertility journey.

This finding aligns with Dube et al. (2021), who captured the theme of infertility being a threat to self-esteem, identity, and purpose for participants' experiences with infertility.

Theme Three: Support Networks and Resources

The third theme is support networks and resources and has four subthemes: community, mental health, challenges with support, and comprehensive and collaborative care. Generally, this finding is aligned with much of the current research regarding perinatal experiences (Abelsohn et al., 2013; Akhter et al., 2020; Atif et al., 2015; Barnett et al., 2022; Bedaso et al., 2021; Bhamani et al., 2023; Helm et al., 2023; Keefe et al., 2016; Nagle & Farrelly, 2018; Soled et al., 2023; Stewart et al., 2022; Tyokighir et al., 2022). Community focuses on the microsystem, or direct influences on the person with a uterus. Participants shared that having a support network or not significantly impacted their perinatal experience. Participants mentioned that this support can look like friends, family, work environments, support groups, and social media. Some participants recognized the privilege of having access to supportive environments and resources, such as support groups in the community based on their geographical location, insurance coverage, and socioeconomic status. Similar results were found when studying perinatal experiences of women with low socioeconomic status related to insufficient partner support and lack of community (King, 2014). Some participants disclosed that they found comfort in knowing they weren't the only ones experiencing difficulty and found validation in being able to share their experiences with others.

Another microsystem influence was mental health, which was also seen as an outlet for support during the perinatal experience. Some participants stated that seeing a counselor during the perinatal period offered a space for them to not be okay and to also feel like they could share openly without judgment or shame. Additionally, many participants discussed that there should be more accessible, culturally competent mental health resources available, especially around miscarriage and infertility. Some participants also mentioned they wished there was more support around the changing relationship with their partners and how to navigate the shifting dynamics in their family. Aspects of mental health during the perinatal experience will be discussed in more detail below in theme six: mental health and well-being.

While having community and mental health support contributes to a positive perinatal experience, there are also challenges with receiving support impacted by both the microsystem and exosystem. From a microsystem perspective, participants disclosed that with a lack of support from family, friends, and other resources, they felt isolated, which contributed to depression and anxiety during their perinatal experience. Participants also shared aspects of the exosystem that created challenges with support, including limitations of the insurance coverage leading to difficulty accessing supportive care, a lack of specialists in rural areas, and their work not being flexible for appointments or paid leave. Similarly, current research found that barriers to care occur at the healthcare system level as treatment can be inaccessible to some, especially based on their insurance status (Keefe et al., 2016; Kirubarajan et al., 2022; Tarasoff, 2017; Tyokighir et al., 2022).

Support was also found through comprehensive and collaborative care, which showcases the mesosystem, or interactions between microsystems. Another study found that a lack of communication between providers creates a barrier to care when providers, postpartum individuals, and mental health professionals were interviewed (Tyokighir et al., 2022). Some participants reported having transformative experiences with supportive professionals such as midwives, doulas, and pelvic floor therapists, all communicating with one another regarding the person with a uterus and their perinatal care. Participants with less holistic and empowering perinatal experience reflected that they desired comprehensive care with interdisciplinary professionals collaborating and advocating for them. Howard and Khalifeh (2020) discussed the importance of collaborative care in the perinatal setting, and Tarasoff (2017) found a barrier to care is the lack of communication and collaboration among providers.

Theme Four: Discrimination and Stigma

The theme of discrimination and stigma in this study is supported by the current perinatal research (Barnett et al., 2022; Goodman, 2009; Guilfoyle et al., 2014; Keefe et al., 2016; Kirubarajan et al., 2022; Nagle & Farrelly, 2018; Ross et al., 2012; Salm Ward et al., 2013; Soled et al., 2023; Tripathy, 2020; Tyokighir et al., 2022). Participants reflected on their experiences of stigma and discrimination related to race, age, weight, gender, mental health, socioeconomic status, chestfeeding, and neurodivergence. One participant disclosed harmful experiences with providers who did not take the time to understand their perspective or were aggressive, which the participant connected to a lack of competency working with autistic individuals. Comparably, Saeed et al. (2022) found that barriers to perinatal care for people with intellectual and developmental abilities included lack of provider experience, ableism, provider assumptions, lack of provider effort, and ableism. Many of the participants of color discussed their fear during the perinatal experience related to the mortality rate for Black mothers and infants in the United States, as well as microaggressions they encountered in their interactions with providers. Some of the participants who discussed chestfeeding reported feeling encouraged to do so for the first year postpartum and noticed a shift in the messaging toward judgment for continued chestfeeding after a year. Participants also named the harm of assumptions in their perinatal experience related to providers assuming they have support in place when they do not, and the assumption if they are more educated, that they should know how to take care of themselves and their children. Most of these narratives are connected to the macrosystem and the cultural values, beliefs, and norms that persist in American society.

Theme Five: Advocacy and Empowerment

The three subthemes for the theme of advocacy and empowerment are lived experience fueling advocacy efforts, resilient narratives, and self-advocacy as needed. Lived experiences fueling advocacy efforts are multidimensional in terms of the ecological systems in that they encompass the microsystem, mesosystem, and exosystem. On the microsystemic level, participants shared that their own perinatal experiences have led them to advocate more for themselves as well as for others who may have similar experiences. This advocacy folds into the exosystem as the advocacy expands to policy changes like paid leave, reproductive choice, and inclusive insurance policies. An example of the mesosystem in this context is the relationship between the participants' experiences of care from their providers and advocating for others' experiences to be more supportive. Carter et al. (2021) call for clinicians to advocate for a paradigm shift in perinatal care. However, further discussion of advocacy in the perinatal research is surprisingly sparse.

Similar to the previous subtheme, resilient narratives are also connected to the mesosystem due to the relationship between advocacy work and building community. Additionally, this subtheme is linked to the microsystem from the perspective of building community through shared experiences as a place to both support and be supported. Finding solace in shared experiences was also a theme from a study conducted by Law et al. (2021) regarding women who experienced postpartum depression. Participants discussed the advocacy work that comes from overcoming the challenging aspects of their perinatal journey. Many participants found that by sharing their perinatal narrative, others began to share, which created a supportive community around similar emotional experiences. Bhamani et al. (2023) focused their research on resilience training and empowerment of pregnant women, and Kirubarajan et al. (2022) found resilience and empowerment as a theme and subtheme to the experiences of LGBTQ2S+ childbearing individuals. Soled et al. (2023) also discovered the theme of resilient narratives of childbearing in their study on gender-diverse childbearing experiences.

Self-advocacy as a need involves aspects that directly impact the individual, or the microsystem. Relatedly, Panko et al. (2022) found a theme of self-advocacy as a facilitator for positive perinatal experiences in their research focusing on women who are deaf. Participants reflected that it is important to advocate for themselves in the healthcare setting and seek out resources, and also found it difficult to advocate when experiencing perinatal events for the first time and unsure what they need or what to ask for. Several of the participants also shared their experiences of consent, autonomy, and choice in making decisions in their perinatal care. Some participants engaged in alternative resource seeking and sought out care from other providers when their needs were not met, or they were dismissed by previous providers.

Theme Six: Mental Health and Well-Being

The theme of mental health and well-being had three subthemes: emotional, psychological, and physical impact; counseling, and questioning/mental load. The emotional, psychological, and physical impact encompassed a range of emotions, including PMADs, traumatic birth experiences, stress, fear, anxiety, vulnerability, shame, guilt, embarrassment, empowerment, isolation, grief, invisibility, self-blame, and inadequacy. Research has found that one in three birthing people report feeling traumatized by their childbirth experience (Pidd et al., 2023). Most of these emotional experiences were connected to the microsystem as participants shared their trauma of miscarriages, powerful birth stories, or disappointment in not being able to enjoy bonding with their child as they were experiencing anxiety and depression postpartum. An experience related to the chronosystem is a participant whose first round of IUI was canceled due to the COVID-19 pandemic, and it was considered an elective procedure. This participant disclosed that this felt like another loss after having multiple miscarriages. Participants also discussed their anxiety when they got pregnant after having a miscarriage and struggling to enjoy that time out of fear of another loss. In their study, Nagle and Farrelly (2018) also found a theme connected to mental health with subthemes: an emotional time, supposed to be happy, and confidence in managing mental health. Additionally, the study by Berry et al. (2021) found a similar subtheme of complex emotional response related to the experience of perinatal loss.

The second subtheme, counseling, was also connected to the microsystem as participants mentioned the need for comprehensive, inclusive mental health care in their perinatal experience. Participants shared that counseling during the perinatal period has offered a space for them to be heard without judgment and to have their experiences normalized and validated. Participants also desired to have perinatal counseling focus on what to expect during the perinatal period and honor their individual experiences. Some participants felt it was important to have a counselor who specialized in perinatal mental health as they would understand the medical system and how to navigate it while other participants thought that the relationship with their counselor was most important. From a macrosystemic perspective, participants discussed the stigma and shame around sharing their mental health issues during the perinatal experience, which led to their hesitation to seek support. Counselors can avoid the cultural taboo against the public recognition of the expression of perinatal grief by offering a space of validation, empathy, attending to cultural differences, and creating mourning rituals (Markin & Zilcha-Mano, 2018).

The third subtheme related to mental health and well-being was questioning/mental load, which combines both micro- and macrosystems. Most participants shared layers of questions about their perinatal experience, which was reflective of the number of choices and decisions that need to be made through the perinatal journey and the burden of those choices. These questions were connected to a feeling of overwhelm by the unknowns, especially for first-time parents. Participants also reported a feeling of self-judgment as they compared their choices to others and questioned if they were doing the right thing. The idea that there is a “right” way to make decisions in the perinatal experience is connected to the cultural and societal norms and values of pregnancy and parenting. Participants discussed feeling pressure around this and found the access to information to be both a benefit and a burden. This particular subtheme is not directly mentioned in the current literature.

Theme Seven: Interactions with Medical Systems

Theme seven is interactions with medical systems, and the subthemes are: relationship with provider, mental health screening, and challenges within healthcare systems. Relationship with provider is connected to the microsystem as participants discussed how their interactions with the care provider impacted their experience directly. This subtheme is also in the current research (Barnett et al., Berry et al., 2021; 2022; Khan et al., 2021; Light et al., 2014; Panko et al., 2023; Reed et al., 2017; Saeed et al., 2022; Simpson & Catling, 2016). Participants discussed that feeling supported and listened to by their provider was a significant element in informing how they felt about their perinatal care. Several participants shared they felt disappointed by the lack of communication, empathy and warmth from their providers. Another study found that Black women described their fear of facing discriminatory services by culturally incompetent healthcare providers through their perinatal journey (Harrison & Pinkney, 2024). Participants also shared that the inherent power dynamics in the medical system left them feeling unheard and pressured to make decisions that were not aligned with their needs, and felt there was a fear-based negative communication style that resulted in a lack of agency. These specific experiences are further aligned with the findings from Reed et al. (2017), which underlined themes of lies and threats from their providers, and feeling violated. Many participants disclosed that they wished they were given more information about what was happening during their perinatal experience to increase their autonomy around decision-making.

In regards to the second subtheme, mental health screening, participants reported feeling as though their mental health was not prioritized and that it felt surface level or like a check-box item during their visits. From an exosystem perspective, the medical system policy typically focuses on the physical care for individuals during their perinatal experience. While it is important that individuals are safe and healthy physically, many individuals experience trauma, grief, loss, depression, and anxiety during the perinatal experience, which should be given more attention by their healthcare providers. The Maternal Mental Health Leadership Alliance (2020) stated that perinatal individuals see a frontline healthcare provider 20–25 times during their perinatal experience and up to a year postpartum. However, the providers lack the training, knowledge, and resources to address perinatal mental health issues and are not reimbursed for doing so. Many participants reported that they were not offered any mental health or other supportive resources throughout their experiences of miscarriage, birth trauma, and postpartum. From a macrosystem standpoint, participants described instances in which providers made assumptions about their mental health status simply by what they looked like. Overall, participants revealed feeling the stigma and silence around mental health, leading to a reluctance to discuss it with their healthcare providers when and if they were asked. Other studies also found stigma (Goodman, 2009) and societal silencing (Law et al., 2021) as barriers to mental health treatment in the perinatal period.

Also related to the exosystem, the third subtheme, challenges within healthcare systems, involved participant experiences of accessing healthcare, which highlighted the disparities based on factors like race, socioeconomic status, and location. Participants reflected that they desired more inclusive and personalized care plans rather than feeling like they were on a conveyor belt during their perinatal experience. These experiences emphasize the cultural norms within the medical system that perpetuate harm and neglect. A few participants even shared that what was written in the notes on their chart was inaccurate and blatantly untrue which is also supported by the theme, Threats and Lies, from the research conducted by Reed et al. (2017).

Theme Eight: Impact of Systems and Policies

The subthemes of theme eight are: access as privilege, financial burden, lack of support, and disparities of care, and are all connected to the exosystem, or indirect impact to perinatal experiences. Participants shared that their geographic location impacted the options of support they have and also influenced their access to a variety of care options and the race of providers. Some participants discussed their move from the Westernized medical system to a more holistic midwifery care, which was not covered by their insurance but aligned with their values. Other participants discussed their desire for midwifery or even a home birth, which they could not utilize due to insurance limitations. Additionally, participants discussed the difficulty of postpartum trying to find affordable childcare as they were not supported with paid leave at their place of employment.

Many participants shared their frustration around the lack of support for the perinatal experience in the United States compared to other countries and communicated a desire for the government to create policies to support perinatal care, healing, and bonding time with their child. Furthermore, one participant shared that they felt privileged to be able to undergo IVF treatments when their insurance does not cover it and that they have to utilize their paid time off to meet the needs of the scheduled treatments. Another participant shared that when she got pregnant with her child, she had just started a new job, and her pregnancy was considered a preexisting condition. This meant that she had to pay out of pocket for her perinatal experience and had to return to work four weeks postpartum due to not having any paid time off days accrued. Policy is a recurring theme in much of the current research around racial and ethnic disparities, insurance coverage, support programs, gender disparities, reproductive rights, childcare, professional training, access to care, and paid leave (Abelsohn et al., 2013; Barnett et al., 2022; Bedaso et al., 2021; Carter et al., 2021; Foster et al., 2021; Khan et al., 2021; Rhodes & Segre, 2013; Saeed et al., 2022 Tyokighir et al., 2022).

Phase Two

Table 5.2

Phase Two Themes, Subthemes, and Ecological Levels

Theme	Subthemes	Ecological Levels
Meaning Making	Impact of Expression	Microsystem
	Meaning through Community	Microsystem
Emotional Impact of Perinatal Experiences	Complex Emotional Responses	Microsystem
	Grief as all Encompassing	Microsystem
	Desperation	Microsystem
	Emotional Rollercoaster	Microsystem
Navigating Roles and Identities	Cultural Identity and Healing	Macrosystem
	Narrative Shifts	Chronosystem
	Identity Transformation	Chronosystem
	Navigating Multiple Roles	Microsystem, Macrosystem

Pressure and Expectations	External	Macrosystem
	Internal	Microsystem, Macrosystem
Advocacy and Empowerment		Microsystem, Exosystem
Social Support and Community	Seeking Community and Supportive Environments	Microsystem
	Navigating Support Systems	Microsystem
Prevalence of Infertility and Miscarriage	Emotional Impact of Infertility	Microsystem
	Intersectionality and Representation	Macrosystem
	Challenges with Infertility	Microsystem, Mesosystem
	Evidence of Loss	Chronosystem
Challenges in Healthcare	Stigma in Healthcare	Exosystem, Macrosystem
	Navigating Healthcare	Microsystem, Exosystem
	Challenges in Advocacy and Communication	Microsystem

Theme One: Meaning Making

Meaning making refers to the photovoice process and the way in which it offered participants a way to make new meaning from their perinatal experiences. The subthemes to this theme, impact of expression and meaning through community, are both connected to the microsystem. Participants shared that they found solace in utilizing a creative outlet to connect to their perinatal story. Some participants reflected that it is often difficult to find words to describe their experience, and so sharing a photo was an opportunity to capture more than words related to their perinatal journey. Furthermore, Some participants found meaning and purpose in sharing their experiences with others and advocating for better support and understanding in perinatal care, which also contributed to feeling less isolated and comforted that others had similar experiences.

Theme Two: Emotional Impact of Perinatal Experiences

The emotional impact of perinatal experiences theme had four subthemes: complex emotional responses, grief as all encompassing, desperation, and emotional rollercoaster all of which are imbedded in the microsystem experience. Many participants reflected on the dialectic emotions during their perinatal experience such as hope and grief, joy and fear, anxiety, and happy. They also discussed that the emotions felt during their perinatal journey were layered; they felt grief alongside desperation, sadness, fear, rage, and hope. Some participants also expressed feelings of resentment and anger towards others who had seemingly "simple" journeys to parenthood and were frustrated with the lack of support and understanding from others. Berry et al. (2021) came across the same theme in their metasynthesis focused on parents who experienced perinatal loss.

Grief as all-encompassing highlights that grief was connected to many different aspects of the participant's perinatal experience. Participants shared that they felt grief around not feeling comfortable or safe to share their experiences with others or feeling grief and fear of getting pregnant after a miscarriage. Participants expressed deep, emotional pain and grief, particularly in response to miscarriages and fertility struggles. One participant shared, "it felt like it was from all areas at one time," and another stated, "grief is a constant companion" as they reflected on their perinatal experiences around loss. Desperation was closely connected to grief and anxiety as participants shared a longing to stay pregnant and wanting their body to cooperate, especially after experiencing a perinatal loss. Perinatal loss is followed by grief, which is a common response, occurring in 80% of patients who have experienced perinatal loss (Riddle et al., 2023).

Several participants discussed the emotional rollercoaster of their perinatal journey. One participant shared that they grieved the relationship they had with their partner previously and also felt jealousy toward their partner for not having gone through the physical challenges of pregnancy. Another participant disclosed that if they did not feel sad all of the time about their perinatal loss, that meant they no longer cared, leading to shame and self-judgment. Many of the participants experienced more than one loss and many challenges during their perinatal journey, which speaks to their resilience and perseverance through this process.

Theme Three: Navigating Roles and Identities

There were four subthemes that emerged from navigating roles and identities: cultural identity and healing, narrative shifts, identity transformation, and navigating multiple roles. Participants explored their cultural identity and heritage as a way to cope with grief and navigate their journey through parenthood. Part of this exploration was also connected to preserving cultural traditions and passing them on to their children as a form of identity affirmation and continuity. One participant shared how reconnecting with her cultural identity through beading provided a therapeutic outlet during her infertility journey. The focus on culture and heritage is linked to the macrosystem around cultural values and beliefs. Furthermore, participants were reflective on their parental identity and cultural aspects of their journey, including the significance of names, heritage, and representation.

Many participants reported that their narratives and focal points shifted over time, which reflected changes in their emotional states and life circumstances. One participant shared that time has had a significant impact on the emotion connected to her perinatal experience and what is salient to her, which was also a reminder that her perinatal story will likely shift again. Another participant mentioned that while she connects to other’s experiences, she was more removed from it emotionally as time passed and was able to offer another perspective to other participants. The shifting of time impacting the perinatal experience reflects the chronosystem by noticing the cycle and transition of events over time.

Another chronosystemic factor was the subtheme of Identity Transformation. Participants with older children reflected on the 'miles traveled' and seeing their child grow and change as a parallel process to their own growth and change. This identity transformation is connected to a process of self-discovery, exploration, and reflection. Some participants also discussed the physical transformation of pregnancy, birth, and postpartum and navigating a new way to be in relationship with their body. Other participants considered the transformation of the relationships around them during their perinatal experience and learning more about themselves and what they need from their environment and the people around them. Law et al. (2021) found a similar theme, coming to terms with a new sense of self, in their study focused on personal narratives of people with postpartum depression.

Participants also discussed the challenges of balancing multiple roles, such as being a parent, professional, student, and partner simultaneously. One participant shared about the moment she graduated from her Master's program with a child at the same time, feeling both grief that she was not as present with her child as she wanted to be and joy for herself for such an accomplishment. Another participant, who is a mental health counselor, shared her experience of trying to navigate being a parent while also feeling like there was an expectation that she was able to manage her emotions during her perinatal journey. While this subtheme is mostly concerned with the microsystem, the expectations that the participants discussed around assumptions to balance all of the different roles are connected to the macrosystem and the societal roles and pressures that are placed on people with uteruses.

Theme Four: Pressure and Expectations

Participants felt pressure externally and internally from societal expectations, family, and themselves to meet certain milestones or conform to specific norms. Participants who were going through fertility treatments, particularly IVF, discussed the emotional weight carried throughout the process. From a macrosystem viewpoint, external pressure was connected to societal pressure around norms and feeling like a failure if they were unable to get pregnant. With that pressure came a stigma surrounding infertility, miscarriages, and mental health during the perinatal period. Some participants felt that if they admitted they were struggling with their mental health during this time, they were not prioritizing their child. Through a systematic review, Hansotte et al. (2017) found that a barrier to accessing care was due to feelings of shame, stigma, guilt, and fear of being considered a "bad mom."

Conversely, internal pressure focuses on both the microsystem and macrosystem. From a microsystemic lens, participants discussed the internalized pressure to advocate and take care of their child while simultaneously seeing any focus on themselves as selfish. Participants also expressed the emotional weight of trying to get pregnant and feeling like their body is failing if they are struggling, leading to even more pressure being put on themselves to have a viable pregnancy. Macrosystemically, one participant shared that while having a child and being a student herself, she questioned if she was making the right choice to do both and felt pressure to be successful in the culture of the United States. Another participant who identifies as an academic shared that she felt a lot of pressure to "know everything" throughout her perinatal journey and put pressure on herself to read and prepare for everything.

Theme Five: Advocacy and Empowerment

Participants emphasized the importance of self-advocacy in seeking appropriate medical care, including advocating for necessary tests and treatments, such as surgery for conditions like varicocele vein, which significantly impacted their ability to conceive. The theme, advocacy and empowerment, is interacting with the microsystem and exosystem. Microsystem influences include participants advocating for the sake of their children so that they can be supported and in relationships that serve them, advocating for their students, and connecting with others. The exosystem connection to this theme is that participants felt like they had no other choice but to advocate because the medical system and policies did not support their needs. Some participants shared that they had to fight to get their non-gestational partner tested because the focus was on something being “wrong” with the person with a uterus. For many participants, this led to a distrust of the healthcare system (Hansotte et al., 2017) and influenced them to seek care elsewhere. Several participants have felt empowered to utilize their perinatal experiences to fuel their advocacy work in their local, regional, and state communities. One participant stated that her supports holding hope is the most important thing for her because she sometimes does not know how to hold hope when she is going through fertility treatments.

Theme Six: Social Support and Community

Participants found support from various sources, including family, friends, animals, online communities, and support groups. Sharing their stories publicly, whether through social media or other means, led to feelings of support and validation. The two subthemes of social support and community are: seeking community and supportive environments and navigating support systems, which are both associated with the microsystem. Many participants found support and community through social media; being able to connect with people throughout the world who are experiencing similar issues with the perinatal experience. Participants discussed feeling validated in these communities and referenced the study's focus group as being another space for them to feel connected by sharing their stories. Overall, participants stated that having support in a community setting is healing, comforting, and empowering. A lack of support at the family level leads to a significantly higher risk for postpartum depression, resulting in a barrier to accessing care (Keefe et al., 2016).

Participants also talked about their experiences navigating support systems. Many reported that trust needs to be established before they can feel like they can share honestly without getting pushback or judgment, and this process can be isolating. One participant offered that she was not able to support others struggling with infertility while she was also going through fertility challenges and loss as she did not have the capacity to do so. Another participant, who is a mental health counselor, stated that she decided to specialize in perinatal mental health for her own healing journey and also to support others who are struggling. It has also been found that low social support was significantly associated with the risk of PMADs during pregnancy and that policy should be geared toward building community-based social support programs (Bedaso et al., 2021).

Theme Seven: Prevalence of Infertility and Miscarriage

The subthemes of theme seven, prevalence of infertility and miscarriage are: emotional impact of infertility, intersectionality and representation, challenges with infertility, and evidence of loss.

Riddle et al. (2023) discuss the current status of mental health, perinatal loss, and infertility and the need for focused screening, prevention, and treatment for this population. In 2022, there were 3.66 million live births (CDC, 2022), which means that approximately a million individuals experienced perinatal loss or infertility. Participants discussed the emotional pain of miscarriage and struggling to enjoy future pregnancies after miscarriage out of fear of another loss. Many participants shared that they also experienced significant pain having to try for at least a year without getting pregnant or to undergo three miscarriages before getting tested. Additionally, participants reported the additional impact of isolation from their friends and family, their microsystem, and not knowing how to talk about loss with them.

Intersectionality and representation was another subtheme of theme seven and involves the macrosystem. Some participants shared the additional isolation they felt when they were struggling with infertility and not seeing other Black people with uteruses represented in media talking about miscarriages and infertility. One participant shared that she saw that the majority of people talking about their experiences were White women with means and felt disconnected. When studying the perinatal experiences of BIPOC women, Barnett et al. (2022) found that participants' experiences were influenced by representation during their perinatal care and had a positive experience when they saw someone who looked like them on their medical team. Pruitt et al. (2020) found that Black women are twice as likely to experience miscarriage or stillbirth due to maternal preconception health, socioeconomic status, intergenerational stress and trauma, racism and bias in the healthcare system, and access to quality health care. Which is to highlight the importance of representation of Black women having a community of support to discuss perinatal challenges and experiences. Harrison and Pinkney (2024) conducted a study on the lived experiences of Black women with primary and secondary infertility which found that Black women carry a societal expectation to reproduce, given racial stereotypes and historical contexts, and found it challenging to receive help for their grief, understanding of their medical and mental health conditions, as well as their treatment by medical professionals.

The third subtheme, challenges with infertility, is influenced by the microsystem and the mesosystem. This subtheme focused on the participants' experience of balancing work responsibilities and fertility challenges, shedding light on the complexities of managing personal and professional aspects simultaneously. The microsystem impact relates to the harmful assumptions around the ease of getting pregnant. One participant shared their frustration with the fear-based education around pregnancy they received, only to struggle getting pregnant when they desired. A mesosystem impact of infertility is the time commitment for IVF treatments and needing work flexibility to get time off to maintain the IVF schedule. One participant shared that their IVF journey comprised medications, shots, calls to insurance companies, doctor visits, and blood draws. Another participant discussed the worry if they were unable to get the medication on time due to insurance complications, and another disclosed the fear of missing the time to take a shot and having to start all over again.

Evidence of loss is connected to the chronosystem or seeing the impact of time on the infertility process. Some participants discussed the physical changes their bodies went through and, after a loss, still saw their bodies as being pregnant. Other participants reported that it was important to honor their miscarriages and the babies that would have been. One participant shared that over time, they still wonder who the baby they lost would have been and want to honor the memory of that child.

Theme Eight: Challenges in Healthcare

The three subthemes for theme eight are stigma in healthcare, navigating healthcare, and challenges in advocacy and communication. Stigma in healthcare is connected to both the exosystem and macrosystem. Participants recalled their struggle to have the non-gestational partner get tested and the exhaustion they experienced from having to repeatedly ask for this care. Additionally, participants reported that they received no mental health assessment or screening after a traumatic experience such as a miscarriage or traumatic birth. Both of these issues are concerned with the policy of the medical system. The macrosystemic aspect of this subtheme is associated with the stigma around mental health and medication during the perinatal period. Many participants reported that medication to help with anxiety or depression was significantly helpful to them during pregnancy, and while some participants received support from their medical providers, others were met with prodding questions, leaving them feeling judged.

Barriers to accessing care include the expense, logistical barriers, social biases, shame, stigma, and distrust of the healthcare system which involved the micro- and exo- systems (Hansotte et al., 2017). Some participants stated that they were treated poorly by their OB-GYN and were forced to seek out other care to be supported, and others reported that they had to advocate and seek out a fertility specialist themselves because they were not being referred. One participant shared that a roadblock in the system was that their insurance would not cover getting testing done until they experienced three miscarriages and reported feeling like this was emotional and physical abuse. Keefe et al. (2016) had a similar finding, concluding that a barrier to accessing mental health care services was inaccessible and unaffordable to some.

Challenges in advocacy and communication **e**xplores the frustrations and challenges in advocating for their medical needs and effectively communicating with healthcare providers. Participants discussed the lack of empathy and warmth from healthcare providers, particularly in addressing mental health concerns during pregnancy, and many participants felt unsupported by healthcare providers, experiencing dismissive attitudes and inadequate communication. Many participants shared that they felt more supported when their providers talked to them about their options, giving them agency to make their own decisions regarding their care. Overall, participants felt defeated and exhausted trying to be heard during their perinatal experience. One participant vocalized her frustration of being so dependent on her provider as being her only hope to have children while she was going through fertility treatments. In the United States, one in five birthing people report experiencing some form of mistreatment during pregnancy or childbirth (Salter et al., 2023). Moreover, a leading factor contributing to birth trauma is the birth person's experience of poor interpersonal care and communication (Reed et al., 2017). Due to the subjective nature of trauma, what may be seen as trauma to the birthing person may seem routine to the provider. However, providers should continue to check in on their patients to understand their perspective of their birth experience. One of the main barriers to seeking help was not knowing what "normal" or "abnormal" emotions in the perinatal period were, and therefore, the need for check-ins by providers is paramount (Nagle & Farrelly, 2018). Furthermore, individual healthcare providers are often unprepared to screen and treat mothers with perinatal mood disorders or symptoms that are dismissed as typical hormonal responses (Keefe et al., 2016).

Implications for Counseling

There are many ways in which counselors should use the information from this study to better support the perinatal population. Considering that there are 3.6 million live births per year (CDC, 2021) and the most common reproductive complication is the development of a mental health condition (MMHLA, 2023) it is likely that a counselor will work with this population in their career. Moreover, 75% of individuals impacted by perinatal mental health conditions are untreated with suicide and overdose being the leading cause of material deaths in the first year postpartum (MMHLA, 2023). Counselors need to be aware of the impact that perinatal experiences have on people with uteruses in order to treat them holistically and effectively. This requires counselors to be curious with their clients and recognize when their bias may be impacting their treatment plan. For example, naming a client experience as ‘normal’ or ‘baby blues’ may be dismissing or invalidating their emotions during postpartum. Nagle and Farrelly (2018) found that many medical professionals asked about the physical health of their postpartum patients and not about their emotional or mental health. Counselors have the ability to close the gap and prioritize the mental health of their perinatal clients.

There is a need for the utilization of focused screening, prevention, and treatment for people with uteruses as well as a need for collaborative efforts between care providers such as OB-GYNS, midwives, psychiatry, and counseling to mitigate poor outcomes (Riddle et al., 2023). Howard and Khalifeh (2020) had a similar finding in their study and also highlighted that the United States does not have specific perinatal training for practitioners. Additionally, a barrier to accessing mental health services has been shown to include the lack of communication between providers (Tyokighir et al., 2022).

A previous study also found that there is a need for timely mental health education and care during the perinatal period, especially when a person with a uterus experiences a loss (Herbert et al., 2022). Currently, there are no universal screening requirements for depressive symptoms, and the implementation of such screenings may reduce inequities and increase counseling services for support during the perinatal period (Declercq et al., 2022). Untreated perinatal mental health conditions lead to a higher risk of suicide and substance use disorders and the cost of these untreated mental health conditions are $32,000 per mother-infant pair, or $14 billion each year in the United States (MMHLA, 2023). Furthermore, untreated perinatal mental health conditions also has harmful effects on pregnancy, birth, and child outcomes (Byatt et al.,

2015) which makes counselor intervention with this population imperative. There have also been significant findings that show the importance of providers having access to cultural competency training to support the perinatal population (Helm et al., 2023).

Counselors have the unique opportunity and access to advocate throughout the ecological levels to support the perinatal population. From a microsystem perspective, to better prioritize the needs of this population, counselors should seek out perinatal training due to the significant risks associated with untreated perinatal mental health symptoms, including suicide, substance use disorders, and negative impact on pregnancy, birth, and child development. Additionally, when working with the perinatal population, counselors can use exclusive language like parental leave rather than maternity leave, or people with uteruses instead of women. Through an exosystem lens, counselors can advocate having academic programs offering a course in perinatal mental health counseling for counselors-in-training and offering student-led perinatal support groups in the community. There could also be a focus of perinatal mental health in lifespan development courses. Counselors can advocate for policy change within their community by connecting with professionals from other disciplines who interact with the perinatal population to implement better collaboration efforts and interdisciplinary training. This training could include supporting medical providers such OB-GYNs, nurses, and midwives getting connected with mental health clinicians to streamline support for their patients. When considering the macrosystem, counselors can advocate to dismantle the stigma of perinatal mental health by creating awareness through conversation, presenting at conferences, additional research, and getting involved in the local community. Through each of these ecological systems, counselors will significantly impact client welfare, identification of early risk factors, and contribute to their clients' overall mental health and physical conditions. Furthermore, counselors supporting the perinatal population will impact parent-child relationships, partner relationships, and child development by listening and validating a client’s perinatal experience relating to trauma, grief, joy, isolation, etc.

Some participants from this study noted that they wished their mental health counselor had a perinatal expertise, while others reported that the relationship with their counselor was more important in discussing their perinatal mental health. Overall, most participants stated that they wanted counseling to be a space where they could be honest about what they were experiencing during their perinatal experience without shame or judgment. Furthermore, the photovoice aspect of this study is something counselors could consider when working with perinatal clients by inviting clients to bring photos related to their experience to explore the meaning to offer another modality to unpack their experience.

Limitations and Recommendations

Limitations

There are some limitations to this study that are worth mentioning to inform further perinatal research initiatives. This study is not inclusive of other parenting experiences such as abortion, fostering, surrogacy, or adoption. Additionally, this study did not include or focus on the experience of non-gestational partners who are also at risk of experiencing mental health conditions related to pregnancy or parenting (MMHLA, 2023). The recursive nature of the study, with the themes from the first phase informing the photovoice prompts, could have contributed to the drop rate of participants between the phases. The open-ended demographic questions were used intentionally to align the participants’ language around their identity. However, there were aspects that were difficult to interpret, such as “white-ish” to refer to racial identity.

The gender diversity of this study is also limited, with most of the participants (*n* =14) identifying as cisgender, heterosexual women. Future studies could focus on capturing the perinatal experience of a non-cisgender population. Additionally, the professional affiliations of many of the participants were in healthcare or counseling. This considers both their education and socioeconomic status and means that members of the system reflect on the system. This may also be seen as a limitation considering the number of individuals who have perinatal experiences who are impacted by the lack of education and/or financial means.

Regarding the photovoice aspect of the study, some participants asked for more guidance with the instructions. The primary researcher gave examples when asked for more guidance, which may have influenced the way the participants responded or the photos they chose. The photovoice prompts were left broad with intention, however, may have created a lack of clarity in what was being asked of the participants. Some participants also shared during the focus groups that one picture could have captured all of the prompts and highlighted the overlapping themes and emotions they experienced.

Recommendations

This work can be extended in a myriad of ways and is meant to be a foundation for future research. This study focused on experiences of individual's residing and having their perinatal experience within the United States. Future research would benefit from looking at perinatal experiences from a global perspective so that cultures and communities can learn from one another. Future studies could also include more participatory action research which would involve the perinatal community and stakeholders in the research process. Future research can strive uplift the voices of people with uteruses in order to continue creating awareness and focus on solutions to support the perinatal population. Continued research can also attempt to understand the impact of other treatment modalities such as strengths-based, solution-focused, or feminist therapies on the perinatal population.

A lot of the current perinatal research limits participation to those who have given birth within the last 5 years, however, the current study found no limitations to removing that restriction as participants recalled their perinatal experience clearly. Using photovoice also seemed to bring participants back to that time, emphasizing the emotional connection to photos. Logistically, having the participants write out a narrative for each photo contributed to a streamlined and accurate analysis process. Finally, future research should focus on interdisciplinary collaboration that focuses on accessible and required perinatal mental health training and advocacy around policy change.

Conclusions

This study adds to current perinatal research by aiming to be gender-expansive, using inclusive language, and connecting photovoice to the perinatal experience. In addition, this study used an ecological systems framework. By considering these various systems, healthcare providers, policymakers, and communities can develop comprehensive approaches to support parental and perinatal health, addressing the complex interactions between individual, family, community, and societal factors.

Counselors can advocate by seeking out perinatal training to better serve this population and meet the unique needs of their clients through curiosity without judgment. By understanding the disparities in perinatal mental health, counselors can de-stigmatize and advocate for a paradigm shift in perinatal care by continuing to have conversations and create awareness. Counselors can also get involved with their community to understand current political structures impacting perinatal policy and connect with other professionals who interact with the perinatal community. Counselor educators can also encourage their academic institutions to offer courses in perinatal mental health or incorporate perinatal care within existing courses such as human development. Additionally, the Council for Accreditation of Counseling and Related Educational Programs (CACREP, 2024) includes collaboration and consultation with interprofessional teams as a role and responsibility for counselors and there is a need for counselors and other professionals to communicate in order to better support the perinatal population. For a paradigm shift to occur in perinatal mental health, intervention will need to occur at each ecological layer of the systems that impact the perinatal population.

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APPENDIX A: PHASE ONE DEMOGRAPHICS

Sociodemographic Characteristics of Participants

Variable	*n*	%
Age		
26-30	3	20
31-35	6	40
36-40	4	27
41-45	1	6
46-50	1	6
Sex Assigned at Birth		
Female	15	100
Gender Identity		
Cisgender	15	100
Sexual Orientation		
Straight/Heterosexual	12	80
Bisexual	2	13
Asexual	1	6
Racial Identity		
African American	2	13
American	1	6
Black	3	20
Caucasian	1	6
White	6	40
White-ish	1	6
White, Native	1	6
Ethnicity or Cultural Background		
African American	2	13
American	1	6
Black	2	13
European	1	6
Hispanic	1	6
Irish, Italian, German	1	6
Irish, Native	1	6
None, N/A	2	13
Non-Hispanic	1	6
Unsure	1	6
White	1	6
Relationship Status		
Married	10	67
Legally Married	1	6
Widowed	1	6

Divorced	1	6
Single	1	6
Employment Status		
Full-Time	12	80
Full-Time, Student	1	6
Part-Time, Student	2	13
Education		
Postgraduate Degree	8	53
Doctoral Degree	1	6
Bachelor’s Degree	1	6
Master’s Degree	5	33
Disability		
None	14	93
Neurodivergent	1	6
Religion or Spiritual Orientation		
Baptist	1	6
Christian	5	33
It’s Complicated	1	6
Lutheran	1	6
Muslim	1	6
Nonreligious	4	27
Spiritual	2	13
Region		
Rural (population less than 2500)	3	20
Urban (population more than 2500)	12	80
Household Income		
60-85k	1	6
86-110k	3	20
111-135k	2	13
136-160k	1	6
161-185k	1	6
186k or more	4	27
Health Insurance during Perinatal Period		
Yes	15	100
No	0	0
Number of Pregnancies		
1	6	40
2	4	27
3	2	13
4	2	13
5	0	0
6	1	6
Number of Live Births		
0	1	6
1	10	67
2	4	27

Current Perinatal Status		
Infertility Treatments	1	6
Currently Pregnant	1	6
Birth- 1 year old	2	13
1-3-year-old	5	33
3-5-year-old	2	13
5-12-year-old	4	27
13-19-year-old	3	20
Postpartum Diagnosis		
None	7	47
PMAD [a]	8	53

Note. *N* = 15. Participants were on average 35.73 years old.

[a] Postpartum Mood and Anxiety Disorder

APPENDIX B: CITI COMPLETION

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APPENDIX C: RECRUITMENT FLYER

CULTURAL EXPERIENCES OF PERINATAL CARE

Study Participants Needed

You are eligible to participate in this study if:

- You are 18 years of age or older
- You are a person with a uterus
- You have experienced any of the following: infertility, conception, pregnancy, miscarriage, childbirth, stillbirth, postpartum

Study activities include completion of the following:

1. An **informed consent** form indicating your consent to participate in this study
2. Filling out a **demographic questionnaire** (5-10 minutes)
3. Participating in a **one-on-one interview** (45-60 minutes)
4. **Taking three new photos or gathering photos** you already have that are connected to your perinatal experience and upload photos to Survey Monkey with descriptions.
5. Participating in a **focus group** (60-90 minutes) to share your photos with other participants. You will receive a $25 Amazon gift card for participating in the focus group.

If you are interested in and eligible to participate in this study, please visit **www.surveymonkey.com/r/PerinatalConsent** to learn more about the study and provide consent. Also, if you know anyone who meets the inclusion criteria listed above, please forward this to them.

If you have any questions about this study, its purpose, and/or its procedures, or encounter any difficulties with accessing the survey, please contact the Principal Investigator, Caitlin Senk, at [redacted]

APPENDIX D: CONSENT FORM

You are invited to participate in a research study conducted by Caitlin Senk, a student at Antioch University. This form describes the study to help you determine if you are comfortable participating.

CRITERIA FOR PARTICIPATION:

You are invited to participate if you meet the following criteria:

- Adults over the age of 18
- Live in the United States
- A person with a uterus who has had a perinatal experience (includes infertility, conception, pregnancy, miscarriage, childbirth, stillbirth, postpartum).

If you *do not* meet this criteria, thank you for your interest. You do not have to proceed further. You may simply close your browser window.

If you *do* meet these criteria, please continue reading the informed consent form for more information and to participate.

STUDY OVERVIEW AND PROCEDURE:

The purpose of this study is to explore the perinatal experience for people with uteruses in order to understand the barriers and facilitators to care. You will be asked to participate in a semi-structured interview (45-60 minutes) as well as an optional focus group (60-90 minutes). This includes an approximate time commitment of 95-120 minutes.

RISKS AND BENEFITS OF PARTICIPATION:

No study is completely risk-free. However, we do not anticipate you will be harmed or distressed during this study. You may stop being in the study at any time if you become uncomfortable. Occasionally, people who participate in counseling or psychology-related research find that they would like to seek out mental health care and/or support. For more information, you may want to contact the National Alliance on Mental Illness (NAMI) at 1800-950-NAMI (6263).

You should also be aware that there is a small possibility that unauthorized parties could view responses because it is an online survey (e.g. computer hackers because your responses are being entered and stored on a web server).

In terms of benefits, there are no immediate benefits to you from your participation. However, we may learn more about perinatal awareness.

DATA PRIVACY:

IP address collection is turned off, and your name or contact information will not be requested except for the purposes of scheduling interviews and consent. Aggregate data will be shared upon conclusion of the study.

YOUR RIGHTS AS A PARTICIPANT:
Your participation in this study is voluntary. You can decide not to be in the study at any time and simply close the browser window. Only completed surveys will be utilized for data analysis. In addition, it is important for you to know that your decision to participate or not to participate will not affect your relations with Antioch University.

CONTACT INFORMATION:
This study has been approved by the Antioch University Institutional Review Board (IRB). If you have ethical concerns about this study or your treatment as a participant, you may contact the IRB chair (Melissa Kennedy), the faculty advisor, or the researcher.

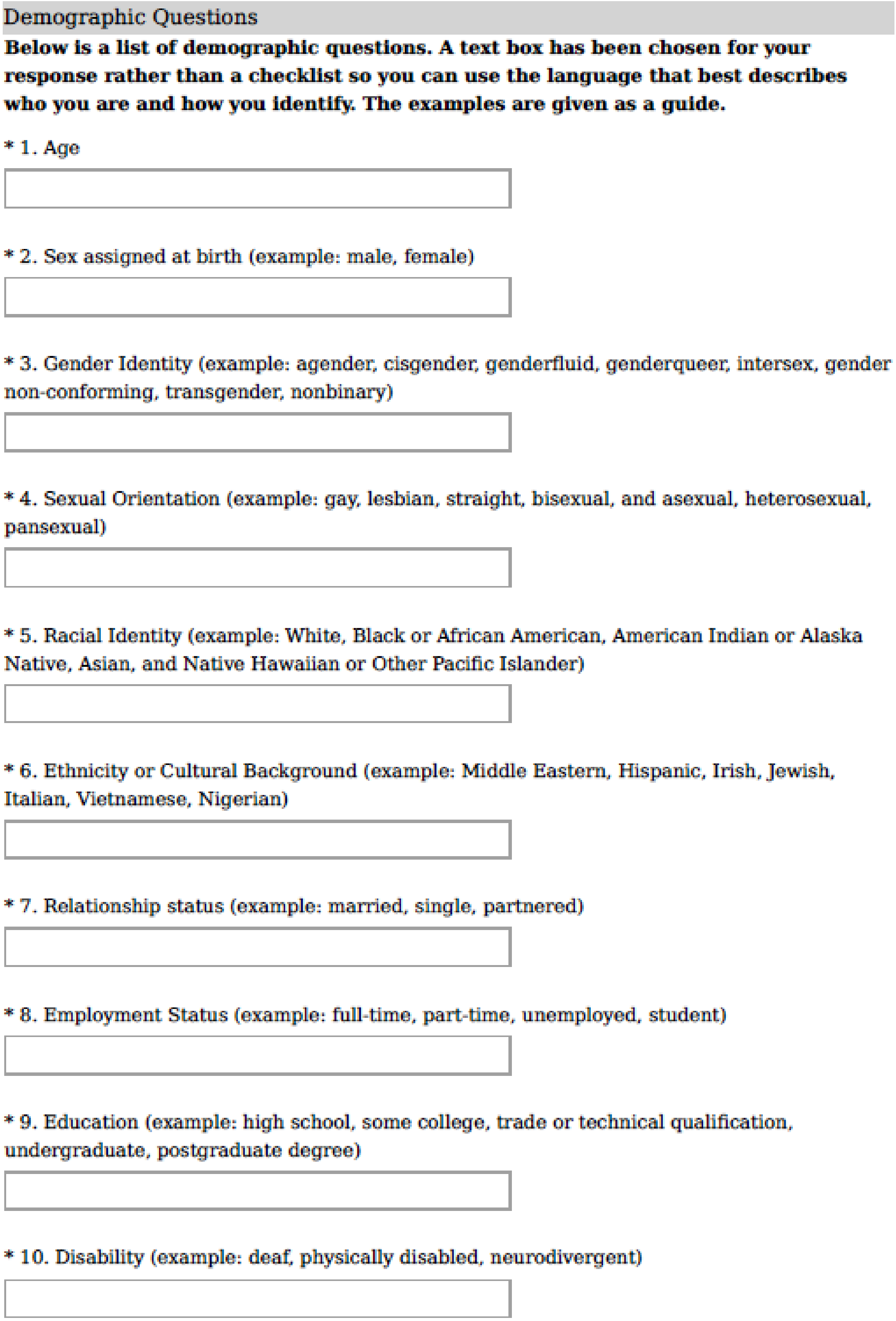
Faculty Advisor: Dr. Katherine Fort
Researcher: Caitlin Senk

If you have questions about or do not understand something in this form, please contact the primary researcher for additional information. Do not complete this form unless the researcher has answered your questions and you decide that you want to be part of this study.

CONSENT TO PARTICIPATION:
By clicking “next,” you agree to the following statements:

- I have read this form and have been able to ask questions about this study.
- I have not given up my rights as a research participant.
- I agree to have interviews recorded (audio only).
- I fit the criteria to participate in this study.
- I voluntarily agree to be in this study.

APPENDIX E: DEMOGRAPHIC SURVEY AND INTERVIEW SCHEDULING



Demographic Questions

Below is a list of demographic questions. A text box has been chosen for your response rather than a checklist so you can use the language that best describes who you are and how you identify. The examples are given as a guide.

* 1. Age

* 2. Sex assigned at birth (example: male, female)

* 3. Gender Identity (example: agender, cisgender, genderfluid, genderqueer, intersex, gender non-conforming, transgender, nonbinary)

* 4. Sexual Orientation (example: gay, lesbian, straight, bisexual, and asexual, heterosexual, pansexual)

* 5. Racial Identity (example: White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander)

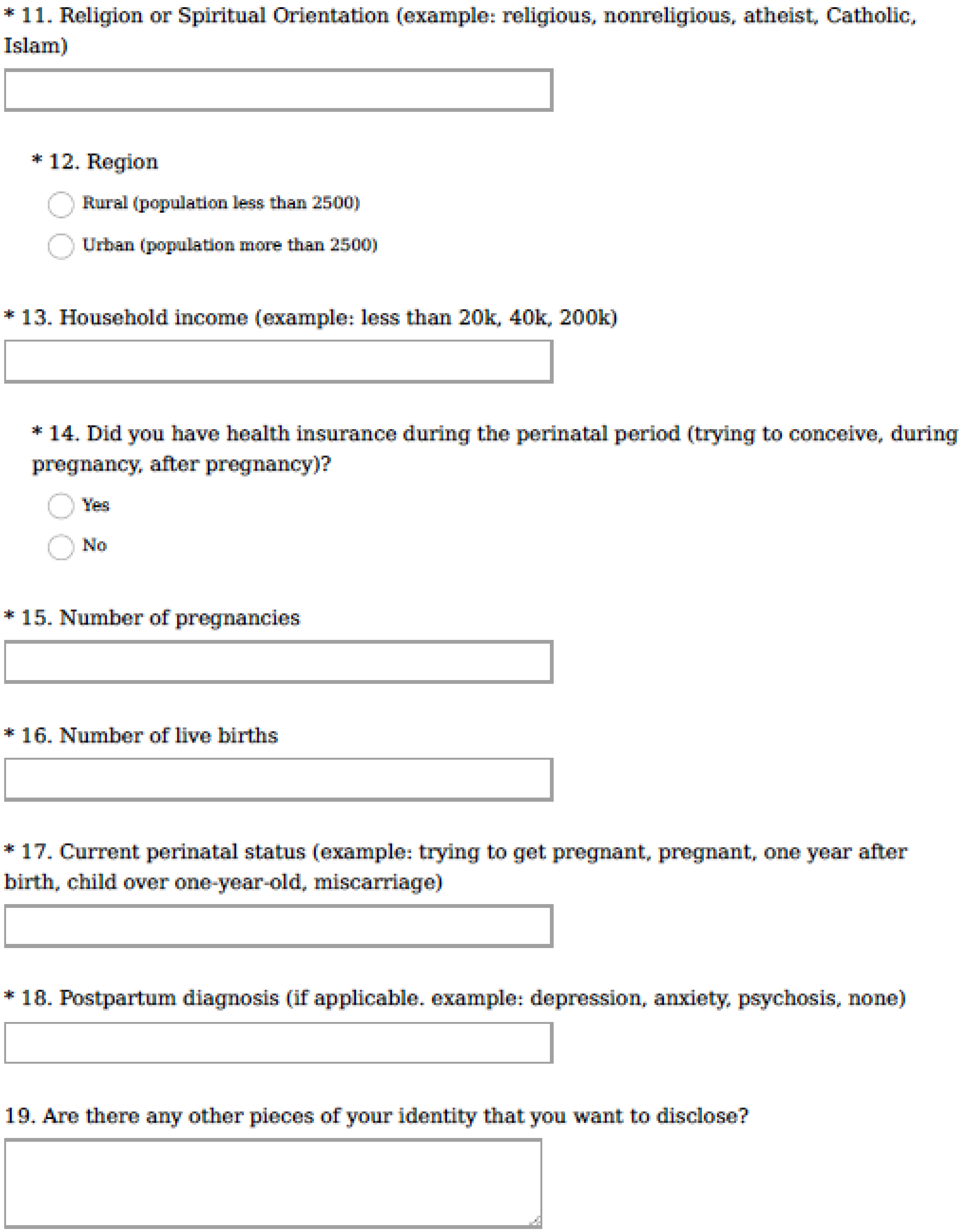
* 6. Ethnicity or Cultural Background (example: Middle Eastern, Hispanic, Irish, Jewish, Italian, Vietnamese, Nigerian)

* 7. Relationship status (example: married, single, partnered)

* 8. Employment Status (example: full-time, part-time, unemployed, student)

* 9. Education (example: high school, some college, trade or technical qualification, undergraduate, postgraduate degree)

* 10. Disability (example: deaf, physically disabled, neurodivergent)



* 11. Religion or Spiritual Orientation (example: religious, nonreligious, atheist, Catholic, Islam)

* 12. Region

○ Rural (population less than 2500)

○ Urban (population more than 2500)

* 13. Household income (example: less than 20k, 40k, 200k)

* 14. Did you have health insurance during the perinatal period (trying to conceive, during pregnancy, after pregnancy)?

○ Yes

○ No

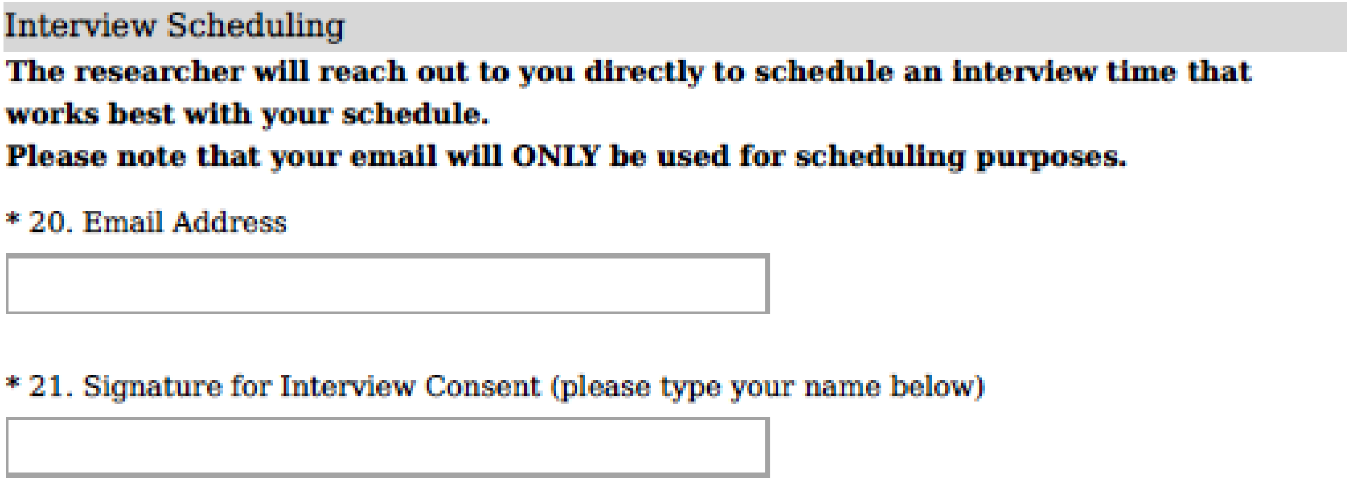
* 15. Number of pregnancies

* 16. Number of live births

* 17. Current perinatal status (example: trying to get pregnant, pregnant, one year after birth, child over one-year-old, miscarriage)

* 18. Postpartum diagnosis (if applicable. example: depression, anxiety, psychosis, none)

19. Are there any other pieces of your identity that you want to disclose?

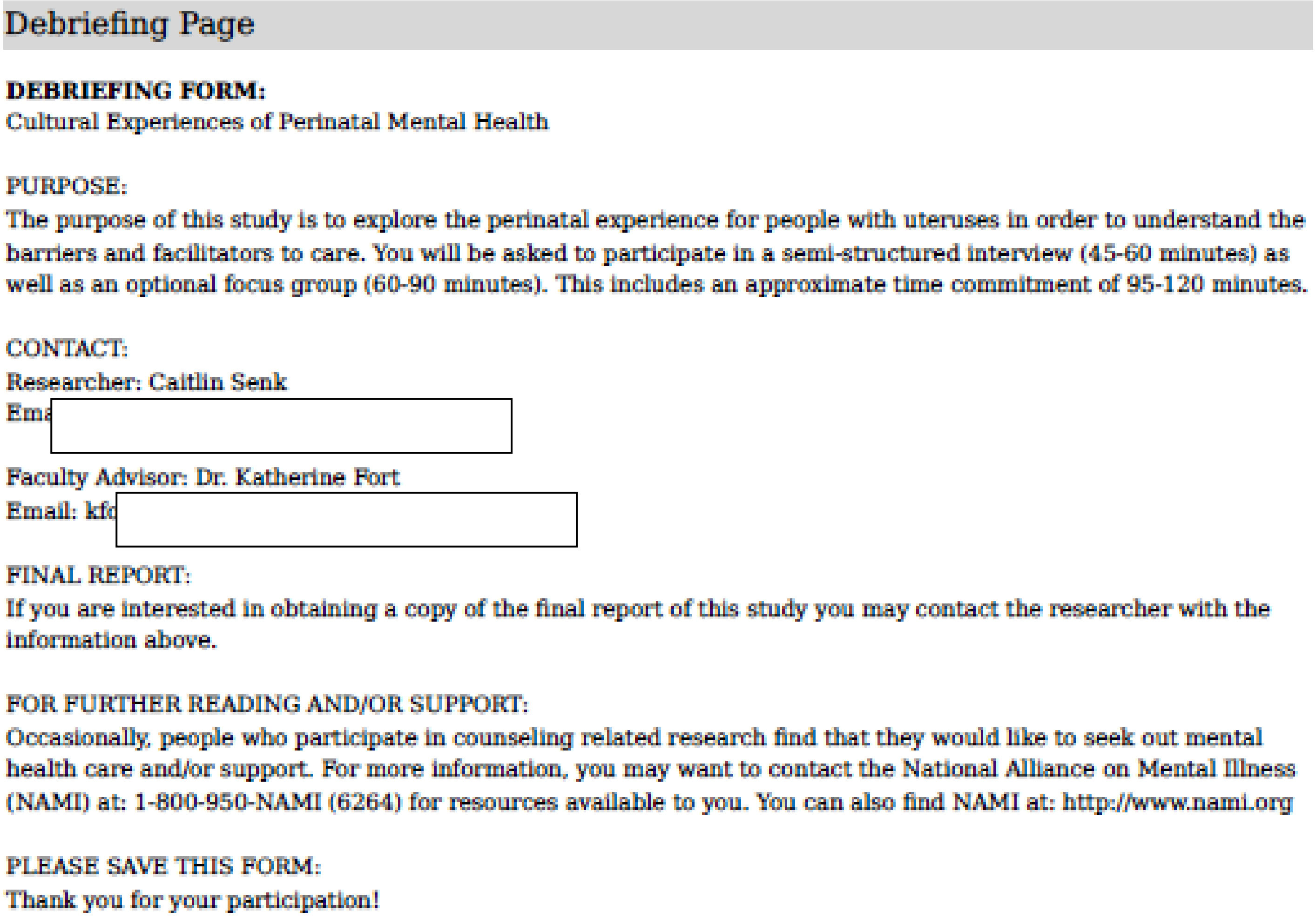


Interview Scheduling

The researcher will reach out to you directly to schedule an interview time that works best with your schedule.
Please note that your email will ONLY be used for scheduling purposes.

* 20. Email Address

* 21. Signature for Interview Consent (please type your name below)



Debriefing Page

DEBRIEFING FORM:
Cultural Experiences of Perinatal Mental Health

PURPOSE:
The purpose of this study is to explore the perinatal experience for people with uteruses in order to understand the barriers and facilitators to care. You will be asked to participate in a semi-structured interview (45-60 minutes) as well as an optional focus group (60-90 minutes). This includes an approximate time commitment of 95-120 minutes.

CONTACT:
Researcher: Caitlin Senk
Ema[redacted]

Faculty Advisor: Dr. Katherine Fort
Email: [redacted]

FINAL REPORT:
If you are interested in obtaining a copy of the final report of this study you may contact the researcher with the information above.

FOR FURTHER READING AND/OR SUPPORT:
Occasionally, people who participate in counseling related research find that they would like to seek out mental health care and/or support. For more information, you may want to contact the National Alliance on Mental Illness (NAMI) at: 1-800-950-NAMI (6264) for resources available to you. You can also find NAMI at: http://www.nami.org

PLEASE SAVE THIS FORM:
Thank you for your participation!