

THE PERINATAL EXPERIENCES OF BLIND WOMEN

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## ABSTRACT

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Women who are blind become mothers at the same rate as sighted women. This qualitative descriptive study is the first exploration of their obstetric experiences from a nursing perspective. This study aimed to identify and describe the physical and attitudinal barriers experienced by blind women during the *perinatal period*. The perinatal period includes the pregnancy, childbirth, and the puerperium. Intersectionality is used as a theoretical underpinning because it is designed to investigate the experiences of historically marginalized individuals with multiple stigmatized identities. Using the multiple axis approach of intersectionality, this study is an initial critical investigation of a group that shares three distinct intersecting identities. All the participants in this study were women (sameness) who are blind (sameness), and who have recently experienced childbirth (sameness). The study explored the significance of these differences in the presence of cultural and healthcare practices and/or expectations (power). The participants described encountering attitudinal, physical, and institutional barriers. The data was analyzed using conventional content analysis, and five main themes emerged: (a) information remains inaccessible, (b) mobility issues, (c) fear of losing custody, (d) comradery among blind mothers, and (e) stigma is real. This study found that paperwork is still inaccessible and that “documents in alternate format” as directed by the Americans

with Disabilities Act (ADA) are unavailable. The findings emphasize that this population is fearful of social services because blind mothers may lose custody of their newborns due to unwarranted interventions of social workers. Blind mother support groups function as catch-all networks for adaptive resources, emotional support, hands-on baby care, and *discourse prep*. Discourse prep teaches new members how to respond to probing questions from healthcare workers and social workers. New findings that were not previously described in the literature are identified. These findings include a decrease in help-seeking behaviors due to the participants' fear of social services. Evidence of stigmatized interactions throughout the entire perinatal period. Nurses and other providers assume that blind women are not able to safely care for their newborns. This study illustrates that there is much opportunity for future research in this topic.

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## CHAPTER I

### INTRODUCTION

#### **Focus of Inquiry**

In the United States, an estimated 4.1 million people with disabilities are parents of young children (Through the Looking Glass, 2018). Statistics indicate that women with mobility and sensory impairments become mothers at the same rate as women without disabilities (Horner-Johnson, Darney, Kulkarni-Rajasekhara, Quigley, & Caughey, 2016). Visual impairment affects an estimated 3.8 million women between the ages of 16 and 64 (National Federation of the Blind [NFB], 2018). The degree of visual impairment varies from “low vision” to “completely blind.” The focus of inquiry for this study is limited to women who are blind, and do not rely on any residual vision. The exact number of blind mothers is unknown, but it appears that severe visual impairment does not preclude blind women from having a family. Like sighted women, blind women tend to care for their children independently in their own homes (Blind Parents Interest Group, n.d.).

Research in the perinatal experiences of women with physical disabilities is not extensively performed in the United States, and there is no evidence of research into the childbearing experiences of blind women from a nursing perspective. Frederick (2015, 2017) studied the postpartum experiences of blind women from a sociological perspective and found they encountered multiple physical and attitudinal barriers as new mothers. Her study findings also suggest that blind mothers are perceived as inadequate caregivers, fear health care workers, and feel pressured to be perfect mothers (Frederick, 2015, 2017). Recent qualitative studies focused on the perinatal experiences of 22

women with physical disabilities (impaired mobility) and identified multiple barriers. The identified barriers included physical barriers related to infrastructure, barriers to adequate care due to educational deficits of the health care providers, as well as attitudinal barriers and expressions of microaggression from health care providers, family members, and strangers (Iezzoni, Wint, Smeltzer, & Ecker, 2017; Lapierre, Zimmerman, & Hall, 2017; Mitra et al., 2017; Powell et al., 2017; Smeltzer, Mitra, Iezzoni, Long-Bellil, & Smith, 2016; Smeltzer, Wint, Ecker, & Iezzoni, 2017). These studies highlight the many obstacles that women with mobility disabilities encounter during pregnancy. These findings also exposed the stigma that is associated with pursuing motherhood as a disabled woman (Powell et al., 2017). Participants in this study who perceived attitudinal barriers from their health care providers also felt more insecure about the quality of their perinatal care, and they expressed an overall lack of trust in their providers (Smeltzer et al., 2016). Blind women were not among the participants and the researchers focused on the experiences of women with impaired physical mobility (e.g., paralysis). Omitting blind participants illustrates a gap in the research of the perinatal experiences of women with physical disabilities.

It appears that, in the context of perinatal care, the experiences of blind women who use mobility aids (white cane, dog guide, sighted guide) have not been addressed. This study is an initial qualitative exploration of the perinatal experiences of blind women. Qualitative research is the most appropriate approach for such an initial inquiry because qualitative methodologies use interviews to generate a rich and thick description of the participants' experiences (Lincoln & Guba, 1985; Mills & Birks, 2014; Ward, Comer, &

Stone, 2018). In this chapter, the researcher will demonstrate the compelling need for a study of an unexplored, marginalized population during what is potentially the most vulnerable time of their lives.

### **Statement of Purpose**

The purpose of this study is to perform an initial investigation into the perinatal experiences of blind women from a nursing perspective. In this study, the definition of *blind* is the inability to navigate outside the home without a mobility aid due to a visual impairment. This need for a mobility aid (white cane, sighted guide, or guide dog) is a visible sign of being blind and thus establishes the minority identity status that is being studied. In this study, nurses, physicians, medical assistants, and lactation consultants may be labelled health care workers, health care providers, health care professionals, providers, or professionals. The focus of the study is the exploration of each woman's experiences within her community as she engages with health care providers, health care workers, family members, friends, colleagues, neighbors, and strangers. This study aims to identify these blind women's experiences of physical and attitudinal barriers specific to the *perinatal period*. The perinatal period, for the purpose of this study, is defined as pregnancy, childbirth, and the puerperium (first 6 weeks postpartum).

### **Rationale for the Study**

The perinatal experiences of women with physical disabilities have not been studied extensively, and the perinatal experiences of blind women are essentially non-existent. Therefore, the primary rationale for this study is to fill this gap in the literature and provide nursing knowledge that will enhance the care of blind women during the

perinatal period. Nurse-patient contact during the perinatal period is extensive, and it is imperative for nurses to understand the patient's experience.

### **The Disability Stigma**

The rationale for this study draws, in part, on the history of people with disabilities in America. This illustrates that, much like other minority groups, people with disabilities have been stigmatized. Stigma is a social identity that corresponds with an attribute that is discrediting to the stigmatized individual (Goffman, 1986). This undesired attribute reduces people to *discounted* persons in their community relationships (Goffman, 1986). This historical review sheds light on the development of this stigma and the response of the community to disabled individuals. This is not a review of the literature, but an exploration of the stigma associated with blindness. Although the focus remains on human blindness, in the majority of instances blind experiences were included under the comprehensive heading "people with physical disabilities." Omvig (2017) states the history of blind people is marked by beliefs, attitudes, and assumptions that provide the foundation for the current destructive and negative social attitudes towards blind people. An exploration of this history is needed to provide a definition and context for the marginalized identity of this study's population and ultimately, the foundation for the rationale for this research endeavor.

**Ancient beliefs.** Historically, those who were unable to hunt or work were dependent on others for their survival. Only able-bodied individuals were able to be providers (male) or nurturers/caregivers (female). It was assumed that people with disabilities were unable to fulfill these traditional roles. A review of ancient beliefs and

practices reveals the community response to people with disabilities went beyond the simple expectation of incompetence.

***Death over blindness.*** In Greek mythology being blinded in battle symbolized a complete defeat and was synonymous with being killed. Examples include Zeus' lightning that blinded (defeated) the Titans as well as Odysseus' blinding of the giant cyclops. These ancient myths accurately reflect the practices of the ancient Greeks, Romans, and Spartans who routinely killed blind or disabled babies at birth (Lowenfeld, 1975). These mercy killings were endorsed by great philosophers such as Plato, Seneca, and Aristotle, who agreed that deformed children should not be allowed to live (Monbeck, 1974). In ancient Rome the attitudes towards the blind were especially harsh. "The person bereft of sight was regarded as a useless burden to society and treated with intentional cruelty" (Lowenfeld, 1975, p. 22–23). These sentiments toward the blind appear to be in contrast with the depiction of the Roman Goddess Justicia who is blindfolded as she dispenses justice. However, in Roman times, Justicia was not blindfolded. Her blindfold first appears in a woodcut by Albrecht Durer in 1494 (De Ville, 2011). This confirms that ancient Romans did not worship blind deities and that they had a distain for blindness. The Jewish Talmud echoes these sentiments. It proclaims that "blindness is considered the greatest evil" and that "the blind man is as one dead" (French, 1932, p. 36). Overwhelmingly, the ancient records suggest that being dead is better than being blind.

***Blindness as punishment.*** A further review of ancient mythology reveals that blindness was often used as a form of punishment. The Gods and Goddesses of old

frequently reacted to transgressions by blinding the offender. In this manner, the demi-God Orion was blinded by the King of Chios for the attempted rape of his daughter. Similarly, Aphrodite choose to blind Erymanthos, the son of Apollo, for watching her bathe. The belief that divine displeasure may cause blindness is also evident in the new testament of the Bible. In John, the disciples ask Jesus: “Who did sin, this man, or his parents, that he was born blind?” (John 9 verse 2. St. James’ Bible). It seems that blindness as a form of punishment is found in several spiritual belief systems.

***Blindness and divination.*** In contrast, the pagan religions of Northern and Western Europe link being blind with insight, divination, and clairvoyance. The Norse God Odin (Wodan), for example, sacrificed one of his eyes to increase his perception. In the Gallic and Celtic traditions, druidic names often contain the Gaelic word for blind (*dall*) alluding to their magical and prophetic abilities (Littleton, 1966). One of the old Irish tales in the Tromdamh Guaire recounts the plight of the Druid Dallan Forgaill, who loses his divinatory abilities when he suddenly regains his sight (Cahill, 2012; Littleton, 1966).

**Modern beliefs.** In the history of the United States, blind people were often included in the larger group of *people with disabilities*. Therefore, this rationale includes the community response to all disabled individuals, as well as blind women.

***16th through 19th century.*** North America was colonized by rugged and independent individuals. Since its infancy, the United States has embodied the ideals of independence and autonomy. Indeed, successful settlers were usually independent, autonomous, and able-bodied men and women. In contrast, adults who were dependent on others were considered inferior. Thus, from an economic focus, individuals with

disabilities who relied on the goodwill of others existed in direct contrast to the American ideals of independence and autonomy (Nielsen, 2012).

Among the first European Americans, the community response to disability varied based on the cause of the disability. Men who became disabled through work accidents or acts of war were often cared for by their families. However, women who delivered deformed infants were believed to have engaged in deviant thoughts or inappropriate behaviors during their pregnancy. The resultant “monstrous births” were thought to be an expression of divine displeasure and many of these children were rejected by their mothers because they symbolized a maternal moral deviance (Longmore & Umansky, 2001; Nielsen, 2012). At that time, severely deformed children were often exploited and displayed at fairs, along with preserved monstrous fetuses.

An organized system of social services was lacking during most of the colonial period. Some larger towns, however, attempted to assume some responsibility for their destitute disabled citizens and sought to care for them in a more-or-less humane way. This resulted in almshouses, which were the catch-all institutions for all those of European descent who could not support themselves (Lerman, 1985). At this time, racial inequality was evident as African Americans and Native Americans were not permitted to reside in almshouses. The Indigenous disabled person could only rely on family and tribal support. On the other hand, people who were both enslaved and disabled were often simply killed. The brutality of the colonial perspective is highlighted by the slaveowner’s utter lack of concern for defective slaves and his willingness to offer these slaves as subjects for medical experimentation (Kenny, 2015).

In the post-Revolutionary years, the United States tackled the issue of citizenship and the delineation of its rights and privileges. Defining who was fit and who was unfit for citizenship was paramount since citizens received the right to vote and non-citizens did not. Gender, race, ethnicity, perceived intellect, bodily capacity, and circumstance became determining factors of civic (and voting) competence (Nielsen, 2012). Clear concerns about giving citizenship to individuals with disabilities were quite evident in early immigration law. Examiners at the nation's entry points ensured that new arrivals into the country were physically and mentally sound. The law stated that "any lunatic, idiotic, deaf, dumb, blind, crippled or infirm, and not accompanied by any relatives able to support them... shall not be permitted to land in this state" (U.S. Circuit Court, District of California, 1874, p. 765–766). Thus, the immigration policy reflected an overall sentiment that a person with a disability was not fit to be an American citizen (Longmore & Umansky, 2001). In contrast, Revolutionary War veterans with disabilities were not considered unfit to be Americans. War-related disabilities were viewed as badges of honor, and these injuries commanded respect from the community. During the post-Revolutionary years, the medical interpretation of physical and mental disabilities became more important. The first nationwide attempt to categorize the disabled was noted when, in the 1830 census, categories for *deaf*, *blind*, and *dumb* individuals were added (Forret, 2016; Nielsen, 2012). Although a clear definition of the term "blind" did not accompany this census, it indicated that 5,444 blind people resided in the United States, totaling slightly more than 0.04% of the total population (Best, 1934). Next, physicians became the authority on diagnosing and treating individuals with disabilities,



and medical authority coincided with the establishment of asylums, community hospitals, and disability-specific schools (Nielsen, 2012). This policy was a marked change from the almshouses that, previously, had provided a catch-all safety net for all indigent. Medical attention combined with religious reform seemed to emphasize humane intervention for the less fortunate. Examples of successful changes in the education of children with disabilities include the foundation of the New England Asylum for the Blind in 1829, which counts Helen Keller among its most successful graduates (Perkins School for the Blind, 2018). The education of blind people became much easier after Louis Braille invented the tactile reading and writing system that bears his name in 1825 (Jimenez et al., 2009). Well-managed schools, often under the control of individuals with disabilities, empowered their disabled students to become productive citizens (Longmore & Umansky, 2001).

Towards the end of the 19th century, attitudes of urban Americans shifted. U.S. citizens wanted to live in clean, appealing, surroundings. To make their cities clean and appealing, voters demanded legislation that would eradicate public ugliness. Unfortunately, people with visible disabilities became part of this ugliness as noted by Peevey and Hulbert (1881) in their resolution:

Whereas the streets and sidewalks of the City of Chicago contain numerous beggars, mendicants, organ-grinders and other unsightly and unseemly objects, which are a reproach to the City, disagreeable to people upon the streets, an offense to business houses along the streets and often dangerous, Therefore be it ordered, That the Mayor at once take steps to remove from the streets all beggars,

mendicants, and all those who by making Exhibition of themselves and their infirmities seek to obtain money from people on and along the streets. (p. 1)

Peevey and Hulbert's resolution echoes what most Americans were feeling at that time. Blind people and other physically disabled people were unsightly, and their physical presence was offensive to able-bodied citizens. These sentiments were the impetus for the *ugly laws*, which essentially criminalized being disabled in public. Ugly laws, dating back to 1867, banned people with obvious physical disabilities from public places throughout all the urban areas of the United States (Baird, Rosenbaum, & Toombs, 2009). Violations of these laws often resulted in removal from public view, imprisonment, monetary fines, and possibly a mandatory lifelong stay in an institution or almshouse (Coco, 2010).

***20th century through present.*** The negative sentiments towards people with disabilities continued to escalate in the beginning of the 20th century. At that time, eugenics, an ideology aimed at improving the genetic make-up of humanity, became popular worldwide. Eugenics, combined with marked medical advances, gave Americans the belief that they could halt the propagation of people with disabilities. Congenital blindness was among the disabilities that America targeted for eugenic removal (Baynton, 2001). The first eugenics law was approved in Indiana on March 9, 1907, which made sterilization mandatory for criminals, idiots, rapists, and imbeciles in state custody (Laws of Indiana, 1907). A commission of three surgeons could legally determine that an inmate of a state institution was "unimprovable, physically and mentally, and unfit for procreation" (Laughlin, 1922, p. 6). Individuals who were born

blind, deaf, deformed, or feeble-minded were often among those targeted by the eugenics laws (Ravin & Stern, 2010). It was believed that sterilization, which often occurred without anesthesia, was preferred over the institutionalization of a degenerate offspring. By 1909, (2 years after the first sterilization law passed) Dr. Harry Sharp, a leading authority on eugenic sterilization, had performed 280 vasectomies on institutionalized men (Melquist, McCaffrey, Schulsinger, & Sheynkin, 2012). Eugenics was considered a modern approach to physically and mentally improve the next generation of humans. The American College of Surgeons, the American Medical Association, and the Supreme Court supported mandatory sterilization to limit the births of defective persons (Melquist et al., 2012).

During the early 1900s, many blind children and youth found their way into residential schools for the blind. These students typically received an excellent education and described their experiences as life changing. Blind people who did not attend residential schools were more likely to remain hidden for fear of being institutionalized. Notable differences existed in the quality of life of institutionalized blind people and those who attended residential schools for the blind. Around this time, charitable organizations suggested to the community that disabled individuals receive the proper care and attention in schools and institutions. In many cases, this offered reassurance to the public and created an illusion that made some cruel and inhumane practices quite acceptable.

Civil rights movements gained much attention during the 20th century. First, Caucasian women sought gender equality; they triumphed in 1920 when they obtained

the right to vote (National Archives, 2016). In 1964, the civil rights of African Americans were recognized (Library of Congress, 2018). From then on, attributes such as gender, race, and ethnicity no longer allowed unequal treatment under the law. People with disabilities had also joined together and were likewise in pursuit of their civil rights. However, their struggle proved to be much longer. Involuntary sterilizations for eugenic purposes, a barbaric transgression against people with disabilities, decreased in the 1960s but did not completely stop until the 1970s (Melquist et al., 2012). Likewise, it was not until 1973 that the last of the ugly laws was officially repealed, and a shift towards legalizing the rights of people with disabilities was seen (Coco, 2010; Schweik, 2009). In effect, people with disabilities had to wait until the end of the 20th century to attain legal equality. It was in 1990, that they finally received the legal protections previously afforded to other suppressed minority groups.

*Americans with Disabilities Act.* The Americans with Disabilities Act (ADA), enacted in 1990, offered people with disabilities protection from discrimination (ADA National Network, 2020). This law targeted equal access to education, employment, and recreation. Among other things, the ADA mandated environmental changes such as wheelchair accessible ramps and braille signs; all these were designed to make work, education, and recreational activities accessible to all Americans (ADA, 1990). The ADA also addressed the attitudinal barriers based on the assumption that physical limitations imply dependence on others (ADA, 1990). However, despite this protective legislation, individuals with disabilities continue to report instances of discrimination, ignorance, and an overall lack of public awareness (Baird et al., 2009). Enforcing

compliance with ADA-mandated environmental changes is accomplished through legal action. Legal judgments typically spur structural changes that make public buildings and infrastructure more accessible to individuals with disabilities. Nevertheless, attitudinal barriers based on a stigmatized identity are not so easily removed.

The spirit of the ADA is to fully integrate people with disabilities into the community. The ADA's success (or failure) can thus be measured by evaluating the presence of people with disabilities in prominent and influential roles within their communities. Many believe that this presence is still lacking and that attitudinal barriers stemming from longstanding negative perceptions are to blame. Changing how people feel about people with disabilities cannot be mandated by the law. Evidence of the ADA's shortcomings is highlighted in workplace-related research that indicates that applicants who disclose a disability on their employment applications are less likely to be interviewed than able-bodied applicants (Rumrill & Fitzgerald, 2010). Rumrill and Scheff (1997) noted blind and visually impaired people were still being discriminated against as job seekers. Dubb (2017) reported national surveys indicate that 70% of people with disabilities are unemployed; this disproportionately large number has not changed since the enactment of the ADA in 1990. Visually impaired women cited negative employer attitudes as the primary barrier to employment (Coffey, Coulopoulos, & Kinghorn, 2014).

Attitudinal barriers continue to limit people with disabilities in all the areas protected by the ADA. Studies found evidence of these barriers in public transportation (Bezyak, Sabella, & Gattis, 2017), in colleges (Shannon, Tansey, & Schoen, 2009), in

housing (Tomlin, 2017), in grocery stores (Khattab, Buelow, & Saccuteli, 2015), in places of worship (McCallister, 2011), in parks and recreation (Siu, 2013), and in health care (Kalpakjian, Grawi, Kreschmer, Evitts, & Parten, 2016). It appears that forcing the full integration of people with disabilities has resulted in community resistance, which includes attempts to change legislation. A push to lessen the impact of the ADA was seen in February 2018, when the U.S. House of Representatives passed the ADA Education and Reform Act, allowing for mediation in place of litigation (GovTrack, 2019; Rothstein, 2018). This bill did not make it through the Senate and did not become a law (GovTrack, 2019). The introduction of the ADA Education and Reform Act combined with the evidence of continued discrimination against people with disabilities suggests that the fight for equality is still ongoing.

**Health care workers' beliefs.** Research indicates that people with disabilities report attitudinal barriers in health care. In fact, the negative attitudes perceived in health care are reportedly more deleterious than the attitudes encountered in other settings (Tervo, Palmer, & Redinius, 2004). Medical students, nursing students, and allied health students had more negative attitudes towards people with disabilities than other college students (Tervo et al., 2004). Interestingly, among these future health care professionals, nursing students had the greatest incidence of negative feelings (Tervo et al., 2004). Clinical practice experiences appeared to intensify these feelings, which could significantly impair the delivery of optimal care for these patients (Tervo et al., 2004). In some cases, disability training appears to lead to an unexpected decrease in empathy for people with disabilities (Shakespeare, Iezzoni, & Groce, 2009). Overall, negative

attitudes and cynicism toward patients with disabilities have increased, and health care workers should be exposed to “the experience of living with a disability” (Shakespeare et al., 2009, p. 1816).

**Disability stigma conclusion.** History indicates blind people (and people with other physical disabilities) have been subjected to significant discrimination and prejudice within their communities. Despite their legal emancipation in 1990, as a stigmatized group, they continue to report violations of their civil rights. These violations include physical barriers such as poorly designed sidewalks and public transportation systems, as well as attitudinal barriers that hinder their employment, education, leisure, and health care. Research findings indicate health care professionals lack empathy for people with disabilities and are unaware of their patients’ experiences.

### **The Stigma of a Minority within a Minority**

**Motherhood with a physical disability.** The community of Americans with disabilities includes nearly 27 million women who report having a disability that affects mobility (Centers for Disease Control and Prevention, 2018). Among them, 25% are women of childbearing age. According to the ADA, these women have the right to a professional life, a social life, and a family life. Unfortunately, attitudinal barriers continue to severely impact these rights, especially the right to a family life. These barriers are perhaps most evident when a woman with a disability elects to become a mother. The social construct of motherhood suggests that these women are unable to be mothers since they themselves need to be cared for (McKay-Moffat, 2007). These attitudes are also rooted in the stereotypical belief that disabled women are asexual

beings, unable to engage in a satisfying relationship and utterly incapable of raising a child (Kuttai, 2010; McKay-Moffat, 2007). Waxman (1994) echoed a eugenic sentiment indicating that, allowing a disabled woman to reproduce is considered a “biological, moral and economic danger” (p. 155). Hence, becoming a mother as a disabled woman is often met with disapproving attitudes (Frederick, 2017; Kuttai, 2010; McKay-Moffat, 2007). It appears that cultural stereotypes and stigmas greatly hinder the societal integration of childbearing women with disabilities (Kuttai, 2010; McKay-Moffat, 2007).

Despite these attitudinal barriers, women with chronic disabilities such as multiple sclerosis pursue motherhood at similar rates as women without disabilities (Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2013). Likewise, a survey of women with spinal cord injuries indicated that 2% of this population reported being pregnant during the previous 12 months (Iezzoni, Chen, & McLain, 2015). Statistics on the exact number of blind mothers in the United States are not available but it is believed that they pursue motherhood at the same rates as non-disabled women (Blind Parents Interest Group, n.d.). It appears that lower rates of pregnancy are only reported in women with multiple and complex disabilities (Horner-Johnson, Dobbertin, Lee, & Andresen, 2014).

An in-depth study of the perinatal experiences of 22 women with mobility impairments emphasized environmental and attitudinal barriers such as deficits in patient-centered communication, provider knowledge, infrastructure accessibility as well as the lack of role-models (Lapierre et al., 2017; Mitra et al., 2017; Smeltzer et al., 2017). Further investigations into the experiences of these 22 women revealed they experienced negative attitudes from health care providers and from family members (Powell et al.,



2017; Smeltzer et al., 2016). Research into the perinatal experiences of blind women is extremely rare and the existing studies are discussed in-depth in the next chapter. To offer a comprehensive overview of the perinatal experiences of women with a visual disability, historical and anecdotal sources were reviewed.

***Motherhood with a visual disability.*** Historical records indicate that administrators of schools for the blind separated their male and female pupils to prohibit relationships between the two sexes. By all accounts, Dr. Samuel G. Howe who founded the first School for the Blind in the United States, is heralded as a visionary and pioneer in the education of the blind. However, Dr. Howe was strongly against blind people marrying. In 1848, he wrote that the marriage of blind people “is forbidden by God’s law, under the pains and penalties of transmission of weakness and infirmity to successive generations” (Howe, 1848, p. 16). In the early 1900s, the printed propaganda for the schools for the blind carefully depicted female students as asexual and eternally pre-pubescent, thus suggesting that they were not destined for marriage or motherhood (Kudlick, 2001). In the early 1900s the eugenic ideals became widespread, and many believed that the marriage between blind people should be illegal (Hilton, 1919). Public sentiment prompted the introduction of a bill in 1921 that would make marriage between two blind people illegal (Campbell, 1921). The bill failed to pass, but it echoed the community’s sentiments towards blind people as spouses.

Historical records indicate that many blind people agreed with this eugenic ideology and its resultant disabling attitudes. The blind in 19th century America agreed that blind intermarriage was taboo (Freeberg, 2002). Clara Aldrich (1892), a blind woman, stated,

“Granting now that blindness is worse than alcoholism, imbecility, lunacy, and that the blind should be kept under stricter discipline than the rest of humanity” (p. 183). She did not approve of blind intermarriage, and she proposed that blind women should abstain from marriage to sighted men unless they could independently maintain a home (Aldrich, 1892). The blind superintendent of the Halifax School for the Blind, Mr. F. Fraser, was also against the intermarriage of blind people (Fraser, 1913). “The (blind) woman who thinks, the unselfish woman, the true woman, will never become the wife of a man to whom she cannot prove a helpmate in all respects” (Fraser, 1913, p. 2). Helen Keller, arguably the most famous deaf-blind woman in our history, felt that no man could ever be interested in marrying her (Kudlick, 2001). However, in 1916 when she was 36 years old, Keller fell in love with Peter Fagan (Kudlick, 2001). Helen and Peter’s application for a marriage license was denied based on her disability. Helen’s family was immediately notified, and she was forcibly removed from Fagan (Keller, 1929). Helen’s mother and Anne Sullivan (her interpreter) decided that Helen’s “circumstances” precluded the possibility of a sexual relationship (Keller, 1929).

In the 21st century, blind mothers continue to give anecdotal accounts of disapproving attitudes. To protect blind parents from uneducated child welfare professionals, the NFB published a brochure for attorneys and social workers. This handout entitled “Parenting without Sight” describes in detail how blind parents can safely care for their children (Blind Parents Interest Group, n.d.). The need for such a brochure reflects the continued negative attitudes towards blind parents and confirms the anecdotal news reports of blind parents losing custody of their children.

## **Conclusion**

It appears that the social construct of motherhood does not include women with physical or sensory disabilities such as blindness. The rationale for this study is to explore if the perinatal experiences of blind women are congruent with the anecdotally reported experiences of this population. This study aims to fill the existing gap in the literature related to the care of a vulnerable group of women during, what may be, the most vulnerable time of their lives.

## **Theoretical Framework**

The social model of disability serves as the theoretical framework for this study. In this model, disability is viewed as a social construct (Scullion, 2010). In this construct, disability is an interplay between the physical disability, the disabled individual, and his/her social environment (Scullion, 2010). This social model of disability has replaced the medical model of disability, which viewed disability as the reason for a person's limitations. The medical model views "blindness" as the reason why a blind woman is unable to complete the printed paperwork in her provider's medical office. The social model of disability, on the other hand, views "the societal barriers" as the reason why someone is disabled. In this model, the disabling factor is not the woman's blindness, but the provider's office barrier to blind women. If the provider offered the blind patient the option of completing the paperwork online, the barrier (or the disabling factor) might be removed. Thus, the social model of disability suggests that society and its constructs are disabling factors. These disabling factors are the physical and attitudinal barriers that prohibit blind people from being equal to their sighted peers.

This study uses intersectionality as a form of critical inquiry into the experiences of a historically marginalized population. Crenshaw (2012) coined the term *intersectionality* and used this term in her studies of the interactions of African American women. Crenshaw focused her work on social control (private and public), race, and gender in institutional settings. Crenshaw's work has its "tenets within standpoint epistemology, acknowledging that experience matters, not simply in incorporating the experiences of individual knowers, but also in seeing women of color as differentially placed knowledge-creators" (Collins & Bilge, 2016, p. 82). Intersectionality has since transcended into a framework that seeks to understand the experiences of other groups with intersecting identities. Since then, race, ethnicity, religion, gender, age, class, sexual orientation, nationality, and disability have been included in studies guided by intersectionality.

Any social injustice that impacts a group that shares two or more of these minority identities can be investigated through the lens of intersectionality. Investigating the experiences of inequality of groups with overlapping identities and exploring how systems produce and support these multiple dimensions of difference is at the heart of intersectionality (Romero, 2018). The lens of intersectionality supports the critical investigation of groups whose standpoints have historically been obscured and seeks to recognize and validate their experiences and embodied knowledge (Grzanka, 2014). Using the multiple axis approach of intersectionality, this study is the initial investigation of the experiences of a group that shares three distinct intersecting identities. All the participants in this study are women (sameness) who are blind (sameness) and who have

recently experienced pregnancy and childbirth (sameness). The intersection of these three similarities is shared by a very small minority, which differs from the population at large. The study explores the significance of these differences in the presence of cultural and healthcare practices and/or expectations (power).

### **Summary**

Visually impaired and blind women are actively pursuing motherhood. Therefore, perinatal health care workers such as obstetricians, Certified Nurse Midwives, obstetric nurses, childbirth educators, anesthesia care providers, and lactation consultants are expected to provide competent care for blind patients. Limited research into the experiences of women with mobility impairments suggests that multiple environmental and attitudinal barriers are present during the perinatal period. A single study into the postpartum experiences of blind women suggests that similar barriers are perceived in addition to a fear of health care professionals. This fear relates to the tendency of nurses (and other providers) to initiate child protective services investigations because they doubt that a blind mother can safely care for her baby. These findings, gathered from sociological research, are quite worrisome. It is therefore important that these experiences are investigated from a nursing perspective. This study is the first step in that process. It is the initial exploration of how blind women experience pregnancy, childbirth, and the postpartum period in the United States.

## CHAPTER II

### REVIEW OF THE LITERATURE

The literature review will focus on articles related to the perinatal experiences of blind women. Multiple databases were searched several times from 2018 through 2020, ensuring a comprehensive review of the current literature. The key words used in these searches were combinations of “visually impaired” and “birth,” “blind” and “birth,” “visually impaired mother,” “blind mother,” “visually impaired” and “pregnant women,” as well as “sensory disability” and “pregnancy.” The articles that were identified through these key words were reviewed for relevancy. Articles that were not peer reviewed were eliminated. Likewise, articles that did not discuss the perinatal experiences of blind or visually impaired women were deemed irrelevant. Research articles that included the experiences of the target population along with the perinatal experiences of women with other disabilities were retained. Articles that discussed the experiences of blind women as mothers (and excluded the perinatal period) were discarded. Non-research articles that discussed the experiences of the target population were tentatively deemed relevant and are included in this review of the literature. Research conducted in developing countries was discarded. Finally, the references of all the retained articles were reviewed with the goal of identifying additional relevant publications.

The databases that generated relevant articles were Academic Search Complete (three articles), SocINDEX (one article), Genderwatch (one article), JSTOR Health & General Sciences (one article), SAGE Premier (two articles), Medline (one article),

Elsevier SD Freedom Collection (one article), Wiley Online Library (one article), and PubMed (three articles). After eliminating duplicates, 12 articles were identified for this review of the literature. Four articles discussed the experiences of blind women in the United States and six articles reported research conducted in other industrialized countries. The six international studies are from countries that provide medical care that is comparable to the medical care in the in the United States. It is possible that cultural factors affect the interactions of blind women during the perinatal period. Therefore, the international studies are grouped by geographical location.

### **Peer-Reviewed Articles within the United States**

Four articles that discussed the perinatal experiences of blind women in the United States were identified. Two of these articles, both authored by A. Frederick, are particularly relevant to the research topic and present original research findings. The other two articles are peer-reviewed but not research-based. Considering that the literature generated in the United States regarding this topic is so minimal, each of the four relevant articles will be discussed in depth.

### **Frederick's Research**

Frederick (2015, 2017) generated qualitative data in 2013 and 2014 when she interviewed 26 blind mothers. She used this data in two articles, which provided relevant findings regarding the perinatal experiences of blind women. The mothers in her study all described themselves as “blind,” albeit that nine of the participants still had a small amount of vision (Frederick, 2015). Ten women reported progressive vision loss; 13 were born blind; the remaining three became blind as children or adolescents (Frederick,

2015). Most of the sample cited genetic disorders as the reason for their blindness, followed by retinopathy of prematurity (Frederick, 2015). Nearly half of the sample (12 women) stated they were employed at the time of the interviews (Frederick, 2015). Most of the participants (nine women) were teachers, counsellors, and administrators in the “blindness field” (Frederick, 2015, p. 1132). The remaining three employed women were an attorney, a health care professional, and a health insurance specialist (Frederick, 2015). All the women reported that they were or had been the primary care giver of their children. Twenty of the participants were married (or cohabiting) while six women were single mothers (Frederick, 2015).

In her first article, Frederick (2015) discussed the postpartum experiences of blind women who delivered in hospitals in the United States. In her second article, Frederick (2017) drew additional conclusions from the 2013–2014 interviews and expanded her findings beyond the postnatal period. In this publication, Frederick (2017) also included the perinatal and mothering experiences of women with other disabilities such as deafness and mobility limitations. Frederick’s research revealed that blind women perceived that they were traumatized by their postpartum experiences. They consistently reported the highest levels of fear and anxiety during the first few days after giving birth in the hospital (Frederick, 2015, 2017). The participants reported being targeted by nurses, physicians, and social workers, who assumed that any blind woman would be an incompetent mother (Frederick, 2015, 2017).

**The medical stare.** Hypervigilant surveillance by the hospital staff was noted by all the research participants. Most participants reported that the postpartum period was



traumatic due to this behavior. The new mothers overwhelmingly agreed that they feared the nurses in postpartum the most.

*Postpartum.* Frederick's research illustrated how the hospital staff collaborates to control the potential risk to newborns. Frederick regards this collaboration as a type of *surveillance medicine* because of the expectation that nurses and physicians must identify all at-risk newborns before they are discharged. This expectation has resulted in the practice to immediately involve social workers in all instances when it is perceived that a postpartum patient might be inadequate in her role as a new mother. Frederick found that her study participants believed that they were identified as *risky mothers* during their hospital stay (Frederick, 2015, 2017). They overwhelmingly perceived the high levels of institutional scrutiny, which Frederick (2015) coined *the medical stare*, as stigmatizing and blaming. An example of how this medical stare was perceived by the participants is illustrated in the account of a blind woman who initially found one of the nurses remarkably helpful during her first postpartum night. However, her appreciation for this nurse was short-lived. This participant and her blind husband later realized that the night nurse had documented that the parents "required 100-percent assistance" (Frederick, 2015, p. 1134). This resulted in a completely disempowering experience for this patient when, early the next morning, she woke up to a roomful of doctors, nurses, and students – all surrounding her hospital bed (Frederick, 2015). One of the physicians stated that the need for "a reality-based conversation" was crucial, and that they were "concerned about how you're going to take care of the baby" (Frederick, 2015, p. 1134–1135). The participant explained how she and her husband had completed extensive preparations for

their baby and that they felt confident in their ability to care for their own child. The conversation with the healthcare team ended with the physician making a social worker referral based on the premise that “*we* need to know that you can care for this baby” (Frederick, 2015, p. 1135).

Over half of the participants reported being visited by social workers during their postpartum stay (Frederick, 2015). One blind mother lost custody of her newborn daughter for 57 days because a social worker stated, “I can’t, in good conscience, send this baby home with blind parents” (Frederick, 2015, p. 1136). This mother suffered emotional trauma and verbalized, “For a while, I had like these horrible dreams that they would come and take her back. It was hard to get over, and sometimes it’s still a struggle for me to get over it” (Frederick, 2015, p. 1136).

Another participant, whose husband is sighted, reported that the social worker wondered if she wanted to give her baby up for adoption. The social worker further explained the reason for this request by stating, “Your husband isn’t going to want to raise this baby by himself” (Frederick, 2015, p. 1134; Frederick, 2017, p. 82) and, thus, completely discounting the abilities of the blind mother.

Overall, the study participants expressed a “great distrust in medical experts” (Frederick, 2015, p. 1133). The perceived assumption of incompetence terrified one participant who understood that other blind mothers had lost custody of their newborns solely based on their inability to see. This woman felt terrified about breastfeeding and reported thinking, “Oh God, I gotta do this perfect the first time or they’re gonna take my kid away” (Frederick, 2017, p. 84).

***Prenatal care.*** Several participants reported that the assumption of incompetence was also felt during their prenatal care. During her first prenatal visit, one blind patient felt that questions such as: “Do all your children live with you? And are you thinking about getting fixed?” (Frederick, 2017, p. 82). This is an example of inappropriate phrasing of a question regarding future fertility. Another participant reported that during one of her first sonograms, her obstetrician informed her that the cause of her (the patient’s) blindness could now be identified by ultrasound. The practitioner then offended the patient greatly when she reportedly said, “Oh, now we can actually tell that on ultrasounds, and that’s one of the reasons we advise women to terminate” (Frederick, 2017, p. 86).

***Invisible patients.*** The participants stated that, in contrast to the heightened scrutiny regarding the ability of blind women to care for their infants, they often felt invisible at other times (Frederick, 2017). None of the new mothers received any information regarding adaptive technologies/techniques for blind mothers (Frederick, 2017). It appears that medical professionals are completely unaware of the resources available to blind parents (Frederick, 2015). All participants reported that they had to access this information independently through support groups and rehabilitation programs (Frederick, 2015, 2017).

The inaccessibility of medical paperwork was another source of frustration for the blind participants. They felt that it emphasized their “invisibility” among the non-disabled cohort of pregnant women (Frederick, 2017). Invariably, the blind patients were handed printed questionnaires in the practitioner’s office. This often resulted in

violations of patient privacy as the blind women were asked to respond verbally to these questions in a crowded waiting room (Frederick, 2017).

**Summary of Frederick's research.** Frederick's research identified a central theme that suggests that blind childbearing women are stigmatized both in society and in health care. Her research indicated that the interactions between the participants and their health care providers were marked by the belief that any deviation from normal must be abnormal. Health care workers thus "pathologized" the blind participants because they did not fit into their medical construct of normalcy (Frederick, 2017, p. 82). This pathology was noted throughout the entire perinatal period. However, Frederick (2015) found that the postpartum period was the most challenging time for blind women. At this time, the new mothers reported feeling stressed, anxious, and afraid because of the perceived medical stare (Frederick, 2015, 2017). The study participants did not trust their medical professionals and felt they had to "reach out" to other blind women for needed guidance and support (Frederick, 2015, 2017).

Frederick's findings also suggest that society disapproves of blind women who pursue motherhood (Frederick, 2015, 2017). In many respects, childless blind women are still pitied and stigmatized. They are perceived as requiring extensive help and assistance because of their physical handicap. On the other hand, blind women who intentionally pursue motherhood are not pitied; they are viewed as deviants. Frederick (2015, 2017) believes that this shift (from pity to dismay) is related to those cultural norms that foster disapproval of those women who decide to have children that they cannot take care of (Frederick, 2015). In effect, Frederick's participants reported feeling

this judgement, labeled as *mother-blame*, from family, friends, and their healthcare providers (Frederick, 2015, 2017). This report confirms that current societal norms propose that blind women “should not” seek motherhood.

**Potential gaps in Frederick’s research.** The researcher, Angela Frederick, is a sociologist and a blind mother (Frederick, 2015, 2017). She describes herself as an educated and well-connected activist for the rights of blind people (Frederick, 2015). The researcher was, therefore, emotionally connected with her participants, and she may have shared some of the participants’ experiences. This bond between researcher and participant may have both positive and negative consequences. It is possible that the participants expanded on their experiences more freely with a researcher who shares their unique attributes. However, the fact that the researcher is very passionate and shares the blind activist identity may have rendered her research less objective. This potential for bias presents the need for additional research from a more detached viewpoint.

An additional concern is that it is conceivable that the researcher knew several of the participants prior to the study. This concern is highlighted when she states, “I recruited the study participants through my extensive networks in disability communities. I myself am blind and have been a member of the NFB (National Federation of the Blind) for 23 years” (Frederick, 2015, p. 1131). She later confirmed that “all but one participant is connected to the NFB in some way” (Frederick, 2015, p. 1131). The researcher also volunteered that she has “participated in a formal network of blind parents in this organization (NFB) for 5 years” (Frederick, 2015, p. 1131). Thus, the participants were recruited from listservs that the researcher has been part of (Frederick, 2015). It is likely

that the researcher was personally acquainted with several of the participants prior to the study. This may have led to researcher bias and tainted data. The researcher mentioned that she “sent individual invitations to blind mothers who were active in the NFB and the blind parent online group” (Frederick, 2015, p. 1131). This action could indicate that the researcher had an emotional attachment to research participants rather than a more casual acquaintance relationship. The personal connections combined with the personal invitations could indicate that some mothers may have felt obliged to take part in the research.

The study sample was very homogenous. In fact, most of the participants were, like the researcher, well-educated and politically active blind mothers who attended the annual convention of the NFB in Orlando, Florida, in July 2013. These participants were disproportionately more socio-economically advantaged. It is, therefore, likely that this sample does not accurately represent the experiences of all blind mothers (Frederick, 2015, 2017). Although these predominantly Caucasian women were experienced self-advocates, they generally reported negative health care experiences. The researcher conceded that blind women who do not share this “activist identity” may be much more vulnerable and, at this time, their experiences remain completely unexplored (Frederick, 2015, p. 1139). Therefore, a clear gap in this research is the oversampling of privileged blind women and the lack of racial, ethnic and socio-economic diversity among the participants.

Frederick stated that most of her participants were women in their thirties who were caring for young children (Frederick, 2015). However, she mentioned that some of

the participants had adult children. Frederick (2015, 2017) did not provide a detailed breakdown of the ages of the women and instead described them as being between the ages of 23 and 66. This indicates that this research may not have analyzed recent perinatal experiences and thus presents a potential gap in the current experiences of blind women.

Frederick stated, “This is a highly educated sample; 18 out of 26 participants have bachelor’s degrees, and 11 have graduate degrees” (Frederick, 2015, p. 1132). This statement suggests that Frederick interviewed 29 participants instead of the reported 26 participants (18 with undergraduate degrees and 11 with graduate degrees). This contradiction shows that inaccurate demographic data was presented, indicating another potential gap in this research.

A total of 26 blind mothers participated in the study. The researcher described having “organic” conversations in focus groups with 15 participants that generated themes that were further explored in individual interviews (Frederick, 2017, p. 82). Therefore, more than half of the participants were interviewed in focus groups that lacked a clear focus, as evidenced by the researcher stating, “I did not go into the field (NFB convention focus groups) intending to focus exclusively on postnatal care. It was only after gathering these data that I recognized that postnatal care was a critical time for blind women” (Frederick, 2015, p. 1131). The organic nature of this research report suggests that the researcher did not pursue a clear qualitative methodology. The researcher does not mention IRB approval or how she obtained consent from the participants. Furthermore, she does not describe how she recorded, transcribed, and coded the data.

The lack of structure and the omission of a clearly defined approach suggests an additional gap in this research.

The researcher is a sociologist and appears unfamiliar with current medical and nursing practices. She reported that a participant was asked if all her children still live with her and if she plans on “getting fixed” (Frederick, 2017, p. 82). Asking a patient if her children live with her is a routine question during prenatal and obstetric admission assessments. This question aims to identify *any* woman who may not have legal custody of her children. Similarly, *every* obstetric patient is asked if she desires permanent sterilization or a bilateral tubal ligation. Granted, the expression *getting fixed* was a very unfortunate choice of words by the person asking the intake questions. However, it is common practice and recommended by professional organizations that health care providers include these questions in the assessment of pregnant women. The researcher incorrectly assumed that these questions were asked because the participant is blind. This highlights the need for additional research into this topic from other (interdisciplinary) perspectives. Professional nurses provide much of the care during the perinatal period. It is, therefore, very important to explore the perinatal experiences of blind women from a nursing perspective.

### **The Blind Mother**

Branson (1975) published her article, “The Blind Mother” in the American Journal of Nursing. In it, Branson (1975) identifies herself as “an obstetrical nurse, an instructor, and a blind mother” (p. 416). The article is a narrative aimed at helping nurses care for perinatal patients who are blind. Among other things, she suggested that the



nurse should introduce herself to the blind mother and that she should communicate with the patient directly. Branson (1975) offered readers practical information regarding the unique mobility needs of blind patients and included safety tips that could be taught to blind mothers. She emphasized that, most importantly, nurses should accept the blind mother and offer her encouraging support.

Branson's article does not include any references and apparently was not research-based. This article offers the opinion of a blind mother who was also a nurse. Indeed, the author's suggestions are valid and relevant to the perinatal care of blind women. However, the article lacks a scientific foundation and was published many decades ago. The obvious limitations of this peer-reviewed work stress the need for a current inquiry into the perinatal experiences of blind women and the nursing education needed to facilitate optimal nursing care for this population.

### **Beyond Expectations**

Kent (2002) published her article, "Beyond Expectations: Being Blind and Becoming a Mother" in *Sexuality and Disability*. This article is very similar to the Branson's (1975) article, "The Blind Mother." Like Branson, Kent provided a personal account of her experiences as a blind mother. Kent (2002), however, also gave insight into her experiences as a blind child, adolescent, and finally as a blind mother. Her narrative is emotional and successfully conveys how a blind girl is taught that blind women do not become mothers. The lack of blind role models and the negative attitudes of sighted people became obstacles in Kent's quest for an equal opportunity at marriage and motherhood. Kent (2002), however, triumphs when, after a few years of marriage,

she finds out that she is expecting her daughter, Janna. However, her joy is tempered because, as a blind pregnant woman, she feels as if she must constantly “prove herself” to her care providers. Her perinatal experiences included a very negative encounter with a postpartum nurse. Kent (2002) stated, “I remember how the ward nurse tried to exclude me from the hospital’s rooming-in program, claiming that I might have trouble finding my baby’s crib when the orderly wheeled it in” (p. 84). Additionally, Kent described the anxiety she felt knowing that she was always being watched. “I knew that wherever I went people were observing me, wondering about me, at time doubting my abilities” (Kent, 2002, p. 85).

Kent (2002) attributed much of her success as a blind mother to the help of other blind women. During her pregnancy, she corresponded with two blind mothers who provided her with emotional support and practical advice. They suggested that she should attach little bells to her child’s shoes so that she may be aware of a toddler on the move. These mothers told her about strollers with reversible handles that can be pulled instead of pushed. Kent (2002) was overjoyed with their input. Networking with other blind mothers became even easier when a blind mother in Arizona started an audio newsletter. The newsletters enabled an exchange of the positive factors associated with motherhood, as well as the negative. Kent (2002) recounted several painful encounters that were shared in the group. One blind mother was troubled by her own mother’s constant presence in her home. The grandmother’s constant attention provided clear evidence that she was concerned that her own daughter could not care for her grandchild. Many blind women were bothered by the fact that people often assumed that their

children were the caretakers of the blind parent. In several situations, directions were given to the children rather than to the blind parent. Some women described truly disturbing experiences. One blind mother who was shopping with her baby in a carrier was verbally assaulted by a stranger who “denounced her for selfishly bringing a child into the world when obviously she couldn’t take care of it” (Kent, 2002, p. 86). This mother reportedly received unannounced visits of Child Protective Service representatives for the next 5 years. Kent (2002) concluded her article with a brief description of how the Internet has facilitated networking among those in the blind community. Simultaneously, she credits the NFB with providing formal avenues for the exchange of information and support (Kent, 2002).

Therefore, much like Branson’s narrative, Kent’s account is not current. Kent (2002) did not use references, and she did not draw on existing research findings. Albeit captivating and compelling, all her statements were purely autobiographical.

**Lack of current research.** The articles by Branson (1975) and Kent (2002) do not include research findings. Instead, they provide autobiographical and anecdotal information related to perinatal experiences in 1975 and 1983. Frederick (2015, 2017) conducted research and personally interviewed other blind mothers in 2013 and 2014. Her participants were, at that time, between the ages of 23 and 66, thus suggesting that some of Frederick’s findings were based on much older perinatal experiences. Angela Frederick is a sociologist and her research was performed from that perspective. Therefore, it appears that there is no current research in the perinatal experiences of blind women in the United States from any perspective (nursing, social work, sociology, etc.).

**Postpartum.** Kent (2002) and Frederick (2015, 2017) both highlight negative interactions with nurses during the postpartum period. Branson (1975) also targeted the nursing care in the postpartum setting but approached postpartum health care from a nursing education angle. Branson maintained a positive undertone throughout her narrative. Although Branson (1975) does not label nursing interactions with blind patients as negative interactions, she does caution nurses not to assume that blind patients are intellectually challenged. A thorough review of all the articles on the perinatal experiences of blind women in the United States suggest troubling nurse-patient interactions during the critical postpartum period. The focus of this research is to gain insight into the comprehensive perinatal experiences of this population with an emphasis on the postpartum period.

**The stare.** Frederick (2015, 2017) coined the term the medical stare, to describe the healthcare providers' constant surveillance of the blind mother. Sadly, this surveillance is not aimed at assisting the blind mother, but instead it seeks to identify her incompetence. Thus, interactions with health care professionals do not lead to increased maternal confidence but lead to increased maternal fear and anxiety (Frederick, 2015, 2017). Kent (2002) echoed this sentiment as she described the anxiety that she experienced from always being watched. She feared, like most blind mothers, that any small mishap could trigger a visit from Child Protective Services. Branson (1975) approached the medical stare in a more subtle manner by focusing on nursing education and by avoiding overt criticism. Branson (1975) did not mention the practice of identifying maternal incompetence. Neither did her narrative suggest involving social

services in the care of the blind mother. She recommended, however, that even though the blind mother may need a bit more assistance, she mostly requires encouragement so that she may become confident in her own abilities (Branson, 1975). Branson (1975) emphasized that “acceptance of the blind mother and her child by the nursing and medical staff will do more to help this family than any other single factor” (p. 416). Branson’s (1975) article suggested that, with a few adaptations, blind patients become very capable mothers. It is possible that Branson (1975) understood the concept (and the consequences) of the medical stare and authored her article to mitigate surveillance behaviors in perinatal nurses.

It appears that the fear of “being watched” is a common theme in the literature on this topic. Apparently, this fear is not unfounded because incidences of blind parents losing child custody are discussed by both Frederick (2015, 2017) and Kent (2002). It is unknown if blind parents lose custody of their children at disproportionately higher rates than sighted parents. Current nursing practice emphasizes making patients feel safe and comfortable; therefore, studies into facilitating this are urgently needed.

**Invisibility.** In stark contrast to the hypervigilance of the medical stare, both Frederick (2015, 2017) and Kent (2002) discussed how the true needs of blind women are largely unnoticed. Frederick (2017) used the term *invisibility* to describe the complete lack of reasonable accommodations for blind expectant parents and a perceived disinterest into their actual needs. Consistently, pregnant blind women reported feeling discounted, irrelevant and bypassed both in health care settings and in social interactions. They attribute this invisibility to the assumption that, regardless of accommodations and

interventions, blind mothers will continue to remain inadequate (Frederick, 2015, 2017; Kent, 2002). Overall, perinatal health care professionals consistently failed to ask key questions to identify the unique needs of this patient population (Frederick, 2015, 2017; Kent, 2002). Again, Branson approached this problem more subtly. She taught nurses that “the majority of blind patients will gladly answer your questions about help if they sense that you respect their independence and yet are willing to aid them” (Branson, 1975, p. 415). It appears that Branson’s aim is to empower blind patients through the implementation of basic blind-friendly nursing actions in the obstetric setting. In contemporary nursing practice, it is deemed unacceptable to discount the needs of a group of patients. It is therefore imperative to conduct research to clarify these patient perceptions.

The consumer market of perinatal products and services is another area in which blind patients perceive themselves as invisible. Most products used to educate expectant parents or to assist the new mother in caring for her child are not designed for blind consumers (Frederick, 2015, 2017; Kent, 2002). Expectant mothers who are blind do not receive any guidance from their health care providers regarding possible product adaptations. Additionally, health care providers and their staff fail to refer these blind patients to outside resources and agencies with expertise in adaptations needed by individuals who are blind (Frederick, 2015, 2017; Kent, 2002). Branson (1975) attempted to make a few practical suggestions to the obstetric nurses related to patient safety. Among other things, she suggested that the blind mother may find it easier to

store supplies such as safety pins in repurposed peanut butter jars with wide mouths and tight lids (Branson, 1975).

The three authors agree that information about products and resources for blind expectant patients are overwhelmingly lacking in the perinatal setting. Blind women appear to combat this invisibility by finding the needed support and resources during the perinatal period elsewhere. Frederick (2015, 2017) and Kent (2002) emphasized that blind women must network with other blind women to access the knowledge needed to be successful blind mothers. Kent (2002) praised other blind women for telling her about a stroller that was more convenient for blind mothers. Frederick (2015, 2017) and Kent (2002) credited the NFB with enhancing their success as blind mothers. These findings provided evidence that this population's perceived invisibility is not imaginary and confirmation that the needs of blind women are primarily visible to other blind women. The NFB, an organization by blind people for blind people, is the primary body in the United States for disseminating information to blind consumers and facilitating interactions between blind people nationwide (Frederick, 2015, 2017; Kent, 2002). It is likely that the NFB can assist nurses with developing updated perinatal practice guidelines, assemble relevant patient teaching materials, as well as give insight into consumer products that aid blind people as they become parents. It appears that sharing this information with perinatal nurses is a task that has not been undertaken since Branson's short article in 1975.

Contemporary nursing emphasizes the importance of patient teaching as well as the importance of linking patients with outside resources. Ultimately, it is the duty of the

professional nurse to engage in patient-centered teaching; it is not the responsibility of the patient to seek out this essential information herself. It needs to be emphasized that some blind patients may not be able to obtain the information they need from the NFB. It would be wrong to assume that all blind women of childbearing age have the resources, know-how, and ability to find, access, and use relevant NFB resources. Nursing should assume this responsibility and research aimed at updating practical information and resources for this population is much needed.

**Attitudes.** Branson (1975) cautions obstetrical nurses to not “equate serious impairments of vision with impaired reasoning power” (p. 414). She also targeted societal perceptions when she highlighted the discriminatory practice of adoption agencies who “do not allow blind parents to care for adopted or foster children” (Branson, 1975, p. 416). Kent (2002) provided many examples of negative attitudes that affected her. She reported that these attitudes excluded her from babysitting neighborhood children, made her feel unattractive and asexual, and left her believing that she was an “unlikely candidate for motherhood” (Kent, 2002, p. 82). Frederick (2015, 2017) reported that negative attitudes towards blind women who become pregnant are amplified. This appears to be due to the assumption that blind people are incompetent and therefore, they should not pursue parenthood (Frederick, 2015, 2017). She reported that health care workers are not immune to this stigma and that they pathologized her study participants for not conforming to societal expectations (Frederick, 2015, 2017). Failing to conform to these societal expectations is equated with deviance and leads to mother-blame (Frederick, 2017). Mother-blame is also noted in attitudes towards other



marginalized (and stigmatized) populations such as pregnant teenagers and pregnant drug users (Smith-Oka, 2012). This review of the literature suggests that negative attitudes in the perinatal setting make it an unsettling environment to navigate for blind women.

**The blind leading the blind.** All the existing peer-reviewed articles about the perinatal experiences of blind women in the United States are written by blind women. Frederick (2015, 2017), Branson (1975), and Kent (2002) each self-identify as blind women. This suggests that, to date, sighted researchers have completely disregarded this population and their perinatal experiences. Considering that blind women, like sighted women, are consumers of all perinatal services in the community.

### **Conclusion of the Peer-Reviewed Articles within the United States**

The gap in the existing literature of the perinatal experiences of blind women is so large that one may conclude that there is no existing research. The few blind authors of peer-reviewed articles on the topic state that they are invisible. This review of the literature suggests that they may be correct. The complete lack of peer-reviewed articles and/or research by sighted researchers may be evidence of this perceived invisibility.

This review of the American literature identified disturbing findings reported by a distinct group of perinatal patients. It is noteworthy that the nursing profession has not yet responded with follow-up inquiries into the validity of these serious patient complaints. Therefore, research into the experiences of these patients who believe that their needs go unnoticed. Obviously, a comprehensive interdisciplinary exploration by researchers outside the blind community would be optimal. Considering the impact of

nursing care during the perinatal period, this exploration should start with an initial inquiry from a nursing perspective.

### **Peer-Reviewed Articles outside the United States**

The online search returned several articles that were generated outside the United States. For the purpose of this review of the literature, articles from developing nations were discarded. However, literature from countries where medical care is comparable to the medical care in the United States was retained. These articles were divided by country of origin. They were reviewed with the purpose of identifying perinatal experiences of blind women outside the United States and, whenever possible, comparisons with the American literature were made.

#### **Canada**

The online search returned one Canadian article. Bieber-Schut (1993) published this peer-reviewed article, “Visually Impaired Women as Mothers” in the Canadian Woman Studies journal. In this article, Bieber-Schut (1993) presented information gathered during 12 weekly support group sessions held in a local Calgary (Canada) rehabilitation center. The author organized the support group meetings because she, as a visually impaired new mother, had reached out to the rehabilitation center for assistance. The rehabilitation center offered the author a convenient meeting place, subsidized travel for the participants and provided snacks and childcare. The support group consisted of nine women whose visual acuity ranged from low vision to totally blind. At the time of the interviews, the participants were either pregnant or mothers of children under the age of 17. Bieber-Schut (1993) reported that she interviewed two additional women outside

the support group setting. The findings presented in this article include parenting experiences as well as perinatal experiences. Considering the topic of this literature review, only the perinatal experiences will be discussed.

**Findings.** The participants agreed that they were very vulnerable while they were giving birth in the hospital (Bieber-Schut, 1993). They felt medical and nursing professionals were “all too ready to take charge of a woman in labour, never mind a woman in labour who could not see” (Bieber-Schut, 1993, p. 3). Prenatal education was perceived as insufficient. The support group participants felt unprepared for their role as new mothers and overwhelmingly reported that breastfeeding was their “most frustrating obstacle” (Bieber-Schut, 1993, p. 3). Some participants were angry about having to give their newborns formula due to lack of support (Bieber-Schut, 1993). On this topic, the author shared that she was successful at breastfeeding her son because she used the services of a private lactation consultant after leaving the hospital. It is of concern that the participants reported biased nursing actions such as not being allowed to hold their newborn unless their (sighted) husbands were present (Bieber-Schut, 1993). Inappropriate nursing comments were noted by a patient who suffered from night blindness and who was told that she was lazy when she asked for help at night (Bieber-Schut, 1993). All the women agreed that “educating yourself about what you need and learn to communicate these needs to others when appropriate” was key (Bieber-Schut, 1993, p. 4).

**Study limitations.** This article presented participant experiences but did not follow the expected format of an article that is reporting study findings. The

demographics of the participants and the philosophical underpinning were minimally discussed. Bieber-Schut simply mentioned, “Because my approach was phenomenological in nature, it was critical that similarities as well as differences in opinions be embraced and that each woman was able to share her experience” (1993, p. 3). The demographic information did not include an evaluation of the participants’ need for mobility aids (white cane, guide dog, etc.). Methodology, consent, data gathering, data analysis, and identified themes were omitted. The author reported that, as a new mother, she, “planned to attend a class at the University towards her Master’s degree” (Bieber-Schut, 1993, p. 1). This means that, at the time of the data collection, the author was planning to pursue a graduate degree.

The article was published in 1993 and the author stated that, when she wrote the article, her son was 4.5 years old. Therefore, the support group meetings were likely held in 1989 when her child was a newborn. The findings are, therefore, not current and highlight the need for an initial exploration into the perinatal experiences of blind women in North America. Ironically, identical to the authors of the articles published in the United States, this Canadian author is also visually impaired.

### **New Zealand**

The online search identified a potentially relevant article from New Zealand. This peer-reviewed work, “It’s Just So Bloody Hard: Recommendations for Improving Health Interventions and Maternity Support Services for Disabled Women” was published in 2017. At the time of publication, the authors were associated with universities in Auckland, New Zealand. In this research paper, published in *Disability and*

Rehabilitation, they presented their findings on the maternity experiences of women with physical and sensory disabilities in New Zealand (Guerin, Payne, Roy, & McPherson, 2017). The focus of the study was to identify recommendations for practitioners in New Zealand.

This quantitative research was performed on a purposive sample recruited from national disability organizations. The researchers emailed a Delphi survey to eligible women between the ages of 18 and 55 who had given birth during the prior 10 years. The participants were asked to rank recommendations for improving maternity care on a Likert-type scale (Guerin et al., 2017). The survey also included space for comments. Twenty women who self-identified as having physical or sensory disabilities completed the survey (Guerin et al., 2017). A review of the participant demographics reveals that only one woman self-identified as having a “severe visual impairment” (Guerin, et al., 2017, p. 2398). This participant was pregnant with her first child at the time of the survey. Considering the topic of this literature review, this research paper was reviewed to identify the recommendations of this single visually impaired participant.

**Findings.** The findings offered in this research paper cannot be considered as findings generated by blind women since only a single participant was visually impaired. An in-depth review of this paper identified two statements from the visually impaired participant. This participant noted that she “would have benefitted from a New Zealand based website about pregnancy and disability” (Guerin et al., 2017, p. 2398). She also recommended that health care professionals receive disability awareness training.

**Study limitations.** This article, aimed at exploring “the maternity experiences of women with physical and sensory impairments”, incorporated the input of a single blind participant (Guerin, et al., 2017, p. 2401). This lack of visually impaired participants implies that the study findings are largely not applicable to the topic of this review of the literature. The blind participant was, at the time of the survey, pregnant with her first child (Guerin et al., 2017). Therefore, her input was limited to her impressions of prenatal care since birth and postpartum had not yet occurred. The demographic information did not include an evaluation of the participant’s need for mobility aids (white cane, guide dog, etc.). Additionally, the accessibility of the emailed survey should be discussed. Did the researchers consider that specialized software might be necessary for blind women to take part in the survey? Finally, the pseudonym assigned to the blind participant in the demographic table did not match the pseudonym attached to the comments of the blind participant. This research study and its findings are problematic because of these deficits. These significant limitations make this research irrelevant to the purpose of this review of the literature.

## **Poland**

The online search returned one article regarding research conducted in Poland. Wolowicz-Ruszkowska (2016) discussed the results of her qualitative study into parenting with a physical or sensory disability in her article, “How Polish Women with Disabilities Challenge the Meaning of Motherhood.” The researcher interviewed four women who identified as blind or visually impaired and 21 women who identified as physically disabled. Data gathering occurred in 2013–2014, when she interviewed the

participants who were between the ages of 30 and 50 (Wolowicz-Ruszkowska, 2016).

Using grounded theory analysis, Wolowicz-Ruszkowska (2016) explored the meaning of motherhood with a disability. The researcher is a non-disabled woman who works for the Polish Department of Special Education in Warsaw. Her participants were identified through organizations that work with people with disabilities. This study, published in the *Psychology of Women Quarterly*, included perinatal experiences as well as experiences beyond the postpartum period (Wolowicz-Ruszkowska, 2016). Considering the topic of this literature review, the findings that focused on the perinatal experiences of the blind participants were noted.

**Findings.** The study identified psychological barriers experienced by mothers with disabilities (Wolowicz-Ruszkowska, 2016). These barriers included the negative opinions of care givers and their general lack of understanding. One of the blind participants stated that her provider, “bluntly assessed my idea of having a child as stupid, though there were no medical contraindications” (Wolowicz-Ruszkowska, 2016, p. 85). Additionally, Wolowicz-Ruszkowska reported that her participants, “experienced unnatural, intensive, even aggressive observation from a number of professionals while in the hospital after giving birth; this constant presence resulted in a sense of abnormal isolation and vulnerability” (2016, p. 85). This description seems to describe feelings consistent with the medical stare, as described by Frederick (2015, 2017). The Polish women also experienced indifference in the hospital which appears to correspond to the feelings of invisibility in the research performed by Frederick (2015, 2017). Congruent with the research performed in the United States, the researcher found that, “the medical

staff attempted to convince them to have an abortion or put the baby up for adoption” (Wolowicz-Ruszkowska, 2016, p. 85). Wolowicz-Ruszkowska (2016) concluded that institutional shortcomings in perinatal education and support for these women exist in the Polish health care system. She also noted that her participants replaced professional education and assistance with interpersonal support and peer networking (Wolowicz-Ruszkowska, 2016). A blind participant described how, in preparation for her baby’s birth, she practiced breastfeeding with a doll (Wolowicz-Ruszkowska, 2016). Overwhelmingly, the findings of the Polish study match the findings of the studies in the United States.

**Study limitations.** The study’s limitations include the small number of blind participants (three visually impaired and one blind). The demographic information did not include an evaluation of the participants’ need for mobility aids (white cane, guide dog, etc.). Additionally, the demographics did not explain how long ago the study participants delivered. Finally, the study considered “women with disabilities” as a homogenous group and did not focus exclusively on women affected by blindness.

### **Austria**

The online search returned an Austrian article, “Experiences of Austrian Mothers with Mobility or Sensory Impairments during Pregnancy, Childbirth and the Puerperium: A Qualitative Study.” Schildberger, Zenzmaier, and Konig-Bachmann (2017) performed this study while associated with the University of Applied Sciences in Innsbruck, Austria. In this research ten participants with mobility or sensory disabilities were asked about their perinatal experiences (Schildberger et al., 2017). The researchers believe that this



was the first study into this topic in Austria. The participants were recruited from Austrian disability organizations and from personal contacts (Schildberger et al., 2017). Four blind women participated in the study. All the participants were interviewed in 2013–2014 and had children between the ages of 1 and 13 years old (Schildberger et al., 2017). Considering the topic of this literature review, the focus will be on the experiences of the blind women.

**Findings.** Schildberger et al. (2017) found that the social and medical environment encountered by the women with disabilities was non-supportive and that their care was complicated by communication problems (lack of information/transparency). The participants reported that, overall, their pregnancies were not accepted (Schildberger et al., 2017). A participant reported being quite distraught because her parents wanted to assume custody of her newborn (Schildberger et al., 2017). Another new mother overheard, “What does she, with her visual disability, her practical blindness, need a child for. She can’t handle it anyway” (Schildberger et al., 2017, p. 5). This same participant also reported frustration during the hospitalization due to the lack of communication. She stated, “And never, ever did someone tell me what he is doing right now, except the anesthetist who did the epidural. And somehow, I felt so left alone. I said, ‘I am visually impaired; I am practically blind’. And there, I just assumed that somebody would maybe tell me what was going to happen” (Schildberger et al., 2017, p. 6). All the blind participants agreed that the medical and nursing staff did not provide them with enough information which made them feel insecure about their care

(Schildberger et al., 2017). The findings of this Austrian research echo the findings of the American literature.

**Study limitations.** The study findings were based on a small sample of 10 disabled women that included only four blind women. The demographic information did not include an evaluation of the participants' need for mobility aids (white cane, guide dog, etc.). Additionally, the demographics did not explain how long ago each participant had given birth. Finally, the study did not focus exclusively on the perinatal experiences of blind women. It is possible that including participants with other disabilities tainted the findings.

### **Great Britain**

The online search returned four articles that were generated in England and Ireland. Two articles describe qualitative research and two articles report on quantitative research.

**Quantitative research.** The quantitative studies, "Women with Disability: The Experience of Maternity Care during Pregnancy, Labour and Birth and the Postnatal Period" and "Access and Quality of Maternity Care for Disabled Women during Pregnancy, Birth and the Postnatal Period in England: Data from a National Survey" were performed by research teams in England. Malouf and Redshaw, researchers who were involved in both studies, were associated with the University of Oxford. In 2010 and in 2015, they sent paper surveys to women who had delivered within the previous 3 months (Malouf, Henderson, & Redshaw, 2017; Redshaw, Malouf, Gao, & Gray, 2013). Each time they sent surveys to over 50,000 women; and received 24,155 (in 2010) and

20,094 (in 2015) responses (Malouf et al., 2017; Redshaw et al., 2013). In 2010, 1,482 women self-identified as having a disability while in 2015 there were 1,958 disabled respondents (Malouf et al., 2017; Redshaw et al., 2013). Among those, 197 (in 2010) and 174 (in 2015) reported having sensory disabilities (Malouf et al., 2017; Redshaw et al., 2013). These sensory disabilities included being deaf (or hearing impaired) as well as blind or (visually impaired; Malouf et al., 2017; Redshaw et al., 2013).

***Findings of quantitative research.*** The 2010 study suggested that women with sensory impairments were as satisfied with their care as non-disabled women (Redshaw et al., 2013). They were, however, less likely to breastfeed and would like to have had more visits with their health care providers (Redshaw et al., 2013). The responses in 2015 indicated again that the participants with sensory disabilities would have preferred more visits (Malouf et al., 2017). In 2015, the researchers found that these participants were, “more likely to be left alone at a time when it worried them during labour or shortly after birth” (Malouf et al., 2017, p. 10).

***Study limitations.*** A major limitation of these studies was that the researchers did not differentiate between deaf participants and blind participants. Considering that paper surveys are not a user-friendly tool for blind participants, it is possible that many blind women did not respond. It is, therefore, likely that visually impaired participants were under-represented (or not represented) in the category of women with sensory disabilities. These limitations render the findings of these two quantitative studies less applicable to the proposed study.

**Qualitative research.** The two qualitative studies included blind women but were conducted to explore the experiences of women with disabilities in general. The first article, “The Ambiguity of Disabled Women’s Experiences of Pregnancy, Childbirth and Motherhood: A Phenomenological Understanding” by Walsh-Gallagher, Sinclair, and McConkey (2012) was published in *Midwifery*. The second article, “(Re)constructing Myself: The Process of Transition to Motherhood for Women with a Disability” by Lawler, Begley and Lalor (2015) was published in the *Journal of Advanced Nursing*. Both articles will be discussed in detail.

*Article one.* The researchers, who were primarily associated with the University of Ulster, performed a descriptive phenomenological study of the experiences of 17 Irish women who had physical, sensory, or intellectual disabilities (Walsh-Gallagher et al., 2012). Two of the participants were blind. All women were interviewed both before and after giving birth. The participants were recruited at the hospitals where they were receiving prenatal care and through snowball sampling (Walsh-Gallagher et al., 2012). Considering the topic of this literature review, the focus is on the experiences of the blind women.

*Findings.* All the participants reported that their health care providers were shocked about their pregnancies and that they focused more on their disability than on their pregnancy (Walsh-Gallagher et al., 2012). Four of the participants reported that they were offered the option to terminate the pregnancy (Walsh-Gallagher et al., 2012). However, it is unclear if this offer to have an abortion was extended to any of the blind participants. The participants felt that health care providers did not give them

information and, many times, educational materials were inaccessible to them (Walsh-Gallagher et al., 2012). A blind participant stated, “There was no information in Braille... that’s where the fall down was... they (midwives) showed videos to teach me... which wasn’t a great idea for me... all the emphasis was put on Mark (husband)... I mean I couldn’t see them at all. I had to just sit there...” (Walsh-Gallagher et al., 2012, p. 160). During their hospital stay, almost every participant encountered bias from health care providers (Walsh-Gallagher et al., 2012). Additionally, all the participants reported that the experience of giving birth was very distressing and marked by a lack of empathy from the medical and nursing staff (Walsh-Gallagher et al., 2012). These findings appear to highlight the stigma that is associated with disabled women who want to become mothers.

Unsupportive reactions from health care workers were also noted in the American literature. During the postpartum period, the participants felt ignored (Walsh-Gallagher et al., 2012). In fact, all the participants reported that, during the customary postpartum follow-up visits at home, their concerns were not addressed by the public health nurse (Walsh-Gallagher et al., 2012). This is reminiscent of the invisibility discussed by Frederick (2015, 2017). Walsh-Gallagher et al. (2012) also reported that nine women felt threatened by the surveillance of professionals after birth. They reported negative conversations with social workers who felt that their disability made them unfit mothers (Walsh-Gallagher et al., 2012). However, it is unclear if any of the blind mothers were among these nine women. These findings are completely congruent with the medical stare discussed by Frederick (2015, 2017).

*Study limitations.* A major limitation of this study was that the researchers included intellectually and physically disabled women and failed to properly identify the participants. The pseudonyms assigned to the participants did not reveal their disability, thus making identifying the experiences of the blind women very difficult. The study findings were based on a small sample of 17 disabled women and included only two blind women. The demographic information does not include an evaluation of the blind participants' need for mobility aids (white cane, guide dog, etc.). The study was published in 2012 but was originally submitted to the journal in 2010. Walsh-Gallagher et al. (2012) did not disclose when the interviews took place, making it difficult to determine when the data was generated.

*Article two.* The researchers, who were associated with the midwifery department at Trinity College in Dublin, performed a grounded theory study of the experiences of 22 Irish women who had physical or sensory disabilities (Lawler et al., 2015). Six participants identified as visually impaired, however, only four of these required assistive technology for mobility (Lawler et al., 2015). The participants were recruited through health care provider systems and through disability agencies in Ireland. The researchers ensured that the solicitation for participants was accessible in written, audio, and braille format (Lawler et al., 2015). Some women were interviewed both before and after giving birth. Considering the topic of this literature review, the focus is on the experiences of the blind women.

*Findings.* The researchers found that the participants' *sense of self* was threatened by clinicians during their perinatal experiences (Lawler et al., 2015). A blind participant

commented, “The subtle patronizing attitudes, there’s almost a kind of horror having to care for someone with a disability, it makes you feel kind of grotesque and unhuman” (Lawler et al., 2015, p. 1678). The participants felt disempowered and their sense of self disintegrated (Lawler et al., 2015). During the postpartum period, the women’s sense of self continued to unravel because of the constant surveillance of the clinicians (Lawler et al., 2015). The participants lost confidence in their ability to mother and worried about potentially losing custody of their child. (Lawler et al., 2015). After leaving the hospital and far removed from the clinicians, the women worked on re-constructing their sense of self and on becoming self-confident mothers (Lawler et al., 2015). The biased attitudes of clinicians and their surveillance practices mirrored the experiences described in the American literature and resemble the medical stare, as described by Frederick (2015, 2017).

*Study limitations.* A limitation of this study was that the researchers included both physically disabled and visually impaired women. It was noted that some of the participants did not use mobility aids. The lack of mobility aids diminishes the perception of disability and alters the social and professional interactions that are being studied. In fact, only four of the six blind women who participated in this study required the use of mobility aids (guide dog).

### **Conclusion**

Research indicates that the transition into motherhood is often associated with feelings of self-doubt and insecurity. To this end, the perinatal experiences of women of various backgrounds have been studied extensively. Interdisciplinary research teams

have recognized the needs of disadvantaged women and extensive research has been done into the perinatal experiences of multiple vulnerable groups. These studies have compelled providers to address the unique needs of vulnerable populations such as pregnant teens and pregnant low-income women, which are now better understood. It is, therefore, surprising that blind women, arguably one of the most vulnerable groups, have been omitted from this research. It appears that, to date, scholars in the fields of nursing, medicine, rehabilitation, and social services have not studied this population. On this continent, a handful of visually impaired female researchers have attempted to expose inadequate and often harmful health care practices during the perinatal experiences of blind women, but, as indicated in this review of the literature, their work has not generated the expected reaction among scholars.

The sparse research generated in Europe considers “women with disabilities” as a homogenous group and studied them as such. It is, however, quite conceivable that the experiences of blind women differ from the experiences of women with physical or intellectual disabilities. Regardless of this, the European literature confirms the disturbing findings of the American research. The medical stare, perceived invisibility, and negative health care worker attitudes were themes seen in all the relevant articles. It seems that blind women who become pregnant are regarded as deviants. They feel mistreated and ignored by perinatal health care professionals. After delivery, professionals become hypervigilant and the new mothers risk losing custody of their child because they are blind. The sparse research suggests that blind women are fearful of perinatal health care workers. It is hard to imagine that blind women are victimized by



professionals while they are at their most vulnerable – during pregnancy, childbirth, and puerperium. The serious implications of these research findings warrant further studies into the perinatal experiences of this population.

## CHAPTER III

### PROCEDURE FOR COLLECTING AND TREATMENT OF DATA

The purpose of this study is to explore the perinatal experiences of blind women in the United States. The review of the literature indicated that research into the experiences of this population is scarce and that the existing research is limited in scope and rigor. In effect, this study is the first exploration of the perinatal experiences of blind women from a nursing perspective. This chapter provides a description of the study's methodology and explains how this methodology is congruent with the theoretical framework. Furthermore, a description of the study's setting, participants, data collection procedure, and data analysis are included in this chapter.

#### **Methodology**

The postmodern philosophical perspective lends itself well to generating knowledge in a socially constructed society that is subjected to identity politics (Elliott, 2009). Postmodern thought considers the obstacles encountered due to inherent individual differences such as gender (Hesse-Biber & Leavy, 2007) and disability (Corker & Shakespeare, 2006). The social model of disability is a result of postmodern thought. In this model, disability is viewed as a social construct (Scullion, 2010). In this construct, disability is an interplay between the physical disability, the disabled individual, and his/her social environment (Scullion, 2010). This social model of disability has replaced the medical model of disability, which viewed disability as the reason for a person's limitations. The medical model views "blindness" as the reason why a blind woman is

unable to complete the printed paperwork in her provider's medical office. The social model of disability, on the other hand, views "the societal barriers" as the reason why someone is disabled. In this model, the disabling factor (or barrier) is not the woman's blindness, but the provider's office. If the provider offered the blind patient the option of completing the paperwork online, the barrier (or the disabling factor) might be removed. Thus, the social model of disability suggests that society and its constructs are disabling factors. These disabling factors are the physical and attitudinal barriers that prohibit a blind person from being equal to her sighted peers. It is the purpose of this study to explore if the participants experienced any of these societal barriers.

The critical paradigm is the theoretical underpinning for this study. This paradigm stems from critical theory which aims to overcome constraints placed on individuals based on personal identity (Creswell, 2013). Interpretive frameworks that have historically been associated with the critical paradigm include feminist theories, race theory, and disability theory (Creswell, 2013). However, these single-axis theories do not fully support a critical inquiry of groups of people who have multiple marginalized identities. This need led to a new critical theory. This new theory, rooted in feminism, framed investigations into the experiences of people with multiple stigmatized identities. Crenshaw (2012), a black feminist, appropriately labeled this new theory, *intersectionality*. Crenshaw subsequently used intersectionality to research the experiences of imprisoned African American women (Crenshaw, 2012). This new multiple axis approach gives context to the "intersecting identities that are contoured by a societal structure that perpetuates inequalities" (Syed, 2010, p. 61).

The stigmatized identities of this study's target population, blind women in the perinatal phase of the human life cycle, were reviewed in Chapter I. Additionally, the review of the literature suggests that this population's stigmatized identity led to inequalities during the perinatal period. Turan et al. (2019) confirmed that intersectional stigmas in health care influence health behaviors, physical health, and mental health. They proposed that multiple stigmas may have an additive effect and that health disparities are more likely in these populations than in groups that are less stigmatized (Turan et al., 2019). Therefore, intersectionality is an appropriate approach for this study that seeks to define the effects of three intersecting vulnerable identities (childbearing, female, and blind) contoured by a societal structure (cultural and health care practices and/or expectations).

Intersectionality is not prescriptive in its methods and proposes no specific guidelines for data collection or data analysis (McCall, 2005). Considering that this study is the first inquiry into this topic from a nursing perspective, a methodology that lends itself to such an initial exploration is needed. Qualitative description was selected precisely because qualitative description aims to describe the experiences of the participants in their truest form, in everyday terms, and from the perspective of the participants (Sandelowski, 2000, 2010). This methodology is also congruent with the overall goal of this research because it aims to generate new knowledge regarding the contextual understanding of human health experiences (Bradshaw, Atkinson, & Doody, 2017). Polit and Beck (2012) stated that qualitative description is often used in health care research and particularly in studies done from a nursing perspective. Additionally,

qualitative description is an excellent method for assessing the health disparities of vulnerable populations as these disparities are typically embedded in cultural and contextual nuances (Sullivan-Bolyai, Bova, & Harper, 2005). The rich description of the participants' experiences, void of researcher interpretation, is most appropriate to describe these health disparities.

This study asks: What are the perinatal experiences of blind women? What (or who) were perceived as physical and attitudinal barriers during this time? Research questions that target the who, what, and where experiences are typical of qualitative descriptive research (Sandelowski, 2000). Sandelowski (2000) also mentioned that qualitative descriptive studies are most often based on naturalistic inquiry. However, the design features of qualitative descriptive studies are nevertheless flexible, and they may include "shadings from larger paradigms, such as feminism" (Sandelowski, 2000, p. 337). Therefore, this methodology is appropriate for an initial nursing study using a critical inquiry approach such as intersectionality.

### **Setting**

The study focused on the perinatal experiences of blind women within the United States. The participants who meet the study criteria were interviewed by phone. The researcher is affiliated with a university but conducted the research from a private home office.

### **Participants**

The research participants were recruited through purposeful sampling because very specific inclusion criteria had to be met (Kim, Sefcik, & Bradway, 2017). In qualitative

description research, this sampling method provides the “advantage of facilitating the selection of participants whose qualities or experiences are required for the study” (Bradshaw et al., 2017, p. 3).

### **Inclusion Criteria**

The study aimed to study participants with observable identities (childbearing, female, and blind). Female and childbearing are both visibly observable attributes. During the perinatal period, a woman initially verbally confirms that she is pregnant, and the characteristic abdominal enlargement of gestation follows. In the postpartum period, the woman cares for her newborn and, in doing so, she publicly identifies as a new mother. Therefore, the childbearing and female identities are visibly observable. In addition, the participant must be blind or severely visually impaired. For this identity to be observable, the visual impairment must not only predate the pregnancy, it must also be significant. Thus, for the purpose of this research, a visual impairment was considered significant and visibly observable if the woman uses a mobility aid 100% of the time when she is not in her private home. Mobility aids consist of a white cane, a guide dog, or a sighted guide. These mobility aids make the participants’ identity (blind) visibly observable. Visually impaired women who do not need mobility aids, do not share the observable identity of the study participants. Therefore, women who do not depend on a mobility aid, such as women with low vision or women who are legally blind, were excluded from this study.

All participants must be over 18 years old and must be able to communicate verbally in English. They must have given birth to at least one child. To ensure that

current perinatal experiences are studied, this delivery must have occurred within the prior 7 years. Participants who delivered more than one child or who delivered multiples are also eligible to participate in the study. The experiences targeted by this study relate to births that occurred within the United States. Intersectionality is a framework that evaluates experiences affected by social and cultural identities (Bowleg, 2008). Therefore, foreign birth experiences, potentially impacted by cultural norms that are not present in the United States, were excluded.

### **Recruitment**

The participants were recruited through an organization that interacts with blind and visually impaired individuals. The NFB was the researcher's primary contact because this organization distributes electronic newsletters and announcements to blind parents on listservs. The NFB agreed to email the solicitation for participants to its members (see Appendix A). The recruitment flyer was a text-only document (see Appendix B) because electronically distributed written text is the most accessible and the most user-friendly mass communication format for the blind. The solicitation also included that volunteers who complete the study would receive a \$75 Visa gift card. Women who were interested in participating were asked to contact the researcher by phone, text, or email. Potential participants came forward thanks to the emailed solicitation as well as snowball sampling. The researcher asked the volunteers questions to determine eligibility during a telephone screening (see Appendix C). Twelve women volunteered for the study and seven were deemed eligible. The seven eligible participants who met the study's inclusion criteria were scheduled for a phone interview. The participants were asked to

schedule this interview at a time when they would be able to talk privately for about 1–2 hours. The researcher emailed the consent form (see Appendix D) to participants immediately after the screening confirmed their eligibility.

### **Sample Size**

The findings of this study are based on the experiences of seven participants who provided enough data to saturate the themes. The inclusion criteria of this study were extremely limiting and targeted a homogenous sample that represents only a very small percentage of the total population. Kim et al. (2018) stated that qualitative descriptive studies on purposeful samples tend to use small samples of around eight participants. These studies generate a thick description of the experiences through in-depth interviewing and therefore typically require smaller samples (Kim et al., 2018). Guest, Bunce, and Johnson (2006) found that in homogenous samples saturation of themes was often reached before the 12th interview.

### **Protection of Human Subjects**

Prior to soliciting potential participants, the researcher obtained the approval of the Institutional Review Board (IRB) at Texas Woman’s University. The researcher explained the unique needs of this population regarding consenting to the IRB board. Written consent forms requiring the participant’s signature are not user-friendly as the participants in this study are blind. The NFB recommends that researchers use an audio-recorded verbal consent (see Appendix E). In order to protect the participants’ privacy, the researcher audio-recorded their verbal consent on a digital file (a first digital audio recorder) that is separate from the digital audio file (a second digital audio recorder) that



contains the telephone interview. The participants only identified themselves by name when they gave consent. The audio file that contains the in-depth interview does not contain the participant's name or any other identifying information. Pseudonyms were used during the interview and in the data analysis. A single paper copy, the only document linking the participants' names with their pseudonyms, is kept in a locked safe in the researcher's home office. After the interviews were completed, the researcher used the participants demographic information to send the gift card (\$75 value) as a token of her appreciation.

### **Data Collection**

Data collection, in many qualitative descriptive studies, is done through audio-recorded interviews and according to a semi-structured interview guide (Kim et al., 2018). This study followed this method and the researcher interviewed her participants while audio-recording the telephone interviews. The use of the telephone interview is a user-friendly method for blind participants who may not have access to computers equipped with adaptive software. Prior to the interview, the researcher asked each participant several demographic questions (see Appendix F). Then, a semi-structured questionnaire was used as a guide during the in-depth interviews (see Appendix G). The researcher asked open-ended and probing questions to obtain a rich description of the participant's experiences (Polit & Beck, 2012).

The interviews were scheduled at the participant's convenience. The researcher communicated to each participant that she should be in a comfortable and private setting, free from potential disturbances and distractions, during the interview. Likewise, the

researcher ensured that she was in a completely private setting so that she could guarantee complete confidentiality. The researcher used two separate digital voice recorders; one to record the participant's verbal consent and one to record the interview. At the beginning of the interview, the researcher reminded the participant that she could stop the interview at any time and for any reason. The seven participants completed their individual interview without requesting a break. The interviews lasted between 30 and 90 minutes each.

### **Data Analysis**

Qualitative descriptive studies seek “straight and largely unadorned answers to questions of special relevance to practitioners and policy makers” (Sandelowski, 2000, p. 337). Congruent with this methodology, the researcher selected qualitative content analysis as the most appropriate data analysis method for this research. The researcher used this method because it is the least interpretive method and allows for data-driven analysis (Sandelowski, 2000). Additionally, this method is widely used by qualitative researchers. A review of 55 qualitative descriptive studies indicated that 30 studies had used qualitative content analysis as the data analysis method (Kim et al., 2018).

Qualitative content analysis offers an inductive approach to the data (Cho & Lee, 2014). This inductive approach, labelled conventional content analysis, allows the research to be guided by the interview data without direction from existing research or established theory (Colorafi & Evans, 2016; Hsieh & Shannon, 2005; Willis, Sullivan-Boyai, Knafl, & Cohen, 2016). This study is an initial nursing inquiry into the perinatal experiences of blind women and this data analysis method is therefore appropriate. Colorafi and Evans

(2016) confirmed that “conventional content analysis is used in studies that aim to describe a phenomenon where existing research and theory are limited” (p. 19).

The data analysis process was aided by NVIVO 12 software. First, the interviews were transcribed verbatim. Sandelowski (2000) stated that, like other forms of qualitative research, the collection and analysis of data occurs simultaneously “whereby both mutually shape each other” (p. 338). Thus, as a first step in the process, the researcher immersed herself in the data and read the transcripts several times (Hsieh & Shannon, 2005). Next, key concepts were highlighted, and the researcher made notes as she started analyzing the content for key thoughts (Hsieh & Shannon, 2005). An initial coding scheme evolved from the notes that reflected the key thoughts (Hsieh & Shannon, 2005). These codes then expanded into categories and clusters and eventually fitting definitions for each category were chosen (Hsieh & Shannon, 2005). These categories were further analyzed and eventually five themes emerged.

### **Trustworthiness**

Validity and reliability in qualitative research are not easily defined and multiple perspectives on its definition exist (Creswell, 2013). Creswell (2013) emphasized that the quality of a qualitative study should not be determined in terms of quantitative equivalents but that it should be determined by “whether the study contributes to our understanding of important questions” (p. 255). Morse, Barrett, Mayan, Olsen, and Spiers (2002) agreed and stated that, in qualitative research, “verification and attention to rigor will be evident in the quality of the text. Excellent inquiry is stunning: the arguments are sophisticated in that they are complex yet elegant, focused yet profound,

surprising yet obvious” (p. 19). Thus, the burden to demonstrate trustworthiness lies with the qualitative researcher who must convince the reader that the study offers important and truthful information. Leading qualitative researchers have developed several perspectives and techniques that assist with demonstrating trustworthiness (Creswell, 2013). However, Sandelowski (1993) cautions researchers and suggests that it is possible to succeed “in our efforts to ensure trustworthiness to the extent that we recognize the complexity of these strategies, analyze them critically, and select among them carefully” (p. 8). Despite these concerns, it appears that many qualitative researchers continue to employ strategies based on the concepts set forth by Lincoln and Guba (1985): *credibility, dependability, confirmability, and transferability*. This researcher, however, followed Sandelowski’s (1993) recommendation and analyzed multiple strategies critically before selecting the ones that were most appropriate for her research.

**Credibility.** Credibility in qualitative research relates to the level of confidence that the study findings reflect the truth (Anney, 2014). Thus, the credibility of a study pertains to how believable the study findings are. In order to demonstrate that the study findings reflect true experiences, this process starts with selecting credible participants. In order to ensure credibility, the researcher must describe the study participants in detail (Elo et al., 2014). In this study, potential participants were first asked key demographic and identifying questions to ensure their credibility. The credibility of a study is enhanced if it uses content rich, thick descriptions to detail their experiences (Sandelowski, 2004). This study generated thick descriptions of the experiences of the study participants. The data analysis of this study presents key participant responses as

direct quotations, thereby connecting the reader to the participants personally and thus enhancing credibility. The researcher further enhanced credibility by asking her peers as well as the members of her dissertation committee for scholarly guidance. This type of peer debriefing enhances the quality and therefore, the credibility of the research findings (Colorafi & Evans, 2016).

Asking participants (members) to review transcripts or analyzed data for accuracy has been a fairly common practice among qualitative researchers to enhance trustworthiness (Doyle, 2007). However, such practices may constrain the qualitative researcher. Sandelowski (1993) stated that “member validation is a threat to validity” (p. 4) because research findings are a synthesis of the data. Sandelowski (1993) explained that members look for their own experiences and that, if they do not recognize their experiences, they will deem the researcher’s findings inaccurate. This is therefore a threat to the validity of the work because the finished work is not written for the members; the target audience of a scholarly work are typically the researcher’s peers (Sandelowski, 1993). Morse (1998) agreed that study participants should not check qualitative research products. “The research product is a synthesis of multiple participants’ perspectives and is more representative than the perspective of one participant” (Morse, 1998, p. 443). Morse (1998) cautions that “the product of qualitative research is and must be different from the descriptive accounts of the experiences provided by participants” (p. 443). However, there are other member checking strategies available to the researcher that do not require asking feedback on study findings. In many cases, member checking consists of giving the interview

transcript to the participant for review (Birt, Scott, Cavers, Campbell, & Walter, 2016).

The researcher offered this option to her participants. To further enhance credibility, the researcher summarized key points during the interview to ensure that her understanding of the data matched what the participant was describing.

**Dependability.** Qualitative research demonstrates dependability by demonstrating consistency. The researcher can demonstrate dependability by developing a monitoring plan in which “data analysis and collection should occur simultaneously, giving the investigator the opportunity to correct errors or make revisions (Colorafi & Evans, 2016). Dependability is further demonstrated by employing a code-recode strategy and by implementing a research audit trail (Schwandt, Lincoln, & Guba, 2007). The code-recode strategy requires an initial coding of the data and then, one or two weeks later, the researcher codes the same data again (Anney, 2014). Dependability is demonstrated if the first and second set of codes are congruent (Anney, 2014). The researcher further enhanced dependability by using memos to create an audit trail as she progressed through the study. This audit trail was shared with the researcher’s dissertation chairperson. Among other things, it included how the data was coded, changes to the codes, and when these steps occur.

**Confirmability.** Confirmability refers to objectivity and accuracy (Elo et al., 2014). The research findings must be based on the statements from the participants and may not be tainted by researcher bias (Lincoln & Guba, 1985). The audit trail assisted with confirmability, as did the constant contact between the researcher and her dissertation committee. The dissertation committee chairperson oversaw the research process. The

use of quotations is essential to demonstrate trustworthiness (Elo et al., 2014; Polit & Beck, 2012). The researcher, therefore focused on including the exact words of the participants when she presented her findings. Koch (2006) states that a reflexive journal enhances confirmability. Therefore, the researcher used journaling to reduce researcher bias. In this journal, the researcher detailed her thoughts and impressions as the study unfolded.

**Transferability.** Transferability of the research assesses its application to other groups as well as to the population itself (Colorafi & Evans, 2016). Transferability in this research thus pertains to whether the findings could apply to blind women outside the sample (but within the population) and if they could apply to women outside the population. The target population is very specific and therefore the sample criteria were very specific. Considering that the study sample is very homogenous, the transferability of the findings to other women with the same characteristics is potentially high (Colorafi & Evans, 2016). It is very likely that the findings are transferable to other women who are blind and childbearing. It is unknown whether the findings will transfer to women outside the target population.

### **Conclusion**

This chapter detailed the study's methodology. The researcher demonstrated that a qualitative descriptive design with conventional content analysis is most appropriate because this study is an initial inquiry into the perinatal experiences of blind women from a nursing perspective. The results of the study are discussed in the next chapter.

## CHAPTER IV

### DATA ANALYSIS

This study is an initial nursing inquiry into the perinatal experiences of blind women. The specific thrust of the study is the exploration of each participant's experiences within her community as she engages with health care providers, health care workers, family members, friends, neighbors, and strangers. It is the goal of this exploratory study to identify these blind women's encounters with physical and attitudinal barriers during the perinatal period.

#### **Description of the Sample**

There are seven participants in this study. These participants are identified by their pseudonym and by their participant number (e.g., P1). Table 1 lists the participants demographic information. Six participants were married and had completed post-secondary education. Three participants were married and had completed post-secondary education. Three participants had only one child, while four participants had two, three, five, and six children respectively. Table 1 also lists the number of children each participant had as well as the age of each child. For example, the first pregnancy of Lily (P6) resulted in twins who are now 13 years old. The researcher limited the scope of the study to perinatal experiences related to pregnancies that occurred within the last 7 years. Therefore, a total of 9 different perinatal experiences described by seven women are included in this study. The children that correspond to these nine perinatal experiences are bolded in Table 1. All participants described themselves as blind (without usable vision) and reported using a white cane for outdoor mobility.



Table 1

*Participants Demographic Information*

Part.	Name	Age	Ethnicity	Relationship Status	Education	Number of Children & Ages	Mobility Aid
1	Amy	35	Asian	Married	Masters	<b>1 – age 7</b>	white cane
2	Faith	30	Hispanic	Married	Bachelors	<b>1 – age 2</b>	white cane
3	Ingrid	39	Hispanic	Married	Associates	<b>1 – age 7</b>	white cane
4	Isabelle	50	Caucasian	Married	Bachelors	1 – age 31 2 – age 29 3 – age 28 4 – age 26 <b>5 – age 7</b> <b>6 – age 4</b>	white cane
5	Kelly	32	Caucasian	Married	Associates	1 – age 9 <b>2 – age 5</b> <b>3 – age 1</b>	white cane
6	Lily	39	Caucasian	Married	Masters	1 – age 13 2 – age 13 3 – age 11 4 – age 8 <b>5 – age 3</b>	white cane
7	Marie	29	Hispanic	Single	High School	1 – age 10 <b>2 – age 3</b>	white cane

**Findings**

Qualitative content analysis was selected as the most appropriate data analysis method for this research. This method is the least interpretive method and allows for data-driven analysis (Sandelowski, 2000). The researcher aimed to stay as close as possible to the data and therefore focused on presenting the exact words of the participants in the findings. The use of quotations to highlight the participants' exact

words are also essential in demonstrating trustworthiness (Elo et al., 2014; Polit & Beck, 2012).

The data analysis process was aided by NVIVO 12 software. First, the researcher transcribed the interviews verbatim and then read the transcripts several times. Next, key concepts were highlighted, and the content was analyzed for key thoughts. An initial coding scheme evolved from the notes that reflected the key thoughts. These codes then expanded into categories and eventually themes emerged. The five themes in this study are: (a) information remains inaccessible, (b) facing mobility issues, (c) fear of losing custody, (d) comradery among blind mothers, and (e) stigma is real. Table 2 indicates which participants provided information that contributed to each theme. A selection of the codes and the categories that led to each theme are also included in Table 2. A more in-depth discussion of the findings combined with comparisons to the existing literature is presented in Chapter 5.

Table 2

*Themes, Categories, Codes, and Participants*

Themes	Categories	Codes	Participants
Information Remains Inaccessible	prenatal information from OB, discharge paperwork from hospital, information that is important to me, consequences of inaccessible information.	prenatal handouts, prenatal classes, could not read prescription, educational info from provider, admission consent, provider questionnaire, discharge information, NICU rules and regulations, etc.	P1, P2, P3, P4, P5, P6, P7

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Facing Mobility Issues	indoor mobility (hospital), outdoor mobility (rides, ride share platforms, public transportation incl. paratransit).	transportation to provider, taking Uber, to NICU by wheelchair, getting a ride, mom picked me up, no assistance to get to shower, etc.	P1, P2, P3, P4, P5, P6, P7
Fear of Losing Custody	distrust of social services, interacting with social services, fighting against social services, consequences of fearing social services.	social worker was not helpful, Social worker wanted to remove baby, friends lost custody due to blindness, questions social services asks, show competence, etc.	P1, P2, P3, P4, P5, P6
Comradery among Blind Mothers	best resources from blind peers, early support, helping others, hands-on experience, discourse prep.	should ask lots of questions, get help from other blind moms, online blind mom group, teaching baby care, helping with depression, etc.	P1, P2, P3, P4, P5, P6, P7
Stigma is Real	interactions with strangers, interactions with friends, interactions with health care workers, sensing the unease, talk to me, too many questions, assumptions about my abilities.	not allowed to change diapers, choose your battles, assume BF problem is blind-related, sensing provider discomfort, ignorant questions on bus, who is going to take care of your baby, etc.	P1, P2, P3, P4, P5, P6, P7

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## **Theme 1: Information Remains Inaccessible**

All the study participants described how, throughout the entire perinatal period information remained inaccessible to them. *Inaccessible information* is the umbrella term used for all materials that the participants received from health care workers and health care institutions that they could not read (or access) independently. This obstacle, noted in both prenatal offices and hospitals, related directly to the widespread use of printed information. All participants talked about receiving a variety of information that they could not access. They all commented on the paperwork that they had received from health care workers, which consistently was only available in printed format. Participant 5 (Kelly) talked about the papers she received from her obstetric provider, “All of the material that you would get in a folder when you went, all of it was in print.” Amy (P1) described that, when she was admitted to the hospital, she signed “a whole bunch of paperwork” but she doesn’t know what she signed. Two participants (Marie P7, Ingrid P3) remembered items that were included in their paperwork, but only because the staff had pointed them out. Participant 7 (Marie) stated that when she received the packet, the staff had suggested that she should note the instructions on how to apply for food stamps and Women, Infants and Children (WIC). Ingrid (P3) remembers being told that she needed to select a doctor for her baby from the list of pediatricians included in her information packet. One participant (Faith P2) was pleasantly surprised that the hospital preadmission staff arranged for her to receive a brailed copy of the consent form, which she greatly appreciated. However, when Faith (P2) left the hospital after she gave birth,

her discharge paperwork was still in printed format. In fact, all the participants were handed inaccessible discharge instructions in print.

Health care institutions are required to engage in patient teaching. None of the participants remembered receiving verbal instructions related to excessive bleeding, signs of infection, or other postpartum emergencies that would require immediate follow-up. All participants stated that the discharge teaching received from the hospital was inaccessible and they remembered being handed a large amount of paperwork. Participant 4 (Isabelle) commented, “So, we were sent home. Yeah. We came home with a big pocket, a big folder of printed material that we couldn’t read.”

Throughout their perinatal care, all participants encountered printed information that they could not read. It appears that health care workers assumed that their blind patients would ask sighted people to read their paperwork and handouts to them. In this sample, inaccessible printed materials mostly resulted in participants missing out on educational opportunities and important discharge teaching. The participants were often frustrated by the lack of accommodation, which, in one instance, may have contributed to a serious medical complication.

**Participants’ reactions to inaccessible information.** Most of the participants did not express much frustration with not being able to read the educational materials they received from their doctor’s offices. Participant 5 (Kelly) commented, “It was all very much just a lot of useless information for me. There wasn’t really much point in me trying to find someone to read all this to me.” Most of the participants believed that the

educational materials from the obstetrician were not of great importance to them. All the participants stated that they eventually discarded prenatal handouts without using them.

However, there was other information that some participants wanted to read. Three participants (Amy P1, Isabelle P4, Kelly P5) verbalized their frustration with not being able to read information that they thought was important to them. Participant 1 (Amy) was frustrated when her provider did not educate her verbally about preeclampsia. She reported, “And they found out my protein level or something was not right because they would give me handouts. And I had nobody to read the handouts to me.” Another participant (Kelly P5) felt the same way regarding the handouts she received as a Neonatal Intensive Care Unit (NICU) parent. Participant 5 (Kelly), complained that essential information was inaccessible to her when her newborn was admitted to the NICU. Kelly (P5) said, “What was really frustrating about the NICU is that they gave me a lot of information about hospital policies, where you go take a shower and things like that. All of it was in print!” Participant 4 (Isabelle) echoed the same frustration when she highlighted being handed inaccessible information repeatedly:

The midwife gave us some handouts that we weren't able to read. The hospital where we had the child gave us lots of handouts that we weren't able to read. The only thing that was actually accessible was the video for shaken baby syndrome that they played for us.

Two participants (Amy P1, Isabelle P4) took steps to make their discharge information accessible; an effort that proved unsuccessful. Participant Amy (P1) stated that, as a first-

time mother, she asked for brailled or electronic discharge information, which the hospital staff did not provide:

They [the nurses] said this. Here's your paperwork. Take it home and have somebody read it to you and I said that does not help me at all. I requested a social worker. If they can somehow get it brailled or even provide it to me electronically. I don't need them to spend money on it because it's costly to get it brailled, but at least e-mail it to me so I can read it, but they refused to do that, either because they don't know how to do it or don't want to do it.

Amy (P1) offered to give the staff instructions on how to make the paperwork electronically available to her. However, the hospital employee (social worker) did not try to accommodate her. Isabelle (P4) attempted to assess what was in her discharge packet. This participant's husband, who is also blind, tried to assist by using the voice record feature on his phone. However, the sheer volume of the discharge information made audio recording impossible. Isabelle (P4) explained:

They [the nurses] went over the main points verbally. This sheet has this on it, and this sheet has these resources on it. They would prioritize which paper is the first one. They said these are the most important and my husband got out his phone. He recorded the reading of the most important papers. But there were other papers that, I mean, the packet was pretty big. So, for someone to read every single page, you know, with all the patients that they had, they weren't going to do that. Even if they said, okay, so the next paper is lactation resources. We would still have to have someone read those lactation numbers, had I needed that resource.

Isabelle (P4) stated that, ultimately, she did not need the resources in her discharge packet. The other participants confirm that, they too, never accessed their printed discharge information or their printed teaching materials, and that they eventually discarded all these papers. Overall, the participants seemed to believe that the burden of accessing the information fell on them instead of on the provider. The women in this sample were fortunate that they did not experience any harm from not being able to access the discharge teaching. However, other paperwork (not discharge related) that remained inaccessible had consequences for other participants.

**Consequences of inaccessible paperwork.** Consequences resulting from not being able to access printed information were noted in the statements of 4 participants (Amy P1, Ingrid P3, Kelly P5, Lily P6). Some consequences were relatively minor, such as those resulting from not being able to read the prenatal education handouts (Ingrid P3, Kelly P5, Lily P6). Other participants suffered more serious consequences (Amy P1, Ingrid P3) and the health of one participant was negatively affected (Amy P1).

Invariably, resources provided during prenatal care visits include information about local perinatal classes (childbirth, breastfeeding, newborn care, infant car seats, etc.). However, it was noted that only two participants (Faith P2, Isabelle P4) attended perinatal classes. The remainder of the sample (5 participants) reported not taking any classes. Three (Ingrid P3, Kelly P5, Lily P6) of the five participants who did not attend classes also stated that they did not know if information regarding perinatal classes was included in the handouts they had received. Additionally, these three participants (Ingrid P3, Kelly P5, Lily P6) believed that they did not miss anything noteworthy by not



accessing this educational information from their provider. They prided themselves on being resourceful and talked about how they obtained the information they needed themselves. Participant 5 (Kelly) stated that she understood that some of the paperwork from her obstetrician included educational resources, but she felt that she could find that information by herself on the internet and in books. Participant 6 (Lily) was proud that she independently found the lactation resources she needed. She (Lily P6) stated that, through calling around, she was able to “figure it out without those handouts.” Just like Participant 6 (Lily), Ingrid (P3) wanted information on breastfeeding and breast pumps. She (Ingrid P3) located a breastfeeding class on her own, but she was unable to attend because the class was exclusively for low-income women and her income disqualified her. However, in the end, she (Ingrid P3) felt that she met her need for lactation education when she found a blind mother who let her explore her breast pump. This same participant (Ingrid P3) also reported that, for exercise, she located and joined a water aerobics class for elderly women. It should be considered that these participants might have been better served if they had accessed the educational materials from their physicians instead of exploring prenatal education independently. It is likely that they could have enrolled in locally offered prenatal exercise classes or lactation classes.

Two participants (Amy P1, Ingrid P3) suffered more serious consequences from not being able to read the paperwork. Inaccessible paperwork resulted in significant complications for Amy (P1) and her newborn. Throughout her pregnancy, Amy (P1) felt that her obstetrician routinely handed her paperwork without explanations. This participant (Amy P1) did not understand her condition and she could not read the

paperwork she was provided. Unable to get clarification, she (Amy P1) decided *not* to take the medication that was prescribed after her preeclampsia diagnosis. Amy (P1)'s frustration was clear in her description of this event:

Nothing was given to me in any accessible way, which was very frustrating. That's why I never took any medication they gave me; I mean prescribed me. I had no clue during my pregnancy. What's on the paper? Nobody was there to read it to me, and I had no help. I was working in (pause). It was like, too embarrassing just to ask the co-workers at work and then everybody would know everybody's business.

Amy (P1) acknowledged that not taking the prescribed medication may have led to her preterm delivery by emergency cesarean section due to the complications of preeclampsia. Amy (P1) regretted this course of action, "I may not have an early delivery if I took care of myself, if I knew what was being given to me, what was being prescribed to me. I could have avoided all that." Amy (P1)'s newborn remained in the NICU for a month. This outcome was the most serious consequence of inaccessible information noted in the sample.

A second potentially serious consequence of not being able to read printed materials was described by Ingrid (P3). She was asked to complete a written questionnaire in her provider's office. The office staff assisted this participant (Ingrid P3) by asking the questions verbally. In doing so, the office staff violated Ingrid's privacy because the questions were asked in the patient waiting area. The participant (Ingrid P3) reported that

it made her very uncomfortable. This was a violation of the Health Insurance Portability and Accountability Act (HIPAA).

## **Theme 2: Facing Mobility Issues**

All participants discussed their transportation and mobility needs during the perinatal period. These comments were unsolicited and reflected the unique needs of these women. Understandably, not being able to drive a motor vehicle complicates transportation, and the participants shared how they navigated travelling outside their home. All participants reported using a white cane as a mobility aid.

**Outdoor transportation.** Many participants used ride share platforms such as Uber for transportation to their medical appointments. They also reported using friends, family and public transportation (buses and paratransit) for rides. Not being able to operate a car themselves, all participants had to problem solve either in advance or on the spot.

Transportation options varied for the participants based on their residence. Public transportation was used by the women who lived in larger cities. Paratransit, a public transportation service, gives qualified riders access to personalized rides. This service allows blind travelers to book trips with individualized pick-ups and drop-offs.

Paratransit often uses cars, vans or small buses and several study participants used it to get to scheduled appointments.

Three participants (Amy P1, Isabelle P4, Kelly P5) reported using public transportation such as buses and paratransit during the perinatal period. Two of these participants (Amy P1, Kelly P5) mentioned unforeseen problems with transportation.

Participant 1 (Amy) remembered when, one evening, her doctor called her and told her to

go to the hospital immediately. Paratransit, her usual mode of transportation, was not an option since it required advance scheduling. Therefore, Amy (P1) called a friend to pick her up and drive her to the hospital. She (Amy P1) stated that she is very independent and rarely asks friends for such favors, but in this case, she did. The other participant (Kelly P5) who reported problems with transportation usually relied on her family for rides. However, during this pregnancy her family withdrew their help. Kelly (P5) said that, when she selected an obstetrician and a hospital that were not located near her residence, her family felt inconvenienced and refused to help with transportation. This participant (Kelly P5) was unwilling to deliver at the local hospital and therefore found alternate transportation. Kelly (P5) described how she and her husband (who is also blind) solved these problems:

My husband and I reworked our work schedules so we could get a paratransit there. One day, when I ended up having to stay longer for an NST, I had to call my friend from childhood's mother to come get me.

Participant Kelly's experience highlighted that paratransit pick-up times are not flexible, and when an obstetric appointment took longer than expected, she missed her ride home. In both cases, the participants (Amy P1, Kelly P5) immediately found friends who gave them rides. Two participants (Ingrid P3, Marie P7) mentioned that their primary mode of transportation was taxi or rideshare. The most well-known rideshare platform is Uber, but most geographical areas have additional options. Participant 7 (Marie), a single parent, reported that she took an Uber home when she was discharged from the hospital with her newborn. Two participants (Ingrid P3, Isabelle P4) mentioned that

transportation with a newborn was a bit harder than expected. Getting the car seat in and out of a vehicle followed by carrying the infant around in the car seat was a lot of work, especially when also holding a white cane. Participant 3 (Ingrid) stated that “getting to appointments for her [newborn daughter] and for me” was the biggest challenge during her postpartum period. However, none of the participants encountered outdoor transportation problems that they could not solve. Overall, the women in this sample proved to be very resourceful and managed their transportation needs with relative ease.

**Indoor mobility.** None of the participants mentioned having difficulties with navigating their patient rooms while hospitalized. However, three participants (Amy P1, Kelly P5, Isabelle P4) encountered mobility issues in the hospital. Amy (P1) and Kelly (P5), whose babies were admitted to the NICU, were appreciative that, initially, the hospital staff helped them with mobility. While these participants were postpartum patients, the staff volunteered to transport them by wheelchair back and forth to the NICU. However, the participants reported different experiences after they were discharged. At this point, they were expected to navigate the hospital independently. Kelly (P5) did not receive assistance and mobility issues kept her from taking a shower:

There was not a resource for me to go. There was supposed to be areas for the parents to be able to go and shower and stuff on the first floor. But when I asked the nurses about it, they'd say, well, we can't leave the third floor, and the volunteers down there, that's not their job. You have to figure it out. So, I felt very isolated in that way, and I knew I could leave and go home and take a shower, but I was breastfeeding and pumping and keeping the pump parts clean,

trying to know where the bathroom was way down at the end of the hall in postpartum. So, I'm back and forth, dealing with that and, at the same time, I just felt very isolated.

When asked if this issue was later resolved, Kelly (P5) responded:

It never did. I just ended up waiting until I went home. I spent the last day and a half there, kind of in tears because I felt really trapped. I thought I'll deal with it later and then, by the time Monday came around, I'm like, I'm going home. I'm not going to fight this battle because I'm exhausted.

Similarly, Participant 1 (Amy) was expected to travel back and forth to the NICU after she was discharged. Her experience was markedly better than Kelly's (P5) because she received assistance from the staff. Amy (P1) described how she immediately expressed her mobility concerns to the NICU nurses:

And then they said I could go home, but the baby had to stay there for a whole month. That's not happening. The baby stays and I go home? No way. But I went that night, my friend made me go. She's like, I'll bring you tomorrow morning, it's too late now to fight them. They were definitely not letting me stay with the baby because they said, you can come every day. I said, I am blind, I cannot come every day and go back and come back. It's difficult for me. Plus, it's my only baby; I don't want to be separated from him. I want to be around my baby. So, I left and the next day, I came down like 6 o'clock in the morning and put the chair right in front of the baby. So, I stayed at that little box and I held him until it is like 7 or 8 in the evening.

As a NICU parent with a local residence, Amy (P1) was not allowed to use the room designated for “out-of-town NICU parents.” However, Amy’s (P1) unique needs as a blind mother swayed the staff in her favor. Amy (P1) said, “Some of the older nurses were very helpful, very supportive. They're like, you know what, just go stay there, there in that room. And I stayed, and I was so happy that some of those good nurses advocated for me.” Amy (P1) credited the NICU nurses for helping her during her son’s month long NICU stay. The third participant who mentioned indoor mobility issues was Isabelle (P4). She (Isabelle P4) felt that the staff was not willing to assist her while she was hospitalized in the mother-baby unit (postpartum) with her son. Isabelle (P4) questioned the motives behind statements made by the nursing staff. She (Isabelle P4) wondered if it was her need for mobility assistance that kept her from attending her baby’s procedures:

They would always tell me that it is standard procedure for them to take the child without me going with him. So, like, I couldn't hold my child when he was getting his blood taken or I couldn't even, something like, stand by the bed? They said, we normally just take him out and then we'll bring him back. That really made me anxious and I realized like. I'm here asking myself in my head. Really? If there really is a policy that parents aren't allowed or aren't supposed to go with you when you do these procedures. Or, is it that you just don't want to have to deal with, maybe, me going because I would have to hold onto the crib? Is it more of a blind thing?

These reports highlighted that the participants did not feel comfortable negotiating larger

and unfamiliar indoor environments such as a hospital without the assistance of a sighted person or sighted guide. Their statements also indicated that while some staff members voluntarily assisted them, others did not.

### **Theme 3: Fear of Losing Custody**

Six participants (Amy P1, Faith P2, Ingrid P3, Isabelle P4, Kelly P5, Lily P6) expressed feeling fearful of social services and one participant (Amy P1) reported that the hospital social worker took steps to remove her baby. All but one participant received a social worker visit during their hospitalization. Marie (P7) was the only participant who did not remember being visited by a hospital social worker. Distrust of social services was a common sentiment among the study participants.

**Distrust of social services.** Apprehension and distrust of social workers was noted in the accounts of 6 study participants (Amy P1, Faith P2, Ingrid P3, Isabelle P4, Kelly P5, Lily P6). These participants were all visited by a social worker while they were hospitalized. Isabelle (P4) was told by hospital staff that every new mother was seen by the social worker. She (Isabelle P4) expressed being suspicious of this statement and did not believe that social service visits were mandatory for every maternity patient. She stated, “You never really know if this is true.” Four out of these six participants (Ingrid P3, Isabelle P4, Kelly P5, Lily P6) brought up stories of blind parents who had lost custody of their newborns because they were blind. Participant 5 (Kelly) expressed being extremely nervous because, while she was pregnant, a blind friend’s newborn baby was placed in foster care for 2 months. Kelly (P5) said:

I was a little paranoid because, you know, I look forward to being a mom. And



now my biggest worry is going into the hospital, going and having a baby and having my baby taken because somebody doesn't know what I am or I'm not capable of.

Participant 6 (Lily) claimed that losing custody due to blindness happens less often now, but it still occurs. She (Lily P6) stated that this practice started in hospitals “because of the views of health care professionals.” These health care professionals do not understand that blind people can be safe parents. Ingrid (P3) claimed that blind mothers experience excessive scrutiny from health care workers and social workers. She (Ingrid P3) stated that if a small mishap were to occur to a sighted mother’s baby, it would be dismissed as “it happened because it was an accident, or it happened because she was tired.” Ingrid (P3) added, “But for a blind mom it is different!”. During their hospitalizations, these four participants (Ingrid P3, Isabelle P4, Kelly P5, Lily P6) tried hard to avoid all interactions with social services. One participant (Amy P1), however, did not avoid the social worker. In fact, she asked to see the social worker.

**Fighting against social services.** As an immigrant, Amy (P1) was not aware of the fear of social services among blind parents, and during her hospitalization she requested to see the social worker. She (Amy P1) asked if the social worker could help with making hospital discharge handouts accessible for her. Amy (P1) was shocked that, instead of providing accessible resources, the social worker initiated the removal of her newborn from her care. She (Amy P1) described the frustration she experienced once the social worker became involved:

They put her in touch with me so she could give me resources, help me out. But

she was the one who started causing more problems. She was the one who wanted me not to stay at the hospital [while her son was in the NICU]. She was the one who wanted the child to be taken away by the Child Protective Services. She was the one who was like, she doesn't have any support system.

The social worker told Amy (P1), whose family does not reside in the United States, that she does not have the needed support to properly care for her son. The participant (Amy P1) described how stressful this was for her:

She was like, worried about me taking the baby home alone because I was a single mom and I had no family support or nothing. And the baby was supposed to come home on the monitors. NICU was sending him on the heart monitors and stuff like that. I mean, the social worker was mean about it. She kept on arguing. No, I think she needs somebody with her. She should not release the baby to her it's not safe. So, I was so stressed out.

Amy (P1) secured the assistance of the NFB who sent a delegate to her custody meeting. She (Amy P1) said, "I called and researched around. I was on the computer looking for resources and all that. So, I contacted the NFB Parents Division and asked them for help." Amy (P1) needed to convince social services that she had the needed skills and resources to care for her son. She (Amy P1) stated that it was helpful that one of her sighted friends offered to assist once her son was discharged from the NICU. Amy (P1) also expressed much gratitude to a few NICU nurses who advocated for her during this custody inquiry:

And I kept on saying that I have a support system. I am capable. I'm a working

mom, but I'll take care of my baby. I have the resources to do it. But the social worker was going to involve Child Protective Services and that's why she scheduled the meeting and everything. So, I had to have the NFB come to advocate for me as well. And some of the nurses came to the meeting. And because those nurses literally taught me how to change the baby's diapers, how to nurse him, how to give him baths, how to change his clothes. They were like, you know what? She can take care of the baby. We saw it. We know how determined she is. We know she stayed with the baby. She did not leave. So, we became good friends and it became like a good relationship with the nurses, especially the helpful ones.

Thanks to the support of the nurses, her friends, and the NFB, this participant (Amy P1) was eventually able to convince the social workers that she was able to care for her son. She (Amy P1) reported that, after her son was discharged, home health nurses visited her several times. Amy (P1) said that she successfully demonstrated that her child was safe in her care and she remained his custodial parent.

**Interacting with social services.** Five of the participants (Faith P2, Ingrid P3, Isabelle P4, Kelly P5, Lily P6) who expressed being fearful of social services described how they reacted to this fear. All described behaviors and techniques aimed at projecting confidence and competence. Participant 6 (Lily) stated that she wanted to come across as a very confident mother by giving clear descriptions of how she was going to take care of her infant. She stated, "I have more of the skills to be like, you know, tell them exactly what I'm going to be doing with the baby and how I'm going to take care of the baby."

This participant (Lily P6) added that she demonstrated her newborn care skills to the staff without them asking and that she never sent her baby to the nursery. Lily (P6) was always mindful of how she was perceived and stated, “I guess, I kind of felt like, I was trying to make sure they knew I could take care of him.” Ingrid (P3) reported similar behaviors. Ingrid (P3) also never sent her daughter to the nursery and described behaving in a very proactive manner. She (Ingrid P3) emphasized that she did not want to give control to the nurses in postpartum. She (Ingrid P3) did not ask for help because she believed that the nurses would “see it as you’re not capable.” Ingrid (P3) described how she immediately “grabbed” her daughter to demonstrate whatever the nurses wanted to see. She (Ingrid P3) described her interactions, “And I would say, well, like this. And I would show them, you know.” Ingrid (P3) also remained aware of how she was perceived when she took her newborn daughter to the pediatrician. Ingrid (P3) described being mindful when requesting assistance to get to the elevator while carrying her newborn. She (Ingrid P3) described asking someone, “Could you show me where the elevator is?” She (Ingrid P3) then stated, “And I would have her [her daughter] and I would kind of, you know, talk to them [the person assisting her], and I would not (pause). I didn’t want to look like they need to be worried.” Projecting confidence and competence was clearly the goal of these participants.

**Consequences of fearing social services.** Consequences resulting from the distrust in social services were noted in the statements of the six participants who acknowledged fearing social service workers. All these participants (Amy P1, Faith P2, Ingrid P3, Isabelle P4, Kelly P5, Lily P6) described a resultant decrease in help-seeking

behaviors and a lack of trust in health care professionals. Isabelle (P4) mentioned that, after being discharged, she had latching issues (breastfeeding). She (Isabelle P4) stated that sighted mothers would just say, “Okay, let’s get this taken care of.” She (Isabelle P4) described that, in blind women “there's an extra step in the back of our mind that goes, well, wait a minute. I really want to get this taken care of. Is there a way that I can get it taken care of without involving professionals?” Isabelle (P4) further described her reluctance in seeking help from a lactation consultant:

I don't want other people making assumptions that I'm either not understanding how to feed my baby, or not feeding my baby, or not wanting to feed my baby. You know, are we going to have a failure to thrive thing? And then, am I going to have a lot of people intruding on my house, making some judgments that I don't feel comfortable with? It just it adds a layer of stress that (pause). Hey, it's not that we don't want to get help. It's not that we don't see a problem. We want to find out what would really help the situation, but sometimes the way people think they're helping is not the way that we really need that help, and the assumptions people make is just (pause). You just don't know where that's going to go.

After their deliveries, both Faith (P2) and Ingrid (P3) reported that they experienced signs and symptoms of a postpartum mood disorder. However, their fear of being perceived as incapable mothers kept them from seeking help. Faith (P2) described how she felt and how she coped with her depression without seeking professional help:

Afterwards, I did a pretty good job at masking the fact that I wasn't okay. He had pediatric appointments where they did ask, are you guys okay? Are you guys

dealing with his NICU stay okay? But I was terrified. I was terrified of having them take him away. I was terrified of them telling me I was worse than I, (pause) than I was. So, I never said anything. I went to counselling to my church and I focused a lot on prayer and my spiritual life, and with time, it got better. You know, on my end, I felt more like a human and I felt more like a mom. And I started to enjoy him more. But no, at that time, I never said anything about it. And I tried very hard to keep it (pause), keep it hidden.

Ingrid (P3) illustrated her lingering lack of trust in health care professionals when she received a phone call after she was discharged home. She (Ingrid P3) stated that the person appeared to be offering some type of care provider, but Ingrid (P3) was unclear who the caller was or what had prompted the call. She acknowledged that it might have been a routine solicitation call, but when she was asked “if she needed help at home with taking care of her daughter,” Ingrid (P3) became suspicious. To this day, she (Ingrid P3) remains unsure about the nature of this call and wonders if it was “a social care call, you know, a social worker.” Amy (P1) was grateful that the hospital’s social services department did not deem it necessary to involve Child Protective Services and she reported feeling much less stressed after this finding. However, after these terrifying experiences, she (Amy P1) now shares the fear of social services that appears so widespread among blind parents. Fear of losing custody is a catalyst for unhealthy behaviors among these participants. Isabelle (P4) accurately summarized the lack of trust and the reluctance to seek care among these mothers. She (Isabelle P4) said, “You really have to feel comfortable and be able to trust that the people you're reaching out to for

help aren't going to take your child. Yeah, that really is a big fear for blind people.”

#### **Theme 4: Comradery among Blind Mothers**

Becoming a mother is a life altering event that tends to require some degree of preparation and all women require some support and guidance during this time. Some participants credited their mothers and other family members with supporting them during this time. However, all seven participants stressed the importance of reaching out to blind peers for information and support. Marie (P7) said that the best advice she got was from “another blind mom.” Ingrid (P3) mentioned that she found the blind mother who showed her the breast pump through a blind group. Lily (P6) suggested that, while pregnant, a blind woman should try to find several blind parents to learn from, and that getting into a blind parent group is “the best way to get advice.” Kelly (P5) agreed and noted that their unique needs can only be met by listening to the experiences of other blind women. She (Kelly P5) said, “I would say that a lot of the best advice I got was from those other moms that have walked through that territory.”

**Early support.** Four participants (Amy P1, Faith P2, Isabelle P4, Lily P6) discussed the need for blind girls and blind women to find these *blind mom groups* before they conceive or early in their pregnancy. Participant 1 (Amy) mentioned that, during her pregnancy, she did not know where to get the support she needed. Now, as the mother of a young child, she (Amy P1) highly recommends that blind pregnant women reach out to experienced blind mothers long before they have a baby. These four participants agreed that it is important to get into a blind mother group as early as possible because, for blind women, problems may arise before their babies are born. Two of the participants (Lily

P6, Isabelle P4) provided more insight into why early support was deemed so important.

Lily (P6) stated that early support is critical to fully prepare a pregnant woman. Lily (P6) expressed concern that an unprepared blind woman might be more likely to have problems with social services. This participant (P6) mentioned that, thanks to early support, experienced blind mothers have the time to prepare those expectant mothers for their upcoming interactions with health care professionals. Lily (P6) stated that blind pregnant women should learn to formulate clear answers in their head, so they are ready to respond to the “different questions that might be asked.” This participant (P6) further recommended that, to form these answers, all expectant mothers should be proactive and “ask what questions they [blind mothers] have been asked in the past and kind of already have solutions in line.” Lily (P6) stated that she was good at giving verbal explanations to health care providers and she suggested that blind expectant mothers should learn to do the same. This participant (Isabelle P6) said that early support will lead to an increase in confidence.

Isabelle (P4) mentioned that early support is very important because, in the blind community, many young women have the disadvantage of not being familiar with babies and baby care. She (Isabelle P4) stated that some blind mothers may not have all the tools to properly care for their newborn. Isabelle (P4) mentioned that in blind mother groups these young women can gain valuable experience by handling live babies and practicing skills such as changing diapers. This participant (Isabelle P4) explained that increasing the level of comfort of blind women prior to becoming a mother is very important to their success as a blind parent. Isabelle (P4) mentioned that the discomfort



of sighted people with blind caregivers is to blame for this lack of exposure in the blind community:

We don't regularly get asked to help with people's children. Babysitting, I mean. Well, some blind people have babysat during their teenage years and some have not. A typical, normal experience for most blind women is that people are really hesitant to let their children be in a blind person's care. And even like daycare workers and childcare workers, like daycare places don't hire blind people. I mean, if they do, they hire partially sighted people, they don't hire blind people. They just find it a little too (pause). Yeah. Yeah (pause). So, we don't get those experiences. So, I get the fact that when a new blind mother has a child, she can't do anything. ... She might not have had those experiences because no one has ever really given her those tools to do that.

Isabelle (P4) added that blind mothers often use different techniques than sighted mothers to care for their children. This participant (Isabelle P4) reported that she has seen how these blind women become much more confident in their abilities when they are exposed to experienced blind mothers. She (Isabelle P4) stated that learning blind baby care basics early from an experienced blind mother is the best way to get ready for blind motherhood.

**Helping others.** Three of the participants (Kelly P5, Isabelle P4, Faith P2) stated that they are very active in blind mother support groups. Participant Kelly (P5) mentioned that she started a group for blind parents online, which then morphed into a blind mothers WhatsApp group. She (Kelly P5) stated that she has developed very strong

bonds with the women in the group and that they rely on each other all the time. She (Kelly P5) reported that the group members primarily text, email, and call each other. Isabelle (P4) mentioned that she is an active member of both online blind mother groups and local blind mother groups. She (Isabelle P4) explained that she offers hands-on experiences for young blind women or pregnant blind women in her home. Isabelle (P4) uses her own children to teach them baby and childcare skills. “These experiences increase their confidence,” she said. Participant Faith (P2) stated that, where she lives, there are not many blind people. After she gave birth, Faith (P2) joined a few blind mother groups on Facebook and on WhatsApp. Faith (P2) recalled how instrumental the support of the women in the group was when she was feeling depressed. She (Faith P2) also highlighted the importance of sharing adaptive technology with each other:

I relied a lot on them. And it was nice to hear the, I've been there, I've done that. And to go from, from the, you know, from the depression and anxiety side to the, how do you do this and how do you know this? And here are tips and tricks to being able to do it. So, yeah, it's been great. It's been one of the most helpful things because I didn't grow up around many blind individuals. I don't have very many blind friends and the only one that I have doesn't have children. And so being able to find a community of people who are, who have done it before me, and who, you know, in some instances they are both blind. It's refreshing and it's very encouraging. I can remember a number of times where I was like, I don't know how to do this. And, you know, they would all chime in and say, okay, well, this is how I do it. And another person would come in and say, well, this is how I

do it. And you just take from all of those and find your own way to do it, and then go, oh, well, here's how I did it!

All the participants mentioned learning from their blind peers and a very strong sense of comradery was noted as well as a willingness to help other new mothers and expectant mothers.

### **Theme 5: Stigma is Real**

In this study, stigma describes the negative social attitudes that the participants perceived in response to the combination of both blindness and pregnancy/new motherhood. Earlier in this chapter (theme 3), the participants exposed their stigmatized identity when they discussed their fear of losing custody. The participants reported that, often, social workers saw blindness as incompatible with motherhood, and blind women had to prove that they were safe and capable mothers. The current theme, *stigma is real*, focuses on the experiences of the study participants during their interactions with strangers, friends, family, and health care workers.

**Interactions with strangers.** Three participants (Faith P2, Isabelle P4, Kelly P5) mentioned experiencing interactions with strangers that made them feel as if they should not be mothers. Kelly (P5) described how, shortly after giving birth, she carried her newborn on her chest in an infant carrier. One day, on the bus, an elderly lady engaged her (Kelly P5) in conversation and said, “Oh, how does the father do it, taking care of her?” Kelly (P5) responded, “What do you mean?” The lady then asked if Kelly’s husband could see or if he was blind too. When Kelly (P5) informed the woman that her husband is blind too, she exclaimed with pity, “Oh, that poor baby!” The participant

(Kelly P5) reported that incidents like this occur quite frequently. Participant 4 (Isabelle) mentioned similar interactions. She (Isabelle P4) too recalled apprehension and questions from strangers while she and her blind husband were on the bus. This participant (Isabelle P4) stated that people did not outright say that they should not have kids, but that they ask, “Who helps you around the house? Who else do you live with?” These interactions indicated to the participants that people in the community questioned their ability to parent.

The study participants then expanded on how they responded to these negative interactions with strangers. Participant 2 (Faith) reported that she usually just tries to ignore it. She stated, “If you're out and about and a stranger makes a comment, or a stranger questions you, or anything like that. You get home, you take a breath, and you deal with it.” Kelly (P5) described that, she too, had to learn to ignore these interactions. This participant (Kelly P5) said:

It became one of those things where I had to learn how not to want to slap people in the face sometimes, because the public is always going to have an opinion, whether that's because I'm a breastfeeding mom, or because I'm a blind mom, or because of both.

Isabelle (P4) agreed with Kelly's and Faith's statements and confirmed that she too mostly ignored these ignorant comments and questions. However, this participant (Isabelle P4) reported that, sometimes, she engaged these strangers in conversation to educate them. Occasionally, she (Isabelle P4) took the time to explain how she functions as a blind mother. She (Isabelle P4) admitted, however, that she did this selectively

because it was not always worth her time:

It just depends upon the situation. ... There are times I feel like that, if I take five minutes to be an educator, I'm not sure that it really has an effect, in terms of like (pause). I don't, I don't know that that will change their opinion or their ideas. I don't know that in their head they go, oh, yeah, that makes sense. Well, I'm going to, I'm going to really change my thought process about that. I don't think it penetrates that deeply. And so, is it worth it? Is it not? And besides that, I want my children to kind of have a (pause), as much of a normal life as possible. And if I'm always educating people, it just feels too exhausting.

The comments made by these three participants confirmed that they were subjected to negative attitudes and opinions while in public.

**Interactions with friends and family.** All participants reported positive interactions with friends and families. Family support was very evident in the accounts of Ingrid (P3) and Isabelle (P4). Five participants (Faith P2, Ingrid P3, Isabelle P4, Kelly P5, Lily P6) had very supportive partners/husbands throughout the entire perinatal period. Amy (P1) and Marie (P7) did not have partners during most of this time. Five participants (Amy P1, Faith P2, Kelly P5, Lily P6, Marie P7) reported negative interactions with family members and friends. They mentioned that their family's primary concern was usually regarding handling the tasks of motherhood while blind. Lily (P6) mentioned, "I know that my husband's mom was not supportive because she felt like, because we're visually impaired, we had too much on our plate. And [she] even didn't acknowledge the pregnancy for several months". Marie (P7) mentioned that her

mother wanted her to move in with her after she got pregnant, but Marie said, “Yes, I'm blind, but I could still do this. And I just have to learn like everybody else does.” Among these five participants who reported negative interactions, the experiences of Amy (P1) and Faith (P2) were the most extreme. Faith (P2) said that, when she got pregnant, they moved in with her husband’s parents. During her pregnancy, her in-laws tried to limit everything she (Faith P2) did:

When I got pregnant, I was working. I got to work by myself. I got home by myself. I did volunteer work, etc. As soon as I got pregnant, they started to question everything I did. They would tell my husband not to let me do this and not to let me do that and questioned everything I did, where I was going, why I was going, when I would be home.

When this participant (Faith P2) had her baby, the behaviors of her in-laws escalated, especially while her husband was at work. Faith (P2) described her time with her in-laws as a terrible ordeal because they considered her to be completely incompetent:

It was everything. It was (pause). Things from, you cannot walk down the stairs while you're holding him. Mind you, I will humbly say, I have great travel skills. I can count on one hand the times that I've fallen off any (pause). I've never fallen down the stairs. I'm not prone to getting hurt around the house or even outside, for that matter. But, you know, they were like, well, you can't go down the stairs while you're holding him. Then, once he had a diaper rash. And when my husband called them from the car to tell them, you know, the pediatrician gave us ointment. She said, oh, well, it's probably because she can't see. And it just went

on from there. It was (pause). It was just a constant, you can't do, you can't do, you can't do. Watch her, help her do it, etc.

The experiences from Participant 1 (Amy) were very similar. Amy (P1) reported that where she grew up (Pakistan), people were not supportive of blind women having children. She (Amy P1) stated, "I thought in America things would be much easier." However, she reported being ostracized by her religious community after she got pregnant because they did not approve of a blind woman, estranged from her husband, having a child:

I had more of a tough time at the mosque, since I am Muslim. I used to be very active at the mosque and during my whole pregnancy and after my childbirth, they had nothing to do with me because of my blindness and because of me being pregnant. They never helped me. They never even called me back, or they never checked on me or anything. And when I would go to the mosque, nobody would talk to me. They would isolate me all the time. ... It had to do with that I'm pregnant and I'm blind. How would I take care of a baby? Stuff like that. Why did I do that? Being, being blind, knowing my situation, I had no support.

Shortly after her son was discharged from the NICU, this participant (Amy P1) reconciled with her husband and they started raising their baby together. Amy (P1) said that her husband, who is American, was extremely unsupportive. She (P1) stated, "I thought he would be more understanding and open minded because he's born and raised here. But I guess it's still the same mentality that sometimes, sighted folks think a blind mom can't do anything." Amy's (P1) husband mirrored the behaviors and attitudes that

Participant 2 (Faith) reported when she described her interactions with her in-laws:

He said, you may not be able to give him a bath, and it's dangerous, and I should do it. ... The baby may fall. The baby may drown. Oh, my goodness. You can't take him. Oh, no, he may fall from the couch. Oh, you shouldn't cook because you should sit with the baby. Oh, you shouldn't do this because you're holding the baby.

Four of the five participants (Amy P1, Kelly P5, Lily P6, Marie P7) who reported having non-supportive family and friends demonstrated resilience and became successful mothers despite it. Amy (P1) stated that she gradually assumed more responsibilities and that she treasured time alone with her baby. Faith (P2), on the other hand, stated that, because she could not escape her in-laws, the situation became unbearable. She explained:

It's not uncommon for blind people, even when you go to something, a friend's house, or a family member's house or a family reunion, and they make comments, and they question (pause). Or, you know, they think they have to take over and care for your child because you can't. You deal with it for a couple hours. You respond to it. You have the energy to do it. Come home. You deal with it. But when you will live with it, it just about destroys you.

At the time of the interview, Faith (P2) confirmed that she does not live with her in-laws anymore. She (Faith P2) and her husband have had their own home for a while now, and she is currently enjoying motherhood very much. However, she (Faith P2) described how her experiences with her in-laws affected her self-image and how it changed her



desire to have more children:

I was determined that I would not have another child as long as I was living with them. And it kind of grew into, I am just not having another child ever. Which unfortunately (pause), and it makes me very sad to say it because I never thought that I would have thought this, but it does have a lot to do with my blindness, because I realized how everybody is questioning everything.

The study participants experienced both supportive and non-supportive behaviors from family and friends. The negative interactions were looked at as “something they had to deal with” and most of the participants continued to see themselves as successful new mothers.

**Interactions with health care workers.** All participants reported very positive interactions with health care workers. Amy (P1) credits NICU nurses with teaching her how to take care of her baby. Marie (P7) felt the nurses did a great job while she was having her baby, and Faith (P2) loved that her physician gave an excellent description of what her growing baby looked like on ultrasound. However, their experiences were still a mixture of good and bad. In fact, all participants reported both positive and negative experiences with health care workers.

***Sensing the unease.*** Three of the participants (Amy P1, Faith P2, Ingrid P3) reported that health care workers were uneasy around them. These participants reported that the professionals were uncomfortable because of their blindness. Faith (P2) stated that she knows that for many doctors and nurses, she was their first blind patient. This participant (Faith P2) described that experience:

I could tell, (pause) I could tell, just by their level of discomfort. You can tell even when they're not saying anything or being, you know, rude or condescending in any way. You can just tell when people are like, okay, I don't know how to handle this, but I'm trying kind of thing. So, I know, they've never had exposure to anybody else who's blind before.

Faith (P2) continued by explaining that some health care workers were not interested in learning more about their blind patient and that they just wanted to do their job and leave:

There are some people that are not willing to listen, that aren't really interested. They're just kind of set in their ways. She's blind. This is weird. I don't know how to handle it. I just want to get in and out, get my job done right. And that's okay too. For me, as long as they aren't, you know, condescending or rude, I just let things be, kind of thing.

Faith (P2) accepted the discomfort of the providers if they remained professional.

However, Amy (P1) appeared to be willing to excuse unhelpful behaviors because of inexperience with blind people. She mentioned how some of the NICU nurses did not know what to do because they had never dealt with a blind NICU mother before:

Some of those nurses are not helpful at all. They didn't know how to help a blind person. I tried to not get the ones who were not very understanding about how to help a blind mom. But that's not their fault, I guess. They had no experience. I was the first one there.

Faith (P2) mentioned that the nurse who checked her when she came to triage “was very uncomfortable” and Ingrid (P3) described how she felt “that tension” at her daughter’s

first pediatric appointment, “You could feel that, even if they don’t mention it or say it. You know, it’s there. I feel it.” One participant (Faith P2) recounted how, on the phone, the lactation consultant had been pleasant, positive, and eager to help. However, when she went to meet her in person for lactation assistance, her attitude changed instantly. This professional appeared to feel too uncomfortable to work with a blind mother and quickly gave up on helping her (Faith P2):

I did have a terrible, terrible experience with a lactation consultant. She was very uncomfortable. ... I walk in the door with my cane and my kiddo, my sister-in-law was with us. And the lactation consultant just about froze and her attitude went downhill from there. She kept coming in and out of the room. She, I mean, she was just not comfortable at all with the situation and couldn't wait to get me out of the room and basically ended the appointment with giving me a pumping schedule that I already had. And she was like, there's nothing else I can do. He does not want to latch. And so, this is all I can offer. She cleaned my pump, put it away, walked out of the room and said, you know, that's it. Take your time.

Overall, it appeared that the participants accepted provider behaviors that were brought on by *feelings of unease*. None of these blind mothers reported making formal complaints about their experiences.

***Genetics and fertility decisions.*** Four of the participants (Ingrid P3, Isabelle P4, Kelly P5, Lily P6) reported that health care workers made them feel very uncomfortable regarding their decision to have children. They believe that their blindness was the only reason for the comments and the actions of these providers. Lily (P6) described how her

obstetrician assumed that she was going to have a tubal ligation to prevent her from having another child:

I guess what stands out the most was that, while I was pregnant with my baby, the doctor did automatically assume that I was going to want my tubes tied because I didn't want any more children. I had never even alluded to that. And so, I did kind of feel like she was assuming that because I was blind, I would not want to have more. You know, that would be my final one.

Isabelle (P4) was very upset about how her physician insisted on performing genetic testing to make sure her fetus was not blind:

The push (for genetic testing) was due to a possibility that the child would be blind. My blindness is not hereditary and my husband's blindness, because he's also blind. My husband's blindness is autosomal recessive, so both parents have to have the genes. So, I was pretty sure that I did not have the gene. He has Leber Congenital Amaurosis. We, for short, call it LCA. And there was still quite a bit of insistence for us to have genetic testing. I was really uncomfortable with it and said so at two or three different times.

Finally, Ingrid (P3) described her discomfort when she saw an infertility specialist. This participant (Ingrid P3) felt that, as a paying customer, she and her husband should not be questioned about her blindness. The specialist asked questions to determine if her (Ingrid P3) blindness could be inherited. Ingrid (P3) felt that the doctor was trying to decide if he would help them get pregnant based on the cause of her blindness. This participant (Ingrid P3) stated, "And they asked me about my eyesight. And I told them, what is what

I have got to do with my treatment? My treatment to get pregnant again.” Ingrid (P3) was very offended and felt that, even if her blindness were hereditary, she should still have the right to have a baby. She said, “And if it's a genetic, you know, I would think that if I was paying, it was not their business to ask. I felt like, it was like, it depends if we help you to reproduce.” These participants were very uncomfortable with situations pertaining to genetics and fertility that were triggered by their blindness. In these three cases, each participant voiced her concern about her right to have a child, regardless of whether the child might be genetically predisposed to blindness or not.

***Talk to me!*** Five of the study participants (Amy P1, Ingrid P3, Isabelle P4, Kelly P5, Lily P6) reported that health care workers tended to not address them if a sighted person was present. Isabelle (P4) described how nurses entered her room in the hospital and talked to her eldest daughter instead of to her, the patient. This participant (Isabelle P4) said that she had to remind the nurses multiple times that “if they had a question for me, to just speak directly to me as opposed to her.” Kelly (P5) said the NICU doctors did not speak to her directly. Ingrid (P3) had the same problem in the hospital. She (Ingrid P3) felt that she solved the problem somewhat when her mother stayed with her instead of her [sighted] husband. Ingrid (P3) said, “My mom doesn't speak English, so they were kind of forced to, kind of like, talk to me in a way (laughs).” Lily (P6) saw a specialist during her pregnancy. She (Lily P6) reported that the staff and providers “talked to her like she was a child.” This participant (Lily P6) remarked, “Sometimes I feel like that's how people deal with individuals with disabilities all together, not really understanding their intelligence level or anything.” Amy (P1) described how she asked a sighted friend

to go with her to her first obstetric appointment. She regretted that decision when her obstetrician started talking to her friend instead of to her (Amy P1):

So, then I went to the doctor and unfortunately, I made the mistake of going with somebody. And when a blind person goes with somebody, then doctors don't talk to us. They talk to the person who is with them, with the blind person. That was so frustrating. They thought I couldn't understand. I can't see doesn't mean I can't understand!

This participant (Amy P1) became even more frustrated when, while the doctor was explaining things to her friend, the nurse wanted to take her vital signs. Amy (P1) remembers being removed from the conversation all together, "The nurse took me away to take the weight and do the basic test and stuff. But then they were explaining everything to my friend! And my friend is like, okay. So, she was listening. I got frustrated." Amy (P1) stated that when she went to her second obstetric appointment the situation was better because she went alone. She (Amy P1) said, "I didn't take anyone because I was like, you know what? They have to deal with me only. I got there and they talked to me!" This participant (Amy P1) experienced the same lack of personal interaction again when she visited her son's pediatrician. At that time, Amy (P1) had reconciled with her [sighted] husband and they went to the pediatrician together. Amy's husband was not very supportive of her and he did not correct the pediatrician when he ignored Amy (P1) during the pediatrician visits. This participant (Amy P1) was very upset with this situation and stated; "The pediatrician would not talk to me as well, because he thought that, oh, he's the one that takes care of the baby, not her. So why

should I talk to her? She's blind.”

These participants were very frustrated when health care workers did not talk to them in a professional manner. They felt that their blindness greatly affected interpersonal communication during their care. Sighted professionals were repeatedly communicating with the sighted companion(s) of the blind patients. Unaccompanied blind patients felt their provider assumed that they were child-like and possessed a limited understanding. Most of the participants verbalized their frustration and tried to take steps to remedy these situations.

*Too many questions.* Six of the study participants (Amy P1, Ingrid P3, Isabelle P4, Kelly P5, Lily P6, Marie P7) reported that they were quizzed by health care workers. These questions, the participants said, were probes to assess their ability to care for their newborn. Two types of questions were noted: (a) assessing assistance at home and (b) assessing how the participant will perform a certain task. Isabelle (P4) has adult children that she raised as a blind woman, which, she felt, proved her ability to raise a child. She (Isabelle P4) used her eldest daughter, who is sighted, as her labor support person while in the hospital. Isabelle (P4) had also informed the staff that her adult daughter does not reside with her anymore. This participant (Isabelle P4) remembered that, repeatedly, the level of assistance from her daughter was being assessed:

That's one of the first things they ask. They ask about family support, which is a good thing. You want to have some support. But I think they were asking like, is your daughter going to be there most of the time to help you take care of the baby? And, she's going to be there, but she's going to be there in the in the role of

a family member who is supportive. She's not going to be there in the role of the caregiver of the baby!

Marie (P7) described that she was very annoyed with her son's pediatrician's questions at his one-week check-up. She (Marie P7) had to describe the most basic newborn tasks to the practitioner. This participant (Marie P7) did not like this interaction and switched to another physician:

It was his pediatrician. I remember he came out of the hospital and I took him for his week checkup. And I took him by myself. And I remember the pediatrician just asking me like "Well how do you feed him?", "How do you change his diaper?" I didn't, I didn't like the way she was like questioning me, you know. I didn't like her attitude. And I would tell her what I'm doing, you know. I warm up his bottles. I measure it and I shake it up just like anybody else would. And, you know, I put it in his mouth, and I hold him, and feed him, and burp him. And then she was like, "Well, how are you going to bathe him?" Well right now since he's so little, I would just take a washcloth and some baby soap and wipe him down. But it's like everything I said, she had like a smart remark. And after that I just I switched pediatricians and I didn't even go back there.

The participants clearly felt that the questions from the health care workers were excessive. They believed that they were being probed because they were blind. Most of these participants answered the questions, but they would rather not have. However, as discussed in theme 3 (fear of losing custody), the women realized that they must prove that they are safe and competent mothers.



*Assumptions about my abilities.* Four of the study participants (Amy P1, Isabelle P4, Kelly P5, Lily P6) reported that health care workers assumed that they could not perform certain tasks due to their blindness. These assumptions were either verbalized or implied. Some participants were stopped from doing things for their newborn, while others were excused from learning new things. Kelly (P5) mentioned that she was an experienced mother because she already had two other children. However, one NICU nurse did not feel comfortable with Kelly (P5) at all. This nurse did not let her change her son's diaper and did not want Kelly (P5) to wash her own breast pump parts because, as a blind person, she would not do it right. Kelly (P5) reported the frustration she felt with this nurse:

Most of them were totally fine with me changing my own baby. I had one nurse who wouldn't let me. Who was telling me that that's their job and that I just needed to let them do it. And she was really nervous about me picking up my own child. Mind you, this is probably the fourth nurse I've worked with. So, three other nurses have already seen me hold my baby, rock my baby, nurse my baby. So, I went to go change his diaper. She would say, "No, I've got this. You might do it wrong." I've only changed diapers for two other children. I don't know. Maybe I don't have this down? Really? (laughs). Yeah. I might change him wrong. And, when I went to wash my pump, she goes, "No, you can't do that. You won't know if they're actually clean or not." And I was just so floored!

Participant 6 (Lily) described that she was being watched by the nursing staff when she was performing basic newborn care. Isabelle (P4) said that, often, ordinary problems

were incorrectly attributed to her blindness. This participant (Isabelle P4) remembered that her breastfeeding issues were initially attributed to her inability to see. However, follow-up with a lactation consultant determined that the problem was not blindness related at all. This participant (Isabelle P4) also mentioned that the nurses were willing to excuse her husband's lack of interest in changing diapers because of his blindness.

Isabelle (P4) said:

It was easy for them to attribute blindness to things that were not blind related. My husband was a bit hesitant and ambivalent about changing diapers or just getting in there with the baby, you know, just taking charge. It had nothing, nothing to do with his blindness. More so due to his personality and the way he processes things. But it was definitely easy for the staff to excuse or to justify his hesitation because he is blind. And yes, that definitely was not it. It was definitely just his personality. And we all thought that, it is interesting that, no matter what, no matter what situation happens, even now, if my child goes outside with two different colors of socks on, most people assume it's because I can't see.

The participants implied that health care workers made incorrect assumptions about their abilities based on their blindness. In some instances, the staff was overbearing, and questioned the participants' ability to perform simple tasks. Other participants reported that the staff did not hold them to the same standard as sighted patients and excused them from performing expected tasks because they were blind. Participant 4 (Isabelle) summarized it well when she said, "We really don't want things done for us. We want to be able to do it ourselves."

## **Conclusion**

This study aimed to identify the physical and attitudinal barriers encountered by blind women during the perinatal period. To this end, the study analyzed the rich data provided by seven participants as they described their interactions health care workers, family members, friends, neighbors, and strangers. This data analysis identified five themes: (a) information remains inaccessible, (b) facing mobility issues, (c) fear of losing custody, (d) comradery among blind mothers, and (e) stigma is real.

The participants voiced frustration with not being able to access the printed information that they needed. All the participants missed potentially valuable patient teaching resources and some participants suffered serious health consequences because they did not receive the documents in an alternate format. It appeared that the providers assumed that the patients would access the printed materials with the help of sighted friends and/or family. However, none of the participants mentioned approaching anyone for visual assistance with their paperwork. The participants discussed their mobility and transportation needs and reportedly solved all outdoor transportation with ease. Mobility inside the hospital typically required the assistance of a sighted guide. Often hospital staff voluntarily assisted them, but some instances of staff refusing to help were also reported. It was noted that the participants were very fearful of social workers and that they did everything they could to avoid interacting with these professionals. Blind expectant mothers believe that they must prove their abilities above and beyond their sighted counterparts to avoid losing custody of their baby. Further evidence of their stigmatized identity was seen in their interactions with strangers, family, friends, and

health care workers. Health care workers were often uneasy around the participants and excluded them from conversations, even though *they* were the patient. Providers surveilled their interactions with their newborns and implicitly or explicitly questioned their ability to be successful mothers. The discrimination they experienced was based on incorrect assumptions regarding what they can and cannot do as blind women and as blind mothers. The peer support networks that the participants belonged to offered practical information, hands-on teaching, resource sharing, emotional support, and the needed preparation for the scrutiny of health care workers.

## CHAPTER V

### SUMMARY OF THE STUDY

This qualitative study explored the perinatal experiences of blind women from a nursing perspective. This chapter summarizes the study and discusses the findings. In this discussion the researcher reviews and verifies the findings of the study. The review includes a deeper exploration of the most important findings. Additionally, the findings are compared to previous studies in the literature to highlight similarities and differences. The discussion also introduces findings that were not previously reported in the literature. This study is the first research study of the perinatal experiences of blind women, and, therefore, elements that are relevant to the nursing profession are discussed in greater detail. These implications to nursing include the researcher's recommendations for nursing practice, education, and policy making. This chapter also offers suggestions for further research from both a nursing perspective and an interdisciplinary perspective.

#### **Summary**

The perinatal experiences of blind women have not been studied from a nursing perspective and this study aims to fill this gap in the literature. The researcher hopes to add to the body of nursing knowledge and enhance the care of blind women during the perinatal period. This study explored the experiences of seven blind women and aimed to identify the physical and attitudinal barriers they experienced during this time period. Data collection was done through digitally recorded phone interviews. The researcher used qualitative content analysis to analyze the data. Qualitative content analysis, as the

least interpretive qualitative methodology, facilitates data-driven investigation (Sandelowski, 2000). NVIVO 12 software aided in the data analysis and eventually five main themes emerged: (a) information remains inaccessible, (b) facing mobility issues, (c) fear of losing custody, (d) comradery among blind mothers, and (e) stigma is real.

### **Discussion of the Findings**

In this discussion, the data presented in chapter four is explored more thoroughly through the lens of intersectionality. The significance of the shared intersecting attributes: (a) blind, (b) women, and (c) childbearing in relationship to the contemporary cultural and health care practices is the focus of this discussion. The findings are compared to the findings in the existing research. Additionally, implications for professional nursing are detailed extensively because this study is the first exploration of these perinatal experiences from a nursing perspective.

#### **Theme 1: Information Remains Inaccessible**

All the study participants encountered inaccessible information that they could not read (or access) independently. This obstacle related directly to the widespread use of printed information in the obstetric setting. The study participants reported that they did not try to find someone to read the information given to them prenatally and that they discarded the paperwork. They acknowledged that they did not know what information was given to them. Despite this acknowledgment, they believed that the prenatal information from their obstetrician was not very useful to them. The existing literature also reported instances of inaccessible information in obstetric care. Previous research determined that obstetric providers routinely distributed printed materials to this

population during their prenatal care (Bieber-Schut, 1993; Branson, 1975; Frederick, 2015, 2017; Kent, 2002; Walsh-Gallagher et al., 2012; Wolowicz-Ruszkowska, 2016). This study found that the participants discarded the prenatal handouts and that they relied on the internet and peers to satisfy their prenatal education needs, which is congruent with Wolowicz-Ruszkowska (2016) who noted that blind expectant mothers replaced printed prenatal education with interpersonal support and peer networking.

The current study found that inaccessible information was not limited to the prenatal care setting as the participants reported being given printed materials throughout the entire perinatal period. It is important to note that this study is the first to point out that physicians and hospitals did not provide their blind obstetric patients with accessible inpatient discharge information, NICU parent information, and treatment consent forms.

A review of the literature suggests that these accommodations are also lacking outside the perinatal setting. Problems due to inaccessible information in health care institutions have been linked to risks to patient safety because visually impaired patients miss the information that is distributed in leaflets and on posters (Cupples, Hart, Johnston, & Jackson, 2012). Like institutions, it appears that providers are also unprepared to accommodate blind patients. A study that included 20 internal medicine physicians found that five of these doctors had some patient information in large print and only one physician mentioned having materials in braille (Agaronnik, Campbell, Ressalam, & Iezzoni, 2019).

**Implications for nursing policy and health care policy.** The implications of these findings not only affect nursing policy; they also impact health care policy. Hospitals

and physicians should accommodate patients who are blind and provide them with information that they can access (U.S. Department of Justice, 2014). The ADA states that blind patients should receive the same service as sighted patients and, therefore, they should be provided with information in an alternate (accessible) format (U.S. Department of Justice, 2014). Options for these alternate formats include large print, read-out-loud by a qualified reader, braille, electronically transmitted and accessible with screen reader software, or audio recording (U.S. Department of Justice, 2014). Policymakers should note that not all blind patients can access *all* alternate formats. The Department of Justice (2014) recommends that the person with the visual impairment should be asked to select the most effective alternate format for them. Thus, the hospital or physician should ask the blind patient which alternative method they prefer. Ideally, conversations regarding accommodations should occur at the beginning of the patient-provider relationship to allow time for preparation of the accessible materials.

**Implications for nursing education.** Contemporary nursing emphasizes the importance of patient teaching and the importance of linking patients with relevant resources. Examples of these expectations include teaching patients with diabetes how to read and interpret food labels as well as instructing them in the proper use of a glucometer (Fisher et al., 2005). Likewise, memory boxes with tangible keepsakes and information about peer support groups are commonly offered to patients who experience a fetal demise (Ravaldi et al., 2018). These examples illustrate that the nursing profession seeks to provide patient-centered teaching and aims to match available resources with the needs of the individual patient. It appears that the accommodation of



visually impaired patients in other medical specialties is more widespread than in obstetrics. Blind patients with diabetes, for example, have access to education and specialized equipment that facilitates independent blood glucose evaluation and insulin administration (Heinemann, Drossel, Freckmann, & Kulzer, 2016). However, the current study found that the needs of blind patients in obstetrics are unmet because (a) information was not accessible and (b) professionals were unaware of their unique needs. These needs, as they relate to patient teaching and patient resources, are further discussed.

***Patient teaching.*** Several of the study participants felt proud that they were able to find information regarding pregnancy, lactation, exercise, and breast pumps for themselves. From a nursing perspective, these statements are very concerning. Most of them did not attend childbirth classes, breastfeeding classes, or prenatal exercise classes. Instead, these resourceful women researched pregnancy related topics online, looked at a friend's breast pump, and attended water-aerobics for elderly women. It is very likely that they would have benefited greatly from reading their prenatal handouts. Instead they missed the information regarding pregnancy milestones, normal and abnormal signs and symptoms, as well as perinatal classes. Not providing blind patients with these materials in an alternate format directly impacts patient safety. It is equally concerning that all the study participants described the discharge information (including discharge teaching) as inaccessible and that none of them remembered being told about postpartum danger signs. This suggests that blind obstetric patients do not receive standardized, updated, and relevant information regarding their health both prenatally from their obstetric

providers and at discharge from their hospital. It should be considered that it is the responsibility of the professional nurse to engage in patient-centered teaching. Some of the core competencies of nursing are listening to patients, giving clear information, and providing patient-centered education (Boykins, 2014). Nurses must identify their patients' individual differences and unique needs before developing a patient specific education plan (Boykins, 2014). Consequently, perinatal nurses should not delegate patient education to the patient herself. Certainly, it is acceptable that patients supplement their education with self-identified resources. However, it should not be expected that blind women seek out their own perinatal education and obstetric resources independently.

*Patient resources.* Contemporary nursing emphasizes the importance of linking patients with appropriate outside resources. Previously published articles confirm that health care providers fail to refer these women to outside resources and agencies where they can learn about common adaptations for blind mothers (Frederick, 2015, 2017; Kent, 2002). In this sample, none of the participants received any information regarding adaptive parenting techniques or regarding online blind mother peer support groups. Several participants stated that they did not expect to receive resources about adaptive parenting from their health care provider. They believed that it was their responsibility to find the information and resources they needed themselves. The participants in this study were fortunate that they were able to network with blind mother support groups and/or the NFB. It is admirable that the community of blind mothers is actively engaged in sharing practical information with pregnant women and new mothers through peer

networking. It is equally amazing that the blind community has access to a nationwide governing body (NFB) for legal information and other resources. However, it cannot be assumed that every blind pregnant woman can link up with these outside resources by herself. Most of the participants in this study were educated and well-connected in the blind community. Frederick (2015) points out that medical professionals are completely unaware of the resources available to blind parents. It is, therefore, incumbent on the nursing profession to (a) identify the information and resources that this population needs, and (b) link this population with agencies and groups that can provide these resources.

## **Theme 2: Facing Mobility Issues**

The study participants discussed their mobility issues with the researcher. None of the studies that previously reported on this population had mentioned transportation and mobility. Typically, the participants managed outdoor transportation in such a way that it did not interfere with their care. They used a combination of rideshare platforms, public transportation options, and rides from friends and relatives. The participants also discussed their indoor mobility needs. Several participants mentioned that the hospital staff assisted them voluntarily with mobility in the hospital. However, problems with indoor mobility occurred for some participants, when nurses were not willing to assist. A blind mother who wanted to remain with her newborn in the NICU after she was discharged from the postpartum unit was told that she could take a shower in a NICU parent area. When she asked the nurses for assistance to walk to this area, she was told that they could not leave their floor. The NICU nurses added that it was not the

responsibility of the volunteers to help her. Unable to locate this designated area without assistance, this blind mother waited to take a shower until after her baby was discharged home. Another blind mother wondered if postpartum nurses were fabricating hospital rules to keep her from accompanying her baby to the nursery for routine procedures. Many NICUs and newborn nurseries allow parents to be present during procedures such as IV starts (American Academy of Pediatrics, 2015). This participant silently questioned if a policy prohibiting mothers from being present during nursery procedures existed, or if it was fabricated by the nurses for their convenience. She wondered if the nurses were just not motivated enough to help her. The literature regarding mobility assistance of people with visual disabilities in the hospital is scarce. However, a study that gauged staff awareness in hospitals indicated that many nurses lack familiarity with mobility techniques (e.g., sighted guide) to assist visually impaired people in the hospital (Carlson, Howe, Pedersen, & Yoder, 2020).

Overall, the participants in this study functioned independently in their patient rooms, but they did not feel comfortable negotiating the entire hospital without the assistance of a sighted person. Their statements also indicated that while some staff members voluntarily assisted them, others did not.

**Implications for nursing policy and health care policy.** The ADA states that commercial facilities such as hospitals and medical offices should provide people who are blind with an equal opportunity to participate in and benefit from all of the goods and services provided by the facility (ADA National Network, 2020). It appeared that most participants were satisfied with the mobility assistance they received during appointments

in provider offices as well as when they were inpatients in the hospital. However, as Title III entities, hospitals should accommodate not only the person who is receiving the care but also the visitors of this patient (Marshall & Joffe, 2006). Consequently, the hospital should provide mobility assistance to a blind mother who is visiting her newborn in the NICU. Many hospitals have volunteers who assist with this service without advance notice. If volunteers are not available, then the staff should make the needed arrangements. In some cases, the person who needs help with mobility on a non-emergent basis, may be asked to schedule the assistance. For example, a blind mother may request help to travel from the NICU to the cafeteria between noon and 1 o'clock. The study participant who was told that nobody could guide her to the NICU parent area to take a shower was very upset about this; however, she did not file a complaint with the hospital unit manager.

**Implications for nursing practice and nursing education.** Nurses should understand that the ADA gives people with disabilities the same right to access as people without disabilities. Therefore, all hospital staff should be oriented to the importance of assisting a blind patient or a blind visitor in the facility. Understandably, the nurse's primary duty is to his/her patients. However, accompanying a blind visitor or blind patient can be delegated to non-licensed staff and in some hospitals, volunteers assume these duties.

Some inpatient obstetric departments do not prohibit parents from accompanying their newborn to the nursery for routine procedures such as blood draws, circumcisions, and assessments. Therefore, if a blind mother requests to be present during these

procedures, she should be accommodated. Nurses may need additional training to meet the needs of visually impaired patients and visitors. Carlson et al. (2020) found that, after educating staff nurses in the use of sighted guide techniques, their level of comfort with assisting blind people improved. It is important that nurses do not assume what type of assistance is required; instead, they should simply ask the person with the disability how their needs are best met.

### **Theme 3: Fear of Losing Custody**

All but one of the study participants expressed a fear of losing custody of their baby. For some participants this fear was the result of personal experiences while for others it was based on stories of what happened to other blind women. The participants reported that they experienced excessive scrutiny from health care workers and that they tried very hard to avoid all contact with the hospital social worker. They also believed that they had to give the postpartum staff the impression that they were perfect mothers in order to ward off potential social services inquiries. The existing literature overwhelmingly agrees with these findings. The existing research described the same excessive scrutiny from professionals and the same generalized fear of losing custody among new mothers who are blind (Branson, 1975; Frederick, 2015, 2017; Kent, 2002; Lawler et al., 2015; Walsh-Gallagher et al., 2012; Wolowicz-Ruszkowska, 2016). Frederick (2015) coined the term the medical stare to describe the high levels of institutional surveillance and scrutiny experienced by this population. A blind participant felt terrified and thought that they would take her baby away if she did not breastfeed perfectly (Frederick, 2017). Similarly, Frederick (2015) interviewed a blind mother who

had lost custody of her newborn daughter for 57 days because a social worker stated, “I can’t, in good conscience, send this baby home with blind parents” (p. 1136). Congruent reports from most participants in the current study were noted inasmuch that they had heard accounts of blind mothers losing custody of their baby because of their blindness. One participant had a friend who had lost custody of her newborn for about two months because of her blindness. The majority of the current study’s sample did not report any personal issues with social services. However, one study participant had to fight for the right to take her baby home and described her struggle.

It appears that asking for help or accepting help is a catalyst for a social services investigation. In this study, the participant who had to fight to take her baby home had initially requested the help of the social worker to make printed information accessible to her. However, instead of receiving this help, the social worker sought to place this new mother’s baby in foster care. The social worker did not believe that the participant, a single mother, had the skills to care for her newborn. This participant was able to prove her ability to parent due to the support of the nursing staff and the legal assistance of the NFB. Frederick (2015) presented a similar account of a blind mother who gratefully accepted the help of a night nurse during her postpartum stay. This nurse then documented that the blind parents were unable to care for their newborn independently, which resulted in a full investigation of their parenting ability (Frederick, 2015). Stories such as these are shared in the blind community, and they cause much fear among blind parents.

The current study found that there are serious consequences for this population when they fear social services. These consequences are the result of the connection between health care workers and social workers. If nurses deem that a blind mother is not able to care for her newborn, then social workers are automatically alerted. The fear of losing custody is thus translated into a fear of social workers *and* a fear of health care workers. Among the participants in this study, this fear of health care providers resulted in a decrease in help-seeking behaviors. This decrease in help-seeking behaviors is a new finding that was not identified in previously performed research. This study pinpointed four separate accounts of participants who described how fearing health care workers altered their thinking as well as their behaviors.

Two study participants stated that, during the puerperium, they exhibited all the signs and symptoms of a postpartum mood disorder. However, they opted not to disclose this to their providers. One of these participants said that her baby's pediatrician asked about her mental health, which terrified her. She did not respond truthfully and hid the signs of her postpartum depression because she feared losing custody of her newborn. A third participant described her hesitation to seek the care she needed. She mentioned that, shortly after being discharged home with her newborn, she had major breastfeeding problems. She realized that she needed the help of a lactation consultant, but this participant was very reluctant to reach out for professional assistance. She explained that a sighted mother would not think twice to get the help she needed, but as a blind mother, she needed to be much more careful. According to her, blind mothers open the door to much scrutiny when they seek professional assistance. A simple request for



breastfeeding assistance could easily lead to a Child Protective Services referral. It all depends on how the professional sees the blind mother. Being subjected to these arbitrary judgments make blind mothers much less likely to seek needed medical treatment. A study participant summarized the problem succinctly, “You really have to feel comfortable and be able to trust that the people you're reaching out to for help aren't going to take your child. Yeah, that really is a big fear for blind people.” Fear of losing custody is thus a catalyst for very unhealthy behaviors among these participants.

**Implications for nursing practice.** Nursing, at its core, is a caring profession. Historically, nurses have been praised for their kindness and selfless dedication to care for the sick. However, it appears that blind pregnant women and blind mothers have a different impression of professional nurses. Granted, every participant in this study mentioned meeting kind and supportive nurses, but it seems from the descriptions of these participants, the positive does not outweigh the negative. The problem that these participants described indicates that only one incident from a single health care worker might instigate the process that could lead to losing custody of their baby. Thus, it only takes a single nurse to negate the positive effects of all the supportive nurses. These women do not know when or where they may encounter that one nurse who does not understand how they function as a mother and, therefore, they have become suspicious of all nurses. The realization that nurses are mistrusted by this population should be a catalyst for an evaluation of this perception. Additionally, the fact that these participants opted to forego essential care due to this mistrust is extremely concerning.

In this study, patient safety of both the mother and the newborn were clearly jeopardized. The women with postpartum mood disorders knew that they needed help, but their fear of health care providers kept them from getting the care they needed. Additionally, the stressors of living in fear of health care workers likely impacted this sample emotionally, mentally, and psychologically. The researcher hopes that these findings will prompt additional interdisciplinary research. Future interdisciplinary research into this perception of mistrust should focus on yielding practical solutions for nursing practice and nursing education.

#### **Theme 4: Comradery among Blind Mothers**

All the study participants emphasized the importance of peer support. Most of this support was provided through peer networks that were accessed online (Facebook, WhatsApp, etc.). In larger cities, participants described attending in-person meetings with peers. The participants invariably recommended that all blind women who are pregnant or who want to become pregnant should join a blind parent support group. The existing literature echoed these findings and emphasized the importance of peer support. Both Frederick (2015, 2017) and Kent (2002) stated that blind women must network with other blind women to access the knowledge needed to be successful blind mothers. Kent (2002) praised other blind women for telling her about a stroller that was more convenient for blind mothers. Frederick (2015, 2017) and Kent (2002) credited the NFB with enhancing their success as blind mothers. The existing research credited peer support with attempting to informally educate new blind mothers and noted that it replaced professional education (Bieber-Shut, 1993; Frederick, 2015, 2017; Kent, 2002).

The findings of this study confirmed these results and emphasized the importance of networking with peers.

However, the participants in this study expanded on the functions of these peer support groups beyond what was previously described in the literature. This study showed that in-person peer support groups often offer blind women access to hands-on baby care. Many blind women who are pregnant for the first time are not familiar with newborn care because they have not been exposed to it. The hands-on experiences offered in these support groups aim to increase the confidence of the inexperienced pregnant women. Additionally, another function of this type of peer networking, not previously discussed in the literature, is *discourse prep*. Discourse prep refers to the preparation that blind mothers give expectant blind women for their upcoming interactions with health care workers and social workers. A participant stated that, in these support groups, new members learn how to respond to the various questions that these professionals ask about their ability to safely care for their baby. Practicing hands-on newborn care and knowing how to respond to these questions are integral elements of peer support. The participants highlighted that it takes time to learn these skills and that blind women should join these peer support groups early, preferably before they become pregnant. In addition to teaching these practical skills, these networks are also the perfect vehicle for providing emotional support to members who feel frustrated, depressed, or vulnerable.

**Implications for nursing practice.** Responsibilities of professional nurses include patient teaching, finding and sharing appropriate patient resources, and providing patients

with emotional support. It appears that, in this population, these nursing responsibilities have been assumed by informal peer support groups. Blackford, Richardson, and Grieve (2000) agreed that there are gaps in the prenatal education of women with disabilities and that their unique needs are often overlooked. Nurses who function as prenatal educators should, therefore, modify their teaching to accommodate these needs and they should increase their educational resources regarding mothering with a disability (Blackford et al., 2000). Adaptive baby care basics tailored to increasing the skill and comfort level of blind women should be taught by the hospital. Obstetric and pediatric patient educators should be given the tools by their employers to provide appropriate patient education. Additionally, nurses should investigate the biased nursing behaviors perceived by this population and strive to alter these perceptions. Finally, it should be a nursing goal to meet the emotional needs of these patients and refer them to professional mental health practitioners when needed.

The nursing profession should foster an ongoing collaboration with local and national blind mother networks as well as with the NFB to accomplish these goals. The nursing profession cannot lead in this endeavor. In this case, nurses must be led, and they must be willing to learn. Nurses should follow the guidance of this population and ask blind mothers how to best meet their needs. It must be noted that, by alleviating some of the responsibilities of the support groups, nurses should not consider these peer networks as redundant. Indeed, educational interventions rolled out by prenatal educators may facilitate a shift in focus for these support groups. Through sharing the responsibilities for education and resources with nurses, these peer networks could potentially spend less

time on diligently preparing for blind motherhood and more time on enjoying the pleasures of becoming a new mother.

### **Theme 5: Stigma is Real**

Stigma refers to a combination of beliefs, attitudes, and assumptions that are the foundation for destructive behaviors towards the stigmatized individual (Omvig, 2017). During the perinatal period, all participants perceived these destructive attitudes from strangers, friends, family, and health care workers.

**Interactions with strangers, friends, and family.** Strangers reportedly asked intrusive questions and made biased comments regarding the participants as expectant mothers or new mothers. These interactions tended to make the participants feel as if they should not be a mother. Study participants reported that negative comments from strangers during this time were not unusual. Most of the time, the women in this study ignored these hurtful remarks. One participant stated that, occasionally, she educated a few biased strangers about the abilities of blind mothers. However, she doubted that it changed their offending beliefs. The existing literature on this population did not report on the interactions with strangers and the results of this study are the first findings on this topic.

The participants in the current study reported incidents of parents, in-laws, extended family, members of their religious congregation, and friends expressing their disapproval of them having children. Overwhelmingly, this disapproval focused on the belief that, as a blind woman, the participant could not be an independent mother and should not elect to have children. Previously performed research confirmed these

findings and found that, during social interactions, blind women received implicit and explicit messages suggesting they should not be mothers (Kent, 2002; Schildberger et al., 2017; Wolowicz-Ruszkowska, 2016). Schildberger et al. (2017) reported that a blind participant was very distraught because her parents wanted to assume custody of her newborn. The current study found that a sighted husband lacked confidence in his wife's ability and tried to assume most of the care of their newborn. Wolowicz-Ruszkowska (2016) described a similar situation in which a blind mother felt left out when her sighted husband assumed not only the care for their infant but also all the decision-making responsibilities. Kent (2002) reported how teenage girls who are blind are not asked to babysit like their sighted peers. This finding was corroborated by a participant in this research study who agrees with Kent (2002) who states that society does not view them as mothers. The current study found that most of the participants who reported having non-supportive family and friends demonstrated resilience and became successful mothers despite these negative encounters.

**Interactions with health care workers.** All participants reported very positive interactions with health care workers. Among other things, nurses and physicians were credited with being very supportive, helpful with infant care and breastfeeding, as well as giving excellent verbal descriptions of their actions. However, in addition to these positive experiences, all participants also reported negative interactions with professionals. Several participants reported sensing how their blindness made their health care providers uncomfortable. The participants reported that they felt the tension when sighted workers felt awkward around them. Participants stated that, when this

happened, interactions were usually short and the person who was uncomfortable did not engage much with them. They attributed this uneasy feeling to the likelihood that these workers were simply unfamiliar with blind people. One participant even excused very unhelpful nursing behaviors because she understood that these nurses had never taken care of a blind patient before. The research on this topic echoes similar findings. One woman expressed her dislike for the tension she perceived. This blind participant, quoted by Lawler et al. (2015) said, “The subtle patronizing attitudes, there’s almost a kind of horror having to care for someone with a disability” (p. 1678). The participants in the current study did not confront their providers and accepted the feelings of unease, if professionalism was maintained.

In this study, several participants mentioned being offended by their providers because they made assumptions regarding their fertility. One obstetric provider fully expected to perform a bilateral tubal ligation on her blind patient after she delivered her baby. The new mother was shocked and did not have the procedure. Likewise, some participants in this study felt that comments from their providers seemed to suggest that a blind fetus should be identified and aborted. A participant was very upset that the push for genetic testing continued even after she had informed her providers that their insistence was making her uncomfortable. Another participant who sought assistance to conceive from a fertility specialist felt she was quizzed extensively about the cause of her blindness. She felt that the doctor was asking these questions to decide IF he would help her get pregnant. There is evidence in the existing research that this population has experienced provider biases such as these before. Wolowicz-Ruszkowska (2016)

reported that a blind participant's physician told her that getting pregnant was a "stupid" idea (p. 85). Likewise, the research also identified instances of health care workers encouraging blind expectant mothers to have abortions or put their babies up for adoption (Frederick, 2015, 2017; Wolowicz-Ruszkowska, 2016). The participants in this study responded to these biased comments and questions by expressing their concern to their providers.

The participants in this study overwhelmingly agreed that health care workers did not address them when a sighted person was with them. Several patients mentioned that, if a sighted friend or family member was present, the professionals communicated exclusively with that person instead of with them. Almost all the participants expressed their frustration with being invisible to the people who were supposed to be providing their care. A woman in this study remembered her frustration when, during her first obstetric visit, the physician was not talking to her but to her friend who had accompanied her to the visit. To make matters worse, the nurse then asked the participant to leave the consultation room so she could assess her vital signs. All this occurred while the physician continued his conversation regarding her care with the participant's friend. A participant who did not bring a sighted person to her appointments reported that the physician and his staff "talked to her like she was a child." This participant remarked that many individuals cannot appreciate the true intelligence of someone with a physical disability. The literature confirmed similar findings of blind expectant mothers who were made to feel invisible by their providers and who



experienced condescending conversations with their health care team (Bieber-Schut, 1993; Branson, 1975; Frederick, 2015, 2017; Schildberger et al., 2017).

All but one of the participants in this study reported being excessively quizzed by health care workers. These questions were probes to assess the blind patient's ability to care for her newborn. Health care providers invariably asked the participants about the type of assistance available to them at home. This question aimed to assess who was going to be the newborn's primary caregiver. A participant, who had adult children, was asked multiple times if her (adult) daughter was going to "help her take care of the baby." Another participant was frustrated when the pediatrician was asking too many detailed questions at her son's first week check-up. Among other things, she had to describe how she mixed his formula, how she fed him, how she changed his diapers, and how she gave him a bath. All the participants believed that sighted mothers were not subjected to such an onslaught of questions. Nevertheless, the participants dutifully answered the questions because they understood that if the health care worker was not satisfied with their answers, a social services inquiry would likely follow. The existing research overwhelmingly agrees with these findings. Wolowicz-Ruszkowska (2016) reported that her participants experienced aggressive observation and questioning, which is consistent with the medical stare as described by Frederick (2015, 2017). Lawler et al. (2015) found that some blind women's sense of self unraveled because of this constant questioning and surveillance.

The findings of this study and the existing literature indicate that health care workers subject these patients to an avalanche of probing questions, aimed at identifying

incompetence instead of identifying learning needs. Frederick (2015, 2017) and Kent (2002) agree that perinatal health care professionals consistently fail to ask key questions to identify the unique needs of this patient population. All the women in this sample, as well as in previously reported research, answered the questions they were asked. No reports of official patient complaints were noted, which might be linked to this population's fear of social services (theme 3).

Several study participants reported that health care workers often made incorrect assumptions about their abilities. Most of the time this would lead to not being allowed to perform basic tasks because they were blind. A participant who was an experienced mother of two older children was told that she could not change her baby's diaper because "she might do it wrong." The same nurse also told her that she could not wash her breast pump parts. She told the blind mother, "You won't know if they're actually clean or not." Previous research provides further evidence of these incorrect assumptions. Bieber-Schut (1993) commented that some of her study participants were not allowed to hold their newborn unless their (sighted) husbands were present. Branson (1975) aimed to educate nurses and emphasized that the foundation for supporting a blind mother is accepting the blind mother. Branson's (1975) article suggested that, with a few adaptations, blind patients become very capable mothers. A participant in the current study highlighted another problem caused by incorrect assumptions. She mentioned that providers often attribute unrelated issues to her blindness. This participant explained that her breastfeeding problems were certainly not caused by her inability to see, but that the nursing staff automatically assumed that it was.

**Implications for nursing.** The study participants experienced stigma while interacting with strangers, while interacting with family members and friends, and while interacting with health care workers. The bias they experienced was based on incorrect assumptions regarding their abilities as blind women and as blind mothers. The nursing profession cannot change the biases of strangers, family members, and friends. It should, however, make changing the bias among health care providers a priority. It can be argued that this population is being bullied and harassed by professionals at a time that they are most vulnerable. Further research into this bias should focus on strategies to remedy it. Interestingly, despite these experiences, none of the participants complained about their health care workers. They did not contact the charge nurses, the supervisors, or the hospital administrators to express their concerns. It should be considered that, possibly, the fear of losing custody reduced their desire to rectify these biases.

### **Recommendations for Future Research**

This study presented new findings and validated findings from the existing literature. The researcher believes that this study also identified new gaps in the body of knowledge and thereby exposing opportunities for further research. Much of this future research would benefit greatly from an interdisciplinary approach and, whenever possible, should be performed in collaboration with the NFB. Further investigation of the inaccessible resources should be considered from a health care policy perspective. In collaboration with blind mother support groups, perinatal educators would benefit greatly from researching the unique needs of this population and developing adaptive perinatal classes. An evaluation of the attitudes and behaviors of obstetric care givers should be

performed to identify and remedy biases. In collaboration with the field of social work, the fear of losing custody should be made a priority for future research. Finally, research that seeks to understand this population's hesitance to stand up for their rights and their failure to lodge official complaints needs to be performed.

### **Significance of the Study**

As expected, an initial inquiry in the experiences of a population is likely to reveal new findings. In this study, these findings are significant to professional nursing as well as to related disciplines. An important new finding is the evidence of a decrease in help-seeking behaviors as a result of the participants' fear of losing custody. Furthermore, the participants in this study expanded on the functions of the blind mother support groups and revealed elements that had previously not been considered. This study is the first to report that this population emphasizes the importance of early peer support which often includes practical infant care experiences as well as discourse preparation for interactions with health care workers. Additionally, the findings described interactions with strangers, which provides a first glimpse in the experiences of this population with the public. This study is the first to point out that inpatient discharge teaching in postpartum is not provided in an accessible format to blind patients. The researcher also noted that none of the participants filed official complaints regarding the barriers they experienced in hospitals and medical offices.

The implications of this study that were relevant to the nursing profession (and related disciplines) were largely theme specific. Therefore, the researcher incorporated these implications within each respective theme earlier in this chapter. However, the

societal implications of the study warrant a brief review. As discussed in chapter three, both intersectionality and the social model of disability framed this critical exploration of the perinatal experiences of blind women. These frameworks are now used to discuss the societal significance of this study.

In the social model of disability, the limitations imposed by blindness are not viewed as the physical implications of not being able to see. This model views the limitations imposed by blindness as a social construct. Thus, the individual's limitations are determined by the interplay between the person herself and her social environment (Scullion, 2010). The results of this study are congruent with this model because most of the limitations imposed on the participants were socially constructed limitations. For example, the participants understood that social workers and health care workers assumed that they were inadequate mothers. The resultant fear of losing custody became a barrier to essential care and limited the participants' help seeking behaviors. Consequently, their care was hampered not because of their blindness but because of the incorrect assumptions about their blindness. The findings illustrate that these socially constructed barriers are rooted in biased attitudes. This indicates that the study findings are congruent with the social model of disability. This model also suggests that, if these biased attitudes were eliminated, most of the limitations caused by the participants' physical blindness would also be eliminated. Consequently, if the assumption that blind women cannot be mothers were eliminated, most of their negative experiences would also be eliminated.

Intersectionality, the second framework selected to guide the study considers the additive effect of multiple stigmatized identities. In line with intersectionality, the researcher explored the experiences of participants who share three intersecting vulnerable identities: (a) female, (b) childbearing, and (c) blind. Intersectionality seeks to investigate the experiences of historically marginalized individuals in the presence of socially constructed power (Syed, 2010). In this study, health care workers and members of the community are the ones who have the socially constructed power. The findings of the study indicate that blind women in the perinatal period are stigmatized by those in these positions of power. In conversations with providers (who hold positions of power), the pregnant blind woman was often discounted and ignored. Then, after this patient delivers, these care providers scrutinize her behaviors, looking for evidence of her inability to care for her child. These findings suggest that the cultural and societal power structures present during the perinatal period negatively affect blind women. These findings are especially significant to the people who occupy these positions of power.

### **Limitations**

This qualitative study has several limitations. The solicitation used to recruit the participants was emailed by the NFB to individuals on their blind parent listserv. This implies that all the participants were interested in receiving notifications and information for blind parents from the leading organization for the blind. It also highlights that the participants had access to a computer or smart phone. Therefore, the women in this sample were likely among the more educated and more privileged blind mothers. This limitation is further substantiated by the level of education of this sample; most had

obtained a college degree. The findings of this study are based on the experiences of a small sample of seven women, which is another study limitation. This small number of participants was a direct result of the study's stringent inclusion criteria. Only English-speaking, adult women, with no useable vision, who had delivered a child in the United States during the last seven years were eligible to participate. The sample consisted of three Caucasian women, three Hispanic women, and one Asian woman. Therefore, the lack of African American and Native American participants is another limitation of this research study. Finally, the interviews were conducted by phone which limited interpersonal contact. It is conceivable that some participants may not have shared all the details of their experiences due to this limitation.

### **Conclusion**

This qualitative study was a critical exploration of the perinatal experiences of blind women. The goal was to describe the barriers these women experienced during this time. This study found that attitudinal, structural, and institutional barriers are present. Evidence of the attitudinal barriers is found in the themes: stigma is real and fear of losing custody. The structural barriers pertained to indoor mobility as described in the second theme facing mobility issues. The institutional barriers related to the lack of accommodations in the hospitals are described primarily in the theme information remains inaccessible. In comradery among blind mothers, the participants discussed how they supported each other and how they negotiated some of these barriers. This exploratory study presented the significance of these findings and emphasized the

implications to nursing and related professions. This research includes recommendations for future interdisciplinary research.



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## APPENDIX A

### National Federation of the Blind Recruitment Agreement

Blake, Lou Ann <LBlake@nfb.org>

Oct 22, 2018, 12:26 PM

Hello Professor Jackson,

I am happy to help you with getting the word out about your research. Once your research has received IRB approval and you are ready to begin collecting data, your research study will need to be reviewed by our research advisory council before NFB members can be solicited to participate. This is a simple process. The first step is to complete the research participant solicitation request form. The form can be accessed at [https://nfb.org/research\\_participant\\_solicitation\\_request\\_form](https://nfb.org/research_participant_solicitation_request_form). I will forward the completed form to our RAC for their review. Once I have received RAC approval of your research for participation by our members, I will ask you to email an announcement to me suitable for posting to the appropriate NFB list(s). Please feel free to contact me if you have any questions. I look forward to hearing from you!

Best regards,

Lou Ann

Lou Ann Blake, J.D.

(410) 659-9314 x 2221

National Federation of the Blind

APPENDIX B

Recruitment Notification

Hello,

I am doing a research study to help the nursing profession understand the perinatal experiences of blind women. Perinatal experiences are the experiences during pregnancy, childbirth, and the first six weeks after giving birth. If you are a blind woman and you had a child in the last seven years, then you may be eligible to participate in my study. I need no more than 2 hours of your time. I will interview you over the phone, at a time that is convenient for you. If you complete the interview, I will give you a \$75 Visa gift card as a token of my appreciation.

My name is Nina Jackson and I am doing this research as a PhD student at Texas Woman's University. If you are interested in participating or if you have questions, please call or text me at 210-843-6338. You can also email me at [njackson6@twu.edu](mailto:njackson6@twu.edu)

I hope to hear from you soon.

## APPENDIX C

### Eligibility Screening Tool

Phone response to a notification of interest from a potential participant.

How did you hear about my study?

May I ask you a few questions to determine if you are eligible to take part in my study?

How old are you?

Do you have at least one child who is seven years old or younger?

In what city was this child born?

What is the cause of your blindness?

Do you use a mobility aid outside your home? If so, what mobility aid do you use? Did you use a mobility aid while you were pregnant?

Do you have time to schedule a phone interview with me within the next few weeks?

This interview may take up to two hours.

**If eligible**

Great! You are eligible to take part in my study. Would you like to participate?

(Researcher discusses the logistics of scheduling the phone interview and explains the consenting process)

**If not eligible**

I am sorry but you do not meet the study's eligibility criteria. I thank you for your time and for contacting me.

APPENDIX D

TWU Consent to Participate in Research



TEXAS WOMAN'S UNIVERSITY (TWU)  
CONSENT TO PARTICIPATE IN RESEARCH

Title: The Perinatal Experiences of Blind Women

Principal Investigator: Nina Jackson.....njackson6@twu.edu  
210/843-6338

Faculty Advisor: Peggy Mancuso, PhD.....pmancuso@twu.edu  
940/898-2425

Summary and Key Information about the Study

You are being asked to participate in a research study conducted by Ms. Nina Jackson, a student at Texas Woman's University, as a part of her dissertation. The purpose of this research is to explore the experiences of blind women during the perinatal period. The perinatal period is time that you were pregnant and gave birth to your baby. The perinatal period also includes the first six weeks after giving birth. You have been invited to participate in this study because you are a blind woman who had a child within the last seven years. As a participant you will be asked to take part in a telephone interview regarding your experiences with health care providers, health care workers, family members, colleagues, and strangers during the perinatal period. This interview will be audio recorded, and we will use a code name to protect your confidentiality. The total time commitment for this study will be about two hours. Following the completion of the interview, you will receive a \$75 gift card for your participation. The greatest risks of this study include potential loss of confidentiality and emotional discomfort. We will discuss these risks and the rest of the study procedures in greater detail below.

Your participation in this study is completely voluntary. If you are interested in learning more about this study, please review this consent form carefully and take your time deciding whether or not you want to participate. Please feel free to ask the researcher any questions you have about the study at any time.

Description of Procedures

As a participant in this study you will be asked to spend about one hour and 30 minutes of your time in a phone interview with the researcher. An additional time of approximately 20-30 minutes may be needed to verify information. The researcher will ask you questions about your experiences during the perinatal period. You and the researcher will decide together on a time when the interview will happen. The researcher will assign a code to your interview. The interview will be audio recorded and then written down so that the researcher can be accurate when studying what you have said. In order to be a participant in this study, you must be 18 years of age or older and you must speak English. You must have had a child in the United States in the last seven years. You must be blind or visually impaired to the degree that you need a mobility aid such as a white cane, a guide dog, or a sighted guide when you travel outside your home.

### Potential Risks

The researcher will ask you questions about your positive and negative experiences during the perinatal period. A possible risk in this study is discomfort with these questions you are asked. If you become tired or upset, you may take breaks as needed. You may also stop answering questions at any time and end the interview. If you feel you need to talk to a professional about your discomfort, the researcher will provide you with a list of resources.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview should be done while you are at a private location. A code name, not your real name, will be used during the interview. No one but the researcher will know your real name.

The audio recording and the written interview will be stored in a locked cabinet in the researcher's office. Only the researcher, her advisor, and the person who writes down the interview will hear the audio recording or read the written interview. The audio recording and the written interview will be destroyed within three years after the study is finished. The audio recording of your verbal consent will be stored separately from all collected information and will be destroyed three years after the study is closed. The results of the study may be reported in scientific magazines or journals but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and internet transactions.

Your audio recording and/or any personal information collected for this study will not be used or distributed for future research even after the researchers remove your personal or identifiable information (e.g. your name, date of birth, contact information).

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will try to help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

### Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the interview, you will receive a \$75 gift card for your participation. If you would like to receive a transcribed copy of your interview, we will email or mail it to you. \*

### Questions Regarding the Study

You have an electronic copy of this consent form. Please keep it and if you have questions about the research study you should ask the researchers; their contact information is at the top of this form. If you have questions about your rights as a participant in this research or the way this study

has been conducted, you may contact the TWU Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

Verbal consent is obtained, and audio recorded by Nina Jackson, Principal Investigator, prior to the interview.

\*If you would like to receive the \$75 Visa gift card and/or a copy of your interview transcript, tell us where you want them sent:

Email: \_\_\_\_\_ or Address: \_\_\_\_\_  
\_\_\_\_\_

Page 2 of 2

APPENDIX E

National Federation of the Blind Verbal Consent Guidelines

Blake, Lou Ann <LBlake@nfb.org>

Fri, Jun 7, 8:41 AM

Hello Nina,

Here is a response I received from one of our Research Advisory Council members to your question:

When doing surveys or interviews over the telephone it is fine for the researcher to read a consent form over the phone and ask the participant if she agrees to participate. In these cases, the conversation is usually recorded, which it most often is for data collection procedures and this information too is included in the consent form.

Please feel free to contact me if I can be of further assistance. Good luck with your research!

Best regards,

Lou Ann

Lou Ann Blake, J.D.

Deputy Executive Director, Blindness Initiatives

200 East Wells Street, Baltimore, MD 21230

(410) 659-9314, extension 2221 | lblake@nfb.org

## APPENDIX F

### Demographic Questionnaire for Qualified Participants

How old are you?

What is your marital status?

What is your ethnicity?

What is your current employment status?

What is your highest level of education?

How many children do you have?

How old is/are your child(ren)?

In what city did you have your child(ren)?

Did you have prenatal care from a physician or midwife?

Did you have your child(ren) in a hospital, birth center, or at home?

Did you have a normal vaginal delivery or a cesarean section?

Did you breastfeed, formula feed, or both?

What is the cause of your blindness?

What mobility aids do you use outside your home?

Did you require these mobility aids at the time of your pregnancy?

## APPENDIX G

### Semi Structured Interview Questions



Introduction: I would like to hear about your perinatal experiences which is from the very beginning of your pregnancy until the time that your baby was about 6 weeks old.

**Main question:**

- **What were your experiences as a woman who is blind and who is having a baby?**

Probing questions – Solicit information about each part of the perinatal period (pregnancy, labor & birth, and postpartum):

- Who was supportive? (explore what their supportive actions/words were)
- Was there, at any time, anyone who was *not* supportive of you? Who were they and what were their concerns? (explore what their non-supportive actions/words were)
- What did the doctors, nurses and other professionals do and say to demonstrate their support for you? (or their lack of support)
- What made you feel that you, as a blind woman, were fully accommodated throughout this perinatal period? (or not fully accommodated)? What was great and what could be improved?

**If participant does not address this spontaneously – Ask:**

- ✓ What resources did the doctor's office give you? Were these resources accessible to you?
- ✓ Where did you have your baby? (hospital, birthing center, homebirth?)
- ✓ (If hospital birth) - Where was the baby during the postpartum period? (rooming in, nursery, NICU)
- ✓ (if hospital birth) - Did a social worker meet with you before you were discharged from the hospital? What resources did the social worker give you?
- ✓ What were the teaching methods used to teach you about baby care?
- ✓ If anything, what could the nurses have done to make your experience better?
- ✓ At any time during this perinatal period did you feel that you were treated differently because you are blind. Did anyone use language that was offensive to you? Were there any issues with anything because of your blindness?

**Ending Questions:**

- Throughout this perinatal period, who gave you the best advice? What did they tell you?
- Having had your baby, what advice do you have for other blind women who are pregnant? What would you tell them?