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Mothers with Disabilities as Health Navigators: Narratives of Pregnancy, Postpartum Depression, and Parenting

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MOTHERS WITH DISABILITIES AS HEALTH NAVIGATORS: NARRATIVES OF PREGNANCY, POSTPARTUM DEPRESSION, AND PARENTING

AGNES AMOAKWA

156 Pages

Scholars have focused on factors that affect pregnancy decisions, linking it to internal factors such as physical attachment and love towards children and feasibility of external factors, among others, while others have focused on experience with health professionals and accessibility of healthcare facilities and equipment during access to maternal care. While these studies are important, fewer focus has been placed on how women with disabilities navigate the postpartum phase of motherhood and the support needed to navigate through this experience. I employed the communicated narrative sense-making theory to explore the meanings of stories shared by mothers with disabilities about their postpartum experiences. The study revealed that, among the participants, five mothers experienced significant challenges with self-care, managing parental obligations, and dealing with internal struggles, all of which led to depression. Despite these challenges, they found motherhood rewarding, describing it as a journey of continuous learning and responsibility, filled with both challenging and fulfilling moments. The study also noted some essential strategies to navigate the postpartum phase, including seeking therapy, joining supportive online communities, getting help from families, and accessing community resource centers. This study is essential as it enlightens us about the unique challenges and experiences of mothers with disabilities.

KEYWORDS*:* Mother with Disabilities, Pregnancy, Postpartum Phase, Postpartum Depression, Parenting, Narrative

MOTHERS WITH DISABILITIES AS HEALTH NAVIGATORS: NARRATIVES OF PREGNANCY, POSTPARTUM DEPRESSION, AND PARENTING

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This thesis stands as a shoutout to all mothers with disabilities out there, who, despite the barriers and challenges encountered, redefine the essence of resilience and greatness in motherhood. I extend my deepest gratitude to God, for blessing me with the opportunity to undertake my master's journey.

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A.A.

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CHAPTER I: INTRODUCTION

There is a prevalent societal perception that women with disabilities are unsuitable candidates for motherhood. This prevailing perception stems from society's categorization of women with disabilities as unhealthy and as carriers of infectious diseases, which raises concerns about their ability to successfully give birth to a child without health complications (Bassoumah & Mohammed, 2020; Devkota et al., 2019; Rugoho & Maphosa, 2017; Taylor & Filax, 2014; Tefera et al., 2018; Thabethe, 2022). In a personal narrative, Walsh (2014) provided an account of her experience at 14 years old when she saw a woman in a wheelchair diagnosed with spina bifida accompanied by a boy who could walk. Initially, Walsh thought the boy might be the woman's nephew and that his mother might be dead. Later, when she learned that the woman in the wheelchair was the boy's biological mother, she wondered, "Where did she get the baby?" (Walsh, 2014, p. 22). The researcher emphasized that the encounter with the woman in the wheelchair redefined her opinion of the potentialities of motherhood available to her as a woman diagnosed with Cerebral Palsy.

A significant number of people around the world live with disabilities. An estimated 1.3 billion people experience a significant disability, accounting for 16% of the world's population today (World Health Organization, 2023). Disability can refer to any physical, sensory, cognitive, or intellectual impairment that hinders an individual's capacity to carry out daily tasks and fully participate in society (Centers for Disease Control and Prevention, 2020; World Health Organization, 2023). The term *disability* includes visible disabilities such as deafness, cerebral palsy, muscular dystrophy, blindness, amputations, or mobility difficulties (Krahn et al., 2015; World Health Organization, 2021). In addition, invisible disabilities include mental and neurological health conditions (Oslund, 2013) that are not immediately obvious (Norstedt, 2019; Prince, 2017; Santuzzi et al., 2014). Common invisible disabilities include learning disabilities, autism spectrum disorder, depression, anxiety, or chronic pain (Oslund, 2013). The United Nations Convention on the Rights of Persons with Disabilities recognizes that persons with disabilities have the right to marry, family, reproduction, parenthood, and relationships on an equal basis with others (Hendriks, 2007). According to the Centers for Disease Control and Prevention (2020), about 35 million women in the U.S. claim to have a disability. This report shows that the number of women with disabilities in the U.S. is increasing. Many of these women have similar aspirations and joy for motherhood as women without disabilities (Litchman et al., 2019).

Motherhood is a complicated journey. However, disability further complicates the journey. For women with disabilities, envisioning themselves as mothers, making the conscious decision to become mothers, and then taking action to fulfill this choice is an act of bravery (Taylor & Filax, 2014). Mitra et al. (2015) argued that women with disabilities are more likely to have problems during pregnancy and childbirth than women without disabilities. For example, researchers at the National Institutes of Health (2021) reported that women with disabilities had more than twice the risk of severe preeclampsia, a potentially life-threatening hypertensive disorder of pregnancy, and 52% risk of placenta previa, which is when the placenta covers all or part of the cervix.

Furthermore, the birth of a baby elicits a range of intense emotional feelings of excitement, fear, and anxiety (Westwall & Liamputtong, 2011). Approximately 50-80% of all new mothers experience some negative feelings or mood swings after the birth of their child, known as postpartum baby blues (Holopainen & Hakulinen, 2019). These hormonal changes frequently include mood swings, anxiety, crying, restlessness, and difficulty falling asleep (Romm, 2010). These symptoms typically manifest within the initial two to three days after delivery and can continue for up to two weeks (Kaźmierczak et al., 2017; Sharma et al., 2015). In addition, some mothers experience a more intense, long-lasting form of depression called postpartum depression (Mayo Clinic, 2022; Oyetunji & Chandra, 2020). New mothers with disabilities are more susceptible to stressful life events and experience worse symptoms associated with postpartum depression (Booth et al., 2021). Booth et al. (2021) revealed that 37.4% of women with disabilities had postpartum depressive symptoms, significantly higher than 8.79% of women without disabilities. Similarly, women with disabilities diagnosed with depression, anxiety, and bipolar disorder are more likely to have postpartum depression (Barkin et al., 2016).

Moreover, disability consists of limitations individuals can overcome or alleviate through specific strategies (Braithwaite & Braithwaite, 2014). Despite the high risk of challenges encountered, currently, the narratives of mothers with disabilities are challenging the accepted notion that women with disabilities do not need to be included in childbearing because of their disability (Khanna et al., 2022; Peta, 2017). In research conducted by Stat News, Cueto and Lyons (2023) reported the stories of seven mothers with disabilities about their experience with becoming pregnant, delivery, and parenting. One 44-year-old woman from Tennessee diagnosed with chronic pain, psoriatic arthritis, anxiety, and depression recounted that her experience as a parent transformed her into an advocate for other parents with disabilities.

Khanna et al. (2022) asserted that even though mothers with disabilities face challenges during pregnancy and after giving birth, these mothers desire to share their experiences with their peers who are pregnant or thinking about getting pregnant, specifically the possibility of being able to navigate pregnancy and parenthood with a disability. According to Litchman et al. (2019), this advocacy tendency positions mothers with disabilities as health navigators. Therefore, research in this dimension can offer ways to inform and understand the experiences of disabled mothers to dispel myths about mothers and disabilities (Taylor & Filax, 2014).

The present study examines the narratives of women with disabilities’ experience with motherhood, ranging from issues that impede their access to maternal and reproductive care. This study also explores how mothers with disabilities cope with and navigate the physical, mental, and behavioral changes during the postpartum phase, which could help potential mothers recognize their ability to give birth. It does this by exploring the importance of storytelling as a tool of support and guidance for women with disabilities. In the review of literature, I provide valuable insights that informs disability organizations and women-led movements to create and promote new support groups for women with disabilities. After the literature review, I describe narrative interviews that will shed light on the lived experiences of mothers with disabilities, which can inform health professionals, health researchers, and advocacy organizations about the diverse strategies that should be employed to address their unique needs. The findings are important not only for women with disabilities but all women, in general, to actively share their experiences about their pregnancy journey to empower potential mothers. They also serve as a wake-up call for healthcare professionals, spouses, families, and friends to become more sensitive to pregnancy and motherhood needs of women with disabilities.

CHAPTER II: REVIEW OF LITERATURE

Chapter 1 focused on the societal perceptions of the roles of women with disabilities in the context of pregnancy, postpartum depression, and motherhood. Despite the risks associated with their disability, I established that they have the capability and right to experience pregnancy and childbirth. Now that I have established the background of the study, I will review the current scholarly literature underlying the essence of this topic for further research. First, I briefly discuss the issues that women with disabilities encounter in their life endeavors. Second, I review the literature on women with disabilities' access to sexual and reproductive care. I then explore research on the experiences of mothers with disabilities navigating pregnancy, postpartum depression, and parenting. Finally, I explain the theoretical background that underpins the study and pose research questions by focusing on topics such as pregnancy narratives, postpartum partum narratives, strategies for coping with and navigating the physical, mental, and behavioral challenges during the postpartum phase and the support systems to assist mothers with disabilities.

Issues for Women with Disabilities

Women with disabilities face diverse, intersecting barriers that significantly impact their lives. Structural barriers such as inaccessible environments impede physical mobility and access to essential services and resources (Pita et al., 2023; Tefera et al., 2018). Structural barriers are aspects of systemic barriers rooted in laws and regulations that restrict the opportunities and rights of women with disabilities. (Albanesi & Nusbaum, 2017; Braunmiller & Dry, 2022). Communication barriers include the absence of sign language interpreters (Young et al., 2019) and widespread disparities in information and communication technology (Tsatsou, 2020).

Attitudinal barriers stem from erroneous societal assumptions, negative attitudes, and judgments (Matin et al., 2021; Ngcobo, 2022). Many researchers have documented that the significant barriers encountered by women with disabilities are mainly societal rather than caused by their actual bodily impairments (Ngcobo, 2022).

Structural Barriers and Systemic Barriers

Women with disabilities experience structural and systemic barriers that hinder their participation in the mainstream society. Research studies on structural barriers have demonstrated that persons with disabilities have limited access to daily living aids and assistive technologies, which impacts education and work, including transportation (Saigal & Narayan, 2014). For example, women with disabilities in low- and middle-income countries suffer from limited availability of educational resources, such as braille facilities (Tefera et al., 2018). This issue is primarily due to the allocation of resources to non-disabled students, as women with disabilities are often perceived as incapable of engaging in education (Tefera et al., 2018).

The absence of accessible public transport poses a significant threat to the livelihoods of persons with disabilities (Jerome, 2011). In a qualitative interview with persons with disabilities, Park and Chowdhury (2018) found that the main barriers for physically impaired public transport users were associated with the urban environment, terminals and stops, services, and quality of pathways. However, the primary obstacles faced by visually challenged individuals were inadequate information presentation and physical impediments on sidewalks. Likewise, in their study, Low et al. (2020) assessed the travel experience of individuals with visual impairments when using public transportation. Their findings indicate that limited access to information is a significant obstacle for travelers with visual impairments. Despite the increased accessibility of information due to the Internet, visually impaired passengers continue to have difficulties organizing their journeys, as there is currently no comprehensive platform that consolidates all the necessary information for them. Consequently, individuals are compelled to alternate between many sources of information to organize a single journey. Low et al. argued that it is vital to implement more targeted policies that address the unique requirements of individual impairments instead of making broad assumptions about suitable assistance.

Attitudinal Barriers

Women with disabilities experience diverse forms of discrimination and inequalities in many parts of the world stemming from attitudinal barriers, prejudices, and stereotypes (Taylor & Filax, 2014). They are often ostracized, resulting in the exclusion of social spheres, such as schools, families, and employment (Pita et al., 2023). Sona (2015) discovered that many women with physical disabilities experience social exclusion and discrimination, which prevent them from participating in social interactions and exercising their rights. For instance, a 39-year-old-monoplegic woman stated that "after an accidental loss of her left hand, she became socially marginalized and excluded from the previous social life since the society perceived her as sinful and punished by God" (Sona, 2015, p. 177). These societal attitudes might lead to feelings of loneliness (Matin et al., 2021). According to the Centers for Disease Control and Prevention (2020), attitudinal barriers are fundamental and lead to additional barriers.

Attitudes in the Workplace

Gender-based discrimination in the labor market can result in women with disabilities encountering difficulties in securing and retaining work (Almalky, 2020). Women with disabilities face unemployment and lack the financial means to provide necessary treatments

(Matin et al., 2021). These individuals are part of low-income households where their family members are jobless or obtain revenue through informal means (Matin et al., 2021). Kim et al. (2020) conducted a study to investigate the impact of the intersection of disability and gender on the work status of women with disabilities in the United Kingdom. The findings indicated that women with disabilities exhibited a much lower likelihood of employment and a higher likelihood of economic inactivity than women without disabilities. They were also more likely to work for the government, be self-employed, and work part-time. Women with disabilities were much less likely to be managers than were men with disabilities. They also felt that they had less control over the type and amount of paid work they could do compared with women without disabilities. Similarly, Mitra and Kruse (2016) found that between 2007 and 2013, women with disabilities in the United States were 75% and 89% more likely to lose their jobs without deciding to leave than women without disabilities.

Attitudes in the Educational Sector

Women with disabilities are more likely than men to have fewer educational opportunities (Chan & Hutchings, 2023). The primary reason for limited educational opportunities for women with disabilities in low- and medium-income countries is the prevailing societal belief that they are incapable of receiving education (Tefera et al., 2018). In Nepali society, for example, children with disabilities often face social stigma, which results in isolation at home during childhood. This isolation significantly hinders access to education (Pita et al., 2023). Women with disabilities face double prejudice because of the societal opinion in some cultures that education is not essential for girls and should not be prioritized (Peta, 2017). Satapathy (2020) investigated the attitudes that disabled women and girls encounter in their communities while pursuing their educational goals. All women acknowledged the opportunity to have an education, attributing it to the assistance of their teachers, families, and friends. Nevertheless, they discussed the difficulties they faced at school, including concrete obstacles, such as limited accessibility, rejection of admission, and lack of encouragement to engage in extracurricular activities. Although there was no explicit discouragement, there was an implicit suggestion that a physical disability would prevent disabled girls from engaging in sports or physically demanding occupations, thereby exacerbating the gap between disabled and non-disabled girls. Satapathy concluded that schools must go beyond mere physical accessibility and foster an inclusive environment that actively promotes and supports the involvement of girls with disabilities in all academic and extracurricular activities.

Relational Barriers

Various forms of love exist, but many people pursue its manifestation in a romantic relationship (Fincham & Cui, 2010; Hielscher et al., 2021) and marriage with a suitable partner (Karandashev, 2016). However, women with disabilities frequently encounter distinct obstacles in dating and love, including cultural biases and hindrances (Mattlin, 2018). In addition, within the context of marriage, these women may face many challenges, spanning from the challenge of finding a partner who can overlook their disability to the complexities of navigating institutions, which may impose several disadvantages on their unions (Alonzo, 2023). This section highlights the diverse and unique challenges faced by disabled women in their pursuit of love and romantic relationships. Hall and Miller-Ott (2019) employed communication privacy management theory to understand how women with fibromyalgia manage their private health information in a work setting. The findings revealed that the women used four main criteria (gender, context, motivational, and risk-benefit assessment) to decide whether to disclose their condition at work. They faced significant difficulties associated with the condition, such as disrupted relationships, isolation, and a lack of career advancement. The study suggests that improving workplace support and reducing stigma can lead to better management of the illness and improve the working lives of those affected by fibromyalgia.

Navigating Romantic Relationships

Society often does not expect women with disabilities to be in romantic relationships (Zewude & Habtegiorgis, 2021). They are assumed to be incompetent and unsuitable romantic partners (Adhikari, 2018; Ruiz et al., 2023) who lack the ability to form and develop romantic relationships (Matin et al., 2021). Women with disabilities desire romantic relationships. Alonzo (2023) described the experiences of six adult women diagnosed with autism spectrum disorder in a romantic relationship. The findings indicated that diagnosis benefits these women's relationships, enabling their partners to better understand their condition. When partners embraced the women's true selves, this improved their self-esteem and self-perception. Conversely, having autism had certain disadvantages that influenced their romantic relationships. For instance, some women raised concerns about communication difficulties, leading to eventual termination of the relationship. Furthermore, societal standards regarding romantic relationships, which dictate the need to spend a specific amount of time with one's partner, conflicted with their choice for solitude. This discrepancy poses challenges to meeting and understanding expectations within their romantic relationships.

Women with disabilities in some cultures face the challenge of their partners preferring to keep the relationship secretive. For example, Njelesani et al. (2021) explored the experiences of

13 women with disabilities in Sierra Leone regarding intimate relationships and violence to understand the intersection of gender and disability. According to the findings non-disabled men typically approach women with disabilities during the daytime, expressing their desire for a romantic relationship while keeping it secret. Furthermore, men engage in sexual encounters with them during the late hours of the night and depart in the early hours of the morning, ensuring that their actions remain unseen by others. Their partners tend to avoid marrying them because of the perception that they are incompetent in fulfilling family responsibilities (Tefera et al., 2018). Thus, women with disabilities see men's attitudes in their relationships as discouraging and feel that they do not deserve love (Njelesani et al., 2021).

Marriage Possibility for Women with Disabilities

Married life is particularly challenging for women with disabilities. As noted above, these women are often seen as incapable of fulfilling the responsibilities of a good wife according to societal norms (Tefera et al., 2018). In Njelesani et al.'s (2021) study, men hesitated to accept women with disabilities as potential wives, mostly due to preconceived notions influenced by the stigma surrounding disabilities. There was an assumption that these women were incapable of taking care of their husbands and, as a result, would not be appropriate as wives.

Gender and disability-specific social norms also negatively impact the attractiveness and confidence that disabled women have in terms of marriage. In an interview-based study, Gartrell et al (2017), examined the sexual and reproductive health rights of 33 women with disabilities in rural Cambodia. The researchers found that marriage was only considered feasible for women without disabilities in Cambodia if both families of the man and the woman agree to the marriage. Women with disabilities who got married honored their parents' desires and accepted spouses that their parents had selected for them. Moreover, even when men developed love toward them, the families of the prospective partners refused to consent to marriage because of their belief that these women lacked the ability to provide care for their husbands and children.

Violence and Abuse

Violence is a widespread problem in society, with almost one in four women with disabilities experiencing abuse in intimate relationships, marital life, and other phases of their lives (Mitra et al., 2015; Rich, 2014;). In nearly 100% of cases, they experience abuse from people they trust, whether family members, intimate partners, or caregivers (Salthouse, 2018). In 2022, the Sanctuary for Families, an organization committed to protecting and recovering those who have experienced domestic abuse and other types of gender violence, indicated that 80% of women with disabilities in the United States have experienced intimate partner violence. They experience intimate partner violence at a rate that is 40% higher than that of non-disabled women, and the acts of violence they endure are not only more frequent but also more severe (Salthouse, 2018). Women with disabilities experience several types of violence from their partners, including emotional, physical, economic, and sexual violence (Gartrell et al., 2017; McGowan & Elliot, 2019; Njelesani et al., 2021).

Physical Abuse

Physical abuse includes acts of violence, such as beating, burning, slapping, choking, kicking, pushing, or biting (Chandraratne et al., 2018; Tsur et al., 2021). Gartrell et al. (2017) identified that non-disabled spouses and family members become frustrated with women with disabilities because of the challenges their disabilities pose to them, resulting in incidents of physical violence. For example, a woman with hearing impairment recounted an incident where her father hit her out of frustration due to the challenge of effectively communicating with her. Ashraf et al. (2017) investigated the accounts of women with disabilities in their encounters with violence and abuse. Women revealed that were beaten by their siblings. One woman's partner subjected her to emotional abuse by calling her demeaning names and physical violence by beating her to reach a point where she could no longer endure pain (Njelesani et al., 2021).

Economic Abuse

Huang et al. (2013) refer to economic abuse as a type of domestic violence that involves exerting control over an individual's ability to obtain, utilize, and maintain financial assets. Njelesani et al. (2021) highlight that partners and spouses of women with disabilities extend the abuse of economic violence as a means of exerting control over their financial assets, housing, and other valuable resources. Women in their intimate relationships and those married claimed that their partners demonstrated love towards them mostly because of their financial resources and displayed exemplary behavior as good partners. On the other hand, the women disclosed that once they realized that their partners were only interested in them because of their assets, the men became abusive towards them.

Verbal Abuse

The intersection of gender and disability greatly amplifies the susceptibility of women with disabilities to a wide range of abuses, such as verbal abuse (Sasseville et al., 2020). McGowan and Elliot (2019) argued that societal attitudes toward disability and gender are significant factors in creating an atmosphere receptive to abuse. Verbal abuse directed against women with disabilities manifests in several ways, ranging from direct derogatory remarks about their condition to more nuanced expressions of patronization (Ellis et al., 2011). According to

Ashraf et al. (2017), women were subjected to sarcastic remarks and derogatory labels that were associated with their disability, such as being blind, deaf, dumb, and physically impaired. When they made the slightest mistakes, they were maltreated and subjected to derogatory terms. This abuse results in emotional abuse, which manifests as heightened susceptibility to mental health issues, including depression and anxiety (McGowan & Elliot, 2019). Likewise, this mistreatment might lead to feelings of despair, anxiety, and a decrease in self-esteem (Copel, 2006).

Sexual Abuse

Sexual abuse includes acts such as rape, sexual harassment, sexual exploitation, or coercing a woman to participate in any unwanted and offensive sexual act (Mohammed & Hashish, 2015; Moolman et al., 2023). Gartrell et al. (2017) found that women recounted unwelcome sexual advances, such as inappropriate touching and kissing from their intimate partners. In addition, they encounter twice the rate of non-consensual sharing of personal and intimate images (Salthouse 2018). Moreover, young girls who are visually impaired reported experiencing many instances of unwanted touching when males helped them cross the road but were unaware that such actions constituted sexual abuse (Salian, 2022). In some cases, the abuse might even come from a partner who, themselves, has a disability (Sona, 2015) or from family members (McGowan & Elliot, 2019).

Burke et al. (2017) discovered that 18% of all female interviewees reported instances of rape and sexual violence. This abuse was most prevalent among women with hearing impairments, with four out of six women reporting being raped once or multiple times. Ledingham et al. (2022) discovered that over 30% of women between the ages of 18 and 44 with sensory, physical, or cognitive impairments reported having experienced forced vaginal intercourse at least once in their lifetime. This prevalence is much higher than that of non-disabled women. These barriers and issues are interrelated factors that impede access to health care (Matin et al., 2021). Specifically, they have access to sexual and reproductive health services, and maternal care (Matin et al., 2021; Nguyen et al., 2022).

Sexual Reproductive Health Care

Women and girls with disabilities encounter discrimination in all spheres, including sexual and reproductive health, and rights. Women with disabilities are typically viewed as asexual (Iezzoni et al., 2015; Mitra et al., 2016; Rich, 2014; Silvers et al., 2016; Tefera et al., 2018; Wood, 2017). Asexuality refers to the absence of sexual desire or fantasies towards others or the presence of low interest in engaging in sexual activities (Carrigan, 2011; Catri, 2021; Gupta, 2016). The idea that women with disabilities have no interest in sex or should lack sexual interest stems from the stereotype that adults with disabilities are like children (Kulick & Rydström, 2015). These perceptions of asexuality may be the reason for the disparities in women with disabilities' access to reproductive healthcare compared to women without disabilities (Silvers et al., 2016). However, women with disabilities do have sex (Bernert & Ogletree et al., 2012; Namkung et al., 2021). Burke et al. (2017) conducted focus group discussions on sexuality and sexual reproductive health to analyze the overall experiences of 50 young people with visual and hearing impairment. Many women informants disclosed their involvement in sexual activities such as "sexual intercourse, flirtations, and petting" (Burke et al., 2017, p. 47). Some informants opposed society's portrayal of them as sexually inactive because of their condition.

Moreover, women with disabilities encounter difficulties in obtaining appropriate gynecological care because of obstacles in the physical environment and the absence or improper accommodations (Wolowicz et al., 2022). Many women, particularly those with physical and visual disabilities, claimed that healthcare facilities generally do not have customized elevators, roadways, expanded entrances to buildings, sufficient adapted sanitary facilities, or gynecological armchairs that meet the demands of patients with disabilities (Wolowicz et al., 2022). These issues pose challenges for women in accessing gynecological treatment and infringes upon their right to privacy and respect during examinations (Wolowicz et al., 2022).

Furthermore, women with disabilities in low- and middle-income countries exhibit a reduced frequency of contraceptive use and a heightened unmet demand for contraceptives compared to non-disabled women (Burke et al., 2017; Wolowicz et al., 2022). Specifically, healthcare providers have been reported to dismiss or neglect the contraceptive needs of disabled women (DiMatteo et al., 2022). In addition, some healthcare providers fail to acknowledge the challenges that menstruation may present in daily lives of women with disabilities (DiMatteo et al., 2022). These barriers have impeded the right of women with disabilities to duties associated with womanhood, such as pregnancy and childbirth (Wood, 2017).

Pregnancy Overview

The intersecting barriers discussed in this chapter influence women with disabilities in their pursuit of pregnancy and motherhood and affect their maternal experiences and outcomes. These challenges often manifest in systemic laws and regulations (Tilley et al., 2012), limited receipt of adequate maternal care (Matin et al., 2021), restricted access to healthcare, information, and support, and difficulties in navigating societal attitudes towards disability (Iezzoni et al., 2017; Mitra et al., 2016).

Historically, widespread forced or involuntary sterilization in all parts of the world has restricted the sexual and reproductive freedom of a significant part of the female population (Barnett et al., 2018; DiMatteo et al., 2022; Serrato Calero et al., 2020; Tilley et al., 2012). Forced sterilization is the non-consensual deprivation of a person's potential to reproduce, typically accomplished through a surgical procedure known as tubal ligation (American College of Obstetricians and Gynecologists, 2017; Leason, 2021). This inhumane policy focused on women belonging to ethnic and racial minorities, women with disabilities, women living with HIV, and economically disadvantaged women (Patel, 2017). The practice of forced sterilization and other invasive treatments specifically manifests systemic violence, primarily targeting girls and young women with disabilities (McConnell & Phelan, 2022). According to the National Council on Disability (2012), this legislative tendency is based on the belief that women with disabilities would have children who would impose a burden on society. In addition, some women were sterilized because of concerns regarding the possibility of sexual assault leading to pregnancy (Tilley et al., 2012). Due to this systemic barrier, many women with disabilities are not able to experience the joy of becoming mothers (Amin et al., 2020).

The United States, specifically, has a dreadful track record of offering ethical care to persons with disabilities, as forced sterilization was prevalent there in the 20th century (Ducharme, 2023). Nevertheless, Barnett et al. (2018) highlight a significant change in systematic policy over the past 40 years, acknowledging the rights of all women to preserve their fertility and have a family. In recent years, the pregnancy and delivery rates among women with disabilities have approached those of women without disabilities (DiMatteo et al., 2022).

According to Li et al. (2017), about 4.4 million out of 65.9 million parents in the United States have a disability. Specifically, the total number of parents with self-care disabilities is approximately 600,000, while the number of parents with vision disabilities is around 900,000.

Additionally, there are about 1 million parents with hearing disabilities, 1.2 million parents with independent living disabilities, 1.8 million parents with ambulatory disabilities, and 1.7 million parents with cognitive disabilities. In 2021, the National Institutes of Health conducted a study in 19 United States hospitals. They found that among 223,000 deliveries, roughly 2,199 women had a disability. The increase in the number of women with disabilities being parents indicates an inclusive approach on the part of societies that recognize the unique experiences and capabilities of women with disabilities in their role as mothers and their desire to be mothers.

Factors that Influence Pregnancy Decision

The decision to pursue pregnancy is complex experience especially for women with disabilities. One of the factors stems from women's biological roles as the carriers of human life and the positive and empowering experience of pregnancy (Ganle et al., 2020). The healthcare aspect of pregnancy such as the risks and cost also play a crucial role in pregnancy consideration for women with disabilities (O'Connor-Terry & Harris, 2022; Strnadová et al., 2019). The decision-making process is complicated by the issue of economic stability (O'Connor-Terry & Harris, 2022). Furthermore, there is a high concern of genetic problems considering not only the dangers to one's personal well-being but also the inherent hereditary implications for the child (Gibson & Mykitiuk, 2012). These factors create a dynamic environment in which mothers must negotiate to make informed decisions about pregnancy (LaPierre et al., 2017).

Internal Motivation Factors to Pursue Pregnancy

The decision to pursue pregnancy and motherhood has increased among women with disabilities due to their anticipation of experiencing physical attachment to the unborn child, a love for children, a tendency to protect their child, and the joy of motherhood (Ganle et al., 2020; Höglund & Larsson, 2013; LaPierre et al., 2017). For example, Höglund and Larsson (2013) found that the anticipated physical experience of the unborn child is one factor that influences the desire for pregnancy among women with disabilities. Women considered the ultrasound checkup to be a memorable experience since they witnessed the baby's movement. Other positive experiences the women mentioned included listening to the baby's heart and feeling the baby's kicks. The pregnancies seemed real for many women when their bellies enlarged. These experiences build a physical connection between the mother and child that might be unique for women with disabilities.

Strnadová et al. (2019) investigated the pregnancy encounters of women with intellectual disabilities. The women described pregnancy as a phase in which they formed a physical connection with their unborn child. Furthermore, 10 of the 11 Israeli women with intellectual disabilities whom Shpigelman and Bar (2023) interviewed indicated a strong desire to become pregnant due to their love for children. Ganle et al. (2020) found that almost all women studied who indicated a desire to have their own children considered the joy of motherhood as a significant driving force. Many of these women agreed that motherhood entails responsibility. Women characterized the journey of motherhood as a positive and powerful experience. Parents actively participated in activities such as playing and drawing with their children. This experience demonstrates the joy derived from motherhood.

Feasibility of Other Factors

The availability of other methods for pregnancy, financial cost, and health risks plays a crucial role for women in making decisions about pregnancy. For example, according to LaPierre et al. (2017), women expressed an interest in adoption, but concerns about the expenses involved and doubts about being approved for adoption due to medical or mental health difficulties generally hindered them from pursuing this option. Women with disabilities expressed concerns about their financial capacity to have a healthy pregnancy and raise a child, considering their health status and available resources. Specifically, women who depend on disability benefits questioned their ability to financially support pregnancy because of the limited resources available. LaPierre et al. concluded that these research findings demonstrate the influence of factors such as feasibility and expenses on making decisions about pregnancy.

Other compelling factors may cause women with disabilities not to consider pregnancy, such as the health risks of pregnancy. For example, Alhusen et al. (2021) found that women with disabilities have a 1.4 times higher risk of facing adverse pregnancy outcomes. These outcomes include giving birth prematurely and having babies with low birth weight, babies requiring admission to Neonatal Intensive Care Units, experiencing cognitive delays, and facing bonding and attachment challenges. Similarly, O'Connor-Terry and Harris (2022) found that women expressed worry the potential risks of blood clots, urinary tract infections, and pressure sores. Women also expressed fear regarding their functional capabilities. Many women voiced concerns over the potential difficulty of mobility and sitting associated with weight increase (O'Connor-Terry & Harris, 2022). Likewise, Colaceci et al. (2023) discovered that a prevalent concern among women with vision impairments contemplating pregnancy was their worry about their ability to care for their children independently as a result of their disability.

Genetic concern is a factor that affects pregnancy decisions of mothers with disabilities. Mothers with hereditary medical conditions were greatly concerned about the possibility of transmitting their health conditions to their children. LaPierre et al. (2017) found that women who were not certain about or poorly understood their genetic medical condition were hesitant to pursue pregnancy due to the potential increased risk for their child. Apart from the immense guilt they expected to feel if they had transmitted their disease, several women were also worried about the additional obstacles they would encounter when tending to a child with severe medical needs. Likewise, Gibson and Mykitiuk (2012) found that women provided stories of being actively discouraged from having children. This discouragement stemmed from questions about their ability to provide care and fear of the potential risk of their children inheriting their genetic condition. In another study, a woman with a hereditary genetic disease, osteogenesis imperfecta (OI), expressed fear of transmitting OI to her baby during pregnancy (O'Connor-Terry & Harris, 2022). LaPierre et al. (2017) concluded that women with disabilities typically prioritize the risks of death and miscarriage while they view other pregnancy concerns as manageable.

Attitudes and Support Towards Pregnancy

The attitudes of family members and other external influences on the pregnancy of women with disabilities have diverse effects on their journey toward motherhood. Recent studies have examined the positive and negative implications of the attitudes and reactions of families, partners, and strangers towards pregnancy in women with disabilities (Malouf et al., 2017; O'Connor-Terry & Harris, 2022; Shpigelman & Bar, 2023). Family support is crucial in fostering resilience and empowerment among women during and after pregnancy (Barnett et al., 2018). However, negative emotions can arise because of concerns about the woman's health, the well-being of the potential child, and the perceived burden on the family, which could discourage them from pursuing pregnancy and motherhood (Powell et al., 2017).

Family Positive Attitudes and Reactions Towards Pregnancy

Powell et al. (2017) interviewed 25 women with physical disabilities from across the United States, who had given birth within the past ten years. The women reported positive attitudes and reactions toward their pregnancy from family members such as parents, siblings, grandparents, aunts, uncles, and in-laws. One woman explained that upon informing her in-laws about her pregnancy, they responded with joy and handled the news well. The same woman reported an even more positive experience when she disclosed her second pregnancy to her family. Similarly, another woman expressed that her parents were exceedingly excited because they knew about her efforts to become pregnant. Other women said that their families were pleasantly surprised and provided strong support as pregnancy advanced. In addition, Barnett et al. (2018) highlighted that responses to news of pregnancy among women with disabilities were predominantly positive and celebratory from their families and partners.

Family Negative Attitudes and Reactions Towards Pregnancy

Despite many women reporting positive attitudes and reactions, others expressed negative experiences when they informed their families about their pregnancies. One woman described her family's reaction in this way: "It's not uncommon at family events where somebody will announce that they're pregnant, and so we announced at a Halloween party and when we announced it, the whole room just got silent" (Powell et al., 2017, p. 347). Another woman recounted feeling anxious while informing her parents of her pregnancy. This reaction was due to her parents, particularly her mother, who consistently discouraged her from becoming pregnant because of her disability. One woman stated that her in-laws were first skeptical and only became supportive around one month prior, since they doubted the possibility of conceiving. She clarified that, before her baby shower, her father-in-law instructed the family to refrain from purchasing anything for the baby until they were sure of its survival.

Höglund and Larsson (2013) found that some women experienced negative attitudes and reactions from their partners upon announcing their pregnancy. For instance, one woman stated that the expectant father expressed his lack of preparedness for being a parent and as result refused to take responsibility to take care of the unborn child. According to Strnadová et al. (2019), parents influence women with intellectual disabilities to opt for abortion. Parents and caregivers told the women that their pregnancy was a mistake and that it should not be repeated. In some cases, doctors were authorized to perform surgical sterilization on women, and this attitude upset the women. Strnadová et al. (2019) argued that family and partner attitudes discouraged them from desiring a child.

According to Powell et al. (2017), many women indicated concerns about their ability to provide adequate care for their baby as the primary cause of their families' unfavorable attitudes toward their pregnancy. For example, one woman recounted her mother's response to her pregnancy by questioning her ability to care for a newborn. Another woman recounted her experience of being pregnant with twins, during which her mother incorrectly thought that she would be unable to care for the babies. Other mothers expressed a sense of obligation to demonstrate their ability to provide care to their babies. One woman described how she showcased her ability to carry her baby while sitting in her wheelchair to her family members, as she felt the need to display her capabilities to them. The findings from these studies serve an appeal for a social approach to pregnancy and motherhood of this marginalized group that is more inclusive and supportive and promotes a sense of belonging.

Public Attitudes Toward Pregnancy

In addition to family and partner attitudes, Iezzoni et al. (2017) conducted telephone interviews with women with mobility disabilities to examine the perceptions and attitudes of the general public towards these women when they were pregnant. Several of the women reported experiencing hostile attitudes from strangers suggesting that their babies would be a burden on society. One mother stated, “The world looks at a mom with four kids, who has a cane, and has had a stroke, and had a chronic illness, and had a multisystem disease and goes, ‘What is wrong with you?’ (Iezzoni et al., 2017, p. 423). Many women reported instances in which strangers doubted their ability to be parents, particularly in terms of providing safe care for a child.

The availability of a formal social support system is also important. According to Malouf et al. (2017), the availability of support from social workers, health visitors, support workers, children centers, and voluntary sector organizations within their community impacts women’s decisions to consider parenting and motherhood. First (2020) discovered that women with intellectual disabilities who lack family support require guidance in areas such as financial management and understanding of official paperwork. Furthermore, social workers played a crucial role for women who did not have informal relationships with friends.

Maternal Care Experiences

Researchers have examined the most recent evidence on the lived experiences of childbirth, prenatal and postnatal care, and services accessed by women with disabilities (Blair et al., 2022; Casebolt, 2020; Matin et al., 2021). Malouf et al. (2017) conducted a study on the emotions women with learning disabilities expressed during maternal care in high-income countries such as the United Kingdom. The researchers observed that these women strongly desired normal childbirth experience. They also preferred to be treated equally to women without disabilities, without being labeled as high-risk due to their disability. Women expressed their intense dislike for being treated differently and stressed the need for information and support related to maternity care, such as increased appointment and screening frequency. These findings imply that women with disabilities encounter disparities in health care before, during, and after pregnancy (Mitra et al., 2015).

Experience with Health Professionals

The provision of adequate care for pregnant women with disabilities depends on the knowledge, communication abilities, positive attitudes, and expertise of the health professionals. Healthcare professionals must possess the ability to effectively communicate intricate medical facts in a clear manner while attentively listening to the concerns of their patients (Rugoho & Maphosa, 2017). Mitra et al. (2016) highlight the significance of interdisciplinary care teams in the management of pregnancies in women with disabilities. Many healthcare professionals still do not understand the unique challenges and concerns associated with pregnancy and disabilities (Strnadová et al., 2019). Healthcare professionals must possess the ability to effectively communicate intricate medical facts in a clear manner while attentively listening to the concerns of their patients (Rugoho & Maphosa, 2017).

Knowledge and Awareness of Disability

According to one study of mothers with physical disabilities, while few women indicated that their perinatal care providers were enthusiastic and open to learning, many reported that they lacked knowledge regarding the experience of caring for women with physical disabilities. Several women also expressed concerns regarding the potential influence of their medications on their infants. These women discovered that their prenatal care providers provided limited information and guidance on this issue (Tarasoff, 2017). Likewise, Kazembe et al. (2022) found that women with physical disabilities frequently reported that healthcare professionals lacked expertise in addressing their pregnancy concerns. Additionally, women express that while their healthcare providers had limited or no knowledge about the potential effects of their disability on pregnancy at the beginning of their antenatal care, they were unwilling to learn from them directly, disregarding their extensive knowledge and lived experiences (Blair et al., 2022). As a result, women become frustrated about health professionals' lack of knowledge and awareness, making them worried about their pregnancy's safety and well-being (Pita et al., 2023).

Lack of Communication Skills

Women with disabilities also expressed concerns about health professionals' lack of effective communication skills. Examples of ineffective communication that the women recounted were feeling that providers were not listening to them and not paying attention to their concerns, leading to frustration (Rugoho & Maphosa, 2017). Tarasoff et al. (2023) explored the childbearing experience of women with physical, sensory, and intellectual developmental disabilities in Ontario, Canada. They found that providers did not communicate directly with the women but instead discussed them with their support person. In an interview study, Colaceci et al. (2023) found that health professionals failed to clearly explain their conditions or treatment procedures, which made patients reluctant to seek further information (Nguyen, 2020). As a result, the patients may see routine procedures, such as being placed in a "hands-and-knee position during labor, as a punishment" (Colaceci et al., 2023, p. 3). Matin et al. (2021) asserted that healthcare providers' lack of effective communication techniques with women with disabilities impacts the quality of interpersonal relationships between providers and these women.

On the other hand, disabilities that affect hearing, speaking, reading, writing, and or understanding encounter communication barriers (Centers for Disease Control and Prevention, 2020). For example, individuals with hearing impairments may lack the ability to participate in conversations or react to auditory signals, thus hindering their ability to sustain personal relationships (Beechey et al., 2020). Women with disabilities resulting from cognitive, hearing, and visual impairments face challenges in successfully communicating with healthcare providers and understanding important information (Casebolt, 2020; Matin et al., 2021; Mitra, 2015) during prenatal care (Tarasoff et al., 2023). Salian (2022) emphasized that in instances where doctors are unable to obtain a comprehensive medical history from a patient who is deaf or cannot receive replies due to communication obstacles, they may have difficulties reaching a precise diagnosis or prescribing targeted medication or investigations. This challenge is due to the lack of sign language interpreters (Salian, 2022; Tarasoff et al., 2023; Wolowicz et al., 2022). For example, a woman reported that the absence of an American Sign Language interpreter at the walk-in clinic led to an incorrect exchange of information with her healthcare provider, which caused her sadness (Tarasoff et al., 2023).

Insensitive and Negative Attitudes

Women with disabilities report encountering negative attitudes about their disability from health professionals (Barnett et al., 2018; Devkota et al., 2019; Malouf et al., 2917; Mitra et al., 2015; Pita et al., 2023; Salian, 2022) and comments about their suitability for parenthood and competence as parents (Malouf et al., 2017). For example, one woman mentioned that nurses questioned her suitability as a mother when she requested help to get out of bed and use the restroom (Tarasoff, 2017). In addition, female nurses were identified as the main perpetrators of verbal abuse of women with disabilities who visited hospitals or sought medical attention throughout their pregnancies (Rugoho & Maphosa, 2017). These remarks were mostly conveyed subtly but occasionally in a blatant and insulting manner (LaPierre et al., 2017).

Kazembe et al. (2022) also discovered that women with physical disabilities experienced disdainful treatment from healthcare professionals, who ridiculed them for their disabilities and held them responsible for their pregnancies. Women view these as disrespectful (Tarasoff et al., 2023), judgmental, and unsupportive (LaPierre et al., 2017; Strnadová et al., 2019). According to LaPierre et al. (2017), women often encountered many healthcare professionals but rarely found a physician who they believed showed empathy and support toward their pregnancy desires. Mitra et al. (2015) argued that these negative encounters and inadequate care received from healthcare professionals may deter women with disabilities from obtaining essential prenatal and postpartum healthcare services (Mitra et al., 2015).

Moreover, the National Council on Disability (2012) pointed out that women with disabilities continue to face coercive strategies to promote sterilization or abortion because of the perception that they are unsuitable for motherhood. Blair et al. (2022) found that many women encountered health professionals who were insensitive, discriminating, and not educated about disability rights. Matin et al. (2021) emphasized that service providers believe that women with intellectual disabilities and visually impaired people lack the ability to conceive, care for a child, engage in safe sexual activities, make decisions, and give birth without medical intervention. Nguyen (2020) found that healthcare professionals in low-to-middle-income countries such as Vietnam instruct women with disabilities to undergo cesarean deliveries, disregarding women's preference for vaginal delivery. According to the findings, health professionals. Failing to perform recognized clinical pelvic tests, ordered cesarean sections due to the possibility of a deformed or narrow pelvis and a lack of strength to deliver the baby naturally due to their condition. Such instances are likely to lead pregnant women with disabilities to be more inclined to choose home birth without the presence of a competent midwife, which can result in higher health risks for both the mother and child (Kazembe et al., 2022). These findings indicate the need to enhance clinical and supportive care for disabled women during the maternity period.

Positive Attitudes of Healthcare Professionals

At the same time, women with disabilities can have positive experiences with healthcare professionals, such as when healthcare practitioners offer assistance during pregnancy and demonstrate confidence in their parenting abilities (Blair et al., 2022; First, 2020; Pita et al., 2023). For example, according to Nguyen (2020), women with disabilities residing in the US, Canada, and Switzerland reported positive experiences in accessing reproductive healthcare, specifically pregnancy and antenatal care. They noted that their healthcare providers displayed favorable attitudes during their pregnancy check-ups and that they found it convenient to consult empathetic providers. The women attributed these positive experiences to the inclusive programs implemented in these countries. Women's labor experiences revealed similar patterns, with the women recounting instances of healthcare personnel who exhibited high levels of support and empathy. This makes women feel more certain and self-assured during delivery.

In low- and middle-income countries, such as Timor-Leste, Nepal, and Vietnam, women indicated that healthcare personnel at private hospitals were more compassionate and knowledgeable than those in public or government hospitals. Private healthcare providers offer extensive access to reproductive healthcare to anyone who can afford their services due to their user-pay structure (Nguyen, 2020). Some women have highly favorable experiences, characterized by a sense of ease, understanding, and reliance on healthcare professionals to assist them in making informed choices regarding their pregnancy (Kalpakjian et al., 2021). Additionally, Mitra et al. (2016) found that more than one woman praised their healthcare providers as excellent and remarkable while discussing nursing personnel. In addition, a few women acknowledged their healthcare professionals as catalysts of support while undergoing the transforming process of recognizing the potential of pregnancy and motherhood (O'Connor-Terry & Harris, 2022). Irrespective of the kind of disability, women emphasized that advocacy was crucial in ensuring that their needs were addressed throughout prenatal care (Tarasoff et al., 2023). Many women said that providers actively supported and championed their needs in relation to their disabilities (Tarasoff et al., 2023).

Inaccessible Healthcare Facilities and Equipment

The limitations of equipment and inaccessible facilities for persons with disabilities noted earlier in this chapter apply specifically to pregnant women. Prior research has focused on inaccessible equipment and facilities as major barriers to accessing prenatal care and childbirth services among pregnant women with disabilities (Casebolt, 2020; Mitra et al., 2015; Pita et al., 2023; Rugoho & Maphosa, 2017). These barriers include the absence of ramps, inaccessible areas for change or check-in, and inadequate equipment, such as tables and beds that are not accessible (Nguyen, 2020). Studies have revealed that these barriers negatively impact the pregnancy experiences of women with disabilities (Blair et al., 2022; Gibson & Mykitiuk, 2012; Mitra et al., 2015; Mitra et al., 2016).

In various interview-based studies, women with disabilities stated that inaccessible washrooms (Devkota et al., 2019; Mitra et al., 2015; Mitra et al., 2016; Tarasoff, 2017) and a lack of accessible parking spots, automatic doors, low-reception desks, and wide corridors pose significant challenges in navigating facilities (Blair et al., 2022). Furthermore, women with disabilities have indicated that some facilities lack adjustable examination tables (DiMatteo et al., 2022; Salian, 2022; Tarasoff, 2017) and weighing scales, which makes physical examinations difficult (Blair et al., 2022; Mitra et al., 2015). Many women stop attending prenatal checkups because health facilities and equipment are not accessible (Salian, 2022). Consequently, diseases such as intrauterine growth restriction, anemia, diabetes, and high blood pressure may remain undetected, negatively impacting their pregnancy and overall functioning and well-being to have successful deliveries (Mitra et al., 2015; Salian, 2022; Seidu et al., 2023).

Furthermore, the limited availability of public transportation makes access to healthcare appointments difficult. Many clinics and hospitals are located far from the homes of women with disabilities (Devkota et al., 2019; DiMatteo et al., 2022; Kazembe et al., 2022; Wolowicz et al., 2022). It becomes more expensive when they require an assistant, as they must cover the cost of transportation for themselves and their helper (Mitra et al., 2015). Sometimes, they also pay for wheelchairs (Mitra et al., 2015). In addition, women with disabilities in rural areas had to walk long distances alone or be transported to healthcare facilities when there was no available public transit (Kazembe et al., 2022). Women with disabilities also mentioned the inconvenient and limited operating hours of health facilities as an additional factor hindering their access to reproductive healthcare services (Devkota et al., 2019).

Postpartum Depression

The postpartum phase of motherhood refers to the period immediately following childbirth as the mother's body and mind adjust to the changes after delivery (Rasminsky, 2018; Rodgers et al., 2024; Watson et al., 2016). Postpartum depression is one of the most common mental disorders among new mothers that can occur during this time. Various researchers have conducted studies to analyze the causes and diagnosis of postpartum depression among mothers (Aoki et al., 2023; Incollingo Rodriguez et al., 2022; Heck et al., 2022). For example, Míguez and Vázquez (2023) conducted a longitudinal study to assess the prevalence of postpartum depression throughout the first year by using a screening instrument and a clinical interview to identify women with the most severe depression. The researchers explained two forms of depression: major depression is the most severe form of depression, while probable depression implies a less severe state of depression. They found that the prevalence of probable depression was highest at two months postpartum, while major depression was highest at one year postpartum. The results indicated a need for extended postpartum mental health care, as the prevalence of major depression increases significantly after six months postpartum.

Xiao et al. (2023) examined the experience of postpartum depression among 15 new mothers in mainland China. The study identified various factors that influence the minds of Chinese women with postpartum depression. These include the gap between expectation and reality about life after birth, lack of family support such as psychological and emotional support, conflicts with family, critical needs for coping with changes, and measures against postpartum depression. Xiao et al. (2023) argued that peer support can strengthen communication among women after delivery. Precisely, mothers sharing childcare and self-care experiences can compensate for the lack of information about caring for the baby and themselves, imbuing women with the confidence to return to work. Likewise, the support of family and friends, joining a mother's support group, and good nutrition and exercise can be helpful for mothers in the phase of postpartum depression (American Psychiatric Association, 2023).

Tesfaye et al. (2023) found a 23.8% prevalence of post postpartum depression among women. Factors significantly associated with postpartum depression included being single, experiencing complications during pregnancy, bottle feeding immediately after birth, and having low perceived psychosocial support. The researchers recommended new mothers have regular screening, follow-up, and mental health care in postnatal periods of pregnancy because the period of childbirth is stressful, especially for new mothers. As a result, they emphasized the importance of emotional and psychosocial support for new mothers in both community and healthcare settings. Similarly, Kim et al. (2014) emphasized the importance of social support, especially after birth, to reduce the risk of postpartum depression in mothers of all ages. This recommendation indicates a need for more research and tailored support for mothers with disabilities who might face unique challenges during this phase. Moreover, Öksüz (2021) focused on the unique challenges and higher risks of postpartum depression faced by women with disabilities. The researchers adopted an ecological perspective to analyze the multiple systemic, social, and environmental factors contributing to postpartum depression in this group. These studies highlight a gap in research and support systems for these women, emphasizing the need for more targeted studies and interventions to support them effectively during the postpartum period. This gap calls for a deeper understanding of the intersection of disability, motherhood, and mental health, along with the development of more inclusive and specialized support systems.

Thomas et al. (2014) sought to understand the experiences of mothers with postpartum depression by exploring health behavior constructs derived from the Integrative Model of Behavioral Prediction. This model was chosen due to its comprehensive nature, allowing for an exploration of multiple postpartum depression-related behavioral constructs. The study specifically aimed to uncover how these constructs appeared in mothers' unsolicited online narratives about their experiences with postpartum depression and how these constructs related to help-seeking behaviors. Many mothers reported severe negative effects of postpartum depression on their lives. Symptoms included irrational thoughts, crippling guilt, sleep disturbances, appetite changes, and in some cases, suicidal ideation. For instance, one mother feared showing affection to her new baby in front of her toddler due to guilt, while another had persistent, irrational fears about her child's health despite reassurances from multiple doctors.

According to Thomas et al. (2014), the mothers identified specific cues or facilitators that led them to seek help. These included interventions by family members, advice from midwives, or connections made through support groups. For instance, one woman was urged to seek help by her mother after confessing her suicidal thoughts, while another was encouraged by the overwhelming support and shared experiences from a mother's support group online. Barriers to seeking help were also evident in the stories, including personal, interpersonal, and institutional obstacles. The mothers cited the lack of a shared experience with close ones, privacy concerns, denial by spouses, embarrassment, lack of knowledge about postpartum depression, and financial or insurance constraints as significant hurdles. Some women described overcoming their fears and seeking treatment successfully, while others expressed feelings of helplessness and doubt about their ability to manage their condition.

Using relational dialectics theory, Scharp and Thomas (2017) investigated how mothers make sense of motherhood in dealing with prenatal depression and postpartum depression within the context of societal expectations and cultural conceptions of motherhood. Their findings reveal two competing discourses: the Discourse of Self-Sacrificing Blissful Moms (DSBM) and the Discourse of Mothers as Whole People (DMWP). Narratives within the first discourse reflected societal expectations that mothers should be selfless, always happy about their motherhood experience, and instantly in love with their children. For instance, one participant shared her struggle to match this ideal by trying to be "motherly" and "nurturing" despite feeling detached and overwhelmed, reflecting the internalization of societal pressures. In contrast, the second discourse challenged the one-dimensional portrayal of motherhood in the first discourse by recognizing that mothers may experience a wide range of emotions, including those that are not exclusively positive. It validates experiences of difficulty, anxiety, or sadness and suggests that love and bonding with a child can develop over time rather than being instantaneous. For example, one woman's narrative countered the self-sacrifice norm by stating, "Don't martyr your mental health over breastfeeding" (p. 9), advocating for the importance of the mother's well-being alongside the child's. The study emphasizes the importance of creating spaces for women to share their experiences openly. It offers insights into the therapeutic potential of narrative and the power of discourse in shaping and reshaping the meanings of motherhood.

Peer Support

The absence of examples of mothers facing similar physical or mental problems frequently leads women to compare their own abilities with idealized concepts of becoming a mother (LaPierre et al., 2017; O'Connor-Terry & Harris, 2022; Powell et al., 2017). LaPierre et al. (2017) argued that the existence of this gap undermined the self-assurance that these women possessed in their capacity to be effective parents and diminished the value they believed they could provide to their children. One woman who uses a wheelchair criticized the media saying, "All of the pictures that we have of motherhood are like healthy, standing women" (p. 422). This finding implies that women with disabilities are unaware of the effective tactics employed by others to navigate parenting.

As a result, women with disabilities leverage peer support as a means to acquire information (First, 2020) that is inaccessible to their healthcare providers and other sources, which positions them as the best and knowledgeable teachers (Mitra et al., 2016). Peer counseling is an effective means of empowering mothers with disabilities to assist them in enhancing their motherhood journey towards a more satisfactory way of life (Barbuto &

Napolitano, 2014). In addition, mothers with mobility disabilities from a study of Iezzoni et al. (2017) recognized the importance of advocating for themselves by establishing a support system and embracing assistance from other mothers with disabilities. The women advised that prospective mothers should engage in conversations with other mothers who have disabilities since it helps to alleviate their fears. Blair et al. (2022) found that women with disabilities sought guidance, practical advice, and a sense of belonging from their peers, namely other mothers with disabilities, who were considered reliable sources of information.

Similarly, Mitra et al. (2016) discovered that women frequently sought guidance from other women with disabilities with similar experiences who had experienced pregnancy. Khanna et al. (2022) explored recommendations from mothers with intellectual and developmental disabilities for other women to improve pregnancy experiences for this population. They found that women referred to mothers with disabilities as coaches and as a support system to help potential mothers navigate through their pregnancies. For example, one woman stated that she gained the greatest knowledge about pregnancy from other mothers with disabilities. Khanna and colleagues concluded that mothers with disabilities eagerness to assist prospective mothers with intellectual and developmental impairments, and positive attitudes towards motherhood while facing negative situations, indicate perseverance among these mothers. Moreover, Höglund and Larsson (2013) highlighted that women with intellectual and developmental disabilities share their experiences of pregnancy and motherhood. The women showed consistent progress, and they demonstrated enthusiasm and fulfillment in telling their stories. Therefore, these measurements highlight the need of initiating empowerment procedures, enabling women with disabilities to recognize their self-worth and comprehend that their disability does not negate their entitlement to a fulfilling and joyful existence (Barbuto & Naplitano, 2014).

Sources of Information

The access to information is crucial for all pregnant women, but it is particularly vital for women with disabilities since it plays a crucial role in their journey to becoming mothers. Women with disabilities express the need for information that may help them navigate pregnancy and make important decisions, particularly those pertaining to childbirth (Iezzoni et al., 2017; Mitra et al., 2016). They express their interest in and efforts to learn more about their disability in relation to pregnancy, a pursuit that is sometimes challenging to fulfill (Kalpakjian et al., 2021). The lack of adequate information is a cause of concern, ranging from worry to extreme fright (Iezzoni et al., 2017). Iezzoni et al. (2017) explored the advice that new mothers with mobility disabilities would give to their peers about the pregnancy journey. Women identified four main sources of information: “self-help books, online resources, and other women, particularly those with mobility disabilities” (p. 77). These sources not only demonstrate the resilience and resourcefulness of women with disabilities but also emphasize a gap in the healthcare system’s delivery of comprehensive medical care.

An increasing number of people, including those with disabilities, use the internet to search for information (Malouf et al., 2017). Women with disabilities have leveraged social media as an accessible and cost-effective means of participating in conversations with their peers about reproductive health issues (Rugoho & Maphosa, 2017). The internet sources women use to access information are organizational websites, social networks, blogs, and YouTube videos that feature women with mobility disabilities who have experienced childbirth (Iezzoni et al., 2017).

For many women, Facebook groups played a crucial role in offering prompt and essential help to numerous women, including encouragement (Iezzoni et al., 2017).

In an interview study examining information sharing among women with disabilities, Litchman et al. (2019) found that blogs offer a medium for women with disabilities to engage in social media interaction with their peers, allowing them to share and gain information and support. Rugoho and Maphosa (2017) also discovered that women accessed WhatsApp groups led by women with disabilities who possessed expertise in health matters to engage in discussions about reproductive health. Walker et al. (2021) examined the experiences of mothers with physical disabilities who had young children. Women stressed that they often did not have peers who were mothers with physical disabilities. Consequently, they embrace internet support, which they classify as having several advantages, such as providing insight into how others have managed mobility limitations while parenting and receiving support from others in similar circumstances.

However, the women still feel that online information is lacking (Mitra et al., 2016). Nguyen (2020) discovered that pregnant women in Austria with physical disabilities have difficulty accessing information specifically tailored to their disabilities, even after conducting thorough web searches. Women also indicated that the website included outdated and insufficient information, since it had not been updated for several years. Iezzoni et al. (2017) also found that women reported that online sources sometimes lacked crucial information regarding their conditions. In addition, women who invested a significant amount of time searching for information doubted their authenticity. Hence, they cautioned that online information should be thoroughly evaluated.

Theoretical Framework

The world is a collection of stories that people select to create a meaningful life (Fisher, 1984). Storytelling is a narrative medicine technique that offers several avenues for improving health, facilitating the healing process (Cummings, 2016; Kreuter et al., 2007; Land, 2007; Lee et al., 2016; Simpson-Gervin, 2016; Yakubu, 2019), and promoting the health of marginalized populations (Houston et al., 2011; Murphy et al., 2013). Fisher (1984) posited that “humans are essentially storytellers” (p. 8). For example, Cummings (2016) recounted the profound effects of her daughter’s illness on her family. She stated that this experience motivated her to write a story titled “A Simple Story of Anorexia Nervosa” to share her daughter’s story with the whole world to eliminate the stigma of eating disorders that had affected her family for many years. Interestingly, the story was published as a book and is now being used by clinicians in Australia. It is also shared with families as a resource to provide assistance and comfort to those experiencing the distressing situation of caring for a family member with an eating problem. Cummings (2016) concluded that personal stories have the potential to contribute to the process of recovery, education, and the creation of new relationships.

Furthermore, Simpson-Gervin (2016) explored a case study of how an eleven-year-old girl used journaling to construct her own story of healing, a story she could revisit and recount as frequently as necessary. Holdsworth (2020) used narrative storytelling to offer a distinctive understanding of the disparities and lived experiences of New Zealand women, who experience both privilege and discrimination. Wieskamp (2018) explored the relationship between sexual violence and cultural norms using storytelling, which portrayed survivors of sexual abuse as knowledgeable and powerful. The study’s narrative approach highlighted the healing power of storytelling and demonstrated ways to overcome challenges. Bates (2023) asserts that lived experiences reflect the knowledge employed to seek and provide peer advice. According to Scott (1984), nothing can resist the power of storytelling as a tool of insight.

Communicated Narrative Sense-Making Theory

Storytelling lies at the core of communicated narrative sense-making theory (Kellas, 2021). Communicated narrative sense-making theory explores how people use communication to understand and evaluate their relationships and life experiences, and how these processes impact and mirror their overall health and well-being. Kellas (2021) stated two primary goals of the theory. The first goal is to comprehend how story narration helps people make meaning in their lives. The second goal was to understand the impact and manifestations of narrative sense-making on people's health, well-being, and relationships. The main functions of storytelling and narrative in the context of health are "creating, connecting, socializing, and coping" (Kellas, 2021, p. 119). This means that the narrative promotes a sense of identity and purpose.

The theory comprises three heuristic principles employed to organize existing and ongoing research and direct researchers and practitioners toward new investigations. These heuristics include retrospective storytelling, interactional storytelling, and translational storytelling. Interactional storytelling focuses on the verbal and non-verbal aspects of the storytelling process. Translational storytelling employs narrative theories, methodologies, and empirical findings to develop interventions and applications that enhance individual well-being. The retrospective storytelling heuristic focuses on the lasting and significant impact of stories that people hear and share. This study focuses on retrospective storytelling heuristics since this heuristic type centers on the content, processes, or structures of stories or storytelling as the object of inquiry. The first proposition that underlines the retrospective storytelling heuristic states that the content of storytelling is “individual, relational, and intergenerational meaning-making” (Kellas, 2021, p. 119). In other words, meanings, values, and beliefs can be inferred by analyzing the content of individuals’ spoken narratives and relational story interactions.

Retrospective storytelling is an effective method to understand past experiences, particularly in the context of family relationships. Consequently, most published research examines proposition one of the retrospective storytelling heuristics from the point of family storytelling. For instance, in an interview-based study, Flood-Grady and Kellas (2018) explored the narratives around mental illness within families and to examine the insights gained by 24 younger individuals from these narratives. They found that family members, particularly parents, communicated stories regarding the mental illnesses of specific family members. These narratives often revolved around themes of struggle and caution, and the researchers discovered that young adults expressed significant insights, such as increased knowledge of mental illness and the significance of understanding mental health issues through the narratives. Flood-Grady and Kellas (2018) concluded that the results shed light on how family narratives on mental illness impart knowledge and expectations to younger adults regarding how to handle mental illness, even if they may inadvertently perpetuate the stigma surrounding mental illness.

Scharp et al. (2015) examined the backstories of 52 adult children in the United States who employed communicative practices to create emotional distance from their parents. The researchers found that the initial part of the story contained descriptions of parental mistreatment, abuse, and apathy. Conversely, ongoing estrangement occurred when grown-up offspring were capable of effectively establishing and preserving emotional distance from their parents, despite societal and family expectations of reuniting. Alternatively, adult children yield external influences and use communicative behaviors to reduce the emotional distance between themselves and their parents. Scharp et al. (2015) concluded that sharing these stories might assist adult children in resisting various demands to rebuild or sustain connections.

Furthermore, Holman and Horstman (2019) conducted a study on how married heterosexual couples employ narrative sense-making theory to understand their miscarriages and assess the consequences of their overall well-being. Seven distinct themes emerged from the stories of miscarriage: "hope lost, factual, time heals, helpful support, unhelpful support, cautiously optimistic, and guilt or shame" (p. 298). The researchers found that husbands and wives tended to recount distinct categories of stories of miscarriage. Specifically, the husbands frequently shared stories that revolved around their efforts to nurture and support their partners throughout pregnancy. Women, on the other hand, often shared narratives that emphasized profound sorrow, a sense of hopelessness, self-blame for miscarriage, and the resulting feelings of guilt and shame. They concluded that recounting personal experiences of miscarriage helps the emotional healing process for both husbands and wives in distinct ways.

Current Study: Postpartum Depression and Mothers with Disabilities

Scholars have focused on factors that affect pregnancy decisions, linking it to internal factors such as physical attachment and love towards children and feasibility of external factors, among others, while others have focused on experience with health professionals and accessibility of healthcare facilities and equipment during access to maternal care. While these studies are important, fewer focus has been placed on how women with disabilities cope with and navigate the physical, mental, and behavioral challenges during the postpartum phase and the support needed to navigate this experience. Women with disabilities experience higher levels of psychosocial stress, such as depression and other mood disorders (Alhusen, 2021; Parish et al., 2015). They encounter significant social and health disparities and are more vulnerable to pregnancy complications than are women without disabilities (Brown et al., 2022). Strnadová et al. (2019) emphasized that the health of women with intellectual disabilities was an internal issue that affected their parents' experiences. Some participants who had experienced postpartum depression and other mental health illnesses reported a need for peer support due to their health conditions (Strnadová et al., 2019). Similarly, Mitra et al. (2016) discovered that several women expressed a lack of information on the relationship between their disability, pregnancy, and postpartum assistance. Mitra et al. (2016) asserted that, in addition to pregnancy experiences, women expressed a need for information on postpartum assistance, including breastfeeding, and the availability of convenient baby equipment such as bassinets, cribs, changing tables, baby bath equipment, and carriers.

Hearing stories of mothers with disabilities can contribute to the management of uncertainty, as their narratives might reduce uncertainty (Reznik, 2019). Aguillard et al. (2021) highlighted that mothers with disabilities sharing personal narratives on pregnancy and motherhood will also help these women to make meaning of their own experiences. Given the comprehensive nature of disabilities impacting physical, mental, and emotional health, it is essential to consider both visible and invisible disabilities in postpartum experiences research. This research is not only responding to a gap in the existing literature but also working towards a more equitable healthcare that recognizes the diverse needs of all mothers. Thus, the current study sought to better understand the postpartum experiences of mothers with disabilities in navigating pregnancy and parenting through storytelling. Therefore, the primary research questions that the study seeks to explore are as follows:

RQ1: In what ways do mothers with disabilities make sense of the postpartum phase through stories they tell?

RQ2: What coping strategies do mothers with disabilities employ and recommend for potential mothers to navigate the postpartum phase?

RQ3: What support systems help mothers with disabilities navigate the postpartum phase?

Conclusion

This chapter discussed the issues of women with disabilities, identifying how structural, systemic, attitudinal, and relational barriers affect their access to education, employment, navigating romantic relationships, and married life. The chapter also explored how these interrelated barriers impede their pursuit of pregnancy and motherhood by examining the internal and other factors influencing their pregnancy decisions and the impact of families, spouses, and public attitudes and reactions toward their pregnancy. In addition, the chapter examined relevant research on pregnant women with disabilities' access to maternal care, looking at healthcare professionals' knowledge and awareness of their disability, communication skills, insensitive and positive attitudes, inaccessible healthcare facilities and equipment, postpartum depression, and peer support. Finally, the chapter examined the theoretical framework guiding this study, demonstrating storytelling as a powerful tool for understanding and evaluating individuals' lived experiences. In the next chapter, I discuss the research method approach to this study by emphasizing study populations, sampling techniques, data collection procedures, and data analysis.

CHAPTER III: METHODS

This study examined the role of narrative and storytelling in health communication to promote more focused strategies in supporting the journey of women with disabilities in their pursuit of pregnancy and parenting. Research has demonstrated that women with disabilities face diverse and intersecting barriers, such as structural, systemic, attitudinal, relational barriers, including violence, and abuse. Consequently, these intersecting barriers, violence, and abuse adversely impact their access to sexual and reproductive health services and maternal care. As women with disabilities experience higher levels of psychological stress, such as depression and other mood disorders, the current study employed the communicated narrative sense-making theory to focus on how these women interpret and understand their lived experiences of postpartum depression. According to Lindlof and Taylor (2019), the qualitative approach fosters the understanding of a phenomenon or process, or the perspectives and worldviews of the individuals involved. Therefore, I conducted narrative interviews with mothers with disabilities to share their stories about the lived experiences of pregnancy, postpartum depression, and parenting.

Participants

There is a diverse range of disabilities that, according to the United Nations Convention on the Rights of Persons with Disabilities, include mental, physical, and sensory disabilities (Hendriks, 2007). As a result, the sample of this study focused on mothers with various disabilities to ensure a comprehensive representation of the disability spectrum; that is, I used purposive sampling, seeking maximum variation among women, but also criterion sampling (Lincoln & Guba, 1985). Specifically, mothers were eligible to participate if they have biologically given birth to a child or children within the past 20 years, can read and communicate in English, and are 18 years of age or older. Disability status was determined based on self-identification to highlight the significance of personal acknowledgment and the impact of the mother's disability experience on their motherhood journey. This approach in research contexts not only upholds the autonomy of persons with disabilities but also offers valuable insights into their distinct experiences (Parekh & Brown, 2020).

The eight participants who participated in the study reported a range of disabling conditions including autism spectrum disorder (ASD), sensorineural hearing loss, mild to moderate hearing loss depression, anxiety, borderline personality disorder (BPD), major depressive disorder, post-traumatic stress disorder (PTSD), obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), dyslexia, and attention deficit disorder (ADD). Four participants had their first pregnancy which was unplanned, and the remaining participants pregnancy was planned. Six had fathers present in the lives of their child and two fathers were not present. Two of the women use some form of assistive technology (hearing aids). Six of the participants identified as White/European American, one participant identified as a Black/African American and the other participant also identified as a Native Hawaiian/other Pacific Islander. Four of the participants' children are diagnosed with various disabling conditions such as dyslexia, dyscalculia, dysgraphia, speech delay, autism, ADD, and ADHD. To achieve saturation, eight interviews may be enough in qualitative studies because qualitative researchers are not interested in the number of people recruited, however, to understand the cultural categories of their participants (Tracy, 2020). I reached saturation at interview eight.

After obtaining approval from the university's Institutional Review Board (IRB), I recruited participants through convenience sampling and snowball sampling. Convenience sampling involves a researcher selecting individuals who are easily accessible, essentially anyone who is willing to participate (Lindlof & Taylor, 2019). I employed this method because "samples are convenient, easy, and relatively inexpensive to access" (Tracy, 2020, p. 83). First, participants were recruited via electronic mailing lists, websites, and social media platforms such as LinkedIn, Facebook, and WhatsApp.

The invitation of participants to participate in this study involved snowball sampling. Snowball sampling, often referred to as chain referral sampling, is particularly appropriate for researching social networks, subcultures, and scattered groups of individuals that share similar characteristics (Lindlof & Taylor, 2019). Participants initially recruited were asked to help recruit participants from their personal or social networks who meet the criteria for the study sample. Lindlof and Taylor (2019) emphasized that the second group of participants referred by the initial participants might be able to help the researcher find other individuals who could be part of a third group of possible interviews. Thus, the chain of referrals generates a large category of respondents (Lindlof & Taylor, 2019). Alternatively, I reached out to my circle of friends, family, research colleagues, work colleagues, and church members, among other people in my social networks, via word of mouth, emails, and social media platforms, such as Facebook, WhatsApp, and LinkedIn. Lindlof and Taylor (2019) emphasized that this sampling method is usually the most effective approach for accessing hard-to-reach participants.

Data Collection

I employed narrative interviews to elicit stories or narratives of mothers with disabilities who have lived experiences. Unlike other types of interviews that focus on extracting some aspects of the narrative shared by participants, researchers employ narrative interviewing to focus on the entire story (Lindlof & Taylor, 2019). Based on the rationale of this study, the focus was on personal narrative. Personal narratives explore how human independence and identity are formed (Lindlof & Taylor, 2019). In personal narratives, stories revolve around the challenges individuals face regarding ethnicity, socioeconomic status, gender, sexuality, and other identities that are subject to scrutiny (Lindlof & Taylor, 2019). In terms of structure, I intended to supplement the narrative interviews with semi-structured questions to enhance the clarity and quality of the mothers' lived experiences. Tracy (2020) posits that semi-structured interviews function as frameworks that guide the interview process, enabling repeated exploration and enhanced adaptability in the interpretation of meaning.

Riessman (2008) suggested that narrative interviewers ought to initiate the interview by employing narrative terms such as 'tell me your story' (See Appendix A). Therefore, participants shared their experiences before, during, and after pregnancy. While the participants shared their story, I listened without interrupting, giving nods and simple sounds of acknowledgment like "hmm" and "okay" to show I was following along (Pederson, 2012). Once the participant signaled the conclusion of their story with phrases like "that's pretty much it," I asked loose-ended questions, such as, "Can you tell more about Y?" These questions according to Pederson (2012) offer the opportunity to explore certain comments more thoroughly at the end of an interview, ensuring that the conversation's natural flow was not interrupted. These questions allowed me to collect more comprehensive data about their experiences. The remainder of the interview consisted of more semi-structured questions.

First, participants shared stories about factors that affect pregnancy decisions, describing their pregnancy journey and emphasizing the significant factors that influenced that journey. Participants then described their maternal care experiences, which focused on their interactions with health providers and provider attitudes, including whether health professionals genuinely attended to their needs. The interview also focused on how their experiences with health professionals impacted the physician-patient relationship. Participants were then asked to recount their parenting experiences, focusing on their interpretations of motherhood and their knowledge of the most fulfilling moment of motherhood despite the challenges they encountered.

Additionally, participants shared their stories about their postpartum experiences. This section included participants' understanding of postpartum depression; the causes, signs, and symptoms; the significant challenges they faced as mothers during this phase; and how their disability has the potential to affect their postpartum experience. A section on coping strategies and support systems covered the types of support systems participants find most helpful during the postpartum period and the importance of how these supports help them navigate through the motherhood journey successfully. Finally, participants answered questions about their motivations for sharing their story. The section also focused on the advice participants would give to potential mothers and other mothers with disabilities and how they think the stories about their lived experiences will help potential mothers. After the interview, participants completed a short demographic question (See Appendix B) regarding age, state of residence, ethnicity or race, type of disability, number of children, marital or partner status, and household living situation.

Seven interviews were conducted via Zoom and the last interview was conducted face to face. The Zoom procedure is called the “technologically mediated context” (Lindlof & Taylor, 2019). Participant made preference for interview mode depending on their geographical location According to Lindlof and Taylor (2019), face-to-face interviews are ideal for interviewing participants. However, if participants reside in distant places, the researcher must conduct interviews in a technologically mediated context. The Zoom interviews included both voice and video, which helped rapport building and aided me in interpreting nonverbal behavior along with participant comments.

Interviews lasted for approximately 60 minutes. Before each interview, I sent the participants an informed consent that informs them of their voluntary participation and sought their consent to record them using audio recording devices. Lindlof and Taylor (2019) state that “consent should be obtained before a person begins his or her research participation” (p. 156). The consent forms provided brief explanations of the objectives, procedures, and anticipated results of the research, including the potential risks and benefits of participation (Tracy, 2020). In addition to consent and permissions, Tracy (2020) emphasized that researchers must engage in practices that protect participants’ private information, such as assigning pseudonyms to participants to guarantee confidentiality. Therefore, I assigned each participant a pseudonym in the transcripts, and any part of the write up. The audio-recorded interviews were transcribed using Otter.ai or Zoom “closed caption.” Otter.ai is an AI-powered automatic transcribing application that enables users to record and transcribe audio conversations. Free subscription assigns an average accuracy of approximately 83%. Therefore, to improve the quality of each interview transcribed, I verified, the content by re-listening to the recorded interview multiple times to guarantee error-free final transcription.

Data Analysis

According to Kellas (2021), thematic analysis method can be used to analyze the content, processes, or structures of stories as objects of inquiry. Therefore, I analyzed data using Braun and Clarke's (2016) thematic analysis. Braun and Clarke (2006) state that "thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data" (p. 79). I employed thematic analysis for various reasons. First, this approach is not limited to a theoretical framework. Braun and Clarke (2006) argued that thematic analysis exempts researchers from the implicit theoretical commitments of grounded theory. In addition, thematic analysis is a flexible method that "reports experiences, meanings, and the reality of participants" (Braun & Clarke, 2006, p. 81).

Based on the first phase of thematic analysis, I familiarized myself with the data by reading all transcripts several times and noting initial ideas that described mothers' experiences across various main topics. In the second phase, I generated initial codes from all the data and their corresponding segments. In the third phase, I searched for themes through open coding and compared the major themes in the interview transcripts, searching for similarities and differences. Across the data, common themes such as pregnancy narratives, postpartum narratives, coping mechanisms, and support systems emerged consistently. Then, I reviewed these themes and merged the codes generated into broad categories (Corbin & Strauss, 1990). In the fourth step, I re-read and refined each of the broad categories and their corresponding segments to produce many major themes. In the fifth step, after defining and naming the major themes, I compiled exemplars for each major theme. The sixth step involved writing out the report. Finally, after writing the results, I conducted member checks. Member checking is the process of testing data, analysis, interpretations, and conclusions with participants from whom the data were originally acquired to ensure the credibility of the results (Lincoln & Guba, 1985). As a result, I contacted participants via email with the interpretations of the interview to verify whether the interpretations accurately represent their lived experiences.

Conclusion

This chapter explained the qualitative approach of the current study. Narrative interviews shed light on the lived experiences of mothers with disabilities, which informed health professionals, health researchers, and advocacy organizations about the diverse strategies that should be employed to address their unique needs. The mothers' experiences becoming evident through the interviews may increase their awareness of the realities of mothers with disabilities, challenge stereotypes and misconceptions, and foster a more inclusive and supportive community. In the next chapter, I discuss the results of the interview alongside the discussion, strengths and weaknesses, practical implications, and recommendations for future research.

CHAPTER IV: RESULTS

The purpose of the current study is to better understand the postpartum experiences of mothers with disabilities in navigating pregnancy and parenting through storytelling.
Also, it explored how the stories that mothers with disabilities share provide strategies that can serve as a tool to cope with and navigate the physical, mental, and behavioral challenges during the postpartum phase, and the support systems they find valuable. The study employed a narrative interview approach to examine the lived experiences of mothers with disabilities, including stories from pregnancy, postpartum phase, and parenting. This chapter presents the major findings of the current study. Direct excerpts from the interview transcriptions are used as exemplars to illustrate major themes and subthemes. The interviews generated four themes: overview of pregnancy narratives, postpartum phase narratives, strategies employed to cope with and navigate the postpartum phase and support systems to navigate the postpartum phase.

One of the primary objectives of narrative research is to provide detailed descriptions of the participants' lived experiences, and realities (Reissman, 2008) to a broader audience (Clandinin & Connelly, 2004). Hence, I used pseudonyms to describe the participants in this research to establish confidentiality before presenting the overarching themes. Before we turn to the categories themselves, the aim of this section is to provide a comprehensive context of each participant's distinct narrative by establishing their type of disability, number of children, level of education, family situation, and employment, among others.

The Participants

Joanna

Joana resides in the Western part of US and is in her late 40s new mother who has Level 1 autism spectrum disorder (ASD) and was diagnosed at the age of 38. She stated: “I didn’t get diagnosed with autism until I was in my late 30s. I spent my whole life knowing that I was like a little bit weird, but not really understanding it until finally, I got an official diagnosis from two different experts.” She is a White/European American, married, and biological mother to a baby girl who is six months old. She has completed a doctoral degree and works full-time as a college professor, working 35 hours or more weekly.

Anna

Anna lives in the Midwestern part of US and is in her late 30’s. She is diagnosed with sensorineural hearing loss. She wears hearing aids in both ears. She recounted: “I wear hearing aids that bring us up just about to normal hearing not quite, and it’s a system to accommodate me.” She identifies as a White/European American, is married, and lives with her partner. She has biologically given birth to a baby boy who is three months old. She holds a Ph.D. and is a college professor, working at least 35 hours weekly.

Julie

Julie resides in the Midwestern part of US and is in her late 20s. She is diagnosed with depression and anxiety and has back pain (due to epidural). She explained: “It’s been almost 11 years now since I’ve been diagnosed with depression.” She is a Native Hawaiian/other Pacific Islander, married, lives with her husband and has three children. She gave birth to her son with her high school sweetheart after graduating high school. She and her boyfriend split up, resulting in her single-handedly taking care of her son. The son is ten years old and is diagnosed with dyslexia. After she was married, she gave birth to her daughter, who is five years of age and is diagnosed with speech delay and autism. Julie is a full-time undergraduate student who is not engaged in paid employment and manages her home.

Rebekah

Rebekah lives in the Midwestern part of US and is in her late 20s. She is diagnosed with borderline personality disorder (BPD), major depressive disorder, and post-traumatic stress disorder (PTSD). She recounted, “I suffer personally from borderline personality disorder. I also have a major depressive disorder and PTSD from my childhood.” She identifies as a White/European American. She lives with her family (mother, brother, and uncle). She is a full-time undergraduate student and works 40 hours per week in a paid position. She gave birth to her son out of wedlock. She stated:

> There was one person that I met, and I didn’t do this with lots of people. It was like one or two people that we just, but it happened. One of those people, I actually saw like once or twice, and somehow, I got pregnant.

Maddie

Maddie is a White/European American who lives in the Midwestern part of US. She is in her late 30s diagnosed with non-specific mood disorder that includes obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), and PTSD. Her baby boy is four years old, and she is a single parent. The son’s father is also diagnosed with four disorders.

Maddie is a victim of abusive relationships and, as a result, is not in a romantic relationship. She has a graduate degree and works as a college professor for at least 35 hours per week.

Olivia

Olivia is in her late 40s and resides in the Midwestern part of US. She is diagnosed with mild to moderate hearing loss and wears hearing aids. She stated, “So, I have a hearing loss, my mom has a hearing loss, my dad has a hearing loss, my brother has a hearing loss. It is absolutely genetic.” She is a White/European American and married. She lives with her husband and has three children. She gave birth to her son with her high school sweetheart after graduating high school. Her second child (daughter) is diagnosed with anxiety disorder and ADHD, and the youngest son is diagnosed as asthmatic and has severe allergies. She has a graduate degree and works as a college professor for at least 35 hours per week.

Amanda

Amanda lives in the Midwestern part of US and is in her late 40s. She is diagnosed with attention deficit disorder (ADD), which is a learning disability. She recounted, “I did not get diagnosed until I was in my doctoral program. I took a class on ADD, and the whole book was my life, and I was like, oh my god, like, what is going on?” She identifies as a Black/African American, married, and she has two daughters. Her children, who are 4 and 18 years of age, are both diagnosed with ADD. Amanda has a graduate degree and works as a college professor for at least 35 hours per week.

Emily

Emily is a White/European American who resides in the Midwestern part of US and is in her late 30s. She is diagnosed with dyslexia (a learning disability). She is not married to either of her two children’s fathers, but she is married and lives with her husband. Her daughter has been diagnosed with ADHD, inattentive type, dyslexia, dyscalculia, and dysgraphia (learning disability). In addition, the daughter has recently been diagnosed with generalized disorder and depression. Her son has sensory integration issues and has recently been diagnosed with borderline ADHD. She is a full-time undergraduate student.

Overview of Pregnancy Narratives

The current research sought to understand the narratives of mothers with disabilities in the context of their post pregnancy experiences. However, to ensure a clear understanding of their postpartum narratives, I deemed it essential to first provide an overview of these mothers’ pregnancy experiences to lay the foundation of the various ways in which their choices before and during pregnancy influence their overall postpartum phase and its impact on postpartum depression.

Factors that Influence Motherhood Decisions

The decision to pursue motherhood is a complex experience especially for mothers with disabilities. This sub-theme explores the positive motivational factors that inspire women with disabilities to pursue pregnancy and motherhood. This narrative also addresses the fears and concerns inherent in their decision-making process and extends to the strategies and attitudes cultivated to cope with and overcome their fear and concerns.

Positive Motivational Factors

Several factors influence the decisions of mothers with disabilities in pursuing motherhood. For example, for Joana, one of her decisions to be a mother revolves around her approaching a significant age of her life, which is turning 40. She stated, “When I was starting to get almost 40, I started thinking, why don't we give it a try?" In addition, Joana understands the pursuit of pregnancy as a life opportunity to live life to its fullest and not letting fear hold her back from achieving it "because," she commented, "I'm the type of person where I just want to make sure that I do everything that I can do. You know, we get one life and why not try to do everything that you can." Also, the observation of peers pursuing pregnancy served as a motivational factor for Joana to evaluate her capabilities to be a mother. She recounted:

> Probably the other thing that impacted it was seeing other people my age, people who I grew up with, who are friends, also doing the same thing and being like, oh, they could do it, like maybe I can too.

Joana added that she sees pregnancy as an avenue to challenge herself and test her own capabilities:

> I mean, I think the main thing really was seeing if I can because when I have a challenge I want to do it. So, for me, it was like, there's a thing people do in their life. Can I do that? So that was like one big factor.

Likewise, one of the factors that influenced Anna's decision to pursue pregnancy is to challenge herself, to step out of her comfort zone and to embrace the hard parts of parenting duties and navigate the challenges and responsibilities that comes with it. According to Anna, "I wanted to not only get to do the fun parts in life but do the hard parts, too."

Furthermore, Anna spoke about her long-standing wish to become a parent influenced by the joy and love she experiences through her relationship with her nieces and nephews: Her statement, "I've always wanted to be a mom. I loved kids. I love my nieces and nephews like they're my own and I wanted to have my own" conveys her sense of purpose in nurturing and caring for children. Anna added, “I wanted to really teach someone how to be a human in the world. It was important to me and, however, I became a mom and was fine.” This statement indicates her responsibility and dedication to nurture and guide her child to navigate the challenges in life. Also, Emily talked about her commitment to have children of her own due to her personal aspiration to be a mother and her professional life as preschool teacher. She said, “I always wanted to be a mother. I’ve always enjoyed it. I’m a teacher and I teach preschool, so kids have always been a big, big part of my life.” Unlike Anna and Emily, according to Amanda, not only the desire to be a mother is a factor that influenced her second pregnancy decision but also the love for her second husband who had no children. She elaborated:

> I met my husband; he doesn’t have children. He’s from Canada and so we met. He didn’t have any children and I know, he really wanted to be a father and I’ve wanted three kids. So, I was like, you do it for love? I mean, I wanted it to, because I love being a mother. I love the pregnancy itself and it is never any problem.

The above example represents a shared desire for parenthood. This shared goal also speaks to their marriage’s foundation on love and compromise. Also, careful planning and readiness in terms of financial capability and being married are the other factors that influenced Amanda’s first pregnancy decision. She stated:

> I know of always wanting to have children, and that was just a goal, I wanted to have children. But I wanted to have children methodically, I didn’t want to make a mistake of having a baby due to some habit. I didn’t want to do those things. I wanted to be ready and prepare. So, I didn’t have my first daughter until I was married and in my doctoral

> program, which I'm okay with financially. I know it costs a lot of money to raise a child and that was just what my head was.

Amanda's narrative reflects a thoughtful and deliberate approach to motherhood as an important life decision as she was aware of the significant cost associated with becoming a mother. However, according to Rebekah, her conversation with her mother's closest friend and her doctor played a critical role in influencing her to keep her pregnancy:

> I actually made the appointment to get the abortion and then, I went in, I talked with them, and something was off, like the lady, and I stopped together, cause I'm like "I just don't know if I can do this. I feel this is one of my only options," and she's just like "this isn't your only option," and I thought about it, and one of my mom's closest friends, that we actually lived with the time, she said, "Hey, Beckie, I can tell you really want to keep this, so why don't we keep it and raise it together?" So, I did keep my son, and he is one of the best things that ever happened to me, honestly.

Rebekah's narrative emphasizes her value for exploring all options and the impact of seeking support on making decisions that led to ultimately becoming a mother.

The study reveals that mothers with disabilities are influenced by a blend of personal aspirations, life milestones, and external support when deciding to pursue motherhood. Approaching a significant age, observing peers, and the intrinsic challenge of motherhood are key motivational factors. Also, a desire to nurture and guide children, methodical planning for financial stability, and critical support from loved ones also significantly impact their decisions. These narratives showcase the resilience and deliberate decision-making of these mothers, showcasing the importance of understanding the unique experiences and strengths inherent in mothers with disabilities. Therefore, recognizing these aspects is crucial to appreciating the diverse pathways to motherhood and fostering supportive environments for potential and existing mothers with disabilities.

Fears and Concerns

While one participant expressed concerns about health risks, many of the participants indicated having genetic concerns. For instance, Joana had the fear of the unknown in relation to not knowing the health challenges she was likely to face. She stated:

> I knew something could happen and I just wasn't sure. There's always a risk that the fetus doesn't make it and that the fetus doesn't develop correctly. You have a really difficult pregnancy that there's something to be concerned about.

In addition, Joana narrated her fear about her daughter potentially being autistic. This fear is due to life challenges associated with autism, societal perceptions of autism and the impact it may have on her daughter's life. She emphasized:

> In terms of like fear, like, oh no, is my daughter going to get autism? When I think like, oh my gosh, she could be autistic that is the fear that I have. For me, I knew like at my age already, she could have defects. She could come out with some type of problem, and she can also grow up and have autism.

Moreover, there is the presence of autism in her family, and this intensified her concerns. She added that, "I remember my dad is autistic too." The mention of her father's autism conveyed an awareness of the genetic conditions that might influence her daughter's development, too. In a similar way, Maddie expressed her biggest fear at the beginning of her pregnancy journey due to the history of mental health issues within her family:

> Genetic concerns were probably the most feared in the very beginning, mostly by my family. There's a genetic predisposition, and I have it, and then John's dad has it. There is a history of mental illness in my family—my dad has ADHD, anxiety and depression, and a couple of grandparents have that as well.

The above narrative indicates Maddie's concern and fear that accompanies her decision to have children when she and her partner have a disability, and she is aware that some of her family faces the same condition. Similarly, Anna explained that there is a history of genetic hearing loss in her family and is preparing to get her son tested:

> I even think about it, and now I'm getting ready. So, it's a genetic hearing loss—many members of my family have it—and I'm getting ready to bring my 3-month-old baby to do a test. My twin sister who has an older kid, a 3-year-old and then now a newborn too has done the test three years ago with her.

Anna's narrative demonstrates the importance of early detection in managing hereditary health conditions. On the other hand, Rebekah's narrative centered around the fear and concern of impacting her children negatively due to her own struggles with mental illness and addiction. She elaborated:

> I have lots of fears and lots of concerns. You hear horror stories of children who have parents with mental illness and how manipulated they were and how much they fucked up their life. Then these kids end up having their own emotional baggage from having to deal with their parents' emotional baggage. I was very concerned that I was going to do that to my son, and I was also scared that I wasn't going to be a good mom. I was scared

> that I wasn't going to be able to stay sober. I was scared of all of the things I was scared of.

In the above narrative, Rebekah's story highlights her greatest fear of creating a cycle of emotional difficulties for her son and demonstrates her desire to be a good mother. According to Maddie, the struggle for support from her boyfriend during her pregnancy stage and the fear of inadequacy with being in three abusive relationships made her question her ability to be a good mother:

> I have my doubts about my ability to be a good mom. From what I understood is it what you know growing up as a kid, like you were the weird kid? I developed this sense of [how] I am not accepted. I develop this kind of mentality that "you're just not good enough." I think that's to me made me susceptible to abuse. I've had three abusive relationships, and the times at which I entered these relationships were times in which I was probably my most vulnerable.

In the above example, Maddie's experiences of feeling unaccepted and not good enough, as well as the abusive relationships she has had, make her question her ability to provide love and care for her child.

Based on the findings, it is evident that concerns about genetic predispositions and the potential transmission of disabilities or health issues to offspring are prominent among mothers with disabilities. These narratives emphasize the need for genetic counseling and psychological support to help mothers manage their concerns and prepare for potential challenges in their children's health and development.

Navigation of Fears and Concerns

Three out of eight participants discussed the personal strategies and attitudes they developed in navigating their genetic concerns. For example, Joana sees her own experience as a source of strength that can help her daughter navigate the potential challenges of autism if it happens that she is autistic too:

> Like, she's so lucky to have me to be able to help her navigate her disability if she has one because I will actually understand and talk to her about it. So, she'll be lucky that I will be aware how she interacts with the world and that she might have a disability and how can we manage that because I wish that someone was doing that for me throughout my life.

Joana's lived experiences become a powerful tool for support and change, which she tends to use to ensure a more supportive environment for her daughter. In a similar way, Anna overcomes her fear and concerns through focusing on her lived experiences as obtaining a doctoral degree as a mother with hearing loss, serving as a tool to teach her child to persevere despite being diagnosed with a similar disability.

> I am a perfectly functioning adult. I'm personally of the belief that I have all this experience and I can teach someone else how to do it. My sister and I have PhDs, and we are out functioning humans in the world. We're not unable to do things, and so I'm really nervous about that, about being treated like, "Oh, what poor you, what was you and your kid has a hearing loss." Yeah, maybe, but like that's never stopped any of the rest of my family members; like, we are just as capable as anybody else. It's just a little different.

In another example, Maddie focuses on her ability to manage her fears in terms of her disability as a tool to effectively support her child in overcoming similar challenges: According to her, “I think as a mom the fears is always there, but I think because I successfully manage mine, I feel kind of an advantage that I have the skill set to be able to help him in those situations.” Her narrative shows that her skill set not only empowers her but also plays a role in empowering her child’s life.

The narrative highlights how mothers with disabilities leverage their personal experiences with disabilities as a means of supporting and empowering their children who may face similar challenges. By focusing on their own lived experiences ranging from navigating autism to achieving academic success despite hearing loss to managing personal fears related to disability—these individuals emphasize the importance of resilience, understanding, and practical support. This approach is significant because it reflects a shift from viewing disabilities solely as limitations to recognizing them as unique perspectives that can foster resilience and empathy.

Self-Care Practices

The narratives of four participants highlighted the self-care practices mothers with disabilities adopt to protect their pregnancy and to ensure the well-being of their unborn child. For instance, Julie reported that she cultivated the daily routine of positive affirmation in promoting her mental well-being which in the short run serves as motivation for her to go about her daily routines. She explained:

> I definitely trusted my instincts with my body. I had a way of taking care of myself by telling myself every single day with affirmations. So, saying that I can get up, make my

> bed, make sure I eat some breakfast, and pamper yourself first and really take care of yourself in the morning, your day goes by like this and it helps with your mentality by making your bed each morning too. If you take your bath each morning, when you wake up, you already completed one task for the day, and you've already started moving so that really helped me get through myself.

Maddie's statement, "I did seek counseling weekly. I am also catching on to the idea of mindfulness. During pregnancy, that was the primary goal of my counseling, and I notice very much that I feel right" demonstrates her pursuit of weekly counseling sessions and mindfulness practices to address her mental health needs. In addition, Maddie mentioned that her consistent resistance training served as a mental health savior during her pregnancy phase. According to her, this exercise routine provided her with not only emotional stability and personal strength but played an essential role in enabling her to leave her abusive relationship:

> I exercised during pregnancy. I exercised four to five times per week that was resistance training and that right now and forever has been my mental health savior and without it, I am a mess. Also, honestly that is the reason why I think that I was able to leave my domestic violent situation is my level of fitness and what I got from it, was something he could never take away.

Emily also claimed that she attended all prenatal checkups, which she deemed as essential to monitor the health of her unborn child. She stated, "I had all the prenatal visits and checkups and scans. I always make sure to take my preview vitamins." In addition, Emily explained, "I didn't eat the things I wasn't supposed to, I stayed away from any sort of alcohol or smoking or anything like that." For Rebekah, it was important to make the conscious decision to abstain from substances like alcohol, cigarettes, and marijuana to ensure the health and safety of her unborn child. She stated:

> I stopped drinking, I stopped smoking cigarettes, I stopped smoking pot. I tried to do everything by the book because they wanted to make sure that he was going to be as healthy as he could. I tried to just be as best as I could because I knew there's so many things that could mess up. People say you could have one glass of wine occasionally, but if you drink that wine while that kid is developing, you can harm the baby and you might not even know, and I just didn't want to hurt him.

Her narrative highlights the fear of blame if her behavior harms her unborn child and points out the extent of her commitment to ensure the safety of her child. In another example, Rebekah stated, "While I was pregnant, I had to stop taking my medicine. I don't remember what medicine I was taking at the time, but I stopped taking my medicines." Again, per this narrative, Rebekah made the conscious effort to discontinue her medication regimen during pregnancy to ensure the health and safety of the unborn baby.

The findings revealed that mothers with disabilities adopt diverse self-care practices during pregnancy. These practices include positive affirmations, counseling, mindfulness, resistance training, attending prenatal checkups, abstaining from harmful substances, and adjusting medication regimes. These stories are crucial as they showcase the proactive and varied approaches these mothers take to ensure their own health and the safety of their unborn child, reflecting a deep sense of responsibility of care towards their unborn child.

Support During Pregnancy

The support of husbands, immediate families, and community of friends of mothers with disabilities has a greater impact on their whole pregnancy experience. Three of the participants described the crucial role husbands, immediate families and community of friends play in their whole pregnancy experience. For instance, Joana's story focused on the significance of her husband's support and shared responsibility in navigating the responsibilities that accompanies childbearing:

> My husband, when I was pregnant and I was like getting up in the middle of night bathing, he would always get up too with me. Like for solidarity or support and I had told him that "when the baby's here, you're going to do all the nighttime stuff."

Again, Joana further indicated the husband's role in advocating for her needs during her delivery experience. She recounted:

> I just had to always ask for another towel and my husband is really good about it and so he would often try to step in before she would try to talk to me and he would be like, "Hey, she needs another towel, like, get her another towel." So, my husband would do that like all the time because he always knew what I would need. He was kind of like a middle person between me and the doctor trying to get them to be aware of these things that we've told them about before, but they just weren't really addressing.

Additionally, Joana shared the various ways her family and community of friends provided their support. She elaborated:

> While I was pregnant, I did feel a good support system for my family like my mom was excited and my husband’s parents came out and visited us. My friend Grace planned the baby shower, and my sister Charlotte helped plan the baby shower.

The example emphasizes the collective effort from her support system to share in her joy of becoming a new mother. On the other hand, she highlighted that the support she received led to her discovery and appreciation of community support specifically in the context of pregnancy:

> I really felt this weird sense of community coming from all these places that I didn’t really know existed out there. They bought us a really nice stroller and helped us prepare. But at the same time, it’s so nice that people care and they are like here, I bought your baby this thing and I bought you this. It was so thoughtful.” I didn’t know that’s what you were supposed to do for people that were pregnant. I never did that for anybody. Now, I kind of see like, oh, you’re supposed to help them. You’re supposed to be a part of that community.

Likewise, Rebekah affirmed that the presence and involvement of her mother throughout the childbirth process, from attending appointments to being the primary support person during labor impacted her significantly. She stated:

> My mom has been here with me this whole time. The dad is not involved. It is just me and my mom. She was my person while I was giving birth, she was there while I labored, and she went to most of my appointments with me. Once we realized that we were going to keep him, we really wanted to just do it altogether because I was scared.

The above example emphasizes the comfort and strength Rebekah found in her mother’s support in navigating the pregnancy phase especially in the absence of other support systems such as the child’s father. On the other hand, Emily recounted the lack of support from her boyfriend during her first pregnancy:

> My child’s father like didn’t want me to be here, didn’t really want my family around so I guess that I moved with him. So being by myself, in an apartment where my family felt unwanted was difficult and challenging. I just didn’t feel very supported, you know, physically, mentally, emotionally.

Emily’s narrative communicates the profound impact of lack of emotional, mental, and physical support during pregnancy, highlighting feelings of isolation, difficulty, and challenge. This situation highlights the importance of a supportive environment for expecting mothers with disabilities, as the absence of such support can lead to feelings of loneliness and stress, potentially affecting both the mother’s and the baby’s well-being.

These narratives highlight the impact of support from husbands, immediate family, and community of friends on the experiences of pregnant mothers with disabilities. These stories demonstrate how such support can vary from sharing responsibilities and advocating for the mother’s needs during delivery to providing emotional support through pregnancy and childbirth. This collective support not only aids in navigating the practicalities and emotional challenges of pregnancy and childbirth but also fosters a sense of community and solidarity.

Narratives of Prenatal Care

The mothers’ narratives shed light on the care they received from their obstetricians (OB) and gynecologists. These narratives focused on their prenatal care experiences in two different ways: the positive experience and the negative experience to account for the factors that contributed to effective and ineffective prenatal care.

Negative Experience

Two of the participants talked about their negative encounters with their OB's and gynecologists. For example, Joana indicated that the choice of her gynecologist was influenced by the doctor's good reputation, the presence of a cat in her office and the general vibe from the doctor's online presence. However, all these positive indicators did not translate into her doctor's ability to offer specific accommodations she needs as a pregnant woman with autism. She stated:

> My gynecologist had a really good record, and she had a cat in her office, and I like a cat. I just had a good vibe from her medical website stuff. I also told her right away; I was like hey! I have autism. I wanted her to be aware that I was different, and she didn't really understand it. She never worked with somebody like me before and she would try very hard to try to understand what was going on with me or why I would behave in a certain way. But ultimately, she's doing her best but didn't really do a good job of helping me in ways that I needed. Like, some things that I'm really sensitive about are things that are sticky or things that are like wet. I have genuine psychological issues. Like if it's sticky, do not get that near me or like it's slimy or wet, I do not want that in my business. When I go to the gynecologist, they are constantly putting like sticky wet things on you, like putting on your belly or putting it in your vagina to test stuff. So, they are doing this all the time and every single time that she went in to examine like uterus area she would use this like gross slimy stuff and afterwards I would feel like fixated on it.

The above narrative emphasizes the need for healthcare providers to have a deeper understanding of autism and to develop specialized care approaches to address the unique challenges autism patients face. Likewise, Anna expressed her concerns regarding the disjointedness with OB's, pediatrician, and hospitals in effectively communicating with one another:

> There are still challenges. For example, my electronic health record at my OB is not connected to the hospital and it was pseudo connected to my son at the pediatrician's office. But these are all things kind of tied together, but it was so disjointed. It is like there is this greater medical system that can't talk to each other. It is really conflicting at times. Then other times I would go in, and they wouldn't even look at my chart and we're having this conversation all over again that if you had just looked at my chart and read what I came here for or where I am then we wouldn't be wasting time.

Her narrative also suggests that some healthcare providers do not have a full understanding of a patient's health status and history which poses a risk of providers missing critical information that influences treatment, diagnosis, and patient's recommendations for effective care.

These findings highlight significant gaps in healthcare experiences for patients with unique needs, such as those with autism, and demonstrate the challenges in communication and care coordination within the healthcare system. These experiences emphasize the importance of a more personalized and integrated approach in healthcare, especially for mothers with disabilities.

Positive Experiences

Most of the participants noted that their OB's and gynecologists displayed positive attitudes during pregnancy checkups. For instance, Julie's narrative centers on the compassionate care she received from her doctor during her first pregnancy. According to her, the doctor emphasized that "there are no ridiculous questions," showing the doctor's willingness to provide the necessary support and information she needs. Amanda's comment, "My doctors were very,

very supportive and were very understanding" communicates the significant support and understanding she received from her doctors. Similarly, Maddie expressed mixed feelings about her obstetric care in her narrative. However, she strongly acknowledged the competence and the supportiveness of her OB and midwives, demonstrating that they were there for her when she needed them:

> I felt like my OB was really good. My midwives, if I needed things, they were supportive. Although, I didn't like one of them one time, because she told me that I was gaining too much weight and I was like, "Screw you," but I actually really ended up liking her in the end, because she's very, very, very supportive, which was good. Mostly, I was like terrified of going into the hospital, but I think I have definitely more help now.

In another example, Olivia, a mother with hearing loss acknowledges the value her OB placed on asking her preferred method of receiving information. She elaborated:

> So, one of the things that comes out of that is, that they ask me what I need, and my OB does that really great anyway? Like, what is your preferred method of receiving information and I'm always like written is great and just remember that I have a hearing loss and so if you are going to give auditory information just make sure I am looking at you. I do this when I'm delivering babies, and I don't know if everybody does this, but I do.

The above account emphasizes the importance of personalized communication in healthcare settings, especially for patients with specific needs, such as hearing loss.

These narratives highlight the positive experiences of patients with their OBs and gynecologists during pregnancy checkups, emphasizing compassionate care, support, understanding, and personalized communication. The willingness of healthcare providers to address all questions, their supportive nature, and the importance of tailored communication for patients with specific needs, like hearing loss, stand out as critical aspects of positive obstetric care. Such treatments contribute significantly to patient satisfaction, trust in healthcare providers, and the overall quality of care, making them unique and essential in healthcare practices.

Postpartum Phase Narratives

The second theme that emerged during participants' interviews relate to their postpartum experiences running from physical challenges with self-care routines, frustrations over difficulty in fulfilling parental duties, and internal conflicts. Five out of eight participants reported experiencing postpartum depression during the postpartum phase of their motherhood journey. Furthermore, this theme explores how these mothers reconcile with and make sense of their role in motherhood despite these challenges.

Struggle with Self-Care

For some participants, navigating the challenges of self-care became a significant struggle during this phase. According to them, the struggle with self-care not only affected their physical recovery but also had a negative impact on their emotional and mental health. Julie shared falling into unhealthy postpartum routines:

> The one routine that you make, it sticks with you until you go and get yourself in that position is when you're like, yes, I need to make a change. I was not showering, and I noticed that. I would just be like, yeah, I can skip a shower and wait a couple of days or whatever. I would go as far as showering for 4 days and it was pretty bad. I've noticed that I was not eating as much. I actually lost a lot of weight after I gave birth to my son

> very quickly and it was not a normal weight loss. I would skip breakfast; I would skip lunch and I would go straight to dinner but when I would eat dinner I would eat like a whole bunch of food and then I would crash for the night.

Julie also talked about the impacts of her self-neglect on her mental health. Her comment, "I wasn't taking care of myself and that's when I realized that I had depression and anxiety because I was putting everybody else's needs before mine" stresses the challenges new mothers like Julie encounter in balancing her needs with the demands of meeting the needs of both family and child. Anna shared a similar experience regarding the impact of lack of sleep on her mental health:

> I am a person with high sleep needs. Even at the end of pregnancy it was not good for my sleep and then because my sleep was so poor, my mental health was so poor. So, I definitely experienced the baby blues those first couple weeks and one during should we have done this and were we ready for this. I love this kid and I want to take care of him but my word this is way harder than I thought it would ever be. The real challenge is the lack of sleep that has an effect on my mental health and then I go spiraling because of it.

This narrative suggests that, despite a mother's love and commitment to care for her child, the physical and emotional effect of sleep loss is overwhelming, making the postpartum experience much more challenging than anticipated.

The narrative highlights the struggles with self-care experienced by new mothers, particularly emphasizing the detrimental effects of neglecting personal hygiene, inadequate nutrition, and lack of sleep on both physical and mental health. These personal accounts reveal how such neglect can lead to severe weight loss, depression, anxiety, and an overall feeling of being overwhelmed. The findings point out the different aspects of postpartum challenges, emphasizing the importance of self-care and mental health support for new mothers. These stories are unique because they show the realities of postpartum life for mothers with disabilities.

Difficulty in Managing Parental Obligations

In the postpartum phase, the struggle in managing the responsibilities that come with the role of motherhood also present significant implications in terms of mental health. As a result, some participants expressed their frustrations as a new mother. According to Olivia, in the early stages, mastering breastfeeding techniques such as pumping alongside managing professional responsibilities was a challenge. She stated, “My postpartum experience, I think, was just learning to be a mom, right? How do you pump, go to work, and like, how do you do all of that. It just felt like a lot to figure out.” Similarly, Rebekah expressed a sense of failure and frustration due to her inability to produce enough milk to nurse her child. According to her, this struggle negatively impacted her postpartum experience as a new mother:

> After birth, one of the biggest struggles that I had personally was that I was not able to nurse him, and I just wasn’t producing enough breast milk. That was something postpartum to begin with and I was like why can’t I do this thing? Literally this is what I was made for and that is to feed this child.

In the above example, Rebekah’s story touches on the emotional impact of her inability to fulfill mothering responsibilities, resulting in feelings of inadequacy, and questioning her capabilities as a mother. Likewise, Emily recounted that her prolonged labor experiences and emergency cesarean section led to physical discomfort and difficulty in performing basic maternal roles such as holding and breastfeeding her baby. According to her, these struggles with maternal roles affected her mental health:

> With my daughter being ended up being an emergency c-section, laboring for 18 hours and then having a c-section, I was really sore and uncomfortable, so like getting up and moving or holding her was hard. I just definitely struggled when it came to breastfeeding. It did not go smoothly; it was a struggle to get her to latch. With all these problems, I think I definitely was tired a lot. I did fill out a form and was diagnosed with postpartum depression and was put on medication.

Here, Emily sought for medical intervention with her struggle with mental health and diagnosis of postpartum depression. For Julie, being confronted with her newborn's health issues negatively impacted her postpartum period. She said:

> After I gave birth to him, we ended up finding out that he had jaundice, and he was also allergic to a lot of things. So, with me being a first-time mom—and he actually developed eczema as well—and all of these things correlated to where I ended up getting depression.

This example demonstrates the positive impact of Julie's newborn's baby health issues on her mental health in the context of being diagnosed with postpartum depression.

The postpartum period can pose significant challenges for new mothers, including mastering breastfeeding, managing professional responsibilities, dealing with physical discomfort from childbirth, and confronting newborn health issues. These difficulties can profoundly impact mental health, including feelings of inadequacy, frustration, and, in some cases, clinical postpartum depression necessitating medical intervention. Each story, while unique, demonstrates the importance of recognizing and addressing the mental health needs of mothers with disabilities.

Internal Struggle

A notable struggle reported by most of the participants centers on the internal battles these mothers face in the postpartum phase. Julie reports that she encountered mental disengagement from her immediate surroundings and environments:

> I just noticed that I was kind of struggling with my mind because my mind would go at a hundred 50 miles per hour with different things, but I wasn't speaking anything. I would zone out, and I could hear people talking to me, but I wouldn't respond back, and I knew that I was within my thoughts, but I could still hear what they were saying. When I went to the doctor, and they said that's depression, and I'm like, really? I didn't think about it, I didn't feel anything, I didn't feel different, but that's because they told me that it started coming naturally to me.

This above example emphasizes that during the postpartum phase new mothers are highly susceptible to mood disorders including postpartum depression. Julie believed that her postpartum depression was a result of her pre-existing diagnosis of depression and anxiety. She felt suffocated and overwhelmed by these conditions:

> My depression and postpartum phase all ties together, especially after postpartum depression. After, I got diagnosed with depression and anxiety and then postpartum came, I kind of felt it was a triangle and then here's me in the middle. So, I'm surrounded by all of these things and how do I pinpoint exactly which one is happening and how I am

> going to manage all of these at once? But they surrounded me to where it was almost like I was being suffocated, and I just needed to just scream and let it out.

According to the above account, the interplay of depression, anxiety and postpartum depression during the postpartum phase creates complicated emotional and mental health challenges for new mothers like Julie. In addition, Julie expressed a desire to maintain her independence in handling everything on her own to prove her capabilities without seeking for assistance. She said:

> I felt it was really hard for me to do it alone, but my pride was so high that I didn't want anybody else's help. I had that mindset where I was like, I don't need anybody else, I can do this on my own and I don't need anybody to be telling me what to do. But that was because I was young too and I wanted to prove to everybody that I didn't need anybody and that was just me thinking that I can do things on my own.

This example reflects a common struggle many new mothers face during the postpartum period regarding the internal conflict between wanting to handle everything on their own and the inherent need for support. Equally, Olivia narrated her personal struggle with postpartum emotion, particularly anger, which she initially does not recognize as a symptom of postpartum depression:

> In my postpartum phase, I was not sad. I was mostly mad, and I never would, would hurt a child. I was never like, was not, not like that my children were in danger, but I was just mad. I was very grumpy, was very, very mad, and would find myself just crying not because I was sad but because I was angry. I don't remember what happened, and it was not long. She must have been a few months old, maybe 6 months old, and my husband was home in the evening, and I said I don't think this is normal. I don't think it's normal

> to feel mad every night. I'm just mad. I love them, and I'm doing bath time, and I'm doing all these things, but then I get to a point in the night I'm just mad. I'm just mad. And he said, "Honey, that sounds like postpartum depression," and I was like, "I'm not depressed. I'm not depressed, I'm mad." Then it hit me.

Olivia's story points out the importance of recognizing the diverse range of emotional experiences as potential indicators of postpartum depression. It also speaks to the concept of self-awareness.

Echoing this, Rebekah articulated a deep sense of inadequacy and self-blame that emerged from her postpartum phase. According to her, this feeling led to a serious emotional distress and a thought of self-harm:

> It is a progression of feelings and that feeling of worthlessness and nothingness and why can't I do this, why isn't this working? Why is this person able to do it? What's wrong with me? Oh, I know I'm the problem, so I'm going to fix it. I must be the problem; then, I'm just going to take myself out of this equation. I know for me personally it was maybe he wouldn't cry so much if he was with somebody else, maybe he would be happy if he was with somebody else, maybe they would be able to fix whatever is wrong with him.

This example illustrates the internal struggle and feelings of worthlessness that new mothers can experience often as postpartum depression. In another example, Rebekah revealed experiencing intense feelings of sadness, despair and harmful thoughts towards herself and her child:

> I got to the point, and it was probably 2 months postpartum, and I really started just wanting to run away. I thought that's where it all started, I wanted to run away because I thought that I wasn't a good mom. I thought that he would be better off without me. Then

> like a month later, it escalated to me wanting to die because I just wasn't good enough at all and it was just bad. I just felt so worthless, and I couldn't do anything. Again, this thing that I'm supposed to be able to do, I just can't do it. I was doing all the things and somehow, he was still so colicky. Then around 4, 5 months, I really got to the point where it was really bad, and I wanted to hurt both him and me and I just wanted to kill us both.

The example affirms that postpartum depression is a significant mental health issue that can lead to dangerous levels of despair, self-harm and in worst cases, suicidal thoughts. On the other hand, Amanda discussed her struggle with dealing with postpartum body image on her self-esteem. According to her, this struggle is a result of the physical transformation she faced after birth:

> Even though I was considered a late bloomer, I think I struggled the most with depression in the sense of not liking my body anymore because I couldn't do the things that I want to do anymore. I couldn't get the weight off. I couldn't get my nutrition together afterwards. I struggled a lot with energy, mobility, things like that. I had diastasis recti, which is the separation of the abdominal muscles during pregnancy and so after I had her, they didn't go back. My muscles didn't go back. So, it still looks like I'm pregnant and people asking you, "Are you pregnant?" And it hurts your self-esteem, too, sometimes.

Diastasis recti, a condition highlighted in the narrative, serves as a specific example of how physical changes after childbirth can persist and affect a mother's self-esteem and body image, especially in a society where there is often the pressure to return to one's pre-pregnancy body. Conversely, Joana's narrative indicated that her past experiences have equipped her with a sense of resilience and strength, which she sees as a powerful tool in handling the postpartum phase. She elaborated:

> No, I do not think I have experienced any degree of postpartum depression. I think it's partly because my family is super-dysfunctional, and there's always kind of weird, weird drama going on with them. You could write a Lifetime movie about my family and the weird stuff that they have going on. I have a lifetime of grit and persistence that I have learned, and so a little thing like a baby is not going to get me down.

The above example highlights how each mother's individual background and life experiences shape how she interprets and manages this phase. While some mothers struggle with postpartum depression due to various factors, others like Joana may note that their previous lived experiences have prepared them to cope more effectively with the mental health.

The narrative suggests that mothers with pre-existing conditions, such as borderline personality disorder, major depressive disorder, post-traumatic stress disorder, hearing loss, attention deficit disorder, dyslexia, depression, and anxiety have a heightened vulnerability to experiencing postpartum depression. These conditions reflect the different internal struggles these mothers face during the postpartum phase, including mental disengagement, suicidal thoughts, emotional turmoil, feelings of inadequacy, and issues with body image. A recognition of these struggles is crucial for providing appropriate support and interventions.

The Neglect of Mental Health

Three out of eight participants' responses to the interview questions revealed significant gaps in addressing women's health issues. These participants highlighted this gap from the lens of lack of discourse about women’s health in the United States, lack of acceptance, and insufficient research in the context of mental health. Echoing this sentiment, Anna stated, “I do feel like women’s health issues are not discussed in the United States and, unfortunately, because I think a lot of women suffer in silence.” Anna further addressed the role of social media in creating unrealistic expectations about pregnancy and childbirth:

> The things like getting pregnant, staying pregnant, giving birth are tough because everyone thinks like, oh, it should be easy and on social media you see every day someone’s pregnant, someone having a baby and we don’t talk about how long it took somebody.

Likewise, Olivia highlighted the lack of acceptance, understanding or validation of mental health issues from her father. She explained:

> My dad is a classic Midwestern white guy, he doesn’t really believe that mental health is a thing. I hate to say that, but I think that that’s the truth. He’s like, “No, just, just be positive everything will be great.” So, he’s not a support for me, when it comes to postpartum.

This example demonstrates that the lack of support and understanding from Olivia’s father in dealing with postpartum represents societal issues of recognizing and validating mental health issues. Adding to this pattern, Maddie mentioned the need for increased research and attention to mental health issues specifically targeting mothers. Maddie states, “This stuff fascinates me and with mental health there is the dearth of literature especially in moms and nothing against people putting research into babies, they do, but I think they forget about the other half,” representing her concerns about the mental well-being of mothers.

The discussion reveals significant gaps in the United States regarding women's health, particularly in mental health issues. It points out the lack of discourse, acceptance, and research, especially concerning the mental well-being of mothers. Also, social media's role in creating unrealistic expectations around pregnancy and childbirth, along with societal disregard for mental health issues highlights the urgency for greater awareness and support.

Perceptions of Motherhood

As a part of the discussion about the post pregnancy phase, participants shared their narratives indicating the diverse ways in which they make sense of the motherhood journey. Through the stories they tell, their interpretations range from motherhood as a journey of continuous learning to motherhood as responsibility as well as a reflection on the concept of motherhood as rewarding despite the challenges they face. For example, Joana stated, "Motherhood is like breathing. It is the most important thing in my life. Breathing is the most important thing I do." The analogy suggests that motherhood, for Joana, is as natural as breathing and it is not something that she has to think about doing. This view of naturalness communicates how effortlessly motherhood has integrated into her.

Continuous Learning

Some of the participants referred to motherhood as a time of exploration, constantly acquiring new insights to ensure effective parenting and to shape the development of well-being of their children. Anna articulated her commitment to motherhood, saying, "Motherhood is still new to me and I'm still figuring it out, but we're learning from each other so far." This given example confirms that Anna sees motherhood as a learning process where both the mother and the child gradually get to know and understand each other. Reflecting similar understanding, Joana's narrative highlights that understanding the needs of a newborn baby is not instant and definite but is a continuous journey of discovery. She stated:

> She was just like this perfect little thing, and she's been like a pretty easy going mellow baby and she's never really caused a lot of problems. She doesn't cry for no reason. When she wants something, she'll get a little fussy and you give it to her and she's like, okay, I'm calm again now. So, we're still learning everything that we can about her.

Her example communicates the transformative nature of motherhood. Emily reflects on this journey as an evolving experience. According to her, the initial expectation and perceived readiness give way to the realization that motherhood is a continuous learning journey:

> I think going into motherhood, you have all these expectations, and you think you have this great game plan and then as motherhood happens to you then realize that you are a student of motherhood, and you are learning as well as your children are learning. You're learning how to be a mother as well and it's like each stage changes and I'm learning a different part of motherhood all the time. So, I would say, yes, at the beginning, you think you are prepared, and I know everything and then it happens and you're like, I don't know anything. Yes, it's a great journey, but it's definitely a journey and a learning process.

Here, Emily acknowledges that despite having a plan and thinking she knows everything about being a mother, the reality of motherhood brings new challenges and lessons every day. Reinforcing this notion, Amanda's story reflects motherhood as a continuous cycle of learning about oneself, learning about one's child, and then teaching the child to learn about themselves. She recounted:

> But as a parent with ADD, raising a child with ADD is not easy. Because not only do I have to manage myself, I have to learn how to manage my youngest child and help my child learn how to manage herself. It's almost like the blind leading the blind. It's like, I have to teach her the skills so that she can learn how to manage herself, her emotions, because that's another thing, is that emotional regulation? That's a challenge. The impulsivity and not being able to make good decisions because it gets jumbled and if you're not comprehending everything around you. So, while I'm learning about myself, I'm having to learn my child, and then, as she gets older, how do I help her? Then how do I help her help herself? That was a challenge, and it is so hard when you have a problem with organization. So, I write a lot of lists. I have boards in the house, and I do a lot of visuals, because I'm a visual learner. She's like, visual, and auditory. So, throughout the years, I would create all these different charts differently just to get her to clean her room, and like it was like, it was so stressful, and still stressful. I'm trying to help your children develop these skills, which are skills that you struggle with.

This example is indicative of motherhood being a relentless learning journey and a process of mutual discovery between a mother and a child.

Responsibility

According to some of the participants, motherhood is deeply rooted in responsibility through mothers nurturing, educating, and instilling values in their children. As per these participants, the responsibility is not just in the day-to-day tasks but in the dedication to their children's well-being and growth. Julie highlighted that self-care is the foundation for effective caregiving. According to her, becoming a responsible mother starts with mothers making the conscious decision to attend to their needs in order to set an example for their children and to enhance their capacity to meet the responsibilities of parenting:

> I like to think of motherhood as taking care of yourself before you take care of others, and you want to set a good example for your kids. So, make sure that you're getting up in the morning, taking a shower, taking care of yourself, making sure that everybody is fed.

Conversely, Anna sees her duty as a mother as prioritizing her child's needs above hers. She stated, "Motherhood is caring for somebody else, putting someone else's needs before your own." This example emphasizes the sacrifice involved in raising a child where mothers such as Anna have the best interests of their child at heart, which, in turn, reflects their understanding of responsibility. Rebekah also discussed her responsibility as a mother particularly in striving for a better future for her child. According to her, motherhood is being present and supportive through all aspects of her child's life:

> I knew that a mother was supposed to be there for everything. You're the person who's there for the good, you are there for the bad and you're there for the worst. Even when you don't want to be there, you have to be there. You do everything in your power to make sure that you are doing the best for that child. I think because that's what I do every day. I do everything I can to make sure that my son has a viable future. I do everything that I can to make sure that I'm being the best of me, and somebody else's best may be different than my best me. I'm thinking about my son in the future and that is why I am going to school to do my bachelor's because I know that I can't work some dead-end job for the rest of my life because it's just not going to end well.

This indicates a series of responsibilities rooted in Rebekah's conscious effort to strive to improve oneself as a mother to benefit her child's future. Likewise, Olivia mentioned that imparting a valuable skill (sign language) to her children from a young age to foster an inclusive family environment reflects her understanding of her responsibility as a mother:

> When they were little, one day a week we had a no voice day in our homes where I would only sign with my kids. So, they all signed from the time that they were little and now nobody fluently signs anymore. Sometimes they pick up on a few things. If I have been with an interpreter all day, I go home and I sign a lot and then they're all like, okay. They can all finger spell and they all know enough to get by with me if we're somewhere where it's loud and I can't hear them.

Olivia values sign language in her family as a way to ensure effective interactions in challenging environments such as loud places where she finds it difficult to hear them.

Reward

Many of the participants viewed motherhood as a rewarding journey despite the challenges they face. These mothers described the rewards of motherhood in various contexts. For instance, Amanda described breastfeeding as a fulfilling and rewarding moment for her as a mother as it enabled her to connect with each of her children in a way that no one else could. Accordion to her, the songs she sang to each child further deepen the connection:

> The best moments with my children were breastfeed[ing] because that was the connection. That was the time it was just me and both of them. It was just such an intimate, private time, and each one had a different song that I chose to sing with them. For me, breastfeeding was the most fulfilling for me because it was just something that

> no one else can do. Like, no one else can give my children the nourishment they need from my breast. I guess you can breastfeed for somebody else, and they still get nourished, but it's just the ability to be able to provide something for my children and have this time because the child was part of me. I like that. It was so sweet breastfeeding and then the fact that the baby needed you, I love that.

Likewise, Julie's recount of her daughter's first expression of love signifies a transformational milestone not just in her child's development but also in her journey as a mother. She stated:

> Then my daughter, the first time that she ever told me that she loves me. —like I said, she has a speech delay, so when she said, "Mama, I love you" and I'm like, "Well, I love you too," and then she told me, "Well, I love you more." I didn't think that she had that type of speech within her at that time. But the first time, it really did fill my heart because of the fact that she has come so far with her speech and for her to even acknowledge what she was saying at that point, I was astonished. I was just like, "Wow, well, I love you more." Then, we kind of got into it and we were like sisters, arguing back and forth on who loves each other more. But it was a fulfilling thing knowing that I created these little humans that spread positivity, and that's fulfilling for me.

Despite the challenges and difficulties in motherhood, Rebekah shared that it is rewarding due to the joy she feels from moments of love and affirmation from her son. She recounted:

> Motherhood is a journey, and there's lots of ups and there's lots of downs, and I feel I've had lots of downs, but those little ups like my son telling me that he loved me for the first time and my son telling me that I am his favorite and being able to see his smile and him knowing that I'm able to do all of these things makes it worth it for me.

Equally, Maddie expresses immense happiness not only from the physical affection she receives from her son but also from witnessing her son's curiosity and engagement with the world:

> I think what puts the biggest smile on my face aside from when my son gives me a hug and seeing my son just look at the world as if it's the most positive place; and his sense of wonder, his sense of humor, his intelligence, his innocence, all of that and just fostering that and seeing this is one, I grew that thing in me, which is just badass. But just seeing him develop, I think is just so cool and knowing that I get to help influence that and knowing at the end of the day there is unconditional love between both of us and that's just completely surreal.

Similarly, the rewarding aspect of motherhood for Olivia lies in the unconditional connection and love she feels for her children. According to her, becoming a mother has revealed a capacity of love that she was unaware of, a love that means a lot to her:

> The biggest thing for me is realizing that I had no idea the intensity of the connection, and nobody could have ever described it to me. And so, before and after I thought that moms love their kids cognitively, I knew that moms love their kids. Then I became a mom, and there are no words that can describe the intensity of that connection and of that love that there's literally nothing my kids could do that would ever make me not love them and there's no other way to describe that.

In another example, Olivia highlighted that motherhood becomes rewarding upon seeing the values she has endeavored to instill in her children reflect in their actions and choices. According to her, such moments affirm the effectiveness of her guidance and positive influence she has a mother:

> Like I had no idea when you're singing the songs you choose to sing to put your babies to sleep, the books that you choose to read become the core of their memory and that's a lot of weight. My 12-year-old—and he is 12 years old for Valentine's Day—they had to do a project in school, and it was like loving books or something like that, and they had to make this poster about their favorite book of all time. His favorite book was the board book that was *Charlie Parker plays Bebop* that we read to him every night when he went to sleep as a baby. He still remembers that, but like that is such a sweet and deep memory for him, and I was like, "Okay yeah, you're messing with this mama heart because I didn't know how important all of those were until I became a mom." I think for the fulfilling moments as a mother is seeing your impact on your child, hearing your child say something to their friends like just overhearing it, overhearing your kid say, "Well if you can't say something nice, don't say anything at all" or like those things that you have really tried as a mother to instill as a value in your kids, you're not ever sure if that's going to hit, right?

For Olivia, these moments provide a sense of fulfillment and joy and demonstrate the irreplaceable role of a mother in her child's life.

These stories reveal motherhood as a dynamic process where mothers adapt, learn, and grow alongside their children, shaping their identity through nurturing, educating, and instilling values. These perspectives are crucial as they highlight the resilience and adaptability of mothers, showcasing how they construct their identities in the face of postpartum challenges. This resilience is not just about overcoming obstacles but also about embracing the complexity of motherhood, finding joy and fulfillment in the journey, and the unique bond formed with their children. The narratives exemplify how motherhood transforms women with disabilities, contributing to a unique, evolving identity shaped by love, learning, and commitment to their children’s well-being and development.

Strategies to Navigate the Postpartum Phase

The third theme that emerged during participant interviews conveyed the strategies mothers with disabilities employ and recommend in navigating and coping with the physical, mental, and behavioral challenges during the postpartum phase. The first strategy involves individual coping strategies that can help women thrive through this phase. The second strategy focuses on empowerment and advocacy among mothers as essential tools to support and uplift one another.

Coping Mechanisms

There are several factors that mothers with disabilities employ to navigate and cope with the physical, mental, and behavioral challenges during the postpartum phase. For example, Julie shared that she finds solace and strength in her interactions with her son, who serves as a “mini therapist” for her. According to her, the interactions not only help her navigate the challenges of the postpartum period but also instill a sense of motivation to go about her endeavors with confidence:

> He likes to talk, and he likes to reassure me that I need to keep my head up and my “crown on.” For example, let’s say I am kind of struggling, I then put my makeup on or something, my son just looks at me and he goes, “Did you put your crown on today, Mom?” “John, what?” and he’ll be like, “Did you put your crown on today? because you look like a princess today.” I didn’t even teach him that. He just said it and that was one

> of the fulfilling moments. So, he uplifted me and threw me off guard. I was like, oh, well, thank you and he says you're going to have a good day and I love you, have a great day, Mom and he'll just go off on the bus and I'm just like, where did this even come from? Honestly, it made me feel good and it made me feel like I can accomplish anything.

The above example reflects a deep emotional connection and understanding between mother and child. Also, it demonstrates the powerful role children can play in the mental health of their parents.

In another example, Julie stated, "I definitely had postpartum depression and I got put on medications to help me relax my muscles and to relax my thoughts and actually give me some sleep. I feel 180 times better." This example highlights the importance of seeking professional medical help when dealing with postpartum depression. Maddie also talked about resuming her medication after the birth of her son to prevent going through postpartum depression. According to her, the medications played a critical role in stabilizing her emotional state which helped her to focus on the wellbeing of her son:

> After the birth of my son, I immediately got back on my meds. I think the meds probably saved my life in the sense that I was able to keep my head on straight and John became my focus, and it was all about him and keeping him safe and I have not gone off my meds since that point. I felt better. I'm really grateful for that because I can't imagine having postpartum depression or postpartum psychosis.

In another example, Maddie's narrative points out a different aspect of navigating the postpartum phase. She read books that offer her strategies to manage her disability and that of her son:

> I actually found a killer book which was *ADHD in Women*, and it was a toolkit, and it gave me ideas on how to explain exactly what my scenario is and then gave me different ideas. I've implemented a ton of those to be able to organize my life in terms of those that are geared towards ADHD, and it has been awesome which is great. I've implemented those in hopes that it can help my son, John since John has ADHD and help him be organized as well. I feel like my situation was unique, especially with all the shit that happened with it and having what feels like a million diagnoses.

The above statement emphasizes the importance of mothers with disabilities seeking valuable resources tailored to their specific needs.

The narrative highlights the coping mechanisms mothers with disabilities employ and recommend in navigating the physical, mental, and the behavioral challenges during the postpartum phase. These mechanisms include finding emotional support and motivation through meaningful interactions with their children, seeking professional medical help and medication to manage their mental health, and leveraging educational resources like books to implement strategies that cater to their specific needs and those of their children. It also demonstrates the importance of emotional bonds, professional healthcare, and personalized strategies in overcoming these challenges. This understanding is unique because it sheds light on the specific experiences and strategies of mothers with disabilities, a group that often faces unique challenges.

Advocacy and Empowerment Among Mothers

Mothers with disabilities learning to advocate for their needs coupled with the realization that seeking support and sharing experiences among mothers serve as a powerful way to navigate the postpartum phase. For example, Anna stated, “Make sure that you are a good advocate for yourself and your needs and if you’re struggling with that find someone close to you who can help you with that.” Anna not only acknowledges the importance of self-advocacy but also underlines that self-advocacy can be challenging and seeking help is important. Julie emphasizes the importance of seeking help and overcoming the barrier of pride especially during the postpartum phase. She recounted:

> It’s okay to get help when you need it even if your pride is so high and you’re sitting there saying that I don’t want anybody else to help me with this, I’m the only person that can do it. It starts with a change, and it starts with you having that acceptance of other people wanting to help you.

This example suggests that mothers seeking help is not a sign of weakness but a step towards healing and better health. Maddie highlighted this need for women to seek support. According to her, the discovery a reliable support system of mothers is essential:

> For women, pregnant women, postpartum, women looking to get pregnant you are not alone and it’s definitely doable because there’s other women out there with the same thing who are all in full support and can be that sounding board if you need it.

Maddie acknowledges community as an invaluable resource for information and strategies to manage pregnancy, childbirth, postpartum phase, and parenting. Likewise, Olivia talked about the significance of community and support among mothers, particularly those who are balancing motherhood with professional careers and disability such as hearing loss:

> I believe that mothers need mothers. I think motherhood can be a very lonely, very, very lonely road especially as a professional mother. You can really feel like you’re the only

> one going through what you’re going through. And so, I also just believe that the research that you’re doing is important to make mothers not feel alone in this work and because I identify as a mother and a professional with hearing loss and my research is in the area of hearing loss. I also feel like that story is not often shared, and so I feel like I am in a position to be able to share that perspective.

Olivia believes she is uniquely able to share her story to contribute to a more inclusive understanding of the diverse challenges mothers face, thereby fostering a sense of community and support.

These findings emphasize the importance of advocacy and empowerment among mothers, particularly during the postpartum phase. It highlights the necessity for mothers to advocate for themselves, recognize when they need help, and overcome barriers such as pride to accept support from others. The text also underlines the value of a supportive community and shared experiences among mothers, acknowledging that such networks can offer essential information and strategies for managing pregnancy, childbirth, and parenting.

Support Systems to Navigate the Postpartum Phase

The fourth theme that emerged during participant interviews centers on the support systems they found invaluable during the postpartum phase. All eight participants acknowledged the significance of the assistance they received in the critical time of their lives. Three sub-themes emerged in support of this theme: informal support, formal support, and online communities.

Informal Support Systems

Many participants in the study highlighted the crucial support they received from their husbands and mothers during the postpartum phase. This assistance played a pivotal role in their journey through the early stages of motherhood. For instance, Olivia said, “My husband is exceptional. He is without a doubt my number one support.” Also, Joana spoke about her husband’s involvement in nighttime baby care. She noted:

> He has done all the stuff that we do at night for the baby like he changes her, gives her bottle. So, that’s been really helpful and that kind of sums up where we are at in the journey. My husband does all the night stuff like when I’m asleep he gets up and changed her. So, I really have been getting really good sleep. We work through it and figure it out.

Joana’s narrative emphasizes the importance of how having support from a partner in the daily care of a newborn baby can significantly ease the challenge of early parenthood. Additionally, it highlights the valuable assistance she has received from her in-laws in the postpartum period. She stated, “Since having the baby, my husband’s parents have come and visited us a couple times and they’ve watched the baby.” Julie also narrated how her husband’s understanding, empathy, and involvement significantly alleviated her struggles with depression following the birth of their daughter:

> Now with my daughter, my biggest support was my husband. I felt I wasn’t feeling too well, or my depression was kicking in a little bit more, my husband just knew, and he instantly took the kids and he’s like, go take a bath and he would just run me a bath and I’m like this is so weird, I’ve never had this before. It was a weird feeling because I usually have to do things on my own and then when he came in, he’s like, you know,

> you’re not alone, you’re fine and we’ll do this together, whatever you’re feeling, I’m feeling it too. So, let’s work on this together. He was my biggest support system when it came to my depression after our daughter was born, and also my son.

In another example, Julie highlighted the pivotal role of maternal support during the postpartum phase, especially in the context of being a single parent after giving birth to her first child:

> The people that helped me the most with my first was my mom. After my parents divorced, when I was 15, it was mostly just me and my mom throughout the rest of my life. She was definitely my rock during that time because I was living with her after I gave birth to my son. She was the one person that I could really go to.

Likewise, Maddie acknowledges her openness to seeking advice and learning from her mother’s expertise in baby care. She appreciated her mother’s readiness to assist with any concerns related to her baby:

> My mom is a guru for babies, and I told her, I am open to whatever and I would reach out if I’m like, “He’s doing this,” or “Is this what diaper rash is?” and giving her a picture of his butt, or what do I do about this or what do I do about that? So, I felt like I had a good strong support if it was something related to John that I could call my mom and be like what is this? and then she was more than willing to help and that was good.

This example suggests that having someone with experience and knowledge in raising a child serves as tremendous help to new mothers. Moreover, Rebekah spoke about the support she received from her mother in navigating the postpartum phase. According to her, her mother’s support has been crucial in enabling her to continue her education and work:

> My mom honestly has been the biggest support for me. She watches my son for me so I can go to school, I can get to work. He's in pre-K right now, but she goes and naps with him, she cooks him food, she cooks him breakfast, and she cooks at lunch. I think without her, I wouldn't have been able to do any of this because I wouldn't have had anybody else to help me. We're very honest with each other about a lot of things. We have become a team. We're almost like an unconventional couple but we're just mother and daughter.

Similarly, Amanda's statement "I had my mom, who would watch her when I had to go run and work and I could come back home. So, I was mostly with my daughter" highlights the role her mother played in supporting her through the postpartum phase, specifically in balancing her responsibilities as a new mother with her professional obligations. Additionally, Joana, Anna, Maddie and Olivia shared receiving support from their friends and sisters. For example, Joana stated, "Since having the baby, my friend Millicent has also come and watched the baby, as has my sister Benedicta".

These findings demonstrate the significance of informal support systems, particularly from partners and mothers, for mothers with disabilities navigating the postpartum phase. The narratives highlight the crucial roles that husbands play in daily newborn care, enabling mothers to recover and adapt to their new roles. Furthermore, maternal support emerges as a key element, with mothers offering invaluable advice, practical help, and emotional support. These findings are essential as they point out the positive impact of having a strong informal support network on the mental and physical well-being of mothers with disabilities.

Formal Support Systems

Some of the participants discussed the support they received from therapy, counseling, and community resource centers in navigating the postpartum phase. According to the participants, through therapy, they found coping mechanisms to support their mental and emotional well-being. For instance, Julie stated, “I just had the therapist and my doctors for sure, just talking to them.” Also, according to Rebekah, engaging in therapy has provided her with a supportive space to navigate the responsibilities of balancing her new role as a mother with her career:

> Therapy is lovely, and I highly recommend it to everyone, and so my therapist and I have really been working on what is my new identity as a mother and balancing that with now I’m back at work and how do I manage it all. So, I think I’m finding support for mental health counseling.

Echoing this, Maddie articulated, “I saw a counselor once a week or at once every other week, and that has been huge for me to stay with that. I have a badass counselor now, which I’m super excited about.” This example illustrates the importance of consistent counseling in managing mental health and personal growth. Furthermore, Maddie shared her journey through the “Butterfly Project,” a program designed for families experiencing domestic violence. According to her, this program empowered her to navigate the complexities of the postpartum phase, despite her fears and challenges:

> My son and I went through the Butterfly Project and it’s for families that experience domestic violence. I have social anxiety and I don’t like being around a lot of people and I just get super exhausted. I was very fearful that John was going to have that, but he’s

> the exact opposite. He's got great skills in the butterfly project, and I definitely credit that. But they taught him and myself how to regulate emotion when he was as young as 18 months, all the way up to 4 years old, which is impeccable.

The example demonstrates the importance of community resource centers in offering specialized programs that address the specific needs of mothers and children in vulnerable situations. Reflecting a similar experience, Rebekah shared the support she received from parental support groups in supporting mothers with disabilities through the postpartum phase:

> When Randy was born, we switched over to parents as teachers. It was the birth-to-three programs. Even when it came to nursing, I had the Nick the Wick ladies like I had all the support I needed, and they all knew about my mental health too and they were all very supportive about that.

Here, Rebekah's story communicates the importance of community networks that empower mothers with disabilities to successfully manage the responsibilities of motherhood, parenting, and the postpartum period. In addition, Rebekah highlighted the tremendous assistance she received from a dedicated nurse. According to her, the support the nurse provided evolved into a long-lasting relationship:

> I had a different nurse come out and see me and was helping me to become a better parent. It started out as once a week, once every 2 weeks and then once every 3 weeks and then once a month, and then it lasted until he was 3 years, and she was also just a wonderful support system. She's actually someone and I still talk to her till this day. She saw my journey in a completely different way than anybody else and was one of my biggest support systems.

This example illustrates the huge impact that continuous assistance and home visit from healthcare professionals can be crucial for new mothers with disabilities in managing their health and caring for their newborns.

The findings revealed the significant role formal support systems, such as therapy, counseling, community resource centers, parental support groups, and dedicated healthcare professionals, play in assisting mothers through the postpartum phase. These systems provide essential coping mechanisms for mental and emotional wellbeing, facilitate personal growth, and offer specialized programs for families in vulnerable situations, such as those experiencing domestic violence. The importance of such support lies in its ability to help mothers navigate the complexities of new motherhood, balance personal and professional life, manage mental health, and foster positive parenting practices.

Online Communities

According to some of the participants, joining and engaging in online communities helped them to navigate the postpartum phase. These participants added that these communities create a safe place where they feel comfortable to share their challenges knowing their identity remains hidden. For example, Julie's narrative illustrated the power of shared experience in online communities. Julie found a sense of belonging and validation from "moms group" for mothers with disabilities that she joined on Facebook:

> I joined this moms' group on Facebook, and it was within the surrounding area and all of these moms were talking the exact same way as I was thinking. There are so many people within this community that have the same postpartum depression issues, breastfeeding issues, anything like that. They have those and those are the people that you can talk to

> that's outside of your comfort zone, outside of the family home and they were a big support system.

This example points out the significance of online platforms for mothers with disabilities as spaces for learning for new mothers with disabilities facing challenges in navigating the postpartum phase. On the other hand, Joana explained the insights she gains and the connection she feels through joining "mom pages" for mothers without disabilities on Facebook:

> I follow a couple of mom pages on Facebook, and, when you are expecting insight, they have a lot of forms and stuff. So, I follow those pages and I do not really interact with them, but I read what other people have posted and every now and then I'll find someone who's had like a similar experience or not really about my autism and disability but they'll post something like how they had this thing happen to them in the hospital and I'll feel like that sense of commonality or I'll get—I'll learn something from their experience.

For Joana, online groups foster a sense of belonging to a community that understands and shares her daily realities. Also, Amanda's narrative highlighted the support she received from an online workout class that assisted mothers dealing with diastasis recti. She elaborated:

> There was a lady from Ireland, during the pandemic, she had an online workout class for women with diastasis recti to try to correct the issue. She just did it like before we exercise, she would have conversations and she would just talk about it because it was other mothers there and that I found most helpful, like a support group kind of thing.

Here, Amanda sees the online workout class as an avenue to understand diastasis recti better and learn effective ways to manage it.

The narratives highlight online communities that offer support and shared learning experiences for mothers with disabilities navigating the postpartum phase. These platforms serve as safe spaces where mothers can find a sense of belonging, validation, and practical advice, all while maintaining anonymity. This insight is important because it demonstrates the potential of online communities to act as vital support networks that complement traditional forms of postpartum care.

Conclusion

This chapter analyzed the narratives of mothers with disabilities. The first part of the chapter analyzes the pregnancy experiences of mothers with disabilities, which includes narratives of factors that influence their motherhood decisions and self-care practices. The second part examined the postpartum narratives, while the third part focused on mothers' strategies to navigate the postpartum phase, such as medical intervention. The final part focused on the support system mothers with disabilities find valuable during this critical phase in their lives. In the next chapter, I will present a discussion of the findings from this chapter.

CHAPTER V: DISCUSSION

The experiences of pregnancy of women with disabilities have been explored in diverse ways. Previous studies examined topics such as recommendations about pregnancy from women with disabilities to their peers, pregnancy among women with physical disabilities, their unmet needs and recommendations on navigating pregnancy, and the perceptions and attitudes of others toward the pregnancy of women with intellectual and developmental disabilities. Yet, we know little about how mothers with disabilities cope with and navigate the physical, mental (postpartum depression), and behavioral challenges during the postpartum phase. Therefore, I employed the communicated narrative sense-making theory to explore the meanings of stories shared by mothers with disabilities about their postpartum experiences, the support systems to assist them during this phase, and the potential of their narratives as guiding tools for future mothers. The study revealed among the participants, five mothers experienced significant challenges with self-care, managing parental obligations, and dealing with internal struggles, all of which led to depression. Despite these challenges, they found motherhood rewarding, describing it as a journey of continuous learning and responsibility, filled with both challenging and fulfilling moments. The study also noted some essential strategies to navigate and cope with the major changes during the postpartum phase, including seeking therapy, joining supportive online communities, getting help from families, and accessing community resource centers. Now that I have established the findings of the study, I will discuss the findings in relation to previous literature. Afterward, I will address the study's limitations, recommendations for future research, and practical implications.

Summary of Findings

Mothers with disabilities embody resilience and determination in their pursuit of motherhood. Taylor and Filax (2014) emphasized that for women with disabilities, envisioning themselves as mothers, making the conscious decision to become mothers, and then taking action to fulfill this choice are acts of bravery. Through the participants' narratives, they also emerge as advocates, inspiring their peers, potential mothers, and other women to recognize their own strength and capabilities in pursuing motherhood.

Pregnancy Narratives

Results showed that the women with disabilities who participated in this study pursued motherhood for various reasons. Some of the factors that influence their motherhood decisions, such as the love for children and the long-standing wish to be mothers and live life to the fullest, have been reported in previous studies. Specifically, Ganle et al. (2020) researched the motivations for childbearing among women with physical disabilities. According to their findings, almost all the participants considered pregnancy due to their desire to have their own children and their view of motherhood as a significant journey to pursue. From these findings, one can argue that these emotional and psychological motivational factors are not unique to mothers with disabilities but are a common thread that also connects to the experiences of mothers without disabilities.

The participants voiced their fears and concerns during pregnancy, with genetic concerns emerging as a significant factor that influences their decision-making process. LaPierre et al. (2017) asserted that mothers with hereditary medical conditions become greatly concerned about the possibility of transmitting their health conditions to their children. In the current study, the mothers expressed worry about the likelihood of their unborn babies inheriting their disability. This concern extended to deliberations about the health challenges their children might face and the impact of societal perceptions of those disabilities. This finding is similar to results from earlier studies that focused on motherhood and pregnancy deliberations among women with disabilities. These studies revealed that women with disabilities are discouraged from having children, and this discouragement stems from questions about the potential risk of their children inheriting their genetic conditions (Gibson & Mykitiuk, 2012; O'Connor-Terry & Harris, 2022).

Previous literature recognized that pregnant women with disabilities have genetic concerns and fears regarding the possibility of their children inheriting their disabilities. However, the current study sheds light on how these women leverage their unique skill sets and experiences with their disabling conditions. For example, despite the fear the women have about their children inheriting their conditions, they view their lived experiences and skill sets as powerful tools to support their children in navigating the potential challenges of disability. These aspects of their experience have not been extensively reported in previous research, which shows the importance of the current study in exploring the complexities of decision-making and resilience among mothers with disabilities.

Compared to mothers without disabilities, this aspect of the findings makes mothers with disabilities unique, especially those that have genetic disability conditions such as ADHD, autism, and hearing loss. Therefore, their decision to continue their pregnancy despite these worries demonstrates a strong commitment to motherhood that is informed and motivated by an awareness of their abilities and determination to provide the best for their children. These findings contrast with societal norms that often portray married life and motherhood as particularly challenging for women with disabilities, who are frequently viewed as incapable of fulfilling these roles (Tefera et al., 2018). Iezzoni et al. (2017) and Mitra et al. (2016) argued that mothers with disabilities possess the capabilities and strength to pursue motherhood and make valuable contributions to their families.

Although the narratives from the mothers in this study did not explicitly highlight concerns about societal perceptions of their competence as parents, the narratives related how those concerns about competence as parents among mothers with mental disabilities such as depression and anxiety stemmed from their personal struggles and vulnerabilities. While societal perceptions may play a role, it is the internal battle with past traumas, mental health issues, and the fear of repeating patterns that predominantly shapes their fears about their parenting abilities.

Healthcare professionals, such as gynecologists and obstetricians, play an essential role in the pregnancy journey of women with disabilities. Tarasoff (2017) found that, while few women in their study indicated that their perinatal care providers were enthusiastic and open to learning, many reported that they lacked knowledge regarding the experience of caring for women with physical disabilities. In the present study, one participant experienced inadequate care due to her obstetrician's limited experience with autistic patients. This gap in understanding of her disability resulted in the obstetrician's failure to accommodate her specific needs, especially her sensitivity to certain textures like the sticky substances often used during gynecological examinations. This finding indicates that the lack of understanding that healthcare professionals have of the unique challenges and concerns associated with pregnancy and disabilities (Strnadová et al., 2019) extend to women with invisible disabilities (as those women constitute the majority of the sample of the present study).

The participants’ narrative highlights the agency of women with disabilities in making informed and conscious decisions regarding motherhood. It illustrates their deep understanding of the implications of their disabilities, not as limitations but as unique contexts within which they plan to nurture and support their offspring. This aspect of the narrative emphasizes the importance of recognizing the autonomy and decision-making capabilities of women with disabilities, advocating for their right to make choices about their bodies and lives.

Postpartum Phase Narratives

In discussing the postpartum narratives of mothers with disabilities, some of the participants’ stories highlighted the challenges that led to depression. First, the results showed that some new mothers become depressed due to difficulties in maintaining daily self-care routines such as regular showering, sleeping, and eating habits. Some new mothers face significant neglect of personal hygiene and proper nutrition. Second, the findings revealed that these mothers encounter challenges in mastering breastfeeding techniques and producing sufficient milk. The health issues that mothers with disabilities face, such as having an emergency cesarean section, also result in physical discomfort and difficulty with maternal tasks like breastfeeding. Also, mothers with disabilities discussed the difficulty in balancing professional responsibilities with new maternal duties as a significant stressor during the postpartum phase.

Third, the results showed that mothers with disabilities struggle with intense internal conflicts and emotional turmoil, including mental disengagement, overwhelming thoughts, anger, frustration, feelings of inadequacy, worthlessness, and intense sadness during the postpartum phase which in turn affect mental health (postpartum depression). Similarly, Romm

(2010) reported that hormonal changes during the postpartum phase frequently include mood swings, anxiety, crying, restlessness, and difficulty falling asleep. The postpartum challenges described by mothers with disabilities in the current study are also commonly reported by mothers without disabilities. The postpartum period can be a vulnerable time for any new mother, with hormonal changes and the transition to new responsibilities often leading postpartum depression.

However, mothers with mental disabilities experience mental health challenges (postpartum depression) in unique ways, influenced by their specific disabilities. Some mothers experience a more intense, long-lasting form of depression called postpartum depression (Mayo Clinic, 2022; Oyetunji & Chandra, 2020). According to the findings, mothers with mental disabilities with pre-existing conditions such as depression and anxiety experienced postpartum depression at higher levels after giving birth due to the demands of caring for a baby, though the findings of the present study are meant to be merely descriptive and not generalizable. For example, one participant diagnosed with borderline personality disorder, major depressive disorder, and PTSD experienced severe emotional distress and thoughts of harm towards herself and her child, as well as suicidal thoughts.

In similar ways, Thomas et al. (2014) explored the impact of postpartum depression on women, emphasizing its severity as reported in online stories. The findings reveal that women struggle with overwhelming, irrational thoughts and guilt. Also, the results revealed the occurrence of severe suicidal thoughts rather than harm toward the child as an impact of postpartum depression among mothers without disabilities (Thomas et al., 2024). The present study findings are also similar to earlier studies about stressful life events and postpartum depressive symptoms among women with disabilities (Booth et al., 2021). Booth et al. (2021) reported that 37.4% of women with disabilities had postpartum depressive symptoms, significantly higher than 8.79% of women without disabilities. Likewise, Barkin et al. (2016) argued that women with disabilities diagnosed with depression, anxiety, and bipolar disorder are more likely to have postpartum depression. The findings of the current study emphasized the diverse impact of pre-existing disabilities and the stresses of motherhood for mothers with disabilities that make childbirth challenging and show their uniqueness in terms of having the confidence to pursue motherhood. While postpartum depression can affect any new mother, the current study findings indicate that mothers with pre-existing mental health conditions such as depression and anxiety are susceptible to experiencing postpartum depression. Their existing mental health challenges intensify the typical strains of motherhood, often resulting in a more intricate experience of postpartum depression.

Moreover, according to the findings, there is a significant gap in addressing and discussing women's health issues, particularly mental health, in the United States. This gap is a result of the lack of discourse, acceptance, and insufficient research focusing on women from marginalized communities (women with disabilities). For example, the findings revealed that the lack of discourse and acceptance of mental health by families leads these women to suffer in silence. These women are impacted by the unrealistic expectations set by social media regarding pregnancy and childbirth, as they fail to report the challenges. This result reaffirms a finding from LaPierre et al. (2017), where one woman who uses a wheelchair criticized the media, saying, "All of the pictures that we have of motherhood are like healthy, standing women" (p.

422). This observation suggests that women with disabilities are not fully informed about the successful strategies that others in similar situations use to manage parenting challenges. Participants also emphasized the need for more focused research on maternal mental health to better support mothers' well-being. Their experiences highlight the need for an adequate representation in media and societal discourse, as well as the reorientation of family perceptions, ensuring that the diversity of motherhood experiences, including those of women with disabilities, is acknowledged and valued.

Despite the challenges they encounter during the postpartum phase, the results of the study also revealed that mothers with disabilities interpret and navigate their journey through motherhood in diverse ways: continuous learning, responsibility, and the rewarding nature of motherhood. According to the findings, motherhood is seen as an intrinsic part of their identity, a natural process as effortless as breathing for some, while for others, it represents a continuous journey of mutual discovery and learning between mother and child. The study highlights the responsibility embedded in motherhood, not only in daily caregiving tasks but in the broader commitment to nurturing, educating, and shaping the well-being and future of their children. In addition, many participants described motherhood as immensely rewarding. They found fulfillment in the intimate moments of connection, witnessed their children's milestones and development, and saw the reflection of their values and teachings in their children's actions. The findings demonstrate their agency and the importance they also place on motherhood as a significant and enriching life experience (Walsh, 2014).

One can argue that the perceptions of motherhood held by mothers with disabilities point out the resilience, capabilities, and adaptability of these mothers, as they not only confront the demands of motherhood but also innovate and adapt strategies to manage their parenting roles effectively. The study highlights the importance of recognizing and valuing the diverse experiences of motherhood, advocating for a more inclusive and supportive understanding of what it means to be a mother, irrespective of disability. These findings relate to Kellas's (2021) proposition of retrospective storytelling which states storytelling is "individual, relational, and intergenerational meaning-making" (p. 119). In other words, meanings, values, and beliefs can be inferred by analyzing the content of individuals' spoken narratives and relational story interactions. The personal fulfillment and unique experiences of motherhood as narrated by these women are individual meaning-making processes. They create personal narratives that make sense of their motherhood experiences in relation to their disabling conditions and the realization of their capabilities as mothers. The way a child's milestones bring joy, how a partner's support offers relief, constructs a relational understanding of motherhood among mothers with disabilities. The values and teachings that mothers with disabilities pass on to their children, and how they see these values reflected, is intergenerational meaning-making. When they speak of instilling resilience, advocating for oneself, or learning together with their children, they are instilling these values into their children. Their resilience and adaptability in facing higher risks of postpartum depression and other difficulties during the postpartum phase highlight their capability. These narratives call for a shift in societal views, advocating for recognition of the diverse strengths of women with disabilities and promoting a more inclusive perspective on motherhood.

Strategies to Navigate the Postpartum Phase

In discussing the strategies and coping mechanisms to navigate the postpartum phase, stories employed by mothers with disabilities suggest two themes: individual coping strategies and advocacy and empowerment. The narratives highlighted the strategies the mothers used to address the challenges they encounter during the postpartum phase. First, participants shared how personal coping mechanisms (seeking comfort and support, receiving uplifting comments from their children, obtaining professional medical intervention, and leveraging resources such as books tailored to their specific needs) were instrumental in their postpartum recovery. The coping mechanisms that mothers with disabilities employ, as highlighted in the study, reflect both unique aspects related to their disabilities and common strategies that any new mother adopt. Seeking comfort and support, particularly from children and loved ones, is a general aspect of coping that many new mothers might experience. However, for mothers with disabilities, professional medical intervention and tailored resources like specialized books are particularly relevant for these mothers as they navigate the complexities of their disabilities in addition to typical postpartum difficulties. One of these strategies has been reported in previous studies (Iezzoni et al., 2017; Kalpakjian et al., 2021; Mitra et al., 2016). Specifically, the women in Iezzoni et al.'s (2017) study identified self-help books as valuable primary sources of information during pregnancy.

Second, the interviews in the present study reveal the importance of self-advocacy, establishing a supportive community among mothers with disabilities, and overcoming barriers to seeking help in empowering mothers to navigate the challenges of motherhood. This finding is consistent with previous studies. First (2020) argued that women with disabilities leverage peer support to acquire information. In addition, mothers with mobility disabilities from a study by Iezzoni et al. (2017) recognized the importance of advocating for themselves by establishing a support system and embracing assistance from other mothers with disabilities. They also report that the women advised that prospective mothers should engage in conversations with other mothers who have disabilities since it helps to alleviate their fears. Blair et al. (2022) found that women with disabilities sought guidance, practical advice, and a sense of belonging from their peers, namely other mothers with disabilities, who were considered reliable sources of information.

Similarly, Mitra et al. (2016) discovered that women frequently sought guidance from other women with disabilities with similar experiences who had experienced pregnancy. Reflecting on the responses of the participants in the present study, it is apparent that “mothers need mothers,” and there should be intentionality to encourage peer support networks for mothers with disabilities, fostering an environment for advocacy and empowerment to help them navigate this course collectively. The personal coping mechanisms and advocacy and empowerment strategies shared by mothers with disabilities point out the importance of communication. According to Kellas (2021), the main functions of storytelling and narrative in the context of health are “creating, connecting, socializing, and coping” (p. 119). Through their stories, they highlight how essential open dialogue, connecting with other mothers and creating support networks are helpful in coping with and navigating the unique aspects of their postpartum experiences. These communications serve not only to share and normalize their experiences but also to advocate for and empower themselves within building their community.

Thus, communication is fundamental not just for information exchange but also for building community and enabling meaningful support networks among mothers with disabilities.

The Support Systems to Navigate the Postpartum Phase

The findings from the participant interviews highlighted the critical role of support systems in helping mothers with disabilities navigate the postpartum phase. These support systems fall into three main categories: informal support, formal support, and online communities, each playing a unique role in the mothers' journeys. Kim et al. (2014) emphasized the importance of social support, especially after birth, to reduce the risk of postpartum depression in mothers of all ages. Also, Thomas et al., (2014) found that mothers identified specific cues or facilitators that led them to seek help. These included interventions by family members, advice from midwives, or connections made through support groups. In the current study, informal support systems emerged as foundational, with participants emphasizing the invaluable assistance received from their close family members, especially husbands and mothers. This support ranged from sharing the nightly duties of baby care to providing emotional support and practical help with daily tasks. Such support was crucial in enabling these mothers to manage their mental health, recover from childbirth, and adjust to the demands of new motherhood.

On the other hand, formal support systems highlighted the importance of professional help, including therapy, counseling, and support from healthcare professionals and community resource centers. These resources offered mothers strategies for coping with mental and emotional challenges, tools for balancing motherhood with other life roles, and programs for managing specific issues related to their disabilities or their children's needs. Continuous engagement with healthcare professionals and specialized support programs was cited as significant for personal growth, mental health management, and effectively navigating parenting responsibilities. These findings are consistent with previous literature. For instance, Xiao et al. (2023) argued that peer support can strengthen communication among women after delivery. In addition, the researchers recommended new mothers have regular screening, follow-up, and mental health care in postnatal periods of pregnancy because the period of childbirth is stressful, especially for new mothers. As a result, they emphasized the importance of emotional and psychosocial support for new mothers in both community and healthcare settings.

Additionally, the results revealed that online communities such as Facebook pages for mothers with disabilities and mothers without disabilities and online workout platforms provided support for mothers with disabilities to connect with others facing similar challenges, offering a sense of belonging and an avenue for sharing experiences and solutions. Mitra et al. (2016) asserted that, in addition to pregnancy experiences, women expressed a need for information on postpartum assistance, including breastfeeding, and the availability of convenient baby equipment such as bassinets, cribs, changing tables, baby bath equipment, and carriers. These virtual spaces allowed mothers to learn from others' experiences, gain insights into managing specific health conditions or parenting challenges, and find emotional support among peers who understand the complexities of parenting with a disability. This finding is supported by an earlier study by Litchman et al. (2019) on the use of blogs by mothers with disabilities to write their own stories. They found that blogs offer a medium for women with disabilities to engage in social media interaction with their peers, allowing them to share and gain information and support. Also, Rugoho and Maphosa (2017) discovered that women accessed WhatsApp groups led by women with disabilities who possessed expertise in health matters to engage in discussions about reproductive health.

The participants' statements suggest that a combination of multiple support systems, including support from family, formal support from professionals, and community support through online platforms, is crucial in empowering them to navigate the challenges of motherhood with confidence. The diverse statuses of the participants highlight the importance of this finding. This comprehensive support is particularly vital given the varied circumstances of the participants. Married mothers often benefit from the support of their spouses and families, whereas single mothers may rely more heavily on community resources and online platforms for assistance. Hence, a well-rounded support system seems essential for providing mothers with disabilities a robust foundation as they embark on the journey of pregnancy and motherhood. In these findings, the role of communication through storytelling emerges distinctly. According to Kellas (2021), the main functions of storytelling are "creating, connecting, socializing, and coping" (p. 119). For these mothers, having a support system becomes a lifeline—a means to convey their needs, articulate their challenges, and find a solution. Whether it is finding solidarity in a Facebook group, healthcare professional, or feeling uplifted by a partner's or family's support, these stories reveal the power of communication in enabling these mothers to process their emotions, reflect on their experiences, and make sense of their motherhood journey.

Limitations and Future Research

Four participants out of eight reported unintended pregnancy, which seems quite close to the national average in the U.S. In the U.S., almost half of all pregnancies are unplanned, and such unintended pregnancies are associated with various adverse effects, such as postpartum depression for both mothers (Centers for Disease Control and Prevention, 2023). This observation might suggest that mothers with disabilities, like mothers without disabilities, have a similar distribution of planned and unplanned pregnancies. However, the specific challenges and considerations faced by mothers with disabilities might influence their planning and decision-making processes differently. Given this context, a future study exploring the impact of disability awareness on pregnancy planning and decision-making among mothers with disabilities could provide valuable insights. Future research could also investigate how unplanned pregnancies among mothers with disabilities might affect experiencing postpartum depression, especially given that three participants out of the five who had unplanned pregnancies experienced postpartum depression.

Despite the goal of the current study to interview mothers having physical, mental, or sensory disabilities, I was unable to achieve this breadth of representation that would give the fullest understanding of this topic. A major limitation of this study is the limited scope of disability representation. The participants interviewed were mothers with hearing loss, ADHD, depression, anxiety, and PTSD. The study excludes a wide range of physical, intellectual, and other sensory disabilities. A lack of representation of these types of disability limited the dynamics and distinct to pregnancy, postpartum, and parenting experiences among mothers with disabilities. Mothers with physical disabilities are not represented in this study. The narratives from mothers with disabilities, including autism spectrum disorder, sensorineural hearing loss, mild to moderate hearing loss, depression, anxiety, borderline personality disorder, major depressive disorder, post-traumatic stress disorder, obsessive-compulsive disorder, attention deficit hyperactivity disorder, dyslexia, and attention deficit disorder, did not highlight concerns about societal perceptions of their competency as parents or describe efforts to persuade family members to accept their decision to have children. Therefore, future research could explore the communicative work women with physical disabilities such as mobility impairments, visual impairments might engage in to justify their decision to have children when family members are aware of their disabilities.

The impact of disabilities on postpartum experiences can vary greatly depending on the nature and severity of the disability. The selected disabling conditions of the participants overlook the unique challenges faced by mothers with physical disabilities, for example, in caring for their infants, accessing healthcare and childcare facilities, or even physical recovery post-birth. In addition, mothers with physical disabilities experience high levels of stigma, social exclusion, abuse, and discrimination from society, family, and health professionals that could affect their postpartum experiences and parenting. Based on these limitations, future studies should collect data on mothers with diverse disabilities. This broader representation will capture the varied and unique challenges and experiences of mothers with various disabilities and provide a more comprehensive understanding of their postpartum needs and experiences. The current study showed five out of eight participants experienced postpartum depression accounting for a 62.5% rate of postpartum depression among participants. This finding contrasts with general statistics indicating that many new mothers experience baby blues (Mayo Clinic, 2022) and about one in eight women with a recent live birth experience symptom of postpartum depression (Centers for Disease Control and Prevention, 2020). However, as the present study is an in-depth interview study with a small sample, there is no attempt to generalize these findings to a larger population. This finding suggests a notably higher rate of postpartum depression among mothers with mental disabilities. Future research could focus on the barriers that these mothers might face in recognizing, reporting, and seeking help for postpartum depression. It may also be valuable to examine how personal, societal, and systemic factors influence these mothers' willingness to seek help. Considering the global diversity of experiences, future research could explore a comparative study analysis among low-income and middle-income countries, which would highlight how different cultural, religious, and social contexts affect the postpartum experiences of mothers with disabilities. This global perspective can contribute to a more inclusive understanding of the challenges and support needs across different regions.

Through the interviews, I reached a point of redundancy where further data collection yielded few additional insights, which solidified the credibility of my findings. The criterion for redundancy, as posited by Lincoln and Guba (1985), was a guiding factor in determining the sufficiency of collected data. Across the data, common themes such as pregnancy narratives, postpartum narratives, coping mechanisms, and support systems emerged consistently. After the eight interviews, no new themes were identified, and the subsequent interviews reinforced the established patterns. Lincoln and Guba (1985) posit that redundancy is indicative of credibility. The repetitive nature of the findings confirms that the collected data is robust, contributing to the credibility and trustworthiness of the research. The present study highlights the absence of research and discussion surrounding the postpartum experiences of mothers with disabilities.

On the other hand, there is a need for further research in this area to understand their experiences better and develop effective interventions for mental health during the postpartum phase. This gap in the findings implies that although my study reached redundancy, theoretical saturation was not achieved. According to Strauss and Corbin (1998), achieving theoretical saturation is essential. It is not merely about collecting enough data until new information stops emerging; it is about reaching a level of understanding where the concepts we are studying are well-developed and interconnected. Therefore, the recommendation for future research would be to expand the participant pool, not just in number but in diversity to understand their experiences better and develop effective interventions for mental health during the postpartum phase.

Practical Implications

The study provides extensive insights into the postpartum experiences of mothers with disabilities. It offers several practical implications for various stakeholders, including healthcare providers, policymakers, families, support organizations, and society. First, healthcare providers, especially obstetricians, and gynecologists, should undergo training to enhance their understanding of the unique needs of mothers with disabilities and develop personalized care plans since mothers with disabilities are becoming aware of their reproductive rights and are developing interests and motivations to give birth to their children and instill values in them. In addition, health professionals having knowledge and understanding of their patient's disability is important because these women are doing extensive research themselves and have a specific preference for care. Moreover, participants' complaints of disjointedness in the healthcare system point out a gap in the current healthcare delivery for mothers with disabilities, which is the lack of effective communication and coordination among healthcare professionals. This shortcoming calls for a well-structured and efficient communication framework that ensures that obstetricians, gynecologists, and pediatrics are on the same page.

Furthermore, policymakers should enforce policies that ensure mothers with disabilities receive equitable care. This includes policies that support genetic counseling and testing where necessary, provide financial and logistical support for specialized prenatal and postnatal care, and mandate the inclusion of disability training in medical education. In-person and online community building and support groups within various communities should establish, promote, and strengthen support groups for mothers with disabilities. These platforms can offer a space for sharing experiences, advice, and coping strategies, as recommended by participants. In addition to these programs, government officials should provide resources to support these organizations that have created the space to advocate for the rights and needs of mothers with disabilities in navigating pregnancy, childbirth, and the postpartum period.

Conclusion

In this study, I utilized the narrative-based interview approach to better understand the postpartum experiences of mothers with disabilities in navigating pregnancy and parenting through storytelling. Since previous interview-based research has focused solely on pregnancy experiences of mothers with disabilities, I employed the communicated narrative sense-making theory to explore the meanings of stories shared by mothers with disabilities about their postpartum experiences, the support systems to assist them during this phase and the potential of their narratives as guiding tools for future mothers. The study revealed among the participants, five mothers experienced significant challenges with self-care, managing parental obligations, and dealing with internal struggles, all of which led to depression.

Despite these challenges, they found motherhood rewarding, describing it as a journey of continuous learning and responsibility, filled with both challenging and fulfilling moments. The study also noted some essential strategies to navigate and cope with the physical, mental and behavioral challenges during the postpartum phase, including seeking therapy, joining supportive online communities, getting help from families, and accessing community resource centers. This study is essential as it enlightens us about the unique challenges and experiences of mothers with disabilities. It also provides evidence of the importance of storytelling as a powerful tool for mothers with disabilities. Through their stories, these mothers create and reinforce their motherhood identities. Their narratives serve to illustrate, inform, and inspire women with disabilities, reinforcing the essential role of storytelling in navigating the complexities of motherhood with a disability.

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APPENDIX A: INTERVIEW PROTOCOL

(Opening comments: I will work on gaining rapport with mothers by asking them how they are and about their day.)

I want to start by thanking you for your willingness to share your story today. I understand that you have taken the time to meet with me, and I want you to know I appreciate your participation in this conversation with me. My goal simply is to understand your motherhood journey. Please talk as much as you want. Our conversation will last as long as you would like it to, so if at any time you would like to end it, please just let me know. Do you have any questions before we begin?

1. I would like you to tell me the story or stories of your motherhood journey. It could be anything before you became pregnant, when you were pregnant and afterwards.

Once the mother tells her story, I will probe for more details about the content of the story by asking the follow-up question, "Can you tell me more about…?"

Post Narrative Interview Prompts

1. What influenced you to get pregnant?
2. How did you take care of yourself during pregnancy?
3. What choices did you make about your children after giving birth?
4. How did you feel about your pregnancy and the prospects of motherhood? Did you experience feelings of joy and excitement or were there concerns and fears, or both?
5. Can you describe your experience with maternal care especially with going to the hospital for checkup and your encounter with a health professional?

6. What does motherhood mean to you? Has the meaning of motherhood changed over time? And if so, in what ways?
7. What are the most fulfilling moments of motherhood despite the challenges?
8. What are the challenges of motherhood?
9. Have you heard of postpartum depression (PPD)? Can you share any personal stories or experiences that helped you understand or identify your feelings related to postpartum depression?
    a. How do interpret or make sense of these experiences in relation to your disability?
10. What kinds of support systems did you find most helpful during your postpartum period? (Family members, friends, spouse, partner, or other mothers with disabilities)
    a. Can you share an experience or instance where a support system (family, friends, healthcare professionals) played a crucial role in your journey through postpartum depression?
    b. Apart from these resources and support systems, how do you personally cope with the emotional and mental health aspects of the postpartum period?
11. What motivated you to share your story today?
    a. Have you ever shared this story or part of it with other pregnant women with disabilities or other mothers with disabilities? If no, whom do you share this story with?
    b. Apart from these resources and support systems, how do you personally cope with the emotional and mental health aspects of the postpartum period?

APPENDIX B: DEMOGRAPHIC QUESTIONS

Please take a few moments to provide me with basic information about yourself. These demographic responses will assist me in better understanding your educational, employment and family background. Please after completing the form, submit it to (Agnes Amoakwa, aamoakw@ilstu.edu, or Dr. John Baldwin, jrbaldw@ilstu.edu)

1. Which State are you currently residing? Provide response in the box.
2. What is your age at your last birthday? Provide response in the box.
3. How would you describe your disability? Provide response in the box.
4. Are you married, living with a partner, single, divorced, widowed, cohabiting, or living with an extended family? Please describe the option that best describes your situation in the box.
5. How many children do you have? Provide your response in the box.
6. Could you please indicate whether any of your children have been identified with a disability or special needs?
7. Could you please indicate your current employment status from the following options?
   A. Employed Full-Time: Working 35 hours or more per week in a paid position.
   B. Employed Part-Time: Working less than 35 hours per week in a paid position.
   C. Self-Employed: Running your own business or working as a freelancer.
   D. Unemployed: Currently not employed and actively looking for work.
   E. Student: Full-time or part-time student, not currently engaged in paid employment.
   F. Homemaker: Managing the home and not currently engaged in paid employment.

G. Unable to Work: Unable to engage in employment due to disability, health issues, or other reasons.
H. Other: Please specify if your situation is not represented by the above options in the box.

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8. What is your current educational status? Please select the option that best describes your situation:
   A. Currently attending high school or equivalent
   B. High school graduate or equivalent
   C. Currently enrolled in a vocational or trade program
   D. Completed a vocational or trade program
   E. Currently an undergraduate student
   F. Completed an undergraduate degree
   G. Currently a graduate student (e.g., Master’s, PhD)
   H. Completed a graduate degree (e.g., Master’s, PhD)
   I. Other educational path or status (please specify in the box)

☐

9. How do you identify? (Select all that apply)
   A. American Indian, Alaska Native, and/or Indigenous
   B. Arab American, Middle Eastern, or North African
   C. Asian or Asian American
   D. Black or African American
   E. Native Hawaiian or other Pacific Islander
   F. Southeast Asian
   G. White/European American
   H. Prefer to self describe in the box

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