

Pregnancy with Fibromyalgia: A Thematic Analysis of Social Support

by

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To the people who have ever had someone tell you what you can and can't do with your body.
You are capable of anything you want.

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Chapter One: Introduction

As the number of individuals with disabilities continues to rise, so too does the number of individuals with disabilities in need of reproductive care (CDC, 2022b; Zablotsky et al., 2019). In the United States, over 3.5 million registered births occurred in 2021 (Osterman et al., 2023), and as such, 3.5 million individuals needed reproductive-related support, guidance, and medical care. Reproductive health broadly includes the “physical, mental, and social well-being...relating to the reproductive systems and its functions and processes” (WHO, 2023). The most common areas met by this definition include (1) sex and sexual health including education and satisfaction, (2) prevention and detection of gender-based violence, (3) contraceptive care, (4) pregnancy and childbirth, (5) abortion care, (6) infertility care, (7) care related to reproductive and sexually transmitted diseases (STIs), including HIV, and (8) prevention and detection of reproductive cancers (CDC, 2022c; Starrs et al., 2018; WHO, 2023). How comprehensive and supportive each area is for individuals, is not always equitable, particularly for Black disabled individuals.

Much of the current research on reproductive and pregnancy experiences for people with disabilities has examined those with physical or apparent disability types. With researchers utilizing different definitions of a ‘physical disability,’ literature most prominently includes individuals who are blind, d/Deaf or hard of hearing, have spina bifida, and/or have spinal cord injury. For individuals with these disability types, research has shown that they often receive incomplete information related to contraceptives (Horner-Johnson et al., 2022); are less likely to receive proper prenatal care, and are more likely to have adverse pregnancy outcomes (Mitria et al., 2015); and tend to experience negative reactions from strangers, family, and friends regarding their pregnancy (Iezzoni et al., 2015; Powell et al., 2017). Some examination has occurred for individuals with more non-apparent disabilities such as schizophrenia (Brown et al., 2019), but much remains unknown for the social support received for those with other disability categories that are not always apparent.

Fibromyalgia is one such non-apparent disability category that has received minimal attention in reproductive research. Often referred to as fibromyalgia syndrome (FMS), it is a chronic disorder often characterized by widespread pain and often presents co-occurring with other diagnoses including migraines, irritable bowel syndrome, depression, and pelvic pain (Hauser et al., 2019). It is most observed in women over men, with symptoms most likely to occur in those of reproductive age (Ostensen et al., 1997; Yunus, 2001). Fibromyalgia has historically and is currently considered a medical controversy based on confusion about the origin and breadth of symptoms one can experience (Bernstein, 2016; Cohen et al., 2017). Regardless, research has confirmed the necessity for social support for this disability population in various contexts and across cultures (Cooper & Gilbert, 2017; Granero-Molina et al., 2016; Lynch-Jordan et al., 2015) and the increased intersection of this disability with pregnancy (Magtanong et al., 2019).

In addition to disability status, race and ethnicity are salient intersecting identities relevant to reproductive experiences. The history of reproductive access for Black and African American individuals with disabilities is filled with oppression, reduced access, and coerced services (Guthrie, 2004; Ross et al., 2017). This has resulted in limited reproductive knowledge and lower successful birth outcomes across many race and ethnicity categories (Nguyen et al., 2018). The intersection of race and disability in reproductive spaces has received acknowledgment in recent literature and advocacy work but remained limited in its scientific depth.

The present study aims to fill in the gap in the literature by examining the role of social support for diverse individuals with fibromyalgia during pregnancy. Chronic health conditions, including fibromyalgia, often make pregnancy and other reproductive endeavors more challenging (Hassan et al., 2022). Those with chronic health condition(s) seeking pregnancy hold specific consideration from the American College of Obstetrics and Gynecology (2019), which notes pregnancy can impose changes on the body that can “exacerbate underlying or preexisting conditions.” Additionally, some essential

medications utilized to manage chronic disease symptoms are unsafe for pregnancy, requiring careful review and attention (Sachdeva et al., 2009). For fibromyalgia specifically, evidence highlights that pregnancy often increases symptoms of pain, depression, and anxiety, which can directly impact the baby (Zioni et al., 2011). Simultaneously, Black individuals are less likely to receive quality pregnancy and birth care from healthcare providers (Berk et al., 2024). With these considerations in mind, few researchers have sought to hear the voices of this intersectional population and the role their diagnosis and social support have on their pregnancy experience.

Historical Note

The disabled population has faced a long history of reduced reproductive rights, many of which continue today (Darney et al., 2017; Horner-Johnson et al., 2022; Kimport, 2022; O'Connor-Terry & Harris, 2021; Tarasoff, 2017). Barriers span from macro-level variables, such as state- and national-level legislation such as *Dobbs v. Jackson* (2022) affecting medical accessibility; to micro-level barriers such as social support from family and friends on reproduction-based behavior. Some possible outcomes for disabled people related to these barriers include going through an unintended and undesired pregnancy (Kimport, 2022), an individual with a disability believing they are simply infertile (O'Connor-Terry & Harris, 2021), and having birthing experiences that are not desired or are to the benefit of the provider rather than the birthing person (Darney et al., 2017; Smeltzer, 2007). These challenges are not isolated to just individuals with disabilities; a disability identity can be intersected by several other identities such as race (Horner-Johnson et al., 2021) and gender (Riggs et al., 2020). These intersections have their own unique historical experiences related to reproductive care in isolation (Hassan et al., 2023). This study aims to highlight the uniqueness of each participant while recognizing the limitation of research being able to fully capture each person's unique, historical, and intersecting identities.

Defining Social Support

Social support is a varied concept that looks different for every individual. Williams and colleagues (2005) worked to synthesize a definition of social support that included the various elements mentioned by diverse researchers. With the theoretical underpinnings of this study in mind, social support is defined as “short-term or enduring” social relationships that provide conditions such as “reciprocity, accessibility, and reliability” (p. 949). The resources provided by social support may include emotional, intimate, cognitive, material, skill, labor, or time. The source of the support will vary and may include individuals from a social network, family members, friends, neighbors, religious institutions, colleagues, caregivers, employers, or support groups (APA, 2023). Who and what is considered socially supportive will ultimately be determined by the participants in this study.

Defining Individuals Who Have Experienced Pregnancy

Throughout the existing literature, few articles directly address the relevance of female reproductive areas for other gender-identifying populations. Transgender and gender diverse individuals assigned female at birth (TGD AFAB), for example, is a group of individuals who have historically experienced mistreatment and discrimination in healthcare settings, including reproductive-related care (Moseson et al., 2020; Safer et al., 2016; Smith et al., 2018). Intentionality has been made throughout this study to combat the erasure of this population in reproductive research by using ‘individuals who have experienced pregnancy.’ Doing so helps uplift the principles of “safety, dignity, and respect” for the other gender-identifying populations who may also be impacted by this research (Coleman et al., 2022). More detail is provided in the methodology chapter (Chapter 3) on how gender identity and pregnancy experience are discussed and how it relates to the sample of this study.

Defining Pregnancy-Related Care

Reproductive care is broad in its elements, ranging from general wellness and STI and cancer screenings to supporting pregnancy and childbirth (WHO, 2023). The definitions of what pregnancy is

and when it occurs also remain up for debate. The American College of Obstetricians and Gynecologists (ACOG) defines pregnancy differently than the scientific community and federal policy (Gold, 2005).

ACOG notes pregnancy begins when a fertilized egg has implanted into the uterus, while some state laws say it begins at fertilization or conception. Pregnancy is also closely tied to contraceptives, a method of either increasing or decreasing chances of pregnancy. Often, the discussion of family planning and contraceptives is considered part of prenatal or pre-pregnancy care, along with the discussion of risk reduction and care for the pregnant person and fetus (Waggoner, 2017). With the depth of interconnection of many reproductive care topics, a singular definition of 'pregnancy-related care' is impossible. Rather, the focus will be on care related to any decision-making to becoming pregnant, and care received during the duration of an individual's pregnancy.

Theoretical Frameworks of Interest

All research must be grounded in theory. It turns research into literature about "social life that holds transferable application to other settings, context, populations, and possibly time periods" (Saldaña & Omasta, 2018, p. 257). Disability Justice, reproductive justice, and the International Classification of Functioning (ICF) theories contribute greatly to the intent and methodology of this study.

Disability Justice

In 2005, several disabled queer activists of color, including Mia Mingus and Patty Bernes, came together to discuss creating a "second wave" of disability rights, which is largely referred to now as the Disability Justice framework (Sins Invalid, 2020). The movement was born out of a collective struggle related to the current disability rights movement's limitations that often left many groups of disabled individuals out of the conversation, particularly "disabled people of color, disabled immigrants, queer individuals with disabilities, trans/nonbinary individuals with disabilities, people with disabilities who are homeless, people with disabilities who are incarcerated, people with disabilities who have had their

ancestral lands stolen,” etc. (Sins Invalid, 2020). At the time of its conception, many disability rights movements were predominantly being led, and focused on, white disabled individuals, and viewed disability as a sole identity with no intersections. Additionally, these movements often centered on individuals with apparent and/or mobility impairments; ignoring those with less apparent disability categories. As such, the initial conceptualization of the Disability Justice framework emphasized the following necessary beliefs:

- “all bodies are unique and essential.
- All bodies have strengths and needs that must be met.
- We are powerful, not despite the complexities of our bodies, but because of them.
- All bodies are confined by ability, race, gender, sexuality, class, nation-state, religion, and more, and we cannot separate them” (Sins Invalid, 2020).

Development of this theory continued for several years, with the foundational principles of Disability Justice published in 2016. These principles were presented as visionary pieces necessary for future disability movement actions; a movement “towards a world in which every body and mind is known as beautiful” (Sins Invalid, 2016). Principles of Disability Justice include:

Intersectionality. Recognizing that every person has numerous identities that interact in unique ways. Each of these identities holds their privileges and sources of oppression.

Leadership of those most impacted. We need to be led by individuals who know and are familiar with systematic and capitalistic ableism.

Anti-capitalistic politics. We do not conform to the capitalistic norms of productivity and labor. We recognize that these capitalistic norms are rooted in ableism, white supremacy, and gender normativity.

Cross-movement solidarity. We work with and support other social justice movements.

Recognizing Wholeness. We value people as a whole; each person has their own life experiences and history that should be considered.

Sustainability. We work to sustain ourselves through pacing to ensure we can continue long-term.

Commitment to cross-disability solidarity. Value is placed on every community member.

Interdependence. We understand that interdependence in our communities.

Collective access. Flexibility and creativity are provided when engaging with each other. We acknowledge that every individual needs access in different ways and we will support each other in finding what that means.

Collective liberation. “How do we move together as people with mixed abilities, multiracial, multi-gendered, mixed class, across the orientation spectrum—where no body/mind is left behind?” (Sins Invalid, 2016).

Disability Justice has been seen in many fields of study, including, but not limited to: nursing (Engelman et al., 2019); art education (Kiefer-Boyd et al., 2018); social work (Berridge et al., 2022; Eiler & D’Angelo, 2020); and drama therapy (Sayre, 2022). Each area holds specific consideration for its contextual use, but shows variability in how Disability Justice can be implemented and practiced.

Reproductive Justice

The work of reproductive justice was going on long before there was a name for it. In 1994, 12 Black women met at a reproductive conference in Chicago, identifying the challenges women of color were facing around reproduction and parenting, and first coined the term ‘reproductive justice’ to describe the work they wanted to do (Ross et al., 2017). Simultaneously, 16 women of color formed the national group of SisterSong in 1997; an organization working to “strengthen and amplify the collective voices of indigenous women and women of color to achieve reproductive justice by eradicating reproductive oppression and securing human rights” (SisterSong, 2023). As these two groups converged,

supported each other, and shared conversations and experiences related to reproductive equity, the theoretical pieces of reproductive justice came together.

As it stands now, reproductive justice contains several key criteria, all of which focus on organizing resistance and building movement using “global human rights standards” (Ross et al., 2017, p. 14, 19-20). These criteria are reproductive justice:

- Is intersectional in nature;
- Connects the local to the global;
- Is based on human rights framework;
- Links the individual and community;
- Addresses government and corporate responsibility;
- Fights all forms of population control;
- Commits to leadership development and results in power shifts;
- Centers marginalized communities;
- Understands political components;
- Is intersectional in theory, strategy, and practice; and
- Applies to everyone.

Reproductive justice as a framework is heavily related to community action work, although some examples highlight its potential in research and academic settings. Examples of such highlight the complexity and applicability of this theoretical framework in many areas of reproduction and parenting, particularly for diverse and marginalized individuals. Specific examples of research on reproductive justice include studies on long-acting reversible contraception (Moniz et al., 2017); examination of contraceptive use specifically for women with intellectual and developmental disabilities (Hillard, 2018); research on how black women explore and make decisions on motherhood (Leath et al., 2022); and

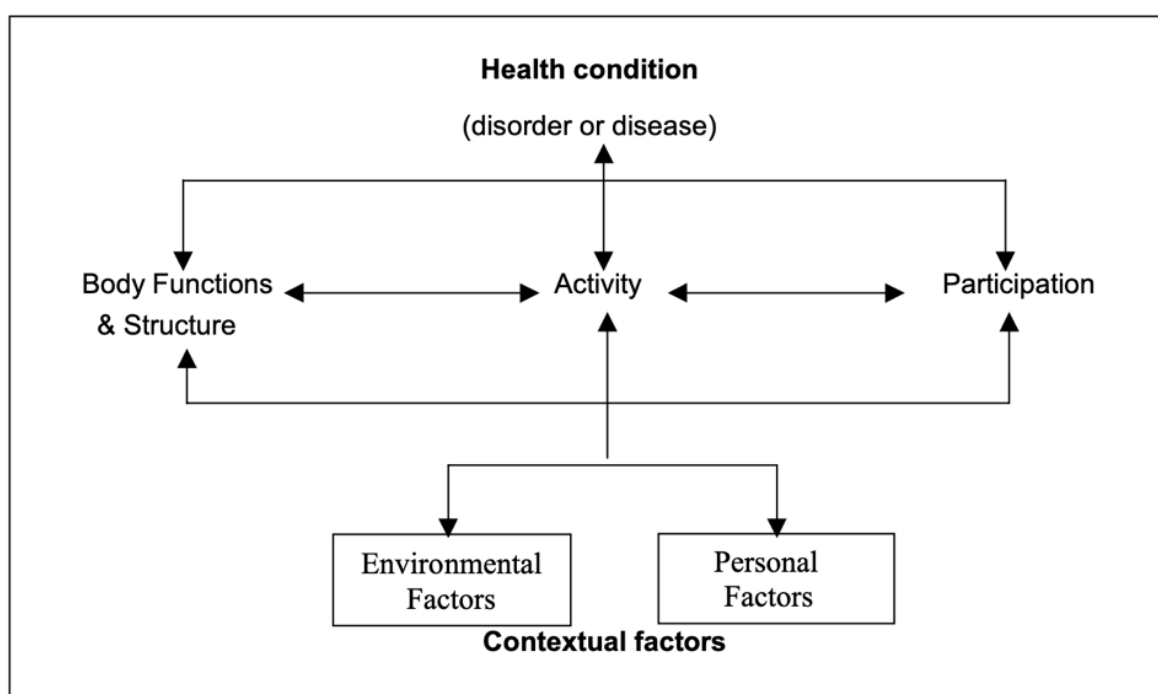
studies conducted within the context of immigration enforcement and family separation (Fleming et al., 2019).

Disability Conceptualization

To conceptualize individuals with fibromyalgia, the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) model is used. The ICF conceptualizes the disability experience using four categories: (1) body function and structures, (2) activities and participation, (3) environmental factors, and (4) personal factors (WHO, 2002). Each of these areas holds its significance and variability for each disabled individual. Body functions and structures include experiences of bodily function and related structural components. Activities and participation entail the execution and involvement in a life situation (WHO, 2002). These concepts vary widely and can be applied to several life situations including, but not limited to, "academic pursuits, employment, recreation, workshop, political expression, and volunteering" (Chan et al., 2009, p. 34). The third component, environmental factors, are those external factors that impact individuals and their lives. These can include a breadth of variables including the attitudes of others, technology access, policies, and/or relationships with others; variables that have been regarded as highly influential to the experience of disability (Chan et al., 2009). The final component of personal factors embodies characteristics of the person: their gender, age, education, health condition, past experience(s), personality, etc.

Within the field of rehabilitation psychology, the ICF model is highly utilized and recognized as an appropriate alternative to previous, less inclusive models of disability. It is unique in its inclusion of environmental and personal factors, and how those "interact with functioning and activity to affect community participation, health status, and ultimately, the quality of life for individuals with disabilities" (Chan et al., 2009, p. 47). Individuals with chronic illness(es) themselves have been found to rate the ICF model higher compared to other models of disability (Perenboom et al., 2012). In addition, the ICF

framework was found to have higher validity and explained variance for individuals in that study. The ICF model has been utilized to not only conceptualize individuals in their current state but to also assess longitudinal changes in chronic illnesses (McDoughall et al., 2012). Further, the ICF has been validated by fibromyalgia patients themselves (Hieblinger et al., 2009). In this study, the ICF model will be used to recognize the contextual factors relevant to individuals with fibromyalgia, specifically social support. The model also serves as a reminder that body functions and structures (i.e., the condition), as well as personal factors of each participant, influence the pregnancy experience; each participant's experience is entirely their own.



Statement of Positionality

As highlighted by Scharp & Thomas (2019), to effectively engage in social science research, we must engage in reflection about our own identities as they may relate to our interpretation of findings. The researcher of this dissertation identifies as a cis-gender, White woman with a chronic health condition. The researcher has experienced barriers and facilitators to reproductive healthcare and has worked directly with pregnant/parenting individuals with various chronic disabilities, both of which

sparked interest in this topic. The researcher acknowledges that their positionality has influenced this project and topic to an extent. Collaboration with dissertation committee members and other professionals in the field will be utilized to avoid bias throughout.

Statement of Purpose

The purpose of this qualitative study is to contribute to the literature on reproductive experiences and barriers for diverse individuals with disabilities. While much has been examined in this area for individuals with apparent disabilities, less is known about the experience of pregnant individuals with non-apparent diagnoses, fibromyalgia included. Additionally, we know the intersection of race and disability status is salient and should be considered when examining experiences. This study will seek to gain an understanding of this under-researched population and identify the key social influences on their pregnancy experience. The following research questions will be examined in this study:

Research Question 1

How do participants describe how their fibromyalgia impacts their pregnancy experience?

Research Question 2

How do participants describe the ways in which social influences, including healthcare provider(s), family, friends, peers, strangers, and others, impact their pregnancy experiences with fibromyalgia?

Research Question 3

How do participants describe the ways in which social influences, including healthcare provider(s), family, friends, peers, strangers, and others, could improve upon how they support pregnancy experiences with fibromyalgia?

Chapter 2: Literature Review

It is estimated that 61 million Americans have a disability (Courtney-Long et al., 2015), 10.6% of whom are of childbearing age, 18-49 (Kraus et al., 2018). With increased medical advances and legal protection for individuals with disabilities, in combination with a decrease in stigmatization of disability, the number of people with reported disabilities in the United States continues to rise. Despite this promising data, negative narratives and poor reproductive health experiences for individuals with disabilities persist. Pregnant people face even higher rates of negative attitudes, such as concern and avoidance from strangers and family members (Iezzoni et al., 2015). They also experience a higher risk of poor pregnancy and birth experiences in general (Deierlein et al., 2021; Horner-Johnson et al., 2019; Kone et al., 2022; Iezzoni et al., 2013; Schiff et al., 2021; Walsh-Gallagher et al., 2012). When deciding to become a parent, an individual with a disability is forced to consider these factors in addition to thinking about general feasibility, cost, accessibility, and other personal factors (LaPierre et al., 2017).

Fibromyalgia is one such disability category that has received increased attention in recent decades but continues to reflect poor pregnancy experiences. Fibromyalgia is categorized as a disease of the central nervous system causing widespread and varied, chronic symptoms, the most common of which include musculoskeletal pain in certain locations, significant fatigue, irritable bowel syndrome, and headaches (Inanici & Yunus, 2004; Yunus, 2001). These symptoms predominantly affect women more than men, particularly in childbearing ages, making it a relevant diagnosis of concern for reproductive care providers. Research has begun to explore how this complex diagnosis impacts the pregnancy experience, with some finding it to significantly increase symptoms and worsen pregnancy outcomes (Genc et al., 2017) and others finding no impact at all (Kone et al., 2022).

Regardless of disability type or status, disabled people historically and currently face healthcare ableism, especially when seeking reproductive support. Ableism, or the preference for and normality of able-bodied individuals, has been highlighted in areas of contraceptive access (Horner-Johnson et al.,

2022); abortion care (Horner-Johnson et al., 2017; Kimport, 2022); prenatal services (Tarasoff, 2017); and pregnancy and birth (Darney et al., 2017; Walsh-Gallagher et al., 2013). In other words, “non-disabled women dominate the discourse of...pregnancy, childbirth, and motherhood” (Tarasoff, 2015, p. 90). Ableism stems from many important pieces of disability and reproductive history including forced sterilization and the eugenics movement (Powell, 2022). While the United States has come a long way, ableist experiences continue to be reported, often coming from healthcare practitioners themselves, many of whom have limited knowledge of disabilities and how they impact the reproductive needs of their patients (Iezzoni, et al., 2021; Taouk et al., 2018; Walsh-Gallagher et al., 2013). This widespread ableism leads to lower rates of satisfaction with reproductive services compared to individuals without disabilities (Brown et al., 2018; Horner-Johnson, 2018; Horner-Johnson et al., 2022).

Ableist beliefs extend beyond the healthcare setting into social contexts for individuals with disabilities. Pregnant women with disabilities have been questioned regarding their ability to become pregnant and parent by both family members (Powell et al., 2017) and strangers (Iezzoni et al., 2015). Social support, whether it be from family, friends, or peers, is regarded as a highly influential factor in individuals with disabilities’ health and functioning (McLaughlin et al., 2012). For those seeking reproductive care, evidence shows social support impacts general access and individuals’ beliefs about the care they should receive (Kimport, 2022).

Pregnant individuals with disabilities may, and often do, hold intersecting identities that impact their reproductive experiences. Intersectionality refers to how identities such as “gender, race, ethnicity, sexual orientation, gender identity, disability, class, and other forms of discrimination “intersect” to create unique dynamics and effects” (CIJ, 2023). Reproductive history for various marginalized identities is vast and varied (Maroto et al., 2019). There is evidence and recognition of the compound effects of numerous identities both inside and outside of reproductive healthcare settings, including disability and race (Simons et al., 2021), disability and gender (Brown, 2014; Maroto et al., 2019), disability and SES

(Doyle et al., 2020), and other identities. This review of literature will highlight some of the unique historical elements or marginalized identities as they pertain to reproductive access and experiences.

Note about the Literature

The terms woman/women are used throughout this chapter. Much of the research reviewed comes from fields with medical model perspectives that view gender and sex synonymously and do not recognize or discuss diversity within the category of 'women.' Very few research articles specify what and how they are categorizing 'women' and who is or is not included. The present researcher acknowledges that this category and assumption is not inclusive of all the individuals impacted by this topic. The research discussed in other chapters highlights an effort to use more inclusive language and inclusion criteria to ensure that the voices of all individuals receiving reproductive health care are heard.

Second, a few articles reviewed within this section will come from the rehabilitation field. Minimal research has been conducted around disability, pregnancy, and/or reproductive access in rehabilitation counseling. Rather, interdisciplinary fields' research will be reviewed to provide insight into the reproductive experience of diverse individuals with disabilities.

Historical Overview of Fibromyalgia

Fibromyalgia has a unique history of varied medical recognition over the last century, with continued controversy over its validity as a diagnosis. The 20th century brought various definitions to what patients were experiencing. The term 'fibrositis' arrived in 1904 by a British neurologist who recognized the inflammation in fibrous tissues leads to spontaneous pain and sensitivity (Inanici & Yunus, 2004). In the decades following, physicians of various specialties continued their exploration of this mysterious diagnosis, identifying matters of pain spots without obvious inflammation. By the 1950s, the frequency of patients with these symptoms continued and medical providers recognized that "there can no longer be any doubt concerning the existence of such a condition" (p. 372). However, debate

continued over the origin of the symptoms, with some arguing it is a mind/brain disease, and others claiming it is a disease of the musculoskeletal system (Bernstein, 2016).

As of 2023, fibromyalgia is a recognized diagnosis by the International Classification of Diseases (ICD-10) (WHO, 2019). However, the criteria of fibromyalgia have frequently been regarded as arbitrary and inaccurate according to physicians (Wolfe et al., 2019). For example, many individuals don't meet the severity criteria set by the ICD; symptom severity varies greatly among patients day-to-day so any improvement could lead them to no longer satisfy criteria. Additionally, because of the complexity of the diagnosis, many physicians have general frustration about fibromyalgia consultation. Homma and colleagues (2016) found that physicians who have preconceived beliefs about the psychological factors contributing to fibromyalgia had poorer doctor-patient relationships compared to those who believe it is connected uncontrollable external factors or biomedical risk factors. Many physicians also reported being resistant to accepting fibromyalgia patients at all because of the difficulty in managing its symptoms. For patients, this diagnosis can support the validation of their experiences; without it, patients may not receive the supportive therapies and tools necessary to manage the complexity of the diagnosis (Winslow et al., 2023).

In addition to fibromyalgia being more commonly experienced by women than men, it is also more likely to be diagnosed in White individuals. Barker (2009) emphasizes that fibromyalgia is deeply connected to gender, race, and class. For example, different racial and cultural groups have differing dispositions towards stress, suffering, and pain that may directly impact the likelihood of seeking a diagnosis, receiving a diagnosis, and accessing services. This hypothesis was confirmed by Pryma (2017) who interviewed women of color who identified as having fibromyalgia. All the women interviewed described at least one instance where their pain was minimized or doubted by medical providers. Personally, many of them also struggled with the legitimacy of having invisible pain. Many individuals

with marginalized identities will likely not only face challenges in receiving a diagnosis, but also must manage additional barriers such as insurance access, financial abilities, and citizenship.

Historical Overview of Reproductive Rights for Individuals with Disabilities

The history of reproductive access for individuals with disabilities is filled with oppression, barriers, and control. In the nineteenth and twentieth centuries, disabled individuals primarily resided at home with family members, having limited access to marriage, reproduction, intimacy, or sexuality (Powell, 2022). At the same time in history, eugenics, or the belief that people in power can control the future of society by restricting the reproduction of less favorable groups of individuals, was widespread. The population most targeted by this effort were those who were 'feeble-minded,' or what is now referred to as someone with a mental health condition (Cohen, 2016). This practice of forced sterilization was deemed legal following the Supreme Court ruling in 1927 of *Buck v. Bell* when a woman deemed mentally disabled was to be forcibly sterilized to improve society and eliminate future generations of disabled individuals. These belief systems and government support led to over 70,000 Americans being sterilized by the 1970s, who were predominantly disabled, poor, and women of color (Cohen, 2016). By 1974, statutes on eugenics marriage laws continued to exist in 40 states across the U.S. (Powell, 2022).

Over the next several decades, increased advocacy efforts in the disability community sparked discussion and political change, most notably in 1990 when the foundational Americans with Disabilities Act (ADA) was enacted. Worldwide, the ADA was revolutionary, as it acknowledged the numerous social barriers experienced by the disability community and created laws to counteract them via several key components. First, the ADA provides a legal definition of a disability: "(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; or (c) being regarded as having such an impairment." Second, the ADA required public spaces, defined under five titles (e.g., employment, state, and local public services such as health care facilities, public accommodations, telecommunication, and miscellaneous topics) to

provide “reasonable accommodations” to individuals with disabilities to ensure they can fully and equally enjoy them.

Title II of the ADA details public service guidelines, which include locally-funded healthcare programs (private healthcare offices are governed by Title III). Within both titles, specific and relevant regulations related to healthcare exist, including it being discriminatory to deny medical services to individuals with disabilities; physicians must provide access to treatment equivalent to those without disabilities; physicians cannot screen out individuals with disabilities from their care; physicians must make modifications in policies, practices, and procedures to those with disabilities unless it would fundamentally alter the nature of the service; auxiliary aids and services must be provided including interpreting services; and architectural and communication barriers must be removed (ADA, 1990, 42 U.S. Code 12182; Grabois, 2001). Several associated enforcement entities, such as the Office of Civil Rights (OCR) and the U.S. Department of Justice (DOJ) engage in investigation of healthcare-related complaints. Based on the minimal changes that have been made to improve healthcare accessibility in the last 30 years, it is assumed that few lawsuits have risen to the point of creating change (Yee & Breslin, 2010).

Historical Notes for Racial and Ethnically Diverse Individuals with Disabilities

The history of reduced reproductive rights and eugenics practices strongly intersect with other marginalized identities such as race and ethnicity (Ross et al., 2017). The early twentieth century’s eugenic practices targeted Black women and those deemed “racially unfit” (Guthrie, 2004, p. 99). The hope through eugenics was to create a “racially superior” world that did not include Black people, Catholics, poor or low-income individuals, or those with disabilities (p. 66). Simultaneously, the United States entered a period of slavery, a time when Black women were either involuntarily sterilized or forced to reproduce (Clouse, 2020). Overarching views, lasting decades, held that racially diverse

individuals were inferior and therefore should not be allowed control over their reproduction (Ross et al., 2017).

If African American/Black women were receiving reproductive care during these decades, it often coincided with medical experimentation. Examples such as the Tuskegee Syphilis Study, coerced and/or unknown hysterectomies in teaching hospitals, and forcing sterilization to receive care, all highlight the sexual and reproductive violence experienced by Black individuals (Prather et al., 2018). Within many of these experiences, individuals were unaware of what care they were receiving due to a lack of understanding and failure to provide informed consent (Freimuth et al., 2001); having limited access to other healthcare support due to segregation or general access (Prather et al., 2018); and lacking educational resources to learn of reproduction functions and processes.

Limited exploration of reproductive history exists for those of other racial, ethnic, or cultural identities. The research that has been done, however, highlights the need for consideration of race and ethnicity in the context of reproductive care. For example, scholars have highlighted the history of colonialism and its impact on Indigenous women's access to reproductive- and female-specific chronic illness support as well as their ability to raise their children in safe environments (Liddell & Kington, 2021; Liddell & Doria, 2022). For Asian American, Native Hawaiian, and Pacific Islander (AANHPI) communities, reproductive history, needs, and experiences are largely unknown, but recent evidence highlights barriers to access, including lack of family support, unavailability of non-English language materials and care, and community stigma (Chandrasekaran et al., 2023). What results in many racially and ethnically diverse communities is limited reproductive knowledge and access (Maher et al., 2022), leading to lower successful birth outcomes (Nguyen et al., 2018).

Historical Notes for LGBTQIA+ Individuals with Disabilities

Individuals with disabilities continue to face misconceptions regarding their general sexuality. They are often assumed to be asexual, that they do not view sex as important, that they do not develop

a need for it, and/or are viewed as childlike and incapable of engaging in sexual activity (Kim, 2011; Pebdani & Tashijan, 2021). For LGBTQIA+ individuals with disabilities, these sexually oppressive beliefs and actions are compounding. For example, a survey of 17–26-year-olds with intellectual disabilities who self-identified as LGBTQ+ noted numerous barriers to finding safe sexual spaces (Simic Stanojevic et al., 2023). Many spoke about the challenge of living arrangements, several of whom lived with parents or in group homes with restrictions on free time, social gatherings, curfews, and parental supervision. Several reported resorting to “uncomfortable and risky physical and social spaces for romantic and sexual encounters” (p. 816). Additional challenges to LGBTQIA+ individuals with disabilities include legislation regulating marriage; the pressure, restriction, and reluctance of individuals to publicly self-identify; and the intersecting discrimination faced by queer individuals (Drummond & Brotman, 2014).

Related Reproductive Legislation

Two related pieces of legislation of note, *Roe v. Wade* (1973) and *Dobbs v. Jackson* (2022), provide peripheral relevance to the topic of family planning. While both cases focus on the right to have an abortion, significant implications exist for the general reproductive autonomy of all individuals. *Roe v. Wade* began in 1970 when Jane Roe (pseudo name) filed a lawsuit against Henry Wade, district attorney in Texas. Roe was a young woman who had become pregnant with her third child and had attempted an illegal abortion without success. She argued that her ability to not receive a wanted abortion directly violated the fundamental freedoms listed in the Constitution. This was the first time a comparison between reproductive decision-making and Constitutional rights was made. The case concluded on January 22, 1973, with a majority rule in favor of Roe, dismantling the criminal ban on abortion due to it being a “fundamental right” and a “personal liberty.” The Roe decision further clarified that it is a pregnant person’s decision whether to continue a pregnancy; the government cannot ban abortion for any reason. With this decision, some restrictions were made on what legal abortions would entail, particularly regarding trimester timing. A specific trimester framework was established, argued as a

medical safeguard to the mother and fetus. At the time, and to this day, abortion and the *Roe v. Wade* (1973) decision remain highly polarized (Greenhouse & Siegel, 2011).

On June 24, 2022, almost 50 years after *Roe v. Wade's* decision-making abortion a Constitutional right, it was overturned in *Dobbs v. Jackson* (2022). In 2018, Mississippi passed a law prohibiting abortions after 15 weeks of gestation. The Jackson Women's Health Organization, an abortion facility in Mississippi, challenged this law based on *Roe v. Wade's* decision for gestation timing. The court argued that the Constitution does not refer to the right to abortion. Moving forward, abortion laws and regulations are to be determined by the state on a "rational basis." This change in legislation is predicted to have rippling effects throughout the world (Kaufman et al., 2022). After six months of this ruling, 24 states have established abortion bans, with more predicted to do so. If states do not ban abortion completely, they have created extremely limited allowances, such as strict gestational timelines that are nearly impossible for most women to meet. While this legislation directly impacted abortion specifically, it is estimated to impact overall reproductive access for all, with women with marginalized identities impacted even more so. The United States often serves as an example for other countries with many adopting the *Roe v. Wade* decision decades ago (Center for Reproductive Rights, 2022). It is predicted that many countries may follow suit following the *Dobbs v. Jackson* decision, changing policies around abortion, and directly impacting individuals across the world.

Reproductive Education Access

While thorough in its rights and regulations, the ADA and other legal protection for health care do not adequately support reproductive access for individuals with disabilities. Reproductive education, or the information one receives on reproductive functioning, is often limited for individuals with disabilities (Pebdani & Tashijan, 2021). Reproductive education is frequently referred to as 'sex education' in public school settings, which has long been the place of access to information. Within the United States, decades of debate and research have revolved around sex education for disabled

students, with no comprehensive, disability- or LGBTQ-inclusive approach having been achieved (Hall et al., 2016; Tarasoff, 2021). Currently, decisions about the implementation of sex education take place at the state, district, and school board levels, and often result in limited in-class time and resources being provided. The results of a survey published in July 2022 showed that only 39 states mandate sex and HIV education within the U.S. (Guttmacher Institute, 2022). Of those 39, only 30 mandate specific requirements to be met when discussing sexual education, and only 10 require instruction to be provided in a way that is appropriate for and unbiased regarding race, sex, or ethnicity. The survey lists no information about sex or sexuality education for students with disabilities.

Reproductive and sexual education for individuals with disabilities has experienced increased attention in research, identifying a lack of satisfaction and a need for improvement. Parents, educators, and health professionals have been found to feel uncomfortable, unprepared, and unqualified to provide sex education to adolescents with disabilities (Neufeld et al., 2002). Those feelings often stem from a lack of disability knowledge, time limitations, inadequate training, and fear of negative reactions from others (Bloor et al., 2022; East & Orchard, 2014; Goli et al., 2022; Neufeld et al., 2002). As a result, disabled adolescents themselves often feel frustrated, unheard, and as if they are seen as a 'non-person' (East & Orchard, 2014). Many individuals reported getting their education from the internet or discussing it with peers instead. Meanwhile, parents report feeling unsure of what to share with their children with physical disabilities or have discussions focused exclusively on safety and abstinence. Success has been found in disability-specific considerations for reproductive-related training and education, such as group menstrual care skills training for individuals with intellectual disabilities (Altundag & Calbayram, 2016), the value of mainstream sex education for d/Deaf teens in school settings (Suter et al., 2012), and training workshops focused on building confidence in educators to support autistic youth in reproductive understanding (Curtiss & Ebata, 2016).

Healthcare Ableism Experiences for Pregnant Individuals with Disabilities

Healthcare, historically and at present, operates from a medical model of health (Chan et al., 2009). The medical model views disability as something to be cured or gotten rid of; it is a problem, impairment, or illness that should be fixed. While this model in healthcare has gradually shifted, the focus continues to be on where functionality is limited, rather than what is going well with an individual. The result of this is an inherent level of ableism in healthcare (Janz, 2019). This is present not just in healthcare professionals (Walsh-Gallagher et al., 2013), but also simply in the buildings in which they operate, such as not having height-adjustable tables or wheelchair-accessible scales (Frost et al., 2015). As highlighted by Janz (2019), this puts individuals with disabilities in a vulnerable position in medical settings. It often looks like individuals being seen as their disability only, rather than as an entire person (Walsh-Gallagher et al., 2012). Evidence also shows this to look like abuse, both physical and mental, and is discriminatory (Wudneh et al., 2022).

Comprehensive maternal, or pregnancy-related care for individuals includes care prenatally, throughout pregnancy, during birth, and post-partum (AAP, 2017). For this study, care related to the fetus/newborn will not be reviewed, as the focus is solely on the pregnant individual. A review of the four main areas of care, and current literature on the healthcare system and healthcare provider ableism associated with each, follows.

Prenatal Care & Decision Making

Prenatal care, or support and experiences before birth, involves supporting individuals in identifying pregnancy intentions, discussing contraception and fertility, identifying factors associated with high-risk pregnancy, and providing education on factors related to pregnancy (AAP, 2017). Prenatal care is recognized as one of several factors that influence birth outcomes for individuals with disabilities (Horner-Johnson et al., 2022). The American Academic of Pediatrics (2017) and the American College of Obstetricians and Gynecologists (2019) have established standards for supporting individuals through

the prepregnancy experience, which includes assessing intentions to become pregnant and conducting health screenings. Specifically, it is recommended that practitioners engage in supportive conversation that may include:

- “An evaluation of her overall health and opportunities to improve health,
- Education about the important effect that social, environmental, occupational, behavioral, and genetic factors have on pregnancy,
- Identification of factors associated with high risk of an adverse pregnancy outcome, with interventions recommended to provide a women’s risk profile before pregnancy” (AAP, 2017, p. 131).

Although these guidelines appear thorough, in practice those with disabilities rarely experience such support. Survey data between 2002-2011 suggest that women with disabilities were less likely to receive prenatal care within their first trimester and were more likely to have adverse pregnancy outcomes (i.e., low-birth-weight babies, preterm birth, and pregnancy complications) (Mitra et al., 2015). O’Connor-Terry & Harris (2021) interviewed 16 cis-gender women with physical disabilities and found that most of them were under the assumption that they were simply infertile.

The literature on pregnancy experiences suggests that practitioners are unprepared for working with women with specific disabilities. Horner-Johnson et al. (2022) found patterns in prenatal care by disability type. Specifically, individuals with intellectual and developmental disabilities (IDD) experienced greater disparities than other disabilities; they were the least likely to receive care within the first trimester and were more likely to have specific considerations around pregnancy detection and important intersecting health conditions (e.g., smoking, obesity). Those with physical disabilities were least likely to reach out for prenatal care, primarily due to concerns about accessibility. Tarasoff’s (2017) findings among 13 women with physical disabilities supported this. Most women reported their perinatal care was provided by practitioners who had minimal understanding of the disability, including a

participant reporting they were told, “We’ve never had anybody like you before” (pp. 429). Additionally, individuals encountered providers who had generally negative attitudes about disability and pregnancy, and their care was received in a location that lacked accessible spaces and tools (e.g., inaccessible examination tables; inaccessible bathrooms with handrails, chairs, or walkers).

With the variability and complexity of chronic health conditions, particularly fibromyalgia, minimal research has explored what decision-making to become pregnant looks like. However, with fibromyalgia associated with sexual impacts (Ablin et al., 2011), scholars have begun to examine what sexual dysfunction support has been provided to navigate these symptoms. Through a qualitative study by Granero-Molina and colleagues (2018), women with fibromyalgia reported healthcare providers frequently trivialize sexuality or do not include it on their professional agenda at all. Many women reported feelings of invisibility and without answers. It is recognized that preemptive pregnancy support for individuals with fibromyalgia is important, but minimal research highlights what that looks like (Mallick-Searle, 2022).

Pregnancy Experiences

Pregnancy experiences for individuals with disabilities vary widely based on diagnoses and personal factors. Compared to individuals without fibromyalgia, those with the diagnosis reported increased painful areas, fatigue, muscle weakness, headaches, pain/cramps, depression, nausea, muscle, and constipation (Genc et al., 2019). It is widely recognized that management of general fibromyalgia symptoms is vital during pregnancy to help reduce flares of symptoms. Mallick-Searle (2022) provides several recommendations for pharmaceutical and non-pharmaceutical interventions including medication management, acupuncture, nutritional support, and green light therapy. However, the availability and access of these resources for diverse individuals have yet to be acknowledged or explored. Additionally, few researchers have examined how prepared reproductive healthcare professionals are to support pregnant patients with fibromyalgia.

Birth and Birthing Care

While birth experiences vary for every woman, those with disabilities have shown patterns of poorer birth outcomes. Compared to women without disabilities, those with disabilities, including those with fibromyalgia, are more likely to experience preterm and/or cesarean deliveries (Horner-Johnson et al., 2017; Darney et al., 2017; Kone et al., 2022). While most researchers do not examine the specific circumstances of each woman, those with physical disabilities were acknowledged as presenting unique challenges during delivery which may be related to some of the risks and delivery choices. No matter the case, women with various disabilities have reported that the decision about the delivery method was made without their input and/or without consideration of other methods (Smeltzer, 2007).

Researchers have looked at the educational preparation healthcare providers receive regarding the prenatal care and delivery of women with disabilities, particularly those with physical disabilities. Before even beginning the discussion of birth, many practitioners admit that they hold stereotypical views of individuals with disabilities, having no experience working with them at all, pregnant or not (Walsh-Gallagher et al., 2013). Healthcare workers are meant to help any individual that comes into their care. If they hold stigmatizing views, the care could be compromised. Additionally, the same study found that among hospital personnel including midwives, social workers, nurses, and managers, most of them noted ambivalent attitudes around working with pregnant women with physical disabilities and that they lacked knowledge about disabilities in general (Walsh-Gallagher et al., 2013). The same results were found by Smeltzer and colleagues (2018) who concluded that most clinicians receive training for this population from hands-on experience only.

Studies that highlight the voices and experiences of those with disabilities giving birth are limited but point to the ableism present in the healthcare system and in practitioners. Through qualitative interviews with women with physical disabilities, Mitra and colleagues (2016) summarized several themes in unmet care during pregnancy and birth including clinician knowledge and attitudes, physical

accessibility of equipment, and information related to their pregnancy, birth, and postpartum care. Similarly, Hall et al. (2018) found that many individuals did not receive needed accommodations for their birth experience and felt poorly respected by staff. Many individuals report having less choice about their place of birth, pain relief options, and whether they received a cesarean section compared to women without disabilities (Redshaw et al., 2013). These experiences can be found in other countries as well; evidence shows birthing individuals with disabilities experience obstetrics violence, including stigma and discrimination, physical and verbal abuse, and general discrimination (Wudneh et al., 2022). While some experiences vary by disability type, most of the evidence points to negative experiences during childbirth.

Similarly negative literature has been highlighted for Black mothers and pregnant individuals. Recent statistics for example have found Black infants are 2.5 times more likely to experience death in the first year of life (Xu et al., 2018), and more likely to experience preterm birth and low birth weights (Martin et al., 2018). A qualitative study by Mehra and colleagues (2020) found that Black pregnant individuals felt devalued throughout their pregnancy and birth experience. Specifically, they encountered healthcare providers who made assumptions that they were low-income, single, and/or already had multiple children. This resulted in increased stress during pregnancy and birth.

Postpartum Care

Postpartum care includes the six to eight weeks after an individual gives birth, or until one's body mostly returns to pre-pregnancy status (Lopez-Gonzalez & Kopparapu, 2022). This period is known for drastic changes in hormones for many, but additional tasks of breastfeeding, vaginal or abdominal healing, and development of the infant are relevant as well. Literature highlights general trends of postpartum care for individuals with disabilities, but consideration of the individualized experience postpartum care entails is necessary.

As women with disabilities experience more adverse births, evidence shows the care following birth is increased compared to those without disabilities. A cohort study of births in California between 2000 and 2012 found women with disabilities to have longer hospital stays following vaginal and cesarean deliveries (Horner-Johnson et al., 2020). Among disability types, the ones most likely to experience longer stays were those with vision disabilities, followed by those with intellectual or developmental disabilities (IDD). Some argue that longer hospital days are necessary and beneficial for those with disabilities (Brown et al., 2022). It may be the case that they need additional support in postpartum tasks or require more healing following birth. An analysis by Brown and colleagues (2022) found individuals with disabilities are also more likely to need and receive acute, emergency room, and postpartum care for reasons including hemorrhage, infection, and abdominal pain. These experiences were high among similar populations of those with IDD or those with multiple disabilities. Individuals with physical disabilities have voiced a need for additional support in their postpartum care, find challenge in navigating parenthood while also figuring out the accessibility of their home and new responsibilities (Becker et al., 2021). Many of these studies have concluded with calls for additional support for individuals postpartum. Minimal research has examined what, if any, is helpful or has examined changes to care.

Social Support Outside of Healthcare

Social support is a highly researched and influential variable in the lives of individuals with disabilities (Chan et al., 2009; McLaughlin et al., 2012). Social support is highly individualized, including family members, friends, partner(s), and other influential people in someone's life. Social influences can determine access to reproductive services, particularly when the support is financial (Kimport, 2022). Social support can also take the form of a protective factor for pregnant individuals; those with higher social support have reported higher overall well-being (Battulga et al., 2021). The influence of social relationships is not always positive; evidence shows family members and partners can negatively

influence pregnant and postpartum women's anxiety when tension is high (Bedaso et al., 2021; Lau et al., 2010). Important social relationships for individuals with disabilities include those with family and friends, peers and strangers, partners, and doulas, with a recognition that this may not be inclusive of all the social support an individual receives.

Family and Friends

Social support is a positive construct with strong evidence of its influence on the pregnancy experience (Renbarger et al., 2021). Family members are known to play an important role in pregnancy, often serving as sources of advice, support, and birth preparedness, and also often attending prenatal and delivery appointments (Hawkins et al., 2021). A study focused on Black women found that this support from family served as a protective factor; having family support predicted psychological health, including decreased depressive symptoms, stress, and pregnancy-related anxiety. In the wake of the COVID-19 pandemic, this family support has been challenging for some pregnant individuals to receive (Wang et al., 2021). Pregnant individuals in China surveyed by Wang and colleagues (2021) who had inadequate family support had higher rates of depression, anxiety, and stress, in addition to psychological distress related to the pandemic.

Similar experiences were reported by Powell and colleagues (2017), who examined family and friend reactions to women with physical disabilities announcing their pregnancies or their interest in becoming pregnant. The attitudes and reactions were categorized into six themes, five of which were negative. For example, the women were questioned about their parenting abilities, with the added concern of genetics (e.g., "Will the baby be at risk of inheriting the mother's disability?"). Parenting capabilities were questioned further, including questions about how mothers were going to get everything done, such as putting the child in the car (Powell et al., 2017). A small portion of women in the study reported excitement and support from their family members, whereby they looked forward to the addition to the family and offered support, but most responses continued to be negative.

For those with disabilities, family social support is regarded highly but it is evident that it does not always occur. Literature highlights the common negative responses disabled pregnant individuals receive including hostility, questioning competence, and intrusive curiosity (Powell et al., 2017). A qualitative study of individuals with intellectual and developmental disabilities sought to identify the main psychosocial factors that impact pregnancy in this population. Over half of the women identified poor social support and unstable relationships with parents and family members to be of concern (Xie & Gemmill, 2018). Many of them shared that these relationships were also the source of sexual, physical, or verbal abuse. The lack of relational support also contributed to financial and housing-related concerns.

Strangers

Social support and ableism may also come from strangers who may have interactions with a pregnant individual with a disability. Iezzoni and colleagues (2015) interviewed 22 women throughout the U.S. with physical disabilities who delivered babies within the last 10 years to determine what responses they received from the public. The women in the study used assistive devices for mobility, including wheeled mobility aids such as wheelchairs. Six common responses were received from strangers related to their pregnancies or newborn infants including: (1) general curiosity, (2) intrusive and persistent curiosity, (3) hostility, (4) questioning competence as a potential parent, (5) oblivion, and (6) positivity. Five out of the six responses can be interpreted as negative, especially when reviewing the specific examples given by the women in the study. One woman was asked by a stranger if she was raped when referring to her current pregnancy, implying nobody would voluntarily have sex with her. Another woman experienced pure disgust from a stranger who asked her, "Someone would have sex with you?" (Iezzoni et al., 2015). Some comments, however, were positive and included words of kindness, as well as those that were complimentary and celebratory. No matter, all women in the study noted the emotional impact these comments had on their well-being.

Peers

With the increased use of technology, many individuals have turned to Web-based resources and social media platforms for support. For disabled individuals in particular, social media has been identified as a positive platform to create friendships, build self-esteem (Caton & Chapman, 2016), and provide support for disability-related experiences (Kingod et al., 2017). Social media also takes the format of blog posts, a method of social media engagement that allows individuals to write Web-based posts and diaries, which are another format utilized by disabled individuals. Litchman and colleagues (2019) examined how blogs are used by women for topics of pregnancy and early motherhood with disabilities, specifically those with spinal cord injuries (SCI), traumatic brain injuries (TBI), and autism. The blogs served as a platform for women to talk about their negative experiences with providers, their desires for motherhood, and how they successfully navigated the challenges of healthcare. Additionally, these posts often included suggestions for others who may be undergoing similar challenges, such as hacks for receiving care or resources to utilize. Similar supportive networks have been identified for pregnant women with physical disabilities (Peterson-Besse et al., 2019) and mothers with intellectual disabilities (Mayes et al., 2008).

Media can be a double-edged sword, often serving as a platform for pregnant individuals with disabilities to be made a spectacle of. Articles and news stories on the Today Show and CBS News feature women with physical disabilities who are pregnant or having babies and sharing their experiences (Anderson, 2019; Bernabe, 2020). While these stories may intend to educate individuals that disabled women can and should experience pregnancy, they may also be perpetuating the idea of women with disabilities as 'inspirational' (see the term 'inspiration porn' from Young, 2012). If these experiences were not something to be questioned or made a spectacle of, they would not be on the news at all.

Partners

Partners play an important role in the pregnancy experience, from the start of conception to serving as co-parents to the new infant. Evidence shows the value of partner support for all individuals in that they have been shown to lower maternal and infant distress and negative outcomes (Stapleton et al., 2012), provide a sense of security to the pregnant individual, and lower pregnancy-related anxiety (Cheng et al., 2016). For pregnant individuals with disabilities, the value of partner support is found to be just as important. For example, for women with visual impairments, having support from partners provides a stronger sense of self-efficacy and confidence in their abilities to parent (Commodari et al., 2022). These partners often want to be involved too. Misra and colleagues (2023) found that most fathers want to be involved in the process of pregnancy and birth.

On the other hand, evidence shows partners to be a source of stress and trauma for individuals with disabilities. Some research points to partners' unpreparedness for pregnancy and birth causes their wives to feel less supported (Sapkota et al., 2012). In some cultural groups, having partners present for birth is forbidden or highly discouraged, leaving birthing individuals without that support at all. For those with disabilities, Chen et al.'s (2023) analysis of births between 2016 and 2020 found higher rates of partner-related stress and lower partner emotional, financial, and social support than those without disabilities. Intimate partner violence (IPV) has higher reported rates among women with disabilities compared to the general population, which can lead some individuals to carry unintended pregnancies (Alhusen et al., 2023). This can have enormous impacts on the pregnancy experience for these individuals, though our scientific understanding of the phenomenon is limited.

Doulas

Doulas, or those trained to provide "physical, emotional and informational support to their client before, during and shortly after childbirth" are there to provide the safest and most holistic experience possible (DONA, 2023). While historically meant to support the birth experience for women, doulas have

expanded to provide a breath of support to individuals experiencing miscarriage, abortion, pregnancy, and parenting (Mahoney & Mitchell, 2016). Their work directly intersects with that of reproductive justice, in that every individual has the right to give birth, the right to not give birth, and the right to safely parent children (Ross et al., 2017). Doulas provide a holistic and individualized approach, tackling systematic factors of racism, ableism, sexism, and class differences in the context of reproduction.

Despite the potential value of doula work for individuals with disabilities, little research has been done on their effectiveness. McGarry et al. (2016) conducted the first study of its kind examining doula experiences for individuals with intellectual disabilities giving birth. Through phenomenological analysis, doulas were found to be useful to the women during pregnancy, during birth, and postpartum. The doulas served as a source of information and support, allowing the mothers to make informed decisions about their care. It is highlighted that those with other intersecting and marginalized identities can greatly benefit from doula support as well (Horton & Hall, 2020; Mahoney & Mitchell, 2016). Additional evidence of doula support occurs in community-based discussions and advocacy efforts through networks such as the Disabled Parenting Project (2023).

Limitations to Literature

Throughout the various topics of reproductive healthcare for individuals with disabilities, specific limitations exist. For many articles, the definition of a physical disability was consistent, however, not all researchers utilized the same disabilities within their samples, limiting their generalizability. For example, most studies were focused on women with multiple sclerosis or spinal cord injuries, while others included other disabilities such as blindness or cerebral palsy. It is important to consider the populations used when examining their experiences. The experiences of a blind individual versus those with a spinal cord injury may be vastly different (Schiff et al., 2021). Further, the experiences cannot be generalized to less apparent disability categories, such as those with fibromyalgia, mental health conditions, and others

(Matkin & Smedema, 2024). The unique experience of different disability categories should not be ignored.

Additionally, the population examined in many studies may pose significant barriers when thinking about a study's generalizability to other gender identities and racial groups. While not explicitly stated, it is assumed that most studies included cis-gender women, many of whom were White and/or Caucasian. The conversation of disability and reproductive autonomy should not exist without acknowledgment of other marginalized identities, particularly those related to race and ethnicity. It is recognized that other marginalized identity groups have their own reproductive rights history (Nelson, 2003), histories that often intersect with disability history. Rehabilitation counselors who follow an intersectional approach should consider where and how these identities influence each other, if at all.

Few studies specifically included a diverse gender-identity population. Who can become pregnant is not exclusive to those who identify as female; transgender men are often still able to experience pregnancy. As of today, there are no reliable statistics available on the number of transgender men who are pregnant, have carried a child, and/or have given birth. Recent research by Riggs et al. (2020) examined the experiences of men, trans/masculine, and non-binary individuals with pregnancy loss in numerous countries, finding there is minimal research on the experiences of non-cisgender individuals and pregnancy. Results showed that this population experiences a narrative that their body is wrong, and they have failed. Most research articles reviewed for the present study did not confirm the gender orientation of participants, aside from labeling them as 'women.' This language alone inherently excludes the possibility of other gender identities. While some have worked to shift language from 'mothers and women' to gender-neutral terms, not everyone has acknowledged or agreed upon this change (Reis, 2020).

Finally, numerous contextual and environmental factors have been explored in the literature on a limited basis. The COVID-19 pandemic impacts individuals around the world, particularly disrupting

healthcare systems. The United States is no exception and has experienced variability in maternal death in pregnancy (Molina et al., 2022). While evaluations of pregnancy-related complications due to COVID-19 are limited, preliminary research highlights its impact, and that it should be considered when evaluating pregnancy experiences in the last few years.

Conclusion

The reproductive experiences of diverse individuals with disabilities are often filled with barriers, limited resources, and poor support. Stemming from a deeply rooted history, the narrative around this population persists in the attitudes of others and access to healthcare services. The lack of reproductive acknowledgment in rehabilitation literature, and the minimal exploration of reproductive experiences related to non-apparent disabilities among diverse individuals leads to further concern. More research is needed to highlight these other population categories so we can identify what is and is not working for individuals with disabilities seeking pregnancy-related care.

Chapter 3: Methodology

This chapter reviews the methodological procedures including research design, participants, procedures, data collection and analysis, and trustworthiness of the design for this reflexive thematic analysis research study.

Research Paradigms

Reflexive thematic analysis (TA) is a method of qualitative research designed by Braun & Clarke (2022) that involves critically examining “what we do, how and why we do it, and the impact and influences of this on our research” (p. 5). It is a flexible method in that it can operate among numerous research paradigms and theoretical orientations. Research paradigms are the basic beliefs of the study. When combined with the philosophy of reflexive TA, the framework for the methodology is created (Creswell, 2013; Guba & Lincoln, 1994; Heppner et al., 2015). There are four common research paradigms in qualitative research - positivism, post-positivism, constructivism, and critical theory - each of which holds its assumptions on the nature of the world, the individual, and the experiences the individual has within the world. For this study, the TA primarily operates within a critical theory paradigm with elements of constructivism.

Positivism

Positivism operates under the assumption that knowledge comes from context-free generalizations. Everything comes from objectivity in the researcher where they only view, and report information gathered from observation and/or data collection. It seeks out cause-and-effect between relationships, aligning closely with many scientific methodologies (Guba & Lincoln, 1994; Park et al., 2020).

Post-Positivism

Post-positivism recognizes that reality is imperfectly attainable because of flaws in individuals and their interaction with the phenomena (Guba & Lincoln, 1994). Therefore, there is no ‘absolute’

answer, rather research can provide us with an approximation of the experience (Creswell, 2013). Post-positivism acknowledges there is no correct way to engage in research either; recognition of the role of the research is important to understand motivation and commitment.

Constructivism

Constructivism operates from the belief that there are numerous and specific realities that exist (Guba & Lincoln, 1994). In this research paradigm, the researcher and the participants are interactively linked; the findings of the research are created from such, along with consideration of contextual factors.

Critical Theory

Critical theory and other related ideologies such as disability, queer, or race-focused frameworks operate under the assumption that over time, reality is shaped by “social, political, cultural, economic, ethnic, and gender factors” that are interconnected and create what is ‘real’ (Guba & Lincoln, 1994, p. 110). The researcher and participant(s) are linked, and information is used to transform, uncover, or correct reality. While numerous critical theories exist, all serve as means to criticize the power relations built within historical and social contexts and help “emancipate oppressed groups” (Ponterotto, 2005, p. 130).

Philosophy of Reflexive Thematic Analysis

This research utilizes reflexive TA to gain insight into the experience of social support in pregnancy with fibromyalgia. While TA holds flexibility in its use, the goal is always to articulate and express themes found within the material (Braun & Clarke, 2022; Fugard & Potts, 2019). How TA does this is highlighted by the five dimensions of scientific philosophy outlined by Ponterotto (2005): ontology, epistemology, axiology, rhetorical structure, and methodology. All these dimensions operate with a critical theory paradigm with elements of constructivism. The philosophical components are deeply connected to, and met by, maintaining reflexivity in qualitative research. For a detailed description of

how this study sought balance among qualitative research threats and their philosophical tenets, see *Maintaining Reflexivity*.

Ontology

Ontology refers to the nature of reality and what can be known about it (Ponterotto, 2005). Reflexive TA maintains a constructivist view of reality, believing it to be a socially constructed concept with multiple truths of equal value (Braun & Clarke, 2022). The reality of pregnancy is historically and presently influenced by values of disability status and is also unique to each diverse individual. Reflexive TA also works to provide situated, interpreted realities. Through recognition of these unique differences and power relations and the social influence that may impact the experience for participants, this reflexive TA study will operate with elements of a critical paradigm of reality.

Epistemology

Epistemology focuses on the relationship between participants and the researcher and what knowledge can be generated from it (Ponterotto, 2005). To capture the experience of participants in this study, a relationship between participants and researcher(s) is necessary. Reflexive TA acknowledges that complete objectivity is not possible (Braun & Clarke, 2022). Rather, the researcher can strengthen or weaken the study depending on how data collection, analysis, and interpretation are conducted. Reflexive TA conducted in a constructivist manner seeks to theorize the “sociocultural contexts, and structural conditions, that enable the individual accounts that are provided” (Braun & Clarke, 2006, p. 85). In this study, the use of semi-structured interview protocols that focus on sociocultural contexts for individuals with fibromyalgia helps strengthen the study’s threats to bias and maintain focus. While TA research should be gathered without the researchers’ past knowledge and experience interfering (Patton, 2015), constructivist and critical theorists argue that through this dialogue, we can help reach deep insights that transform our understanding of experiences.

Axiology

Axiology further clarifies the role of the researcher in the scientific process (Ponterotto, 2005). In reflexive TA, the researcher is part of the study, serving as the interviewer, coder, and/or analyst, positioning them to be deeply enmeshed in the project (Braun & Clark, 2022). This axiology operates closely with constructivism in that researchers cannot be completely detached and therefore should engage in reflexivity to “own their perspectives” (Elliott et al., 1999). Reflexive TA holds this practice to its core, as the research team works to acknowledge their values, engage in bias reduction strategies, and reflect on their process of knowledge creation, throughout the project.

Rhetorical Structure

The rhetorical structure of a study refers to how the interview data from participants is presented (Ponterotto, 2005). Reflexive TA provides specific processes for analyzing and presenting the information (Nowell et al., 2017) that will operate in a constructivist paradigm; specific notes of contextual and social factors will be highlighted as they relate to codes and themes. The research team will work to support the rigor of the data by identifying consistent themes regarding participants’ experiences of the phenomenon without the influence of bias and expectation(s) (Nowell et al., 2017). The research team will actively engage in core reflexive practices to manage bias, expectation, and impact throughout the study (see *Addressing Bias & Expectation* section for more information). While the generalizability of the data will be noted as a limitation of this study, important themes will be highlighted in a manner that summarizes participants’ experiences (Braun & Clarke, 2020).

Methodology

Methodology is how we go about discovering knowledge, which directly flows from the ontology, epistemology, and axiology of a study (Ponterotto, 2005). Qualitative research cannot be done without a level of interaction between the interviewer and interviewee; this interaction and dialogue is what helps identify the social constructs and phenomena (Guba & Lincoln, 1994). Additionally, reflexive

TA poses that researchers need to be immersed in the data and project to ensure quality coding and themes emerge (Braun & Clarke, 2022; Javadi & Karea, 2016). Aligning with constructivism and critical theory, the methodology aims to reconstruct how we previously thought of the experience for pregnant individuals with fibromyalgia.

Appropriateness of Study for Qualitative Research

This study is particularly appropriate for a qualitative approach. Most of the current literature on elements of pregnancy experiences for individuals with disabilities has been done using a qualitative inquiry, as scholars know little about the experiences of these populations. Additionally, reproductive experiences are viewed as uniquely individual. No two pregnancy experiences are the same, requiring an individualized approach and generalization limitations. Finally, with little research existing on individuals who have experienced pregnancy with fibromyalgia and their social support experiences, a qualitative approach provides the best means to begin the exploration.

Research Team

To support the trustworthiness and representation of our findings, a team was created that consisted of the researcher, a second coder, and an auditor. The researcher served as the interviewer and one of the coders. A Rehabilitation Counselor Education doctoral student served as the second coder of the data analysis. Both coders played an important role in determining the codes and themes of the project. As such, recognition of each coder's uniqueness and efforts to reduce bias and expectations in the data and coding process is outlined in the *Maintaining Reflexivity* section.

The auditor of the study was a dissertation committee member and is a member of the Rehabilitation Counselor Education department. The auditor holds experience in thematic analysis and serves as a reviewer for the final structure of the codes and themes. While it may have supported the trustworthiness further to have research team members outside of the department and UW-Madison,

the team helped ensure the project aligned with the values of the rehabilitation counseling field by uplifting the voices of a population with disabilities.

Compensation

Recruitment to be part of the research team included authorship of future publication of this study. Additionally, the second coder was treated to snacks and meals when team meetings took place, as well as after the project.

Training

To support the trustworthiness and competence of this qualitative inquiry, several training procedures were implemented for the second coder. First, the coder was provided with several resources and readings on thematic analysis research to support their understanding of the theoretical and conceptual basis of the study. Second, the coder was provided with a brief literature review on the topic. This supported their familiarity with the contents and focus of the interviews. Lastly, both coders used the pilot interview as a training exercise on coding, addressing procedural concerns as they came up. The pilot interview also helped support the development of the future coding system with changes noted within the audit trail.

Reflexivity in Qualitative Research

Quality qualitative research “does not just involve embracing subjectivity, it requires us to interrogate it” (Braun & Clarke, 2022, p. 13). As noted in its name, reflexive TA involves the continued reflexive practices of its researchers. Reflexive practices include critically examining personal values and biases, aspects of research design methods, and how research knowledge is produced. All research is vulnerable to bias and expectations, both of which can take many forms including an inclination, prejudice for or against a person or group, and systematic distortion of results (Smith & Noble, 2014). Bias and expectations pose direct threats to the trustworthiness of a qualitative study, requiring particular attention to the reflexivity of its researchers (Lincoln & Guba, 1985; Nowell et al., 2017). A

frequent starting point is critically examining researchers' positionality as it inevitably shapes engagement, often referred to as "researcher-as-instrument" in qualitative research (Yoon & Uliassi, 2022). Maintaining reflexivity throughout a study is a journey and there is no systematic list of how to do it (Braun & Clarke, 2022). Rather, this study has identified key reflexivity practices that will be focused on throughout the project.

Maintaining Reflexivity

Before engagement in the research study, both coders engaged in reflection on their positionality to this project, which included salient identities, biases or expectations, personal experiences, and relevant qualifications. The responses of each team member are provided in the *Researcher-as-Instrument* section. Following this, the second coder was provided with articles discussing the nature of reflexive TA research and its key concepts. Specific time and attention were spent reviewing the importance of reflexivity and all it encompasses, including the personal, functional, disciplinary, and political elements.

Beyond this initial preparation, the coders met regularly to process and reflect on the relevant stages of the research. During these times, particular attention was paid to personal biases that came up that could impact methodology. Research team members were encouraged to interrogate why they are having those responses and why it matters to the research endeavor (Braun & Clarke, 2022). The expectation of data was a concern most relevant to the researcher. The researcher had spent several years enmeshed in the literature on this topic and has had personal experiences with reproductive access limitations as someone with a chronic health condition. The second coder also had personal experiences and familiarity with this topic and diagnosis that had the potential to impact expectations of what would be found in this study. Discussing and interrogating these expectations that arose during team discussion was useful in ensuring the study's credibility.

To monitor and document the reflexivity practices throughout the study, an audit trail was used. Audit trails provide evidence of decision-making and choices made by the research team throughout the study (Nowell et al., 2017). This included a personal, reflexive journal, raw data, transcripts, and more, as it relates to the study. The audit trail also contained exchanges made during the data analysis process, such as disagreements between coders or themes identified among research team members. The audit trail was kept in a confidential location, with access limited only to the coders as needed.

Researcher-as-Instrument

The researcher, Katelyn Matkin, is a 29-year-old, White, cis-gender woman with a chronic health condition. She received her bachelor's degree from UW-Madison in Rehabilitation Psychology in 2016, followed by her master's in Rehabilitation Counseling in 2018. Her master's practicum and internship experiences were held at Madison Area Technical College, in the Career and Employment Services and Disability Services offices. Both spaces supported diverse college students, including those of diverse race/ethnic backgrounds, ability status, veteran status, and criminal justice background. Following completion of her master's degree, the researcher continued working in higher education settings, serving as an Academic Director at a private organization supporting college students with disabilities, and as an Access Consultant at McBurney Disability Resource Center on UW-Madison's campus. The researcher is currently pursuing a PhD in Rehabilitation Counselor Education at UW-Madison. Her doctoral practicum experience was at ARC Community Services, Inc.; a non-profit organization supporting women primarily affected by substance use. Many of the women served were also either pregnant or parenting.

The researcher acknowledges her biases related to the topic of chronic health conditions. Having lived with a chronic health condition for several years, the researcher has had numerous experiences of ableism in academic, employment, and social settings. Additionally, she was told by a neurologist that she could never be on her symptom management medication while pregnant, so she would need to

learn to “live without it” if she wanted to have children. This comment was made unprompted to her, without first inquiring about her desire for children. She has also had positive experiences, including an OBGYN telling her their staff will work with her to find medication alternatives to help manage her chronic illness while pregnant. These experiences are ones that sparked her interest in this topic. The researcher also acknowledges that the experiences she has had are privileged, particularly regarding her gender and racial identity. While the researcher doesn’t have first-hand knowledge of intersecting levels of oppression, she assumes others who do may have similar, different, or more severe interactions with medical staff or others regarding their reproductive endeavors.

This study is inherently political, which poses bias in the review and writing of this study. In recent years, the topic of reproductive equity has received increased focus in media and advocacy. As *Roe v. Wade* was overturned in 2022, the divisiveness in the world on topics of reproductive control has increased. The researcher’s identity as pro-choice is recognized to impact the expectations of the participants and readers of this study. While the study does not require or directly address the opinions of reproductive equity, it is a peripheral topic that can influence pregnancy outcomes and desires. This expectation may influence the tone of the research, how responses are interpreted, and the implications for advocates.

The second coder of the project, Megan Baumunk, is a 33-year-old, Caucasian, cis-gender woman with CID. She received her bachelor’s degree from the University of Iowa in Human Relations in 2018, followed by her master’s degree from the University of Wisconsin-Madison in Clinical Rehabilitation Counseling in 2021. Her master’s practicum experiences were at the Green Lake County Behavioral Health Unit in mental health counseling and Professional Rehabilitation Services in forensic rehabilitation. Her internship experience was at the Division of Vocational Rehabilitation in Milwaukee, WI. The second coder is currently pursuing a PhD in Rehabilitation Counselor Education at UW-Madison. She currently works part-time as a therapist and group facilitator at Gilda’s Club – Madison.

The coder acknowledges her biases related to the topics of chronic illness, disability, and reproductive care. Living with CID since childhood, she has many experiences of ableism and sexism. She was told at age 17 that she may not be able to have children due to her chronic illness, without testing for confirmation. At 22 years old, she was questioned if her partner (cis-gender, male) had approved the removal of her birth control. At 27 years old, her primary care doctor told her to “seriously consider” having children soon. Despite her declining the conversation on the basis that she would not have children, the doctor continued the unprompted discussion and asked about her partner’s desire for children. She has had positive experiences with some medical providers, including a pain specialist recognizing how difficult carrying, birthing, and raising a child would be with chronic pain and her other CID symptoms, and validating her desire to not bear children.

Further, with changes in legislation regarding access to resources and medical care (e.g., Planned Parenthood, Roe v. Wade, etc.), the auditor recognizes her biases toward access to reproductive care and associated legislation and political movements. As a survivor of domestic and sexual violence and having required access to reproductive care through Planned Parenthood, she recognizes her passion-driven advocacy toward equitable reproductive care. While this is not the intended purpose of the study, it may influence expectations of the study and how responses are interpreted.

Interview Procedure

The main source of data for this study came from semi-structured interviews. The interview protocol was developed by the researcher and reviewed by dissertation committee members.

Interview Protocol

To ensure the interview protocol aligned with the research goals and questions, an initial pool of questions was created by the researcher (Appendix I). Questions include clarification of demographic information gathered from the screening questionnaire (e.g., personal identities, pregnancy dates, etc.),

followed by questions clarifying their fibromyalgia and how they experience it. Subsequent questions focused on social interactions with healthcare providers and other important social influences for the participants as they relate to their pregnancy experience. Following a review of questions by the dissertation committee, the final interview protocol consisted of a semi-structured interview estimated to be conducted in approximately 45-60 minutes.

Elements of accessibility and disability justice were incorporated into the interview protocol in several ways. Participants were given a copy of the interview questions at the start of the interview and shared via screenshare in Zoom. Participants were offered to receive it via email in a Word document with accessible formatting if needed. Second, to allow participants additional space to share information, and time to think and answer questions at an accessible speed, the total time for interviews was scheduled for 60 minutes. At the beginning of the interview, participants were encouraged to ask for breaks throughout as needed. Lastly, participants were offered the option to reach out to the research team with additional thoughts that may have come up following the completion of the interview. This was to ensure the study captured the phenomenon most accurately while acknowledging the limits of a one-time 60-minute interview.

Informed Consent

Informed consent is ethically essential for research with human subjects (Gupta, 2013). Informed consent review appeared at several points in this research to ensure participants were aware of their autonomy in this endeavor. Before individuals took the screening questionnaire, informed consent was required before answering questions (Appendix III). If individuals were chosen to be interviewed, the interview began with a review of key elements of informed consent again. Participants were allowed to ask questions or voice concerns if they had any. All participants agreed to the elements of the study and the interview protocol continued.

Pilot Interview

Pilot testing for semi-structured qualitative interviews is an important step in a study's process. It helps refine questions and provide insight into the coding system of the data (Bartholomew et al., 2000). As such, a pilot interview was conducted following an initial review of the interview protocol. Within the screening questionnaire, individuals were asked if they wished to be considered for the pilot interview. The question contained a description of what it would entail, including a requirement to provide feedback on the interview process. Feedback included a question at the end of the interview with the research team member, as well as an electronic feedback survey, which was asked to be completed within one week of the interview. Compensation for engaging in the pilot interview was an additional \$25 to the \$50 participants received for completing an interview. The pilot interview participant was someone who met the study criteria and whose data was included in the final analysis.

The feedback received from the pilot interview solidified the significance of our questions. During the interview, the pilot interview participant noted no concerns with how the interview went. The questionnaire feedback provided a few days after informed us that the interview atmosphere was comfortable for them and provided a safe space to talk about these challenges. Additionally, the feedback noted that the questions were appropriate and "not too much or too personal."

Based on the feedback, no specific changes were made to the interview protocol. The researcher took intentional time following the pilot interview to assess personal emotions and reflections on the interview. This helped contribute to the reflexivity necessary in qualitative research.

Interviews

To allow for maximum access, Zoom videoconference software was utilized for interviews. Zoom is a platform that allows participants to choose how they join whether via computer video or phone. Participants were informed that the interview is expected to last between 45 to 60 minutes. The average interview time was 33 minutes for this study.

The researcher, also serving as the interviewer for this study, sought to provide interviews most effectively for all involved. The philosophical nature of this study emphasizes a necessary level of interaction between the researcher and the participant. As such, some important techniques were implemented to ensure that interaction evokes participants' comfort in sharing their lived experiences (Patton, 2015). These skills were practiced in the pilot interview and received confirmation of their helpfulness. First, the researcher aimed to build rapport with clients by sharing information about themselves, as it relates to the study including being a doctoral student with an interest in reproductive equity research. Open-ended questions to the participant followed, to build safety in the interview process and give space for participants to share to the level they feel comfortable. Through the remaining questions, the researcher focused on additional interview skills proposed by Patton (2015) including listening carefully and probing further when necessary, observing non-verbal or physical reactions if possible and taking note of them, being mindful of topic transitions, being present throughout and eliminating distractions, and preparing for unexpected experiences including interruptions and time limitations.

Data

All interviews were recorded using Zoom meeting record and caption features. Captions of interviews were edited until they were identified as accurate transcripts and subsequently uploaded to DeDoose software for coding. All recorded interview data was kept in an encrypted file for safe data storage following IRB requirements. The data recording and storage method was discussed with participants as part of the informed consent. After this data analysis and the completion of the research project, interview recordings will be deleted.

Data Analysis Procedure

This study implemented the six-phase data analysis procedure outlined by Nowell and colleagues (2017) for TA: (1) familiarization with data, (2) generating initial codes, (3) searching for themes, (4)

reviewing themes, (5) defining and naming themes, and (6) producing the report. This procedure has been deemed trustworthy according to the Lincoln & Guba (1985) criteria for qualitative research. While listed linearly, qualitative TA scholars recognize that this process is anything but; it more likely will involve moving between phases as needed to reach the point of presenting findings (Braun & Clark, 2006).

Phase 1: Familiarizing with Data

Familiarization of data begins during data collection. The researcher took note of thoughts, interpretations, and observations, to become more familiar with the content (Braun & Clark, 2022). The interviewer worked to take these notes honestly and reflexively during interviews to support the contextual understanding of participants' experiences. From there, the primary researcher actively, critically, and analytically read through each interview at least once to support familiarization (Nowell et al., 2017). Since the interviews were gathered in the form of an audio transcript, intentional time was spent reviewing the transcript according to the recommendations of Braun & Clarke (2013). This included ensuring transcript quality and accuracy, adding personal notes and observations, and adding notations. Familiarization with data also included having the researcher take notes of personal ideas, observations, or themes that emerge as a form of data saturation (Saunders et al., 2023).

Phase 2: Generating Initial Codes

Once the researcher felt familiar with the data, a list of initial codes was determined. The codes are features of the data that seem interesting to the researcher as they related to the study and consist of "basic segments, or elements, of the raw data" that information or essence of the experience can be drawn from (Braun & Clarke, 2006, p. 88). While some initial code ideas came from the pilot interview, the researcher maintained openness to new observations with the data used for analysis. The researcher used DeDoose software to support the organization of data and initial codes. Full and equal attention was paid to all interviews and data, with the same method of analysis used throughout the review (Nowell et al., 2017).

Like all phases of TA, generating codes requires flexibility, thoughtfulness, and reflexivity to support the trustworthiness of the study. There is no limit to how many codes one generates for themes and patterns, and those codes may change throughout the process (Braun & Clarke, 2006). To support the organization, structure, and pragmatic demands of this applied research, an additional codebook was created. Thematic analysis recognizes that creating some kind of coding framework or book is less organic than reflexive TA, it may serve as a helpful tool to guide the additional steps of analysis (Braun & Clarke, 2022). Utilizing a coding reference sheet supported coding reliability, ensuring there is agreement between the definitions of codes and their application to the data. Each coder utilized the same codebook structure but worked on it independently through phase 2 and 3. The coders met after the initial code and reference tool was developed to review and discuss (Nowell et al., 2017). Any disagreements, changes, or reflections that come from the meeting were documented on the recommended audit trail (Lincoln & Guba, 1985).

Phase 3: Searching for Themes

Once codes had been identified and audited, each coder worked to sort them into potential themes (Braun & Clarke, 2006). Themes are defined as abstract identities that “bring meaning and identity to a recurrent experience and its variant manifestations” (DeSantis & Ugarriza, 2000, p. 362). Nowell and colleagues (2017) recommend starting with some predefined codes that may come from the pilot interview, to guide the analysis. However, it is also recommended that the research team not approach analysis with predetermined ideas of what is to come as it may disregard themes that are not obvious (King, 2004). The coders also kept in mind the frequency of the theme(s). While quantity does not necessarily equate to higher significance, when relevant, the frequency of a theme may be noted (Braun & Clarke, 2006).

Like Phase 2, both coders reviewed codes and created the initial list of themes. The research team then met and discussed discrepancies or disagreements, noting any changes within the audit log.

Use of independent codebooks continued to help identify relationships within themes, codes, and levels of themes (Braun & Wilkinson, 2003). This supported the review of themes in Phase 4.

Phase 4: Reviewing Themes

Phase 4 involves continuous refinement of codes and themes to ensure they accurately reflect the meaning of the data (Braun & Clarke, 2006). Braun & Clarke (2006) recommend doing this in two stages. First, reviewing codes and theme development to ensure they form a coherent pattern. This involved rewording, changing, or reorganizing themes if they were problematic or inaccurate. The conclusion of this step was a refined codebook that was a combination of both coders' books that was agreed upon that adequately represented the data (Braun & Wilkinson, 2003). The second stage involves reviewing the entire data set and considering the validity of the analysis (Braun & Clarke, 2006). After the coders agreed that the overall codebook reflected the data set as a whole, it was set to the auditor for review. This was used to ensure themes and subthemes were appropriately labeled based on their definitions and content.

Phase 5: Defining and Naming Themes

As the codebook was finalized, the research team entered Phase 5, involving continued refinement of themes and initial descriptions of them (Braun & Clarke, 2006). The 'story' of the research began to take shape as the researcher worked to describe the themes of the data as it pertains to the research questions. The researcher used the recommendation by King (2004) of using peer debrief to ensure the themes are clearly articulated and comprehensive. Any changes, recommendations, or modifications made throughout this process were noted in the audit log. This also involved considering the order in which the themes are presented in the data analysis. Collaboration with the research team members throughout this process was utilized.

Phase 6: Producing the Report

The final step in TA is to produce a written report of the data; one that portrays the story “accurately, consistently, and logically” so that it provides the essence of the experience (Braun & Clarke, 2006, p. 93). This included the meaning and significance of the themes, each of which should have little to no overlap (Braun & Clarke, 2022). Discussion of themes in the data analysis included short quotes from participants that are embedded within the narrative to give validity and merit to the analysis (Braun & Clarke, 2006; Nowell et al., 2017). Each theme was presented in a contextual manner to support the scholarly value and align with the theoretical underpinnings of the study; simply reporting the codes and themes will not offer depth or richness to the study and its findings (King, 2004). To ensure the report contained all necessary components in an accessible manner, the Consolidated Criteria for Reported Qualitative Research (COREQ) Checklist (Tong et al., 2007) and the Journal Article Reporting Standards for Qualitative Research (JARS-Qual) (Levitt et al., 2018) were used.

Trustworthiness of Study

Due to the variability in qualitative inquiry, establishing the trustworthiness of a study is essential. As defined by Lincoln and Guba (1986), trustworthiness is the credibility, authenticity, dependability, and confirmability of a study; it is the way we can provide validity to a qualitative endeavor and identify it as worthy of attention (Creswell, 2013; Lincoln & Guba, 1985; Nowell et al., 2017). Lincoln & Guba (1985) summarized six components of establishing trustworthiness in qualitative research, all of which were addressed in this study in specific ways.

Credibility

Credibility is defined as the fit between the researcher and the study (Nowell et al., 2017). It is not only a way to identify the researcher(s), but also serves as a check between the findings and interpretations (Lincoln & Guba, 1985). One of the ways credibility was addressed was in reporting personal and professional information that may impact the study (Patton, 1999). Both the primary

researcher and second coder reflexively did so in the *Researcher-as-Instrument* section. An additional way credibility was met was in identifying the research team members' training, experience, and relevant preparation. While both coders were new to the field as Doctoral Candidates, external checks on the research through from dissertation committee members, along with the auditor, helped support the qualification requirements of credible research.

Transferability

Transferability is the generalizability of a study (Nowell et al., 2017). Qualitative endeavors by nature are not meant to be generalized to large populations. Due to the specific population criteria for this study, it will not and should not be useful to all pregnant individuals, nor for all pregnant individuals with fibromyalgia. Additionally, a researcher may not know all avenues in which a study's findings may be transferable. The researcher's responsibility then, is to provide thick and rich descriptions of the experience so that whoever seeks to transfer the findings can do so using their own judgment (Lincoln & Guba, 1985). This was achieved through the final stages of the data analysis process and discussion section, and in noting the limitations of the study's generalizability.

Audit Trail

A main source of trustworthiness lies in the auditory component of this study (Hays & Singh, 2023). Koch (2006) argues that by utilizing a decision or audit trail, a researcher can show the influence of actions, increase dependability and confirmability, and ensure the quality of their work. The audit trail was kept in a secure location that could be accessed by the researcher and second coder as needed. It included all necessary research materials, reflections, and documents. The audit trail also contained detailed log of the research team's decisions throughout the data analysis process, including discrepancies, changes, and recommendations.

Another significant component of the audit log is reflexivity (Lincoln & Guba, 1985). Reflexivity, or self-critical reflection throughout the research process, helps support the trustworthiness of this

reflexive TA study. Reflexivity is an essential element, as highlighted in the *Maintaining Reflexivity* section. This reflexivity was documented as part of the audit trail, in both team-based reflections and individual journals. These individual journals included various reflections on decisions, data, values, and interests, insight about oneself, biases that arise throughout the process, and the critical interrogation of why those reflections are coming up (Lincoln & Guba, 1985; Nowell et al., 2017).

Sample

The following section will outline how the sample of participants was recruited and screened, along with a breakdown of their demographic characteristics.

Recruitment

The researcher completed the required University of Wisconsin-Madison Institutional Review Board (IRB) training and obtained approval before recruitment. To collect a purposeful sample of individuals, a community-focused method of recruitment was implemented with accessibility in mind. Critical-action research theories argue that a community approach “generates knowledge or understanding” and brings about change (Gustafson & Brunger, 2014). The researcher utilized local and national community-based organizations and groups focused on reproductive equity and/or fibromyalgia support. This included UW-Madison’s Center for Reproductive Equity (CORE), and several fibromyalgia- and pregnancy-focused Facebook pages (comprehensive list found in Appendix IV). The recruitment flyer (Appendix II), including information on criteria, time expectation of interview, compensation, and screening questionnaire, was provided to each organization and asked to be shared with individuals with whom they work. The flyer was created with disability justice accessibility recommendations in mind (Sins Invalid, 2016) including alt text, accessible font size, and style, and the researcher offered participants accommodations as needed.

Screening Questionnaire

Within the flyer, a QR code and URL provided participants with direct access to the screening questionnaire. The questionnaire began with demographic questions including racial/ethnic identity, fibromyalgia identity, other disability identities (if any), current gender identity, health insurance status/type, location, income, and age. Following demographic questions, several questions inquired about their pregnancy. This included the date of their last pregnancy, and whether the most recent pregnancy was their first, second, third, or more. The remainder of the survey inquired about participant interview availability asking them (1) whether they were able and interested in participating in a Zoom interview, (2) availability for an interview with a variety of one-hour time frames, and (3) preferred method of contact about the interview (i.e., text, phone call, or email).

The screening questionnaire received 261 total responses. Each response was screened by the researcher to identify individuals who fit the desired criteria for this study: (1) over the age of 18, (2) identify as having fibromyalgia before their most recent pregnancy, and (3) have experienced pregnancy and birth to a live child within the last 12 months. To assist in the avoidance of ‘imposter participants,’ a phenomenon of significance in qualitative research in online formats (Ridge et al., 2023), several additional screening protocols were implemented including (1) removal of participant responses from the same IP addresses, (2) removal of participants who provided the same email address in their contact information, (3) removal of participants who provided a phone number that wasn’t one belonging to the United States, and (4) removal of participants who provided the same responses to all screening questions. 12 participants met the criteria and were contacted regarding an interview. They were offered several interview dates and times based on the availability they provided, all via their preferred method of contact (all participants requested email contact). Participants were asked to respond to confirm their interview time within five days of it being offered.

Sample Size

A definitive sample size necessary for qualitative research doesn't exist (Patton, 2015), nor is there specific guidance on sample size for TA (Javardi & Zarea, 2016). Braun & Clark (2021) reject the notion of data saturation in TA, or that there is a point in which relationships can be explained based on data. Rather, it is recommended that TA researchers make an interpretive, situated, and pragmatic judgment regarding sample size and maintain flexibility in expectations. Guidance from other scholars, including Guest et al. (2006), found saturation and theme identification to be found with sample sizes of six to twelve. Based on Braun & Clarke's (2022) recommendation to propose a sample size range, the study aimed to recruit 12-15 participants. It was predicted that not all participants would respond or complete the interview, reaching a final target of 6-12 participants. 12 participants were contacted for interviews and 8 completed the initial scheduling and interview, reaching an overall response rate of 67%. Of the participants who did not complete the process, two participants' interviews were canceled due to identifying their IP address in repeated and more recent screening questionnaire responses (17%), one never confirmed their interview time (8%), and one participant confirmed their interview time but did not show up on Zoom (8%).

Participant Characteristics

The participant pool of eight trended towards Black American/African American ($n=7$) individuals. The average age of participants was 29.9 years. Regionally, the sample was spread throughout the United States, half of whom lived in rural locations ($n=4$) and half living in urban or city locations ($n=4$). For most of the participants ($n=5$), their most recent pregnancy was their second. A summary of these selected participant demographics can be found in Table 1. Table 2 includes additional demographic information including marital status, education level, type of insurance, and comorbid disabilities. Additional summaries of participants will be discussed in *Chapter 4: Results*.

Table 1. Selective Participant Demographic Breakdown.

Participant	Age	Race/Ethnicity	Gender Identity	Number of Pregnancies	Geographic Region
1	33	African American	Female	1	Midwest, rural
2	32	White	Female	2	Midwest, rural
3	30	Black American	Male	2	South, rural
4	28	African American	Female	1	West Coast, rural
5	27	African American	Female	1	East Coast, urban
6	28	African American	Female	2	Midwest, urban
7	32	African American	Female	2	East Coast, urban
8	29	African American	Female	2	South, urban

Note. The Midwest included the states of Wisconsin and Minnesota. South included the state of Texas. East Coast included the state of New York. West Coast included the state of California.

Table 2. Participant Characteristics Summary.

	<i>Frequency (n)</i>
Race/Ethnicity	
African American/Black American	7 (88%)
White	1 (12%)
Marital Status	
Married	6 (75%)
Living with domestic partner(s)	1 (12.5%)
Single	1 (12.5%)
Education Level	
Some postsecondary experience	1 (12.5%)
College degree (Bachelor's)	6 (75%)
Graduate degree (Master's level or higher)	1 (12.5%)
Employment Status	
Employed full time	6 (75%)
Employed part time	1 (12.5%)
Non-paid work (e.g., volunteering or freelance work)	1 (12.5%)
Household Income (US dollars)	
\$10,000 to \$29,999	2 (25%)
\$30,000 to \$49,999	2 (25%)
\$50,000 to \$69,999	0
\$70,000 to \$99,999	4 (50%)

Type of Insurance	
Medicaid	5 (62.5%)
Medicare	1 (12.5%)
PPO	1 (12.5%)
HMO	1 (12.5%)
Number of Pregnancies	
1	3 (37.5%)
2	5 (62.5%)
Comorbid Disabilities/Diagnoses*	
Chronic Migraines	1 (12.5%)
Posttraumatic Stress Disorder	1 (12.5%)

*Note. Including disabilities/diagnoses that were formally diagnosed.

Chapter 4: Results

This chapter contains the results of this reflexive thematic analysis conducted to answer the following research questions:

RQ1: How do participants describe how their fibromyalgia impacts their pregnancy experience?

RQ2: How do participants describe how social influences, including healthcare provider(s), family, friends, peers, strangers, and others, impact their pregnancy experiences with fibromyalgia?

RQ3: How do participants describe how social influences, including healthcare provider(s), family, friends, peers, strangers, and others, could improve upon how they support pregnancy experiences with fibromyalgia?

Sample

The final sample for this study consisted of eight participants. All participants were diagnosed with fibromyalgia before their most recent pregnancy. Most recent pregnancies ranged from 11 months to 4 months ago at the time of being interviewed. Five participants had experienced a prior pregnancy, although not all resulted in the birth of a child; two participants noted experiencing miscarriages in the past. Seven participants identified themselves as African American/Black American and one identified as White. Seven participants identified as female, with one identifying as male.

Most participants (n=6) were married to a partner and worked full-time (n=6). Education levels varied but the majority were college-educated (e.g., Bachelor's degree) (n=6). Comorbid diagnoses with fibromyalgia included chronic migraines and posttraumatic stress disorder. However, several participants also noted additional mental health experiences, most notably anxiety and depression, but were not formally diagnosed.

Through data analysis, this sample produced a robust description of the experience of pregnancy with fibromyalgia. In collaboration with a second coder and auditor, a final version of all themes and

subthemes, and their corresponding research questions, was determined. A summary of the themes and subthemes can be found in Table 3.

Table 3. Summary of themes and subthemes from data analysis.

Research Question 1	Research Question 1	Research Questions 2 and 3	Research Questions 2 and 3
Theme 1: Acquiring a Chronic and Unpredictable Condition	Theme 2: Adjustment to Pregnancy/Parenting	Theme 3: Building Trust and Addressing Doubt: Healthcare Dynamics in Fibromyalgia Management	Theme 4: Seeking and Receiving Social Support: A Multifaceted Experience
Fibromyalgia symptomatology: pain, fatigue, brain fog, and unpredictability	Pregnancy decision making: ambivalence, certainty, and level of preparedness	Stigma and invalidation in healthcare	Physical presence and daily support: daily activity support and managing healthcare
Adjusting to fibromyalgia diagnosis: determining abnormality, relief, burdensome, and stress	Fibromyalgia and pregnancy symptomatology: pregnancy complications and symptom management	Competence in fibromyalgia	Support impacting emotional well-being: checking in, dismissal of challenges, pseudo- advocates, hope, empowerment, willingness to learn, and role models
Mental and emotional impact: anxiety and depression	Mental and emotional impact: anxiety, depression, and suicidal ideations	Establishing trust between provider and patient	Financial support
		Demographic match	Bridging the gap: Received support vs. desired support
		An individualized approach	

Fibromyalgia Impact on Pregnancy

To fully understand the impact of fibromyalgia on pregnancy for participants, it was important to acknowledge what fibromyalgia looked like for them before their pregnancies. Two salient themes emerged that provide a comprehensive picture of fibromyalgia and its impact on pregnancy that

answered research question one: (1) acquiring a chronic and unpredictable condition, and (2) adjustment to pregnancy/parenting. The first theme highlights the complexities of a fibromyalgia diagnosis and its symptom management. The second theme highlights the unique experience of pregnancy with fibromyalgia including the decision-making process and symptomology. Each theme contained salient subthemes that further explained each experience.

Acquiring a Chronic Condition and Unpredictable Condition

Theme one describes participants' experience being diagnosed, and managing, fibromyalgia. Participants describe their fibromyalgia experience through the salient subtheme of *fibromyalgia symptomology*. While symptoms vary across participants, similarities are highlighted among the unpredictable nature of chronic pain. Several participants discuss the *mental and emotional impacts* of fibromyalgia's experience, including the *adjustment to fibromyalgia* process. All these components create an understanding of participants' experience with their chronic and unpredictable condition.

It's been like a roller coaster. So sometimes there are days where I can actually manage it well. And there are days where there's, like, intense pain. Where it's like, my emotions are all over the place, intense fatigue, and stuff like that, where it gets like difficult to even complete the simplest tasks.

When asked to describe what fibromyalgia looked like to participants, many of them began by discussing the symptomology, the most salient of which was pain. Pain was described as 'consistent and constant,' sharp, intermittent, severe, achy, stiff, and widespread. The pain was often the first noticeable symptom experienced before diagnosis. It was something that would come and go until it became persistent and disruptive, enough so that it prompted individuals to seek medical advice. Pain locations varied by participant, and included areas of the back, hips, and joints.

The pain wasn't simply pain. Many participants described how this pain spread to other areas of their daily functioning including their 'battle with sleeping.' Due to the pain location and severity, getting

comfortable at night is more challenging, and frequently results in sleep disturbances. This often leaves participants experiencing excessive tiredness and fatigue during the day. This fatigue, noted by all participants, was described as something that, *“no matter how much [they] sleep, nothing fixes it.”* It leaves individuals feeling consistently ‘out of it’ and for some, turned into a constant feeling of brain fog. Brain fog, described by participants as a sense of confusion and difficulty coming up with words, also makes concentrating on the simplest of tasks more challenging.

All symptoms of fibromyalgia held the common subtheme of unpredictability; a feeling of being out of control of one’s body and what symptoms come up at a given time. Among the participants, various responses to this lack of control over fibromyalgia’s unpredictability were present. For some, it creates immense frustration not knowing when symptoms will show up and impact one’s ability to do things they had planned. For a few participants, a level of acceptance over the unpredictability was stated. For example, one participant expressed knowing they *“can’t...control [her] life”* and therefore when symptoms emerge, it does not upset them. No matter the response, this unpredictability impacted participants in numerous ways, often leading to their inability to complete daily tasks around the house, take care of their child(ren), and/or engage in work. It requires an immediate change to plans, immense flexibility, and close access to resources, all depending on symptom severity.

The *adjusting to fibromyalgia* diagnosis was described as a complex and time-consuming process for individuals, followed by a variety of emotional responses. Coding for this subtheme produced several common responses from participants including (1) the process of determining abnormality, (2) feelings of relief, (3) being burdensome, and (4) stress.

Adjusting to a diagnosis first required a diagnosis to be found. For most participants, pain was cited as the first sign of something being wrong.

It kind of took awhile...I had the symptoms but I didn't really know it was it. You know, at first, okay, I took some over-the-counter pain reliever. [Thinking that], you know, [this is]

something that is just temporary. Not until I went to the hospital...because [the pain] stayed for a longer time...then the doctor diagnosed me and said, oh, this is [fibromyalgia].

As symptoms progressed and began to reach the point of unbearable and severe, it made many participants, along with healthcare professionals, realize something bigger was wrong. This process of determining abnormality looked different for every participant. For some, it took seeing several different doctors including specialists (i.e., rheumatologists) to receive an official diagnosis. Some doctors dismissed the symptoms completely as described by one participant, “No one seemed to like, you know, know what was wrong with me. [it was] just like, okay take pain medications and stuff like that and I knew it was more than just ordinary pain.” For others, it took a process of trial and error, and several medical tests, to rule out other diagnoses before reaching fibromyalgia. This process was long for many individuals, spanning several months, and described as ‘exhausting.’

Once a diagnosis was determined, the emotional responses varied, with two participants referencing a feeling of relief. “I was relieved that...finally, I knew exactly what was wrong, like there was a name for it.” After several months of tests and waiting, a diagnosis felt like a confirmation of the symptoms experienced. This feeling of peace and validation was hugely impactful for many participants, now knowing where they could direct their energies on managing their fibromyalgia and symptomology. The duration of feeling relief wasn’t always a long one; it was often followed by additional responses including stress.

I was thinking maybe...[I] was going through just [a] phase of my life. I [didn't expect] it was actually something that was going to have a name. It was very hard for me at that point in time to accept that, okay, this is what I'm going through, this is the name of my ailment.

With a diagnosis often comes information on management strategies and possible symptoms. While the information was helpful to many participants, the realization of these symptoms occurring throughout the rest of their life was overwhelming. They were now taking on a lifelong chronic illness that varies drastically and unpredictably. This, partnered with the realization that symptoms need to be managed while simultaneously maintaining their home, their family, and other commitments, was deeply overwhelming. This was all new territory.

The reality and stress of a chronic, lifelong condition, partnered closely with feelings of being burdensome. Many participants shared stories of symptoms emerging and needing someone to step in and complete daily tasks they suddenly couldn't do themselves. For example, *"sometimes tasks as simple as carrying groceries or typing, or easy things, get really exhausting for me."* During these times, important social support figures including partners or family members often stepped in to assist. Simply asking for help, however, was challenging for many. Asking loved ones to do things for them, especially ones that seem simple to people on the outside, such as doing the dishes or cleaning up the house, was hard. Participants immediately felt burdensome to their loved ones, regardless of whether they did ask for help or not. As one participant explained, *"I feel like I'm stressing everyone else...because everyone has to take care of me when I go through [flares]."* This same participant spoke at length about feeling that her partner deserved a break from taking care of her. Her partner should be able to say 'no' to things, have time to clear his head, and feel sad about the situation too, although he rarely does.

The adjustment to fibromyalgia and its associated symptoms was challenging for all participants, not just physically. The unpredictable nature of fibromyalgia, partnered with the severity of symptoms, resulted in *mental and emotional impacts* that often took the form of anxiety and depression. For some, the ebbs and flows of chronic symptoms were closely tied to the psychological symptoms. When they weren't impacted greatly and feeling good, they felt anxious about the possibility of symptoms arising at

any moment. When symptoms were high and participants had low mobility, intense fatigue, and a decrease in their ability to complete their daily obligations, depression was highest.

Discussing the psychological impacts of fibromyalgia was challenging for participants. Few wanted to dive deeply into the emotional experiences, simply noting it was hard. A few experienced emotions while talking about it, through a shaky voice, tears, and sighs. When asked what assists in this area for them, many discussed their sources of social support. No participant mentioned the psychological symptoms being discussed or touched on during their diagnosis process.

The first theme of data analysis highlights experience of fibromyalgia as one that is complex and challenging one for many participants. In addition to the intermittent and unpredictable symptoms, which largely included pain, fatigue, and brain fog, many experienced emotional impacts including anxiety and depression. While these experiences occurred, many fought hard to receive a diagnosis. This diagnosis sometimes came with feelings of relief, but also stress and feelings of being burdensome with the information of what could come with fibromyalgia.

Adjustment to Pregnancy and Parenting

The second theme found reflected the overarching journey of individuals as they faced the complexities of pregnancy while managing fibromyalgia. This was a process that varied among each participant and contributed greatly to research question one. Data analysis identified several important subthemes for this area including (1) pregnancy decision-making, (2) fibromyalgia and pregnancy symptomology, and (3) mental and emotional impacts.

The *pregnancy decision-making* process was a highly personal and emotional one. The two most referenced emotions in the participant's decision to become pregnant were ambivalence and preparedness.

With how significant some of the participants' symptoms were without pregnancy, concerns arose when thinking about the added complication of pregnancy and its symptomology. Many were

unsure if their fibromyalgia symptoms would become worse or evolve into something more challenging to deal with, resulting in it being, *“a hard decision to make for me.”* Due to of this uncertainty, many were reluctant to become pregnant and took additional time to consider these factors. For participants who had already experienced a pregnancy, ambivalent attitudes were even more salient. One participant stated, *“I actually don’t think I would want to go through the pain and stress that I did go through [again].”* Another participant expressed even more ambivalence and concern, stating, *“I don’t know if saying this makes me sound like a bad mother, but I went through hell and I do not want to go through or live that again.”* The experience of a pregnancy with fibromyalgia was enough to dissuade some participants from doing it again.

For others, there was no ambivalence regarding one’s decision to become pregnant; they were certain they would have children regardless of fibromyalgia. This was the case for two participants who weren’t concerned by the unpredictability of their chronic illness, one of whom stated, *“I’ve always wanted a baby, so I knew at some phase in my life I would definitely have a baby.”* This level of certainty was expressed with confidence among these two participants, who presented their response with a level of determination that they would not let fibromyalgia get in the way of the future they wanted.

Feelings of being prepared for pregnancy with fibromyalgia varied based on whether it was someone’s first or second pregnancy. For those who hadn’t experienced pregnancy, feelings of being prepared were low. *“I haven’t like, experienced it before...I haven’t been pregnant [with] fibromyalgia. So...everything along the way was surprising.”* Another participant noted similar feelings stating:

I was told maybe the symptoms will be manageable. I [didn’t] know what to expect in terms of the pregnancy aspect, but I did know what to expect [for fibromyalgia]. So combining the two of them together was a lot...it [was] hell for me.

The unpredictability of fibromyalgia symptoms was the driving force of feeling unprepared for several participants. One individual was told by a healthcare provider that the symptoms would be manageable, but with an unpredictable condition, the certainty of the statement was lost. No participants mentioned the various pregnancy-related symptoms that could emerge as a consideration.

For those who had experienced a pregnancy with fibromyalgia before, feelings of preparedness were high. As one participant stated, *"I was ready and prepared...I knew what I was getting into. It wasn't really a surprise during the second pregnancy."* Having experienced pregnancy before provided them with knowledge of what was to come, including what symptoms to expect and how to manage them best. Additionally, the participant knew what to expect pregnancy-wise including related symptoms, what it would feel like to be pregnant, and how to care for oneself prenatal and postpartum. For this participant, that knowledge was instrumental in their pregnancy decision-making and emotions going into the process.

Fibromyalgia and pregnancy together made for unique *symptomology* experiences for each participant. For some, pregnancy symptoms alone were challenging to manage and added another layer of difficulty to individuals' lives. Symptoms included high blood pressure, swelling, pre-eclampsia, and nausea or morning sickness. Pregnancy symptoms seemed to intensify fibromyalgia symptoms for most participants. For example, the added weight of pregnancy on the body puts additional strain on already sensitive joints and muscles and increases overall discomfort. Pain was most often cited in areas of the back, hips, thighs, and legs; all of which are areas that fibromyalgia impacted before pregnancy and only increased once pregnant.

Outside of pain and discomfort, difficulty managing pregnancy and fibromyalgia was commonly discussed. One participant described the experience as a 'balancing' act between managing the fibromyalgia or pregnancy symptoms, whichever one came up on a given day. Both pregnancy and fibromyalgia were unpredictable to them, making it an experience that needed a lot of attention and

flexibility. For example, what worked to manage their fibromyalgia before pregnancy, may have not worked during pregnancy. For one, *“during pregnancy, medication options are limited, so managing my pain became...much more difficult.”* Participants cited several different symptom management activities that were encouraged by healthcare providers during pregnancy, including specific physical exercises, massage and stretching, physical therapy, walking, and meditation exercises. Each management technique varied in its usefulness and ease of implementation. However, they were regarded as their only options for symptom support.

Like the *mental and emotional impacts* of adjusting to fibromyalgia, similar symptoms emerged when participants discussed adjustment to parenting. The emotional variability of fibromyalgia was still present, with anxiety and depression continuing to be reported as the most experienced mental health symptoms. With pregnancy, an added layer of hormone changes and for some, parenting another child, were present. This created an even more unique psychological experience for many participants.

For one participant, the combination of pregnancy’s psychological challenges and fibromyalgia resulted in suicidal thoughts.

It’s just a lot for me. I was so stressed. My anxiety skyrocketed...I was depressed. I...had a suicidal thought, because at some point I feel like I’m just dealing with 2 things in one body, and it’s hard for me to take it...very hard.

The combination of two physically and mentally intense experiences is unique to this study’s population. However, social support continued to be the most referenced source of emotional support, often helping normalize these experiences independently or together.

The adjustment to pregnancy and parenting for participants with fibromyalgia was one with unique challenges. Outside of general decision-making to become a parent, participants had to consider the role their fibromyalgia might play in the experience. For some, it was a relevant factor, while others remained certain they would become pregnant regardless. While pregnant, symptomology varied and

included pregnancy-related symptoms, as well as variability in their fibromyalgia. Most participants were greatly affected and needed to alter their symptom management to new therapies. Mental and emotional considerations remained salient for numerous participants with anxiety and depression cited most frequently.

Social Influences on Pregnancy with Fibromyalgia

To comprehensively understand the role that social support played in pregnancy for individuals with fibromyalgia, and to seek answers to research questions two and three, participants were asked about healthcare providers and specific social support areas of their choosing. Through this interview protocol, unique social experiences were identified specific to both healthcare and their social support networks. Coding produced two themes to represent responses most comprehensively including: (1) building trust and addressing doubt: healthcare dynamics in fibromyalgia management, and (2) seeking and receiving social support: a multifaceted experience.

Building Trust and Addressing Doubt: Healthcare Dynamics in Fibromyalgia Management

“They actually did play a crucial role in my pregnancy journey.”

Healthcare providers played a significant role in the experiences of fibromyalgia and pregnancy for participants in positive and negative ways. Participants discussed how some healthcare providers were incredibly supportive through their competence and trust established, while simultaneously acknowledging the presence of doubt and skepticism surrounding fibromyalgia. Coding highlighted several commonalities among responses, including intersections among topics, as well as recommendations for how healthcare providers could improve upon their care of this population. Subthemes included: (1) stigma and invalidation in healthcare, (2) establishing trust between provider and patient, (4) competence in fibromyalgia, (5) demographic match, and (6) providing an individualized approach.

Several participants described situations with healthcare providers where a complete *invalidation and stigmatization of fibromyalgia* was present. Not only was it, *“It’s such a slap in the face to hear,”* but also partnered with dismissal of symptom severity. One participant explained the situation as:

I started getting symptoms. I went to the first doctor and they really didn’t like say anything...I didn’t get any diagnosis, just said I should rest more often and it wasn’t something I should worry about. And then it became like, really, serious and extreme. Then, I was able to see a rheumatologist who gave me my diagnosis.

Other participants expressed similar situations where healthcare providers recommended simple solutions, such as over-the-counter pain medication, or exploring mindfulness. This resulted in participants feeling completely dismissed and prolonging the diagnosis process overall. For one participant, this dismissal resulted in questioning herself and her experiences; if a doctor didn’t think this was severe or important, why should she? For a different participant, this resulted in needing to continue advocating for herself for additional tests and validation. *“I wish more people understood fibro is something that forces you to really be in tune with your body. So if I’m saying ‘this isn’t right,’ hear me.”* Among the participants who experienced invalidation of fibromyalgia by healthcare providers, a clear consensus was that this should not be the case. Rather, healthcare providers should be competent in fibromyalgia as a diagnosis and all it entails.

Competence in fibromyalgia was described as a sense of knowledge, understanding, and resources for the diagnosis. For those who had a healthcare provider who was competent in fibromyalgia, it was incredibly beneficial during their pregnancy. *“They helped me...throughout my pregnancy, considering my condition and medication.”* Some healthcare providers took time to support the individuals with their fibromyalgia medication and find alternatives that were safe during pregnancy.

Other healthcare providers told the participant that it wasn't their first time having a pregnant patient with fibromyalgia, which provided additional reassurance.

Finding a provider who was competent in fibromyalgia was not an easy task. Sometimes it required participants to switch providers, either to someone else in the practice, or an outside source. Word-of-mouth recommendations via support groups or other individuals with similar chronic illness experiences assisted in the process of finding competent providers. If that wasn't available, it required individuals to do research themselves to find someone with fibromyalgia experience; a task that was cumbersome and time-consuming, *"Finding a healthcare provider who can serve [both fibromyalgia and pregnancy] is very exhausting. And some people do not have the resources...to find very good healthcare providers."*

For participants who had healthcare providers who were not competent in fibromyalgia, it served as the main recommendation for how they could support this population better in the future. As one participant stated, *"The best way I think [healthcare providers] can actually support pregnant women with fibromyalgia is to know what they are doing and how to handle the whole situation."* Having a competent healthcare provider removes the pressure on individuals to advocate and educate others on what it entails. Healthcare providers should already be aware of fibromyalgia as a diagnosis and its associated symptoms and have recommendations for resources and alternative therapies. This would provide individuals a more comfortable and safe space, along with a piece of mind that their provider is giving them the best care possible.

Establishing trust was defined as a complex concept, marked by an individual's comfortability with a provider, belief that their provider will take care of them, maintain the patient's best interest, and keep the individual and their baby safe. This trust was something that took time to build, through active and passive actions on the provider's side. This included things such as the time spent in appointments, body language, active listening, and overall connection. If any of these factors wasn't present, such as

appointment times being very limited and the provider rushing the appointment, trust was harder to build. But if those things were there, trust was easier to establish, and patients were more comfortable.

They listen[ed] to my concerns about managing my symptoms during pregnancy and they walked with me to make sure I got the best kind of treatment. It was good to know I had someone to rely on...it gave me this sense of security. I felt like I was in good hands and nothing would go wrong.

Not all participants established robust trust with their healthcare providers. Some found it particularly challenging to do so when intersecting variables, such as their lack of competence in fibromyalgia, were present. This trust became the most referenced improvement for healthcare providers when working with future fibromyalgia patients. Participants recommended healthcare providers focus on listening and understanding their patients to establish this trust. Even if the healthcare provider doesn't know what fibromyalgia is, or hasn't experienced it firsthand, having someone lend a listening ear and validate their challenges is often just as useful. As one participant stated, *"Working on the trust and connection with the patient will go a long way."*

Another contributing factor to the patient-provider relationship was the *demographic and identity match*. Both racial and gender matches were important factors that made participants feel more comfortable. For example, one participant stated, *"The fact that she's a lady, I feel like she could resonate with me...and I feel like I understand her more."* Without an identity match, participants struggled to feel heard and supported, and some opted to find new providers altogether. For one participant, an African American woman matched with a White, male provider the struggle was evident from the start.

I couldn't resonate with him. Maybe it has something to do with the race, ethnicity, or stuff like that...I would love to not feel like that's the reason. [But] the body language tells me a lot and I couldn't just open up and be vulnerable and communicate with him. There was just no

connection. The vibe is not there and I couldn't just be myself around him. I couldn't just be vulnerable.

This individual sought out a new healthcare provider, one that would end up having a closer match to her, and she instantly felt more comfortable with her care.

Finding a provider with a demographic match, or having the ability to switch providers, was not always an easy task. For many, the option to pick and choose who they worked with wasn't available, or they didn't know it was available as an option. It was more likely the case that they were assigned a healthcare provider without their input. Ideally, patients would have more autonomy to choose their provider, and have diverse options available, so that comfortability, trust, and relatability may be experienced.

The final area of recommendation for healthcare providers from participants was encouraging an *individualized approach* to care. Each participant in this study recognized their unique experience of fibromyalgia and pregnancy; two experiences in and of themselves that are vastly different from person to person. An individualized approach to caring for a pregnant patient with fibromyalgia would take those considerations into account. Ideally, treatment would be tailored to support the symptoms experienced, keeping in mind the health and safety of the pregnant individual and the baby. For one participant, this looked like having their healthcare provider *"[help] me with health advice...and guidance and care throughout my pregnancy while [considering] my condition and everything. They always put everything I have into consideration."* This individualized care could also include referral to support groups or connection to resources that are salient to the individual. This personalized approach supports the feeling of safety for the participant and establishes trust in the process. Without an individualized approach, fibromyalgia symptoms may not feel acknowledged and may result in participants feeling like they are just a name on a list of patients a provider may see.

Healthcare providers played a significant role in pregnancy experiences with fibromyalgia. For some participants, strong and trusting relationships were built through their providers' competence, individualized approach, and general patient care. Almost all participants noted the gaps in care for pregnancy with fibromyalgia, including some experiencing fibromyalgia stigma, demographic mismatch with their provider, and rushed appointment times. Regardless of the variability, healthcare dynamics were salient for this sample and resulted in numerous contributions to how healthcare providers can improve upon their disabled pregnancy care.

Seeking and Receiving Social Support: A Multifaceted Experience

To identify the role other social support categories played in pregnancy for participants, and contribute to research questions two and three, the interview protocol inquired about the individual's top three social support areas and their impact on pregnancy. Social support areas varied widely among participants and included parents, partners, siblings and other family members, church members, doulas, support groups, and coworkers. The experience of social support regardless of its source, was multifaceted, encompassing areas of physical, financial, and emotional support. Data analysis produced four subthemes including (1) physical presence and daily support, (2) support impacting emotional well-being, (3) financial support, and (4) received support vs. desired support.

When participants were impacted by symptoms of fibromyalgia and pregnancy, help was often needed to engage in daily activities. Partners and close family members were frequently the ones to step in and assist in household chores such as cleaning, shopping, and cooking meals. For those who already had a child, this physical presence also included childcare or playing with the child so the participant could rest or keep movement to a minimum.

This physical presence was something many regarded as greatly appreciated. One participant described her partner as: *"like someone you would see in a lifetime movie...he carried a really heavy weight just trying to keep the house in order."* Physical support removed stress for many individuals so

they could focus their energy on taking care of themselves and managing symptoms. While this physical presence was common for many participants, there was a resounding desire for more daily support. Not everyone had family and friends that lived nearby so physical support wasn't as thorough or regular for those people. This often puts more physical support pressure on partners instead if they had one. Partners did not always have the time to engage in physical support, or participants felt bad about adding that layer to their daily lives, especially if their partner was the primary source of income for their household. Rather, many participants wished family members or other intimate social support individuals lived closer so they could engage in more daily support.

With the complex emotional challenges of fibromyalgia and pregnancy noted by participants, *support impacting emotional well-being* was regarded as highly impactful in several ways. Emotional support came in numerous forms including individuals being pseudo-advocates, willingness to learn, and providing hope and empowerment to the participants.

Many social support figures did not understand fibromyalgia before their loved one was diagnosed. Rather, the diagnosis was a learning process for both the individual getting diagnosed and everyone around them. As one participant stated, *"[Fibromyalgia] was new to both of us, but when we both found out, we were asking questions...he also like did research on his own and went online...to see how he can be supportive too."* One's willingness to learn, either through their own independent research, through active listening from their loved one with fibromyalgia, or through learning together, was regarded as incredibly valuable. For some loved ones, this diagnosis was just as shocking as it was for the one getting diagnosed.

From the name [of the diagnosis], my partner was kind of thinking that this is something very huge and something very terrible. But then when he was educated and told about it, he was calm and understood how to handle the whole thing and [be supportive].

The more invested social support figures were in learning about fibromyalgia, the more participants felt cared for and emotionally supported. This factor was valued just as much during pregnancy as well which was another experience filled with unknown changes and new experiences for many. Friends, family, and partners who maintained an open mind and sought out information to grow their understanding were more likely to provide the support desired by the pregnant individual.

A thorough involvement in fibromyalgia management and pregnancy also looked like social support figures serving as pseudo-advocates for the individual. One participant's partner was present for the entire diagnosis process and developed a strong understanding of what fibromyalgia entails. The participant's mother, however, continued to hold a disbelieving attitude towards the diagnosis, often dismissing the symptoms her daughter experiences and its impact on her pregnancy. In these instances, her partner often would step in: *"My husband told [my mom]...you've got to stop saying that it's not real."* Not only were these pseudo-advocacy efforts present in social settings, but other participants mentioned the value of loved ones doing so in healthcare and employment settings. This often looked like verifying that fibromyalgia was real, that its symptoms are in fact impactful, and that combined with pregnancy, things can be challenging for individuals.

These physical actions resulted in a lot of emotional well-being impacts for individuals, leaving many with feelings of hope and empowerment. Many participants spoke about the powerful nature of online communities for individuals going through similar situations. These groups were sometimes recommended by healthcare providers or other individuals in their lives or were found by the individuals themselves by doing simple internet research. One participant found an online community through their exploration after feeling like nobody around them really knew what they were going through. They stated, *"I see these people overcome challenges and obstacles. They make me believe in myself and feel like, okay I can actually do this. I became very optimistic."*

For another participant, support groups were a place to seek positive emotional support especially when symptoms were high.

On some days when [symptoms] are really extreme, I could cry out on the group, and someone would tell me, 'I've been there and it's going to get better' or 'Don't worry it's going to pass' or 'just keep going, you're strong,' and other similar words of encouragement. It was really helpful mentally.

Within these spaces, participants found role models in individuals who had experienced what they are currently experiencing, whether fibromyalgia- or pregnancy-related, or both. One participant *"Found someone who was like me [with fibromyalgia] with 2 kids now so...I [believed in] myself and felt like I can do it."* Role models were most referenced in online support group spaces but also existed in employment and other community settings.

These peer-based spaces also taught participants the skills of advocating for themselves. Social support members would provide recommendations on questions to ask or ways to explain fibromyalgia to others. They would also provide tips on managing pregnancy while having symptoms. Among all participants, whether this type of support was experienced or not, a resounding agreement was present that these skills would be useful for anyone going through pregnancy with fibromyalgia. It would be incredibly valuable for social support sources to recommend these spaces and provide skills around advocacy and empowerment. As one participant noted, *"We really don't have a lot of information on [fibromyalgia and pregnancy],"* which makes it challenging for individuals to advocate for themselves. Without information, individuals are left unable to advocate, not knowing what to advocate for, and feeling like they don't have a seat at the table for their treatment plan.

Participants noted that even if social support members couldn't engage in all of these areas of care, simply checking in on them often contributed to their emotional well-being. Checking in took many forms including in-person check-ins from partners, text messages or phone calls from family and friends,

or just quick check-ins from neighbors and community members. Checking in on fibromyalgia and pregnancy were both useful and showed participants that others were thinking about them. This also provided a sense of safety; that other people were there for them if needed.

In addition to physical and emotional support, *financial support* was a valued resource for participants. Financial support was most often received from partners and close family and friends. This included paying for necessities, medications, or other relevant needs. Of all the support covered by participants, financial support was the least likely to be received. Financial assistance was desired by many participants, with no preference for its source (i.e., family members, support groups, or community organizations). Not only would it be beneficial to the maintenance of fibromyalgia, but also to fund resources for pregnancy and parenting.

While many participants highlighted the ways social support and healthcare providers have positively contributed to their pregnancy with fibromyalgia, a discrepancy persisted when comparing it to what was truly desired. This resulted in the subtheme *received vs. desired support*. Not every participant felt comfortable voicing specific examples of what they wished social support figures could do. However, many mentioned their social support is “*doing their best.*” At the same time, this ‘best’ often left participants unfulfilled in certain areas, whether it being social support dismissing the challenges of fibromyalgia or its existence as a diagnosis, or wishing more family and friends lived closer to help.

At the same time, what is desired might be impossible for anyone to fill. As one participant highlighted, “*There was nothing anyone could do. Nobody could help me carry the baby. Nobody could help through the pain. I [felt this way] even though there were people there. They can’t take the pain away.*” There are some elements of pregnancy with fibromyalgia that just can’t be supported physically, mentally, or financially, leaving the individual to manage on their own. None of the participants were

able to put into words what could assist them in these moments. Rather, they recognized the embodied experience nobody can understand but the person going through it.

Social support was a multifaceted experience among participants, encompassing physical, emotional, and financial variables. Support was received from a variety of sources, including partners, family members, friends, and more. Each participant had varied experiences with each area, but everyone regarded each as uniquely important and necessary. Simultaneously, it was acknowledged that this gap between what is received and desired is present and may not be able to be fully bridged.

Conclusion

This chapter contained the results of the eight interviews collected by the research team. Each of the eight participants held unique characteristics, including the number of pregnancies, geographic location, and salient experiences with fibromyalgia pregnancy. Through these interviews, major themes and subthemes were identified that answered all three of the research questions. Themes one and two provided insight into the experience of fibromyalgia before, and during, pregnancy. Themes three and four answered the remaining research questions, highlighting the various ways healthcare providers, friends, family members, and others can influence the pregnancy experience in positive and negative ways. While much of the support received by these participants was positive, they provided examples of how these social influences could improve including more education and training on fibromyalgia, connection to resources, and financial assistance.

Chapter 5: Discussion

This study sought to provide insight into the experiences of pregnancy with fibromyalgia and the role social support can, and does, play. Eight participants with fibromyalgia who experienced pregnancy within the last year engaged in semi-structured interviews designed to answer three research questions: (1) how do participants describe how their fibromyalgia impacts their pregnancy experience, (2) how do participants describe how social influences, including healthcare provider(s), family, friends, peers, strangers, and others, impact their pregnancy experiences with fibromyalgia, and (3) how do participants describe how social influences, including healthcare provider(s), family, friends, peers, strangers, and others, could improve upon how they support pregnancy experiences with fibromyalgia?

This chapter summarizes the main findings and interpretations from the data analysis. Additionally, implications for specific groups of individuals including rehabilitation counselors, healthcare professionals, and social support personnel, are discussed. Limitations to this study and future research recommendations conclude the chapter.

Fibromyalgia: It's Real

All participants in this study highlighted the experience of having fibromyalgia. While it looked different for each participant, it was regarded as something real that wasn't always received as such. Participants discussed the dismissal of symptoms in numerous contexts including healthcare settings and among family members and friends. Their experiences support previous research that highlights fibromyalgia being a highly stigmatized condition (Hamma et al., 2016). In this study, this looked like family members not believing the condition was real, healthcare providers dismissing the severity of symptoms, and many not knowing what fibromyalgia was at all. The implications of these experiences were severe. It impacted not only individual's emotional well-being but also their ability to build trusting relationships with healthcare providers. All participants desired additional conversation and

acknowledgment of fibromyalgia as a real, chronic condition among everyone including healthcare providers and others.

Fibromyalgia and Pregnancy: A Unique Experience

Pregnancy with fibromyalgia was described as a varied and complex experience, with notable symptoms of pain, discomfort, and fatigue. For most participants, these symptoms of chronic and unpredictable pain were present before pregnancy and often worsened during the pregnancy's duration, which supports previous research findings (Genc et al., 2019). As with any pregnancy, unique symptomology occurred for some participants including morning sickness, swelling, and preeclampsia. Pregnancy also brought about many physical changes for participants that resulted in additional weight and strain on already sensitive joints. These symptoms left many feeling additional fatigue and discomfort. Managing the new symptoms that arose during pregnancy was complex as many medications for management weren't safe during pregnancy. Like the recommendations noted in the literature on non-pharmaceutical interventions (Mallick-Searle, 2022), participants sought and engaged in new interventions including gentle stretching, massage, and physical therapy.

Minimal research has examined the decision-making process to become pregnant for individuals with fibromyalgia, making the experiences noted by participants some of the first of its kind. The decision to become pregnant was one many participants did not take lightly. Fibromyalgia symptoms, along with other personal factors, made deciding to become pregnant a challenging one for some. Feelings of fear of the unknown and reluctance to do it again if they'd been pregnant in the past were salient. For others, fibromyalgia did not impact decision-making at all. Some participants were certain they would have children, and/or were not concerned about what the experience would entail. For many of the participants, the decision to become pregnant was one with nuance and thought; it wasn't one made lightly. Having experienced a pregnancy in the past impacted decision-making as well, often leaving individuals feeling more prepared but still reluctant.

Having fibromyalgia, and experiencing a pregnancy with it, held important mental health implications for several participants. Participants noted several relevant mental health experiences, both diagnosed and undiagnosed, most notably anxiety and depression. This supports previous research that has examined mental health experiences in individuals with fibromyalgia (Toussaint et al., 2017). Having a chronic condition with symptoms that can emerge without warning, often leaves participants feeling anxious about onset. Simultaneously, when symptoms are heightened, it was easy for many participants to feel utterly defeated and depressed. For many participants in this study, anxiety and depression symptoms persisted into pregnancy. Minimal research has examined the mental health of pregnant individuals with fibromyalgia. However, this study does support research on the mental health of other chronic health conditions experienced during pregnancy (Abu-Zaid et al., 2023).

The Role of Healthcare Providers in Fibromyalgia Pregnancy

Participants in this study highlighted the various ways healthcare providers were both useful in pregnancy management with fibromyalgia, and where they lacked competence and care. Previous research has highlighted healthcare providers' lack of preparation when working with pregnant individuals with physical disabilities (Hall et al., 2018), mostly due to minimal training and education around such topics. The healthcare providers that worked with the participants in this study varied in their experience with chronic health conditions. Some had experience with previous patients with fibromyalgia, whereas others had not. Regardless, many participants reported feeling stigma from their healthcare provider(s) about their diagnosis; a historical trend that seems to have only diminished a little (Homma et al., 2016). This directly influenced participants' ability to trust their provider and build a supportive relationship. Further, if healthcare providers did not have competence in fibromyalgia, it left participants needing to advocate for themselves, which was a task not everyone felt comfortable or prepared for.

Participants had more to say in areas where healthcare providers could improve their care for diverse and disabled populations. In addition to competence in fibromyalgia, participants deeply desired an individualized approach to care and one that allowed trust to be established. The patient-provider relationship is extremely impactful on maternal well-being (Lerman et al., 2007). This was supported by many participants who spoke volumes about the impact the trust in their relationship with their provider played in their pregnancy. When the trust was established, participants felt more comfortable, less concerned, and had lower levels of stress. Without trust, emotional well-being was more likely to be negatively affected and led some participants to switch providers altogether.

When thinking about healthcare experiences for this population, notice should be taken regarding the sample's demographic characteristics. Some participants in the sample noted the significance of a demographic match between themselves and their healthcare provider. When demographics of race and gender-matched, participants tended to feel more heard, supported, and comfortable. While the interview protocol did not include questions that specifically inquired about racial identity, the intersection of disability and race was present for all participants. How salient it felt to them internally and within their relationships with others, was not part of data analysis but remains an important consideration for future implications.

The Role of Social Support in Fibromyalgia Pregnancy

Social support played an essential role in participants' physical and emotional well-being, aligning closely with previous research on social support significance (Stapleton et al., 2012; Renbarger et al., 2021). Physically, close family, friends, and partners provide support with daily activities, including assisting with chores, providing childcare to other children in the home, and transporting the individual to doctor appointments. This assistance was deeply impactful to participants when symptomology was heightened, and they couldn't engage in these activities on their own. It left participants with some peace of mind that the home was being maintained and they weren't falling behind on tasks.

Just as significant to participants was the emotional support received. Emotional support varied from small things such as family and friends checking in on them to their overall willingness to learn about fibromyalgia and pregnancy. This support provided participants with a feeling of hope that they would get through whatever challenge they were experiencing. It also left participants feeling empowered in their autonomy, a feeling not everyone received but that was desired by many. Some instances of emotional support impacted participants negatively, particularly when individuals dismissed participants' fibromyalgia diagnosis and symptoms. Overall, a vast majority of emotional support was positive and regarded as very influential to the pregnancy experience.

The final area of support individuals experienced was financial. Close family members and partners were the most referenced source of financial support. Financial support was the least satisfactory area of support; many participants spoke about their desire for additional financial assistance to help cover the costs of medication, healthcare, and reproductive needs.

Financial support, along with emotional and physical support, all experienced a level of discrepancy between what was received and what participants truly desired. While social support providers 'tried their best,' it wasn't always enough. Family members might check in, but still not believe that fibromyalgia is a real diagnosis. Or partners were there physically but didn't have time to attend to the emotional needs of the pregnant individual. At the same time, participants highlighted the difficulty of truly meeting every need they may have. Nobody will be able to take away the fibromyalgia symptoms or the physical and mental weight of pregnancy.

Study Implications

This study holds numerous implications for individuals who may interact with diverse pregnant individuals with fibromyalgia and/or other chronic health conditions. Implications are most salient to three groups including rehabilitation counselors and healthcare professionals.

Expanding Discussion for Rehabilitation Counselors

Reproductive access for individuals with disabilities is a salient and necessary topic for rehabilitation counselors (Matkin & Smedema, 2024). The literature reviewed for this study highlighted the significant lack of discussion of reproductive topics for rehabilitation counselors with much of the literature coming from other disciplines. As a field that values the independence and autonomy of individuals with disabilities, this study is salient to growing awareness on reproductive experiences.

Educating rehabilitation counselors (RCs) must be the first step to expanding their role in supporting individuals with disabilities in receiving equitable reproductive experiences. For Certified Rehabilitation Counselors (CRCs) and other individuals in accredited counseling programs, no educational accreditation standard or ethical principle exists around reproductive topics (CACREP, 2024; CRCC, 2023; Matkin & Smedema, 2024). Discussion must take place around how to adapt and expand standards to fit reproductive topics. Additional research on what education is most impactful and in what formats, whether it be through master's programs or continuing education, will be useful. Expanded education and training on these topics will ensure that RCs are prepared to support diverse individuals in their reproductive needs and provide them with the necessary skills to advocate for equitable access in relevant contexts for their clients.

This study unintendedly highlighted a significant area of rehabilitation counseling research: adjustment to disability. Numerous models have been proposed to conceptualize the adjustment to disability process (see Livneh et al., 2014, for a review). While not the main purpose of this study, participants provided a small narrative on some aspects of the adjustment process for individuals with fibromyalgia. While social support was the main area of inquiry, participants discussed several important areas of the adjustment process including healthcare providers' perception of fibromyalgia, the diagnosis process, and the important ways social support influenced the adjustment process. Applying a disability adjustment model to individuals who may be simultaneously engaging in reproductive activities, such as

pregnancy, may help rehabilitation counselors conceptualize individuals and their experiences most holistically.

Healthcare Providers and Equitable Reproductive Care Experiences

Healthcare providers play a salient role in pregnancy. Serving as the source of medical management for patients, they have a large influence on the physical and emotional impact of pregnant individuals. This study highlighted the ways in which some healthcare providers have managed to do so successfully, such as those who engage in active listening, provide individualized care, and take their time during appointments. Others, however, seem to remain stuck in ableist ways, dismissing fibromyalgia symptoms, spending little time growing trust in their patients, and remaining unaware of support for disabled individuals. Almost all participants expressed a desire for healthcare providers to be more competent in fibromyalgia, pointing to the need for additional education and training. Additionally, healthcare providers should be cognizant of other important intersecting identities of patients with whom they may work. This includes awareness of and attention to the unique identities (e.g., gender and race/ethnicity) that may impact access to care, decision-making processes, and willingness to trust the healthcare system.

Future Research

With this research being the first of its kind to examine social support during pregnancy for fibromyalgia, numerous areas for further research are evident. The experience of fibromyalgia and pregnancy is complex and varied, as seen by the small sample of this study. Additional research on a larger scale may provide a deeper understanding of the general experience of fibromyalgia and fibromyalgia while pregnant, including salient symptoms and experiences.

The decision-making process about pregnancy also varied among this sample, with a mix of reluctance, various levels of preparedness, and certainty. Prior research has left out individuals with chronic health conditions in samples that explore what pregnancy decision-making looks like (O'Connor-

Terry & Harris, 2021; Tarasoff, 2017; Mallick-Searle, 2022). Additionally, research has yet to explore how different variables, such as symptomology, social support, or access to resources, are valued when making that decision. An analysis of these variables and others may help identify how individuals with chronic health conditions make decisions about their reproductive future and areas that may benefit from support.

While this study holds implications for rehabilitation counselors, further research is needed to explore the level of preparation and comfortability in reproductive endeavors for practitioners. First, it will be important to identify where in rehabilitation counseling contexts reproductive-related topics arise. This information will help contribute to educational interventions and relevant ethical implications. Second, the literature review, as well as findings from this study, point to negative attitudes healthcare professionals and social support individuals hold towards individuals with disabilities, particularly those with fibromyalgia, who are engaging in reproductive autonomy. Do rehabilitation counselors hold similar biases or preconceived notions toward this population or topic? If so, determining appropriate interventions will be necessary.

The literature highlighted the various research studies that have already been done on healthcare providers' preparation for working with patients with disabilities (Smeltzer et al., 2018; Walsh-Gallagher et al., 2013). However, few studies have examined populations with nonapparent, or chronic health condition populations (Matkin & Smedema, 2024). This study has begun to contribute to the understanding of chronic health condition experiences in reproductive spaces, but more is needed. Examining how healthcare providers feel about their competence, level of preparation, and comfortability, with this population may highlight areas needing further education. This additional research would not only assist in the preparation of healthcare providers but also contribute to the reproductive care individuals with disabilities receive.

Like healthcare providers, this research only examined the perspective of the individual with fibromyalgia and pregnancy. The perspective of social support providers, including family members, friends, partners, and others, remains unknown. Previous research on pregnancy response for disabled individuals has utilized samples with physical, or apparent, disability types (Matkin & Smedema, 2024). Research examining the difference between previous research and responses for non-apparent, chronic illness categories, would provide insight to help understand social support dynamics. Continuing to explore the perspective of social support providers may support their understanding of helping loved ones and identify areas where advocacy or education would be fruitful.

Limitations of the Study

The present study holds limitations that should be acknowledged. The primary limitation of the study lies in recruitment and data collection. While efforts were made to recruit participants in the most community-based and accessible way through Facebook, social media holds important limitations. Posting on Facebook requires scholars to utilize their accounts of choice, making their online persona incredibly salient (Sikkens et al., 2017). Efforts were made to ensure the researcher's personal Facebook account was mostly private and what was visible was professional, however, there is no telling if it impacted individuals' willingness to fill out the screening questionnaire. Additionally, evidence shows that Facebook can be a challenging recruiting method when seeking out a reflective sample of the larger community (Archer-Kuhn et al., 2022). While this study was not meant to be generalized, our sample may not be as diverse as it could have been should a different recruitment method have been used.

While accessibility was at the forefront of this study, it could be argued that without the confirmation of participants visually (e.g., opting to turn cameras on in Zoom), our data collection holds limitations in its ability to verify the identities of participants. The researcher worked to increase reliability when possible, including having participants review their screening questionnaire responses

and confirm their location within the United States. However, it's impossible to fully confirm who the individuals truly were.

This study sought to understand pregnancy experiences specifically, with no attention paid to the conception of pregnancy, or birth experience of participants. The conception of pregnancy is a topic discussed on a limited basis in the scientific literature but is impactful to pregnancy, nonetheless. It remains unknown if any of the participants intended to become pregnant in the first place, and if it involved any medical intervention (e.g., in vitro fertilization (IVF)). Literature has highlighted birth experience and the impact it can have on outcomes. For individuals with disabilities, this historically has meant healthcare providers frequently disregard their preferences, resulting in undesirable birthing experiences (Horner-Johnson et al., 2017; Darney et al., 2017; Kone et al., 2022). This has the potential to impact one's recovery postpartum and overall feelings toward their pregnancy. Some participants voluntarily referenced their birth experiences, but the majority did not. Without knowledge of their birth, it remains unclear if their reported pregnancy experience was impacted by their birth experience. Additional research on the experience of birth for individuals with fibromyalgia or other non-apparent disabilities will be beneficial in determining its impact.

Lastly, this study engaged in a semi-structured interview method, which may have limited the information received from participants. In addition to inquiring about birth experience and conception, it would have been fruitful to ask about intersecting identities of participants and how they perceived it to impact their pregnancy. Was it their identities that drew them to participate in the study in the first place? While we hypothesize participants did so to finally be heard in their reproductive experiences, this can't be confirmed without their input. A less structured interview methodology may have provided space for participants and the researcher to discuss these important topics further.

Conclusion

This study was the first of its kind to examine social support for individuals with fibromyalgia during pregnancy. Through thematic analysis, key factors of fibromyalgia and pregnancy were identified, including the significant roles healthcare providers and social support providers can play in the experience. Rehabilitation counselors have historically not been part of the conversation of reproductive healthcare experiences for disabled individuals but have the potential to play a unique role including significant advocacy work. This advocacy could help improve healthcare experiences for individuals with disabilities and help social support figures in the reproductive care experience. Additional research is needed to comprehensively understand reproductive healthcare experiences for individuals with unique disabilities and other intersecting identities so that further necessary changes can be identified.

References

- Ablin J. N., Gurevitz I., Cohen H., Buskila D. (2011). Sexual dysfunction is correlated with tenderness in female fibromyalgia patients. *Clinical and Experimental Rheumatology*, 29, 44-48.
- Abu-Zaid, A., Gari, A., Alsharif, S. A., Alshahrani, M. S., Khadawardi, K., Ahmed, A. M., Baradwan, A., Bukhari, I. A., Alyousef, A., Alharbi, F. S., Saleh, S. A. K., Adly, H. M., Abuzaid, M., & Baradwan, S. (2023). Exploring the impact of chronic medical conditions on maternal mental health: A National Inpatient Sample analysis. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 289, 42–47. <https://doi.org/10.1016/j.ejogrb.2023.08.011>
- Alhusen, J., Lyons, G., Laughon, K., & Hughes, R. (2023). Intimate partner violence during the perinatal period by disability status: Findings from a United States population-based analysis. *Journal of Advanced Nursing*, 79(4). <https://doi.org/10.1111/jan.15340>
- Altunag, S., & Calbayram, N.C. (2016). Teaching menstrual care skills to intellectually disabled female students. *Journal of Clinical Nursing*, 25, 1962-1968. <https://doi.org/10.1111/jocn.13215>
- American Academy of Pediatrics [AAP] (2017). *Guidelines for Perinatal Care* (8th ed.). Elk Grove, IL: American Academy of Pediatrics.
- American College of Obstetrics and Gynecology. (2019). *Abortion can be medically necessary*. www.acog.org/news/news-releases/2019/09/abortion-can-be-medically-necessary
- American Psychology Association [APA] (2023). *Definition of social support*. <https://dictionary.apa.org/social-support>
- Americans with Disabilities Act [ADA] (1990), 42 U.S.C. 12101, Pub. Law 101-336.
- Anderson, K. (2019, June 25). Yes, people like me can have babies. *Today's Parent*. <https://www.todaysparent.com/family/special-needs/yes-people-like-me-can-have-babies/>
- Archer-Kuhn, B., Beltrano, N. R., Hughes, J., Saini, M., & Tam, D. (2022). Recruitment in response to a

pandemic: Pivoting a community-based recruitment strategy to Facebook for hard-to-reach populations during COVID-19. *International Journal of Social Research Methodology*, 25(6), 797-808.

<https://doi.org/10.1080/13645579.2021.1941647>

Bartholomew, K., Henderson, A., & Marcia, J. (2000). Coded semistructured interviews in social psychological research in Reis, H.T., & Judd, C.M. (Eds.) *Handbook of research methods in social and personality psychology*. Cambridge University Press.

Barker, K. (2009). *The fibromyalgia story: Medical authority and women's worlds of pain*. Temple University Press.

Battulga, B., Benjamin, M. R., Chen, H., & Bat-Enkh, E. (2021). The impact of social support and pregnancy on subjective well-being: A systematic review. *Frontiers in psychology*, 12, 710858.

<https://doi.org/10.3389/fpsyg.2021.710858>

Becker, H., Andrews, E., Walker, L., & Phillips, C. (2021). Health and well-being among women with physical disabilities after childbirth: An exploratory study. *Women's Health Issues*, 31(2), 140-

147. <https://doi.org/10.1016/j.whi.2020.10.007>

Bedaso, A., Adams, J., Peng, W., & Sibbritt, D. (2021). The relationship between social support and mental health problems during pregnancy: A systematic review and meta-analysis. *Reproductive Health*, 18(162).

<https://doi.org/10.1186/s12978-021-01209-5>

Berk, A. L., Pickett, A., Kusters, I. S., & Gregory, M. E. (2024). Healthcare experiences of Black patients during and after pregnancy: A needs assessment for provider training to improve quality of care.

Journal of Racial and Ethnic Health Disparities, 11(2), 992-1004. <https://doi.org/10.1007/s40615-023-01579-5>

Berridge, C., Ganti, A., Taylor, D., Rain, B., & Bahl, S. (2022). Infusing MSW programs with disability studies and disability justice: How to create explicit curriculum. *Journal of Social Work Education*,

<https://doi.org/10.1080/10437797.2022.2029309>

- Bernabe, A.J. (2020). Woman with spinal cord injury shares pregnancy journey to bring visibility to people in wheelchairs: 'Never say never.' *Good Morning America*.
<https://www.goodmorningamerica.com/living/story/woman-spinal-cord-injury-shares-pregnancy-journey-bring-74632250>
- Bernell, S., & Howard, S. W. (2016). Use Your Words Carefully: What Is a Chronic Disease?. *Frontiers in Public Health*, 4, 159. <https://doi.org/10.3389/fpubh.2016.00159>
- Bernstein J. (2016). Not the Last Word: Fibromyalgia is Real. *Clinical orthopaedics and related research*, 474(2), 304–309. <https://doi-org.ezproxy.library.wisc.edu/10.1007/s11999-015-4670-6>
- Bloor, D., Ballantyne, C., Gillespie-Smith, K., Wilson, C., & Hendry, G. (2022). Investigating the challenges of teaching sex education to autistic learners: A qualitative exploration of teachers' experiences. *Research in Developmental Disabilities*, 131. <https://doi.org/10.1016/j.ridd.2022.104344>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. <https://psycnet.apa.org/doi/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research*. SAGE Publishing.
- Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counseling Psychotherapy Research*, 21, 37-47. <https://doi.org/10.1002/capr.12360>
- Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13(2), 201-216. <https://doi.org/10.1080/2159676X.2019.1704846>
- Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, 9(1), 3-26. <https://psycnet.apa.org/doi/10.1037/qap0000196>
- Braun, V., & Wilkinson, S. (2003). Liability or asset? Women talk about the vagina. *Psychology of Women Section Review*, 5, 28-42.

- Brown, R. L. (2014). Psychological distress and the intersection of gender and physical disability: Considering gender and disability-related risk factors. *Sex Roles*, 71, 171-181.
<https://psycnet.apa.org/doi/10.1007/s11199-014-0385-5>
- Brown, H., Chen, S., Vigod, S., Guttmann, A., Havercamp, S., Parish, S., Tarasoff, L., & Lunskey, Y. (2022). A population-based analysis of postpartum acute care use among women with disabilities. *American Journal of Obstetrics & Gynecology*, 4(3). <https://doi.org/10.1016/j.ajogmf.2022.100607>
- Brown, H., Dennis, C.L., Kurdyak, P., & Vigod, S. (2019). A population-based study of the frequency and predictors of induced abortion among women with schizophrenia. *The British Journal of Psychiatry*, 215. <https://doi.org/10.1192/bjp.2018.262>
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability*, 41(2). <https://doi.org/10.3109/13668250.2016.1153052>
- Centers for Disease Control [CDC]. (2021). New ICD-10-CM code for post-COVID conditions, following the 2019 novel coronavirus (COVID-19). <https://www.cdc.gov/nchs/data/icd/announcement-new-icd-code-for-post-covid-condition-april-2022-final.pdf>
- Center for Disease Control and Prevention [CDC] (2022a). *About Chronic Diseases*.
<https://www.cdc.gov/chronicdisease/about/index.htm>
- Centers for Disease Control and Prevention [CDC] (2022b). *Disability and Health Data System (DHDS)*.
<http://dhds.cdc.gov>
- Center for Disease Control and Prevention [CDC] (2022c). *Reproductive Health*.
<https://www.cdc.gov/reproductivehealth/drh/about-us/index.htm>
- Center for Intersectional Justice [CIJ] (2023). *What is intersectionality*.
<https://www.intersectionaljustice.org/what-is-intersectionality>

Center for Reproductive Rights (2022). *The World's Abortion Laws*.

<https://reproductiverights.org/maps/worlds-abortion-laws/>

Chan, F., Gelman, J.S., Ditchman, N., Kim, J., Chiu, C. (2009). The world health organization ICF model as a conceptual framework of disability in Chan, F., Cardoso, E.D.S., and Chronister, J. (Eds.). *Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation*. Springer Publishing.

Chandrasekaran, S., Key, K., Ow, A., Lindsey, A., Chin, J., Goode, B., Dinh, Q., Choi, I., & Yeon, S. (2023). The role of community and culture in abortion perceptions, decisions, and experiences among Asian Americans. *Frontiers in Public Health*, 10. <https://doi.org/10.3389/fpubh.2022.982215>

Chen, L., Pan, W.L., Mu, P.F., & Gau, M.L. (2023). Birth environment interventions and outcomes: A scoping review. *Birth Issues in Perinatal Care*, (00), 1-14. <https://doi.org/10.1111/birt.12767>

Cheng, E., Rifas-Shiman, S., Perkins, M., Rich-Edwards, J.W., Gillman, M., Wright, R., & Taveras, E. (2016). The influence of antenatal partner support on pregnancy outcomes. *Journal of Women's Health*, 25(7). <https://doi.org/10.1089/jwh.2015.5462>

Chronic Conditions Warehouse [CCW] (2022). *Impact of Transition from 27 to 30 CCW Chronic Conditions*. CCW.

Chronic Conditions Warehouse [CCW] (2023). *30 CCW Chronic Conditions Algorithms*. CCW.

Clouse, W. (2020). The forced sterilization of Black women as reproductive injustice. *Ramifications*, 2(1). <https://digitalcommons.wcupa.edu/ramifications/vol2/iss1/4>

Cohen, A. (2016). *Imbeciles: The Supreme Court, American eugenics, and the Steralization of Carrie Buck*. New York, NY: Penguin Books.

Coleman, E., Radix, A. E., Bouman, W.P., Brown, G.R., de Vries, A. L. C., Deutsch, M. B., Ettner, R., Fraser, L., Goodman, M., Green, J., Hancock, A. B., Johnson, T. W., Karasic, D. H., Knudson, G. A., Leibowitz, S. F., Meyer-Bahlburg, H. F.L., Monstrey, S. J., Motmans, J., Nahata, L., & Arcelus, J.

- (2022). Standards of Care for the Health of Transgender and Gender Diverse People, Version 8. *International Journal of Transgender Health*, 23(S1), S1-S260.
<https://doi.org/10.1080/26895269.2022.2100644>
- Commission on Rehabilitation Counselor Certification [CRCC] (2023). *Code of Professional Ethics for Certified Rehabilitation Counselors*. Schaumburg, IL: CRCC.
- Commodari, E., La Rosa, V.L., & Nania, G.S. (2022). Pregnancy, motherhood and partner support in visually impaired women: A qualitative study. *International Journal of Environmental Research and Public Health*, 19(4308). <https://doi.org/10.3390/ijerph19074308>
- Council for Accreditation of Counseling and Related Educational Programs [CACREP] (2024). 2024 CACREP Standards. Alexandria, VA: CACREP.
- Courtney-Long, E. A., Carroll, D., Zhang, Q., Stevens, A., Griffin-Blake, S., Armour, B., & Campbell, V. (2015). Prevalence of Disability and Disability Type Among Adults—United States, 2013. *MMWR. Morbidity and mortality weekly report*, 64(29), 777–783.
<https://doi.org/10.15585/mmwr.mm6429a2>
- Creswell, J. (2013). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (3rd Ed.). Thousand Oaks, CA: SAGE Publications, Inc.
- Curtiss, S.L., & Ebata, A.T. (2016). Building capacity to deliver sex education to individuals with autism. *Sexuality and Disability*, 34, 27-47. <https://doi.org/10.1007/s11195-016-9429-9>
- Darney, B., Biel, F., Quigley, B., Caughey, A., Horner-Johnson, W. (2017). Primary cesarean delivery patterns among women with physical, sensory, or intellectual disabilities. *Women's Health Issues*, 27(3), 336-344. <https://doi.org/10.1016/j.whi.2016.12.007>
- Deierlein, A., Antoniak, K., Chan, M., Sassano, C., & Stein, C. (2021). Pregnancy-related outcomes among women with physical disabilities: A systematic review. *Paediatric and Perinatal Epidemiology*, 35, 758-778. <https://doi.org/10.1111/ppe.12781>

DeSantis, L., & Ugarriza, D. (2000). The concept of themes as used in qualitative nursing research.

Western Journal of Nursing Research, 22, 351-372.

Disabled Parenting Project. (2023). *About Us*. <https://disabledparenting.com/about-us/mission-statement/>

Dobbs v. Jackson, No. 19-1392, WL 2276808 (2022).

DONA International. (2014). *Code of ethics for birth doulas*.

http://www.dona.org/aboutus/code_of_ethics_birth.php

Doyle, K., Sionean, C., Paz-Bailey, G., Hollis, N.D., Kanny, D., Wejnert, C. (2020). High prevalence of disability and HIV risk among low socioeconomic status urban adults, 17 U.S. cities. *Disability and Health Journal*, 13. <https://doi.org/10.1016/j.dhjo.2019.100834>

Drummond, J.D., & Brotman, S. (2014). Intersecting and embodied identities: A queer woman's experience of disability and sexuality. *Sex and Disability*, 32, 533-539.

<https://doi.org/10.1007/s11195-014-9382-4>

East, L., & Orchard, T. (2014). Somebody else's job: Experiences of sex education among health professionals, parents and adolescents with physical disabilities in southwestern Ontario.

Sexuality and Disability, 32, 335-350. <https://doi.org/10.1007/s11195-013-9289-5>

Eiler, E.C. & D'Angelo, K. (2020). Tensions and connections between social work and anti-capitalist disability activism: disability rights, disability justice, and implications for practice. *Journal of Community Practice*, 28(4), 356-372. <https://doi.org/10.1080/10705422.2020.1842278>

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(3), 215–229.

<https://doi.org/10.1348/014466599162782>

- Engelman, A., Valderama-Wallace, C., Nouredini, S. (2019). State of the profession: The landscape of disability justice, health inequities, and access for patients with disabilities. *Advances in Nursing*, 42(3), 231-242. <https://doi.org/10.1097/ANS.0000000000000261>
- Fleming P.J., Lopez. W., Ledon, C., Llanes, M., Waller, A., Harner, M., Martinez, R., & Kruger, D. (2019). 'I'm going to look for you and take your kids': Reproductive justice in the context of immigration enforcement. *PLoS ONE*, 14(6). <https://doi.org/10.1371/journal.pone.0217898>
- Freimuth, V., Quinn, S.C., Thomas, S., Cole, G., Zook, E., & Duncan, T. (2001). African Americans' views on research and the Tuskegee syphilis study. *Social Science and Medicine*, 52, 797-808.
- Fugard, A., & Potts, H. W., (2019). Thematic Analysis, In P. Atkinson, S. Delamont, A. Cernat, J.W. Sakshaug, & R.A. Williams (Eds.), *SAGE Research Methods Foundations*. <https://doi.org/10.4135/9781526421036858333>
- Genç, H., Atasever, M., Duyur Çakit, B., Seval, M., & Koç, A. (2017). The Effects of Fibromyalgia Syndrome on Physical Function and Psychological Status of Pregnant Females. *Archives of rheumatology*, 32(2), 129–140. <https://doi.org/10.5606/ArchRheumatol.2017.6028>
- Grabois, E. (2001). Guide to getting reproductive healthcare services for women with disabilities under the Americans with Disabilities Act of 1990. *Sexuality and Disability*, 19(3).
- Granero-Molina, J., Matarín Jiménez, T. M., Ramos Rodríguez, C., Hernández-Padilla, J. M., Castro-Sánchez, A. M., and Fernández-Sola, C. (2018). Social support for female sexual dysfunction in fibromyalgia. *Clinical Nursing Research*, 27(3), 296-314. <https://doi.org/10.1177/1054773816676941>
- Gold, R.B. (2005). The implications of defining when a woman is pregnant. *The Guttmacher Report on Public Policy*, 8(2). <https://www.guttmacher.org/gpr/2005/05/implications-defining-when-woman-pregnant>

- Goli, S., Rahimi, F., & Goli, M. (2022). Experiences of teachers, educators, and school counselors about the sexual and reproductive health of educable intellectually disabled adolescent girls: A qualitative study. *Reproductive Health*, 19(96). <https://doi.org/10.1186/s12978-022-01397-8>
- Greenhouse, L., & Siegel, R. B. (2011). Before (and after) roe v. wade: new questions about backlash. *Yale Law Journal*, 120(8), 2028-2087. <http://hdl.handle.net/20.500.13051/3596>
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications, Inc.
- Guest, G., Bunce, R., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
<https://doi.org/10.1177/1525822X0527990>
- Gupta U. C. (2013). Informed consent in clinical research: Revisiting few concepts and areas. *Perspectives in clinical research*, 4(1), 26–32. <https://doi.org/10.4103/2229-3485.106373>
- Gustafson, D., & Brunger, F. (2014). Ethics, “vulnerability,” and feminist participatory action research with a disability community. *Qualitative Health Research*, 24(7).
<https://doi.org/10.1177/1049732314538122>
- Guthrie, R.V. (2004). *Even the rate was white: A historical view of psychology* (2nd Ed.). Boston, MA: Allyn and Bacon Classics in Psychology.
- Guttmacher Institute. (2022). *Facts on American teens’ sources of information about sex*. Retrieved July 22, 2022 from: <http://www.guttmacher.org/pubs/FB-Teen-Sex-Ed.html>
- Hall, K., Sales, J.M., Komro, K., & Santelli, J. (2016). The state of sex education in the United States. *Journal of Adolescent Health*, 58(6), 595-597. <https://doi.org/10.1016/j.jadohealth.2016.03.032>
- Hassan, A., Hirz, A., Yates, L., & Hing, A. (2023). Rebuilding a reproductive future informed by disability and reproductive justice. *Women’s Health Issues*, 33(4), 345-348.
<https://doi.org/10.1016/j.whi.2023.04.006>

- Hassan, A., Yates, L., Hing, A., Hirz, A., & Hardeman, R. (2022). Dobbs and disability: Implications of abortion restrictions for people with fibromyalgias. *Health Services Research, 58*(1), 197-201. <https://doi.org/10.1111/1475-6773.14108>
- Hawkins, M., Misra, D., Zhang, L., Price, M., Dailey, R., & Giurgescu, C. (2021). Family involvement in pregnancy and psychological health among pregnant black women. *Archives of Psychiatric Nursing, 35*(1), 42-48. <https://doi.org/10.1016/j.apnu.2020.09.012>
- Hayes, D., & Singh, A., (2023). *Qualitative research in education and social sciences* (2nd Ed.). Solana Beach, CA: Cognella Academic Publishing.
- Heppner, P., Wampold, B., Owens, J. Wang, K., & Thompson, M. (2015). *Research design in counseling*. Cengage Learning.
- Hillard, P. (2018). Contraception for women with intellectual and developmental disabilities. *Obstetrics & Gynecology, 132*(3), 555-558. <https://doi.org/10.1097/AOG.0000000000002814>
- Homma, M., Ishikawa, H., & Kiuchi, T. (2016). Association of physicians' illness perception of fibromyalgia with frustration and resistance to accepting patients: A cross-sectional study. *Clinical Rheumatology, 35*, 1019-1027.
- Horner-Johnson, W., Akobirshoev, I., Amutah-Onukagha, N.N., Slaughter-Acey, J., & Mitra, M. (2021). Preconception health risks among U.S. women: Disparities at the intersection of disability and race or ethnicity. *Women's Health Issues, 31*, 65-74. <https://doi.org/10.1016/j.whi.2020.10.001>
- Horner-Johnson, W., Biel, F., Caughey, A., Darney, B. (2019). Differences in prenatal care by presence and type of maternal disability. *American Journal of Preventative Medicine, 56*(3), 376-382. <https://doi.org/10.1016/j.amepre.2018.10.021>
- Horner-Johnson, W., Klein, K., Campbell, J., & Guise, J.M. (2022). "It would have been nice to have a choice": Barriers to contraceptive decision-making among women with disabilities. *Women's Health Issue, 32*(3). <https://doi.org/10.1016/j.whi.2022.01.001>

- Horner-Johnson, W., Kulkarni-Rajasekhara, S., Darney, B. G., Dissanayake, M., & Caughey, A. B. (2017). Live birth, miscarriage, and abortion among U.S. women with and without disabilities. *Disability and Health Journal*, 10(3), 382–386. <https://doi.org/10.1016/j.dhjo.2017.02.006>
- Horton, C., & Hall, S. (2020). Enhanced doula support to improve pregnancy outcomes among African American women with disabilities. *The Journal of Perinatal Education*, 29(4), 188-196. <https://doi.org/10.1891/J-PE-D-19-00021>
- Iezzoni, L., Rao, S., Rssalam, J., Bolcic-Jankovic, D., Agaronnik, N., Donelan, K., Lagu, T., & Campbell, E. (2021). Physicians' perceptions of people with disability and their health care. *Health Affairs*, 40(2), 297-306. <https://doi.org/10.1377/hlthaff.2020.01452>
- Iezzoni, L., Wint, A., Smelzer, S., & Ecker, J. (2015). "How did that happen?" Public response to women with mobility disability during pregnancy. *Disability and Health Journal*, (8), 380-387. <https://doi.org/10.1016/j.dhjo.2015.02.002>
- Iezzoni, L., Yu, J., Wint, A., Smeltzer, S., & Ecker, J. (2013). Prevalence of current pregnancy among U.S. women with and without chronic physical disabilities. *Med Care*, 51(6), 555-562. <https://doi.org/10.1097/MLR.0b013e318290218d>
- Inanici, F., & Yunus, M. (2004). History of fibromyalgia: Past to present. *Current Pain and Headache Reports*, 8, 369-378.
- Janz, H. (2019). Ableism: The undiagnosed malady afflicting medicine. *Canadian Medical Association Journal*, 191(17). <https://doi.org/10.1503/cmaj.180903>
- Javadi, M., & Zarea, K. (2016). Understanding thematic analysis and its pitfalls. *Journal of Client Care*, 1(1), 34-40. <https://doi.org/10.15412/J.JCC.02010107>
- Kaufman, R., Brown, R., Coral, C.M., Jacob, J., Onyango, M., & Thomasen, K. (2022). Global impacts of *Dobbs v. Jackson Women's Health Organization* and abortion regression in the United States.

Sexual and Reproductive Health Matters, 30(1).

<https://doi.org/10.1080/26410397.2022.2135574>

Keifer-Boyd, K., Bastos, F., Richardson, J., & Wexler, A. (2018). Disability Justice: Rethinking “inclusion” in arts education research. *Studies in Art Education*, 59(3), 267-

271. <https://doi.org/10.1080/00393541.2018.1476954>

Kim, E. (2011). Asexuality in disability narratives. *Sexualities*, 14(4), 479-493.

<https://doi.org/10.1177%2F1363460711406463>

Kimport, K. (2022). *No real choice: How culture and politics matter for reproductive autonomy*. Rutgers University Press.

King, N. (2004). Using templates in the thematic analysis of text. In C. Cassell & G. Symons (Eds.), *Essential guide to qualitative methods in organizational research* (pp. 257-270). London, UK: Sage Publishing.

Kingod, N., Cleal, B., Wahlberg, A., & Husted, G.R. (2017). Online peer-to-peer communities in the daily lives of people with chronic illness: A qualitative systematic review. *Qualitative Health Research*, 27(1), 89-99. <https://doi.org/10.1177/1049732316680203>

Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Leading Global Nursing Research*, 53(1), 91-100. <https://doi.org/10.1111/j.1365-2648.2006.03681.x>

Kone, M.C., Kambire, N.A., Kouakou, K., & Ahoua, Y. (2022). Fibromyalgia of women who gave birth and pregnancy outcome parameters. *Open Journal of Epidemiology*, 12, 1-12.

<https://doi.org/10.4236/ojepi.2022.121001>

Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). *2017 Disability Statistics Annual Report*. Durham, NH: University of New Hampshire.

- LaPierre, T., Zimmerman, M., & Hall, J. (2017). "Paying the price to get there": Motherhood and the dynamics of pregnant deliberations among women with disabilities. *Disability and Health Journal*, 10(3), 419-425. <https://doi.org/10.1016/j.dhjo.2017.02.011>
- Lau, Y., Yin, L., & Wang, Y. (2010). Antenatal depressive symptomatology, family conflict, and social support among Chengdu Chinese women. *Maternal and Child Health Journal*, 15, 1416-1426. <https://doi.org/10.1007/s10995-010-0699-z>
- Leath, S., Wright, P., Charity-Parker, B., & Stephens, E. (2022). Exploring black women's pathways to motherhood within a reproductive justice framework. *Qualitative Health Research*, 32(4), 694–709. <https://doi.org/10.1177/10497323211066869>
- Lerman, S. F., Shahar, G., Czarkowski, K. A., Kurshan, N., Mgriples, U., Mayes, L., & Epperson, C. N. (2007). Predictors of satisfaction with obstetric care in high-risk pregnancy: The importance of patient-provider relationship. *Journal of Clinical Psychology in Medical Settings*, 14(4), 330-334. <https://doi.org/10.1007/s10880-007-9080-9>
- Levitt, H. M., Bamberg, M., Creswell, J., Frost, D., Josselson, R., & Suarez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA publications and communications board task force report. *American Psychological Association*, 73(1), 26-46. <http://dx.doi.org/10.1037/amp0000151>
- Liddell, J., & Doria, C. (2022). Barriers to achieving reproductive justice for an indigenous gulf coast tribe. *Feminist Inquiry in Social Work*, 37(3), 396-413. <https://doi.org/10.1177/08861099221083029>
- Liddell, J., & Kington, S. (2021). "Something was attacking them and their reproductive organs": Environmental reproductive justice for an indigenous tribe in the United States gulf coast. *International Journal of Environmental Research and Public Health*, 18. <https://doi.org/10.3390/ijerph18020666>

- Litchman, M., Tran, M.J., Dearden, S., Guo, J.W., Simonsen, S., & Clark, L. (2019). What women with disabilities write in personal blogs about pregnancy and early motherhood: Qualitative analysis of blogs. *JMIR Pediatrics and Parenting*, 2(1). <https://doi.org/10.2196/12355>
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lincoln, Y.S., & Guba, E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*, (30), 73-84.
- Livneh, H., Bishop, M., & Anctil, T. M. (2014). Modern models of psychosocial adaptation to chronic illness and disability as viewed through the prism of Lewin's field theory: A comparative review. *Rehabilitation Research, Policy, and Education*, 28(3). <http://dx.doi.org/10.1891/2168-6653.28.3.126>
- Lopez-Gonzalez, D. M., & Kopparapu, A. K. (2022). *Postpartum Care of the New Mother*. Treasure Island, FL: StatPearls Publishing.
- Maher, J., Pal, L., Illuzzi, J., Achong, N., & Lundsberg, L. (2022). Racial and ethnic differences in reproductive knowledge and awareness among women in the United States. *Fertility and Sterilization Reports*, 3(25). <https://doi.org/10.1016/j.xfre.2022.03.006>
- Mahoney, M., Mitchell, L., Ross, L., & Parker, W. (2016). *The Doulas: Radical Care for Pregnant People*. New York: The Feminist Press.
- Mallick-Searle, T. (2022). Fibromyalgia/Generalized Body Pain during Pregnancy. In T. Mallick-Searle (Ed.), *Holistic Pain Management in Pregnancy: What RNs, APRNs, Midwives and Mental Health Professionals Need to Know* (pp. 141–151). Springer International Publishing. https://doi.org/10.1007/978-3-031-06322-0_8
- Maroto, M., Pettincchio, D., & Patterson, A. (2019). Hierarchies of categorical disadvantage: Economic insecurity at the intersection of disability, gender, and race. *Gender and Society*, 33(1), 64-93. <https://doi.org/10.1177/0891243218794648>

- Martin, J. A., Hamilton, B. E., Osterman, M. J. K., Driscoll, A. K., & Drake, P. (2018). Births: Final Data for 2017. *National vital statistics reports : from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*, 67(8), 1–50.
- Matkin, K., & Smedema, S. (2023). Reproductive autonomy for individuals with disabilities: Necessary knowledge for rehabilitation counselors. *Rehabilitation Counselors and Educators Journals*.
<https://doi.org/10.52017/001c.92936>
- Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disabilities*, 21, 341-350.
- Mehra, R., Boyd, L., Magriples, U., Kershaw, T., Ickovics, J., & Keene, D. (2020). Black pregnancy women “get the most judgment”: A qualitative study of the experiences of Black women at the intersection of race, gender, and pregnancy. *Women’s Health Issues*, 30(6), 484-492.
<https://doi.org/10.1016/j.whi.2020.08.001>
- McDougall, J., Wright, V., Schmidt, J., Miller, L., & Lowry, K. (2011). Applying the ICF framework to study changes in quality-of-life for youth with chronic conditions. *Developmental Neurorehabilitation*, 14(1), 41-53. <https://doi.org/10.3109/17518423.2010.521795>
- McGarry, A., Kroese, B.S., & Cox, R. (2016). How to women with an intellectual disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child? *Journal of Applied Research in Intellectual Disabilities*, 29, 21-33. <https://doi.org/10.1111/jar.12155>
- McLaughlin, D., Leung, J., Pachana, N., Flicker, L., Hankey, G., & Dobson, A. (2012). Social support and subsequent disability: it is not the size of your network that counts. *Age and Ageing*, 41, 674-677. <https://doi.org/10.1093/ageing/afs036>

- Misra, D., Giurgescu, C., Caldwell, C., Song, P., Hu, M., Adaji, R. & Vaughan, S. (2023). Fathers Matter. *MCN, The American Journal of Maternal/Child Nursing*, 48(6), 295-302. <https://doi.org/10.1097/NMC.0000000000000953>
- Mitra, M., Clements, K., Zhang, J., Iezzoni, L., Smeltzer, S., & Long-Bellil, L. (2015). Maternal characteristics, pregnancy complications, and adverse birth outcomes among women with disabilities. *Medical Care*, 53(12). <https://doi.org/10.1097/MLR.0000000000000427>
- Molina, R., Tsai, T., Dai, D., Soto, M., Rosenthal, N., Orav, J., & Figueiroa, J. (2022). Comparison of pregnancy and birth outcomes before vs during the COVID-19 pandemic. *JAMA Network*, 5(8). <https://www.doi.org/10.1001/jamanetworkopen.2022.26531>
- Moniz, M., Spector-Bagdady, K., Heisler, M. & Harris, L. (2017). Inpatient postpartum long-acting reversible contraception. *Obstetrics & Gynecology*, 130(4), 783-787. <https://www.doi.org/10.1097/AOG.0000000000002262>
- Moseson, H., Zazanis, N., Goldberg, E., Fix, L., Durden, M., Stoeffler, A., Hastings, J., Cudlitz, L., Lesser-Lee, B., Letcher, L., Reyes, A., & Obedin-Maliver, J. (2020). The Imperative for Transgender and Gender Nonbinary Inclusion: Beyond Women's Health. *Obstetrics and gynecology*, 135(5), 1059–1068. <https://doi.org/10.1097/AOG.0000000000003816>
- National Disability Services (n.d.). *Disability types and descriptions*. <https://www.nds.org.au/disability-types-and-descriptions#:~:text=The%20primary%20disability%20is%20the,context%20of%20the%20support%20offered>).
- Nelson, J. (2003). *Women of color and the reproductive rights movement*. New York, NY: New York University Press.

- Neufeld, J., Klingbeil, F., Bryen, D.N., Silverman, B., & Thomas, A. (2002). Adolescent sexuality and disability. *Physical Medicine and Rehabilitation Clinics of North American*, 13(4), 857-873.
[https://doi.org/10.1016/S1047-9651\(02\)00045-1](https://doi.org/10.1016/S1047-9651(02)00045-1)
- Nguyen, T., Meng, H.W., Sandeep, S., McCullough, M., Yu, W., Lau, Y., Huang, D., & Nguyen, Q. (2018). Twitter-derived measures of sentiment towards minorities (2015-2016) and associations with low birth weight and preterm birth in the United States. *Computers in Human Behavior*, 89, 308-315. <https://doi.org/10.1016/j.chb.2018.08.010>
- Nowell, L., Norris, J., White, D., & Moules, N. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16, 1-13.
- O'Connor-Terry, C., Harris, J. (2021). Pregnancy decision-making in women with physical disabilities. *Disability and Health Journal*, 15(1). <https://doi.org/10.1016/j.dhjo.2021.101176>
- Osterman, M., Hamilton, B., Martin, J., Driscoll, A., & Valenzuela, C. (2023). Births: Final data for 2021. *National Vital Statistics Reports*, 72(1).
- Park, Y.S., Konge, L., & Artino Jr., A. (2020). The positivism paradigm of research. *Academic Medicine: Journal of the Association of American Medical Colleges*, 95(5), 690-694.
<https://doi.org/10.1097/ACM.0000000000003093>
- Patton, P.Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, 34(5), 1189-1208.
- Patton, M.Q. (2015). *Qualitative research and evaluation methods: Integrating theory and practice*. Saint Paul, MN: Sage Publications, Inc.
- Pebdani, R., & Tashjian, A. (2021). An analysis of the attitudes of the general public towards the sexuality of individuals with disabilities through a systematic literature review. *Sexuality and Disability*, 40, 21-55. <https://doi.org/10.1007/s11195-021-09700-4>

- Perenboom, R., Wijlhuizen, G.J., Garre, F.G., Heerkens, Y.F., & van Meeteren, N.L.U. (2012). An empirical exploration of the relations between the health component of the International Classification of Functioning, Disability, and Health (ICF). *Disability and Rehabilitation*, 34(18), 1556-1561. <https://doi.org/10.3109/09638288.2011.647233>
- Peterson-Besse, J., Knoll, J.E., Horner-Johnson, W. (2019). Internet networks as a source of social support for women with mobility disabilities during pregnancy. *Disability and Health Journal*, 12(4), 722-726. <https://doi.org/10.1016/j.dhjo.2019.04.003>
- Ponterotto, J.G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, 52(2), 126-136. <https://psycnet.apa.org/doi/10.1037/0022-0167.52.2.126>
- Powell, R., Mitra, M., Smeltzer, S., Long-Bellil, L., Smith, L., & Iezzoni, L. (2017). Family attitudes and reactions toward pregnancy among women with physical disabilities. *Women's Health Issue*, 27(3): 345-350. <https://doi.org/10.1016/j.whi.2017.01.003>
- Prather, C., Fuller, T., Jeffries, W., Marshall, K. J., Howell, A. V., Belyue-Umole, A., & King, W. (2018). Racism, African American women, and their sexual and reproductive health: A review of historical and contemporary evidence and implications for health equity. *Health Equity*, 2(1), 249–259. <https://doi.org/10.1089/heq.2017.0045>
- Pryma, J. (2017). “Even my sister says I’m acting like a crazy to get a check”: Race, gender, and moral boundary-work in women’s claims of disabling chronic pain. *Social Science and Medicine*, 181, 66-73. <http://dx.doi.org/10.1016/j.socscimed.2017.03.048>
- Redshaw, M., Malouf, R., Gao, H., & Gray, R. (2013). Women with disability: The experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth*, 13(174). <https://doi.org/10.1186/1471-2393-13-174>

- Reis, E. (2020). Midwives and pregnant men: Labouring toward ethical care in the United States. *Canadian Medical Association Journal*, 192(2), E169-E170. <https://doi.org/10.1503/cmaj.190959>
- Renbarger, K. M., Place, J. M., & Schreiner, M. (2021). The Influence of Four Constructs of Social Support on Pregnancy Experiences in Group Prenatal Care. *Women's health reports (New Rochelle, N.Y.)*, 2(1), 154–162. <https://doi.org/10.1089/whr.2020.0113>
- Ridge, D., Bullock, L., Causer, H., Fisher, T., Hider, S., Kingstone, T., Gray, L., Riley, R., Smyth, N., Silverwood, V., Spiers, J., & Southam, J. (2023). ‘Imposter participants’ in online qualitative research, a new and increasing threat to data integrity? *Health Expectations*, 26(3), 941-944. <https://doi.org/10.1111/hex.13724>
- Riggs, D., Pearce, R., Pfeffer, C., Hines, S., White, F., & Ruspini, E. (2020). Men, trans/masculine, and non-binary people’s experiences of pregnancy loss: An international qualitative study. *MBC Pregnancy and Childbirth*, 20(482). <https://doi.org/10.1186/s12884-020-03166-6>
- Roe v. Wade, 410 U.S. 113 (1973).
- Ross, L., Roberts, L., Derkas, E., Peoples, W., & Bridgewater, P. (2017). *Radical Reproductive Justice: Foundations, Theory, Practice, Critique*. New York, NY: First Feminist Press.
- Sachdeva, P., Patel, B. G., & Patel, B. K. (2009). Drug use in pregnancy; a point to ponder!. *Indian Journal of Pharmaceutical Sciences*, 71(1), 1–7. <https://doi.org/10.4103/0250-474X.51941>
- Safer, J. D., Coleman, E., Feldman, J., Garofalo, R., Hembree, W., Radix, A., & Sevelius, J. (2016). Barriers to healthcare for transgender individuals. *Current Opinion in Endocrinology, Diabetes, and Obesity*, 23(2), 168–171. <https://doi.org/10.1097/MED.0000000000000227>
- Saldaña, J., & Omasta, M. (2018). *Qualitative research: Analyzing life*. Los Angeles: Sage Publishing.
- Sapkota, S., Kobayashi, T., & Takese, M. (2012). Husbands’ experiences of supporting their wives during childbirth in Nepal. *Midwifery*, 28(1), 45-51. <https://doi.org/10.1016/j.midw.2010.10.010>

- Saunders, C., Sierpe, A., Plessen, C.V., Kennedy, A., Leviton, L., Bernstein, S., Goldwag, J., King, J., Marx, C., Pogue, J., Saunders, R., Can Citters, A., Yen, R., Elwyn, G., & Leyenaar, J. (2023). Practical thematic analysis: A guide for multidisciplinary health service research teams engaging in qualitative analysis. *BMJ*, *381*. <https://doi.org/10.1136/bmj-2022-074256>
- Sayre, D. (2022). Care work and social justice in creative art therapy: Putting queer performance theory and disability justice in conversations with drama therapy. *The Arts in Psychotherapy*, *80*. <https://doi.org/10.1016/j.aip.2022.101940>
- Schiff, M., Doody, D., Crane, D., & Mueller, B. (2021). Pregnancy outcomes among visually impaired women in Washington State, 1987-2014. *Disability and Health Journal*, *14*(3), 101057-101057. <https://doi.org/10.1016/j.dhjo.2020.101057>
- Scharp, K. M., & Thomas, L. J. (2019). Disrupting the humanities and social science binary: framing communication studies as a transformative discipline. *Review of Communication*, *19*(2), 147–163. <https://doi.org/10.1080/15358593.2019.1595702>
- Sikkens, E., von San, M., Sieckelink, S., Boeije, H., & Winter, M. d. (2017). Participant recruitment through social media: Lessons learned from a qualitative radicalization study using Facebook. *Field Methods*, *29*(2), 130-139. <https://doi.org/10.1016/j.drugpo.2014.12.004>
- Simić Stanojević, I., Baugh, M., Greer, K.M., Piatt, J., & Yarber, W. (2023). Increasing opportunities for healthy sexual socialization in LGBTQ+ people with IDD: The role of LGBTQ+ organizations and community. *Sexuality and Disability*, *41*, 531-541. <https://doi.org/10.1007/s11195-023-09789-9>
- Simons, R. L., Lei, M. K., Klopach, E., Zhang, Y., Gibbons, F. X., & Beach, S. R. H. (2021). Racial discrimination, inflammation, and chronic illness among African American women at midlife: Support for the weathering perspective. *Journal of Racial and Ethnic Health Disparities*, *8*(2), 339–349. <https://doi.org/10.1007/s40615-020-00786-8>

- Sins Invalid. (2020). *What is disability justice?* <https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>
- Sins Invalid (2016). *Skin, Tooth, and Bone - The Basis of Movement is Our People: A Disability Justice Primer.*
- SisterSong. (2023). *About us.* <https://www.sistersong.net/about-x2>
- Starrs, A., Ezeh, A., Barker, G., Basu, A., Bertrand, J., Blum, R., Coll-Seck, A., Grover, A., Laski, L., Roa, M., Sathar, Z., Say, L., Serour, G., Singh, S., Stenberg, K., Temmerman, M., Biddlecom, A., Popinchalk, A., Summers, C., & Ashford, L. (2018). Accelerate progress-sexual and reproductive health and rights for all: Report of the Guttmacher-Lancet Commission. *The Lancet Commissions*, 391(10140), 2642-2692. [https://doi.org/10.1016/S0140-6736\(18\)30293-9](https://doi.org/10.1016/S0140-6736(18)30293-9)
- Smeltzer, S.C. (2007). Pregnancy in women with physical disabilities. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 36, 88-96. <https://doi.org/10.1111/j.1552-6909.2006.00121.x>
- Smith, J., & Noble, H. (2014). Bias in research. *Evidence-Based Nursing*, 17(4), 100-101. <https://doi.org/10.1136/eb-2014-101946>
- Smith, A. J., Hallum-Montes, R., Nevin, K., Zenker, R., Sutherland, B., Reagor, S., Ortiz, M. E., Woods, C., Frost, M., Cochran, B., Oost, K., Gleason, H., & Brennan, J. M. (2018). Determinants of Transgender Individuals' Well-Being, Mental Health, and Suicidality in a Rural State. *Rural mental health*, 42(2), 116–132. <https://doi.org/10.1037/rmh0000089>
- Stapleton, L.R., Schette, C.D., Westling, E., Rini, C., Glynn, L., Hobel, C., & Sandman, C. (2012). Perceived partner support in pregnancy predicts lower maternal and infant distress. *Journal of the Division of Family Psychology of the American Psychological Association*, 26(3), 453-463. <https://doi.org/10.1037/a0028332>

- Suter, S., McCracken, W., & Calam, R. (2012). The views, verdict and recommendations for school and home sex and relationships education by young deaf and hearing people. *Sexuality, Society and Learning*, 12(2). <https://doi.org/10.1080/14681811.2011.609042>
- Tarasoff, L. (2015). Experiences of women with physical disabilities during the perinatal period: A review of the literature and recommendations to improve care. *Health care for Women International*, 36, 88-107. <https://doi.org/10.1080/07399332.2013.815756>
- Tarasoff, L. (2017). “Who don’t know. We’ve never had anybody like you before”: Barriers to perinatal care for women with physical disabilities. *Disability and Health Journal*, 10, 426-433. <https://doi.org/10.1016/j.dhjo.2017.03.017>
- Tarasoff, L. (2021). A call for comprehensive, disability- and LGBTQ-inclusive sexual and reproductive health education. *Journal of Adolescent Health*, 69(2), 185-186. <https://doi.org/10.1016/j.jadohealth.2021.05.013>
- Taouk, L. H., Fialkow, M. F., & Schulkin, J. A. (2018). Provision of reproductive healthcare to women with disabilities: A survey of obstetrician-gynecologists' training, practices, and perceived barriers. *Health equity*, 2(1), 207–215. <https://doi.org/10.1089/heq.2018.0014>
- Tong, A., Sainsburg, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
- Toussaint, L. L., Whipple M. O., Vincent A. (2017). Post-traumatic stress disorder symptoms may explain poor mental health in patients with fibromyalgia. *Journal of Health Psychology*, 22(6), 697-706. <https://doi.org/10.1177/1359105315611957>
- Waggoner, M. (2017). *The Zero Trimester*. University of California Press.

- Walsh-Gallagher, D., Sinclair, M., & Conkey, R. (2012). The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery*, *28*, 156-162. <https://doi.org/10.1016/j.midw.2011.01.003>
- Walsh-Gallagher, D., Conkey, R., Sinclair, M., & Clarke, R. (2013). Normalising birth for women with a disability: The challenges facing practitioners. *Midwifery*, *29*, 294-299. <https://doi.org/10.1016/j.midw.2011.10.007>
- Wang, Y.N., Yuan, Z.J., Leng, W.C., Xia, L.Y., Wang, R.X., Li, Z.Z., Zhou, Y.J., & Zhang, X.Y. (2021). Role of perceived family support in psychological distress for pregnant women during the COVID-19 pandemic. *World Journal of Psychiatry*, *11*(7), 365-374. <https://www.wjgnet.com/2220-3206/full/v11/i7/365.htm>
- Williams P, Barclay L, Schmied V. Defining Social Support in Context: A Necessary Step in Improving Research, Intervention, and Practice. *Qualitative Health Research*. 2004;14(7):942-960. <https://doi.org/10.1177/1049732304266997>
- Winslow, B., Vandal, C., & Dang, L. (2023). Fibromyalgia: Diagnosis and management. *American Family Physician*, *107*(2), 137-144.
- Wolfe, F., Schumker, J., Jamal, S., Castrejon, I., Gibson, K., Srinivasan, S., Hauser, W., & Pincus, T. (2019). Diagnosis of fibromyalgia: Disagreement between fibromyalgia criteria and clinician-based fibromyalgia diagnosis in a University clinic. *Arthritis Care & Research*, *71*(3), 343-351.
- World Health Organization [WHO] (2002). *Toward a common language for functioning, disability, and health: ICF*. Geneva: World Health Organization.
- World Health Organization [WHO]. (2019). *International statistical classification of diseases and related health problems* (11th ed.). <https://icd.who.int/>
- World Health Organization [WHO] (2022). *Noncommunicable diseases*. <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>

World Health Organization [WHO] (2023). *Reproductive Health*.

<https://www.who.int/westernpacific/health-topics/reproductive-health>

Wudneh, A., Cherinet, A., Abebe, M., Bayisa, Y., Mengistu, N., & Molla, W. (2022). Obstetric violence and disability overlaps: Obstetric violence during child birth among womens with disabilities: A qualitative study. *BMC Women's Health*, 22. <https://doi.org/10.1186/s12905-022-01883-y>

Xie, E., & Gemmill, M. (2018). Exploring the prenatal experience of women with intellectual and developmental disabilities in a Southeastern Ontario family health team. *Canadian Family Physician*, 64(2).

Xu, J., Murphy, S. L., Kochanek, K. D., Bastian, B., & Arias, E. (2018). Deaths: Final data for 2016. *National Vital Statistics Report*, 67(5), 1–76.

Yee, S., & Breslin, M.L. (2010). Achieving accessible health care for people with disabilities: Why the ADA is only part of the solution. *Disability and Health Journal*, 3, 253-261.

<http://dx.doi.org/10.1016/j.dhjo.2010.07.006>

Yoon, B., & Uliassi, C. (2022). “Researcher-as-instrument” in qualitative research: The complexities of the educational researcher’s identities. *The Qualitative Report*, 27(4), 1088-1102.

<https://doi.org/10.46743/2160-3715/2022.5074>

Young, S. (2012). We’re not here for your inspiration. *ABC News*. <https://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006>

Yunus, M.N. (2001). The role of gender in fibromyalgia syndrome. *Current rheumatology reports*, 3, 128-134. <https://doi.org/10.1007/s11926-001-0008-3>

Zablotsky, B., Black, L., Maenner, M.J., Schieve, L., Danielson, M., Bitsko, R., Blumberg, S., Kogan, M., & Boyle, C. (2019). Prevalence and trends of developmental disabilities among children in the US: 2009-2017. *Pediatrics*, 144(4). <https://doi.org/10.1542/peds.2019-0811>

Appendix I: Research Protocol

Introduction

- Review of informed consent, opportunity for questions, verbal agreement
- Review of information provided in the screening questionnaire
- Provide intro to the interview: expect 45-60 minutes of 10 total questions focused on pregnancy experience, your diagnosis, and social support impact.

Interview Protocol

1. Tell me about what fibromyalgia looks like for you.
 - A. When were you diagnosed? How were you diagnosed?
 - B. What are your salient symptoms?
 - C. What areas of your life are impacted by fibromyalgia?
 - D. Do you have any salient co-occurring disabilities?

2. How did your fibromyalgia impact your pregnancy experience?
 - A. Did your fibromyalgia impact your decision to become pregnant?
 - B. Please describe any specific challenges you faced during your pregnancy due to your fibromyalgia.
 - C. Please describe any specific positive experiences you faced during your pregnancy due to your fibromyalgia
 - D. What was surprising to you about your fibromyalgia and your pregnancy experience?

3. In general, how did those healthcare providers influence or affect your pregnancy experience?
 - A. How competent were they in how your fibromyalgia would impact pregnancy?
 - B. Please describe any positive or challenging experiences you had with your health care provider regarding your fibromyalgia.

4. How can healthcare providers could better support individuals with fibromyalgias during their pregnancy?

5. From the list below, what 3 sources did you receive the most social support from during your pregnancy?
 - Partner(s)
 - Family Members
 - Peers/Friends
 - Doulas
 - Coworkers
 - Counselors
 - Classmates
 - Teachers
 - Ministry/Clergy Members
 - Neighbors
 - Community Members
 - Other (specify)

6. How did (source 1) impact your pregnancy experience?
 - A. Do they understand what your chronic condition entails?
 - B. Please describe any positive support they provided to you that affected your pregnancy.
 - C. Please describe any negative support they provided you that affected your pregnancy.
 - D. How could they have better supported your pregnancy?

7. How did (source 2) impact your pregnancy experience?
 - A. Do they understand what your chronic condition entails?
 - B. Please describe any positive support they provided to you that affected your pregnancy.
 - C. Please describe any negative support they provided you that affected your pregnancy.
 - D. How could they have better supported your pregnancy?

8. How did (source 3) impact your pregnancy experience?
 - A. Do they understand what your chronic condition entails?
 - B. Please describe any positive support they provided to you that affected your pregnancy.
 - C. Please describe any negative support they provided you that affected your pregnancy.
 - D. How could they have better supported your pregnancy?

9. Please describe any interactions you had with strangers regarding your pregnancy with fibromyalgia.

10. Is there anything else you would like to share about your pregnancy experience with a chronic condition?

Additional Pilot Interview Question:

11. What feedback do you have regarding your interview experience? This may include the wording of questions, number of questions, overall time commitment, etc.

Appendix II: Recruitment Flyer**Seeking Participants with Fibromyalgia Who Have Experienced Pregnancy and Birth in the Last 12 Months**

Researchers at the University of Wisconsin-Madison are seeking insight into social support received during pregnancy with fibromyalgia.

Participant Criteria:

- Be over the age of 18
- Identify as having fibromyalgia prior to most recent pregnancy
- Have experienced pregnancy and birth within the last 12 months

Participation Involves:

- Completing screening questionnaire of demographic information
- If you qualify, you will be invited for a 45-60-minute interview that takes place over the phone or Zoom (camera optional).

Those who are eligible and complete the interview will be compensated with a \$50 Amazon Gift card. If you are interested in participating, please fill out the screening questionnaire found using the following [link](#) or scan the QR code below:



If you have questions or concerns, or have accommodation requests to participate in this study, please contact researcher Katelyn Matkin at matkin@wisc.edu or the project PI Dr. Susan Smedema at ssmedema@wisc.edu.

Appendix III: Informed Consent

University of Wisconsin-Madison Consent to Participate in a Research Study Social Support for Pregnancy with Fibromyalgia

To be eligible for this study you must:

- Be over the age of 18
- Have experienced a pregnancy to a live child within the last 12 months
- Identify as having fibromyalgia at least 1 year prior to your most recent pregnancy

Description of the Research

You are invited to participate in a research study about the experience of fibromyalgia in pregnancy and the impact of social support. Researchers are required to provide the necessary information to inform you about the research study to convey that participation is voluntary, to explain the risks and benefits of participation, and to empower you to make an informed decision. The study will help researchers at the University of Wisconsin-Madison better understand the pregnancy experience(s) of individuals with fibromyalgia. Demographic information will be collected to better understand the factors influencing individuals' lives.

If you meet the criteria of the study, you will be invited to participate in a 45-60-minute interview via Zoom or Phone. You will receive a \$50 Amazon gift card for completing an interview.

What Will My Participation Involve?

The research team will ask you to complete a brief web-based survey. The survey contains 20 questions to answer and should take around 10 minutes for you to complete. You can save your selected answers by clicking the next button. Further, you have the option to save your responses log out and return to the survey where you left off. However, you will be unable to go back and change your answers once you have submitted them. The survey response will include providing contact information so an interview can be scheduled if you meet the study criteria.

If you meet the study criteria, you will be invited to participate in a 45-60 minute interview with a research team member via Zoom or phone call. If you participate via Zoom you have the option to keep your camera on or off. The interview will consist of 10 total questions to answer. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. Your interview will be audio-recorded by the research team member so that it can be transcribed for data analysis.

Cost and Compensation for Being in the Study:

There are no costs associated with your participation in this research study. There is also no compensation for completing the screening questionnaire. If you are chosen for an interview, you will be compensated with an electronic \$50 Amazon gift card provided to you via email.

Are There Any Risks to Me?

There may be minimal risk of breaching confidentiality. However, all efforts will be made to protect your confidentiality. The main risk to you is fatigue you may experience while filling out the survey. The main risk for the interview is also fatigue as it can take up to 60 minutes to complete. You will be offered the option to take a short break halfway through should you need it. Another risk is you may feel upset due

to certain questions of the study. If you feel uncomfortable answering any question on the survey or during the interview, you can skip them and/or withdraw from the study at any time, without penalty.

We take the following steps to ensure your personal information is not shared:

- Researchers are obligated to follow the Code of Ethics for their practice.
- All study data will be stored securely and only accessed by approved personnel.
- Your data from the screening questionnaire and/or interview will be destroyed after completion of this study.
- The study team will work with the PI and IRB to address any unanticipated problems that may occur.

Are There Any Benefits to Me?

There are no direct benefits to you for participating in this study. However, your participation in this study may generate useful data for a comprehensive understanding of pregnancy experiences with fibromyalgia and the impact of social support.

How Will My Confidentiality Be Protected?

All data for the current study will be kept completely confidential. No names or identifiers will be used in the study. All research materials will be treated confidentially and not provided to others. Information obtained through your participation may be published in professional journals or presented at professional conferences, but the identities of all research participants will stay confidential.

Participation in this research project is completely voluntary. You can choose not to participate. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

Optional Pilot Interview Participation:

This part of the consent form is about additional research activities that you can choose to take part in. You can still take part in the main study even if you say “no” to this activity. The optional activity will not help you directly, however, it will help the researchers inform how we move forward in interviews with other participants.

The optional activity will entail your interview being the pilot interview. This means you are the first interview for this study. You will engage in the 45-60 minute survey, with an additional requirement of providing feedback on the interview process. You will be asked a general question at the end of the interview about any feedback you have for the interview. You will also receive a required feedback survey the day after your interview with specific questions regarding your interview experience. By participating in the pilot interview, you will be compensated an additional \$25 Amazon gift card amount provided to you via email for your participation.

Whom Should I Contact with Questions or Concerns?

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact one of the researchers, Katelyn Matkin, MS, CRC at matkin@wisc.edu or Susan Smedema, PhD, CRC, LPC at ssmedema@wisc.edu.

If you have questions about your rights as a research participant or have complains about the research study or study team, call the confidential research compliance line at 1-833-652-2506. Staff will work with you to address concerns about research participation and assist in resolving problems.

Appendix IV: List of Social Media Pages Recruitment Flyer was Posted

Twitter Pages

- UW-Madison Collaborative for Reproductive Equity (CORE)

Facebook Pages

- Fibromyalgia and Pregnancy
- Fibromyalgia Community: Support Resources and Discussion
- Mommies with Fibromyalgia
- Women with Fibromyalgia
- Fibromyalgia and Chronic Pain Women Warriors
- Women Suffering with Fibromyalgia
- Fibromyalgia Support Group
- Understanding Fibromyalgia
- Pregnancy and Chronic Pain (Planning/During/Postpartum) 4 US Members Only