

**Deaf women's experiences of pregnancy and perinatal healthcare access:
A qualitative study**

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Objective: Deaf women experience higher rates of reproductive healthcare barriers and adverse birth outcomes compared to their hearing peers. This study explores the pregnancy experiences of deaf women to better understand their barriers and facilitators to optimal pregnancy-related healthcare.

Design: Qualitative study using thematic analysis.

Setting: Semi-structured, individual remote or in-person interviews in the United States of America.

Sample: Forty-five deaf women who communicate using American Sign Language (ASL) and gave birth in the United States within the past five years participated in the interviews.

Methods: Semi-structured interviews explored how deaf mothers experienced pregnancy and birth, including access to perinatal information and resources, relationships with healthcare providers, communication access, and their involvement with the healthcare system throughout pregnancy. A thematic analysis was conducted.

Main outcome measures: The barriers and facilitators related to a positive experience of perinatal care access among deaf women.

Results: Three major themes emerged: (1) communication accessibility, (2) communication satisfaction, and (3) healthcare provider and team support. Common barriers included choosing healthcare providers, inconsistent communication access, and difficulty accessing health information. However, when deaf women were able to use ASL interpreters, they had more positive pregnancy and birth experiences. Self-advocacy served as a common facilitator to more positive pregnancy and healthcare experiences.

Conclusions: Healthcare providers need to be more aware of the communication and support needs of their deaf patients, especially how to communicate effectively. Increased cultural

awareness and consistent provision of on-site interpreters can improve pregnancy and birth experiences for deaf women.

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Keywords: Maternity services, antenatal care, qualitative research

Tweetable abstract: Deaf patients report positive pregnancy experiences when healthcare communication is accessible and in-depth.

Introduction

In the United States, there are close to one million people, with approximately 500,000 being women, who are deaf and use sign language.^{1,2} Deaf women face multiple healthcare barriers, including barriers to accessing quality and appropriate reproductive healthcare.^{3,4} Many of these barriers are related to lack of effective communication, including failure to provide sign language interpreters in healthcare settings,³⁻⁵ and limited health literacy.⁶ Healthcare providers often struggle to communicate effectively with deaf patients, resulting in poor healthcare satisfaction, adherence, and outcomes.^{3,7-12} Despite the implementation of the Americans with Disabilities Act (ADA) in the United States in 1990, accommodations (e.g., interpreters) remain inconsistently provided,¹³⁻¹⁵ and when they are, interpreters may not be qualified or on-site, which is preferred over a remote interpreter.¹⁶ Communication breakdowns with providers, negative healthcare experiences, and barriers to access place many deaf individuals at risk for significant knowledge gaps and worse health outcomes compared to their hearing peers, including worse reproductive and birth outcomes.¹⁷⁻¹⁹ Deaf women report receiving less information from their providers than hearing women, and note knowledge gaps about preventive reproductive healthcare.^{3,4} Deaf women have fewer overall prenatal care appointments than their hearing peers and are less likely to receive timely prenatal care.^{3,20-22} They report avoiding healthcare when communication barriers with their healthcare providers are present.²³ Conversely, when communication with providers is accessible and effective, deaf patients have higher rates of appropriate healthcare and preventive service use.^{4,17}

Although deaf women experience poorer pregnancy and birth outcomes than hearing women,^{3,4,18,19} factors contributing to these disparities are unclear. During pregnancy, deaf

women have elevated risks of gestational diabetes, hypertension, and preeclampsia, and they are significantly more likely than their hearing peers to experience preterm birth, low birth weight infants, and cesarean delivery.^{18,19,24,25} Due to higher rates of adverse pregnancy and birth outcomes, coupled with increased risk for inaccessible and inadequate healthcare, an in-depth study was needed to understand deaf women's pregnancy experiences. To address these gaps, we conducted qualitative study with deaf mothers to better understand their perinatal healthcare experiences. The findings from this study will be used to develop practice recommendations to improve the perinatal healthcare experiences and outcomes of deaf women and their infants.

Methods

Ethical approval for this study was obtained from the authors' Institutional Review Boards. The Perinatal Health Framework for Women with Physical Disabilities²⁶ was adapted for use with deaf women as a group with a sensory disability. As part of a larger study on the pregnancy experiences and outcomes of deaf and hard of hearing women,¹⁹ interviews with 45 deaf women were conducted, a sample size chosen based on data saturation.²⁷ Participants were asked about their access to pregnancy information and resources, communication access, satisfaction with healthcare providers, and experiences with the healthcare system throughout pregnancy.

Participants with multiple pregnancies were invited to discuss the pregnancy they perceived as the most relevant. Deaf community members and researchers were involved in all stages of the research.

This study focused on the subset of women who self-identified as deaf and preferred to communicate in American Sign Language (ASL) as their primary language. To be eligible for

participation, women had to be between 21-50 years of age and have given birth within the past five years in the United States. Participants were recruited by a mix of purposive, convenience, and snowball sampling via email, social media, and in-person recruitment at community events. To maximize diverse representation, study flyers and social media graphics were distributed widely, targeting organizations serving deaf people, including within different ethnic communities.

Data collection

From May 2018 to November 2019 the research team conducted 90-minute-long semi-structured qualitative interviews in ASL with 45 deaf participants. Initially, we conducted in-person interviews at three main sites (Rochester, NY, n=10; Rio Grande Valley, TX, n=2; Chicago, IL, n=8). To increase participation and diverse representation, we augmented our approach through a national recruitment strategy and remote interviews; interviews that were not conducted in-person were conducted via videophone or the online BlueJeans video conferencing app. Prospective participants that did not have in-person interviews completed a web-based questionnaire (via a Qualtrics survey) to determine their eligibility. Eligible participants were directed to a web-based informed consent, then a demographic questionnaire. Study staff contacted eligible participants to schedule interviews. After completing the interviews, participants received a \$50 incentive. Interviews were video-recorded for later transcription from ASL to written English by bilingual transcriptionists.

Analysis

Interview transcripts and information from the background survey were uploaded to the web-based qualitative analysis application Dedoose Version 8.3.35 to manage coding. Thematic analysis was used to identify and generate patterns across participants.²⁸⁻³⁰ Investigators reviewed transcripts to identify preliminary codes, continually re-read transcripts to update the coding scheme as new themes emerged, and conferred throughout the process to approve a final codebook with descriptors encompassing the phenomenon of the deaf experience of pregnancy within the healthcare system. Each interview was subsequently independently coded by one of the authors. Another author reviewed the coded transcripts and any coding discrepancies were discussed until consensus was reached. Major themes were identified by code application frequency.

Results

A total of 45 deaf, ASL-using women participated in the semi-structured qualitative interviews. Participating women were predominantly white, married, reported an annual income less than \$80,000 and college educated. Most women chose their first pregnancy to discuss for the interviews (Table 1).

[Table 1 here]

Three major themes emerged from our analysis: (1) communication accessibility, (2) communication satisfaction, and (3) healthcare provider and team support. Under each of these major themes are two sub-themes, (a) barriers, and (b) facilitators, that interfered with or promoted positive pregnancy experiences. Self-advocacy was also identified as a theme that acted as a facilitator across the three major themes. Unlike the three major themes, we did not

identify a barrier such as lack of self-advocacy in our sample; challenges experienced can be attributed more to unsuccessful self-advocacy or larger healthcare systemic issues as demonstrated in the other themes' barriers. Table 2 summarizes these barriers and facilitators with codes and their definitions.

[Table 2 here]

Communication accessibility

Barrier: Communication access

All study participants preferred to communicate with their healthcare providers with an interpreter physically present (on-site interpreter), which allowed for more effective communication. However, due to refusal to provide accommodations (reported by 27 participants) or logistical difficulties (e.g., scheduling), having an on-site interpreter was not always possible. Many participants (n=32) expressed interpreter concerns, particularly difficulties with appointments with video remote interpreters: *“When I made an appointment there was no interpreter. I did [ask for] an interpreter but they said ‘I’m sorry we don’t have an interpreter, we can’t afford to get one,’ so we tried using a video interpreter but [the video screen image] was really fuzzy and froze a lot. It was a waste of my time. I really need an [on-site] interpreter, period.”* (Third birth, age 41). Inconsistent access to on-site interpretation led to poor care continuity for this mother, as she needed to find a new healthcare provider who would accommodate on-site interpreters.

Another mother had an on-site interpreter, but not for the first hour of her unexpected delivery: *“It was very awkward because it was a first-time pregnancy and I was very nervous. The [doctor] didn’t explain much. The last-minute delivery I was forced into really scared me*

because I didn't know why. He didn't explain why until after they finally got an interpreter."

(First birth, age 35). In this case, delayed access to interpretation resulted in limited health information, adding to the mother's stress and confusion during an unplanned delivery.

Facilitator: Communication accommodations

When healthcare providers accommodated participants' communication needs, 28 study participants reported positive healthcare encounters. This participant recalled the ease of her prenatal appointments: *"The doctor knows me so when I make an appointment [her staff schedule] an interpreter immediately. Then we meet when I show up and the appointment runs smoothly. I've never had a problem."* (First birth, age 27). Having an interpreter to facilitate communication and minimize burden on the deaf patient became especially important when participants were in labor: *"I did want an interpreter because I knew that once I was in pain, I would want my cochlear implants off so I can focus [on my labor]."* (First birth, age 35).

In addition to ease of arranging interpretation for appointments, healthcare providers' perceived cultural competency for their deaf patients was an important aspect of ensuring good communication: *"If an interpreter is not available at the time of the appointment, the doctor will let me know [if I should show up or reschedule] because she knows how I would feel if the interpreter did not show up. ... Her actions show that she is accepting of who I am [and of my identity]."* (First birth, age 27).

Communication Satisfaction

Barrier: Limited health information shared

Many participants (n=30) recalled situations where healthcare providers did not share as much information as the participants needed. For some participants, gaps in health information led to misconceptions about what to expect, as this mother realized: *“I asked for [an epidural] for the pain and they gave it to me but they weren’t clear that it made you numb ... I was in a lot of pain and it was hard to breathe so they said it would help with my back pain and it did but then I passed out. I remember a little but my friend explained that it makes you numb and I finally understood later on.”* (First birth, age 33). For other mothers, health information gaps became apparent in retrospect, like for this mother: *“I just wish I understood that once you have more than two C-sections, [my doctor would not allow you to] have a natural birth. ... I didn’t know until later. After the second C-section, it was too late.”* (First birth, age 43).

Facilitator: In-depth health information shared

Thirty-two participants talked about the importance of getting in-depth information from their healthcare provider. When women reported positive interactions, these included an encounter where they got in-depth information, did not feel rushed, and got all of their questions answered (n=19). As one mother said, *“[I’d rate my doctor a 4 or 5 out of 5 because] they are always very thorough and very willing to give me more time that I need instead of cutting me off. They don’t say ‘no it’s fine, let’s move on.’ They are very clear [when explaining any planned procedures] ... which helps me to understand the whole process better.”* (First birth, age 32).

Healthcare provider and team support

Barrier: Healthcare provider selection issues

Twenty participants reported difficulties finding an ideal prenatal care provider. A few mothers chose healthcare providers who could sign, even with limited fluency, or clinics that had a reputation in the deaf community for ease of obtaining interpreters for prenatal appointments. For instance, one mother drove 45 minutes each way to appointments at a clinic that was supposed to be deaf-friendly, but changed providers after feeling dismissed: *“I didn’t like the hospital’s [rigid] approach. ... It felt like they weren’t willing to listen. Also, for the first few weeks I was happy to drive back and forth but I imagined doing that just to be ignored and told no. I wasn’t happy to do that.”* (First birth, age 37).

Other mothers did not, or could not, consider deaf-specific criteria: *“No [I didn’t look for someone who already had experience working with deaf women.] I wanted someone close to home making it easy to commute and that is covered by insurance. Those were my two primary considerations.”* (Second birth, age 44). However, this meant searching for a healthcare provider could be challenging if offices were not prepared to interact with deaf patients: *“There were some offices that hung up on me because I used Video Relay Services [to call them using an interpreter]. I called back and asked why? Have you ever experienced a deaf person before? They said no.”* (First birth, age 43).

Facilitator: Additional team support

Availability of qualified interpreters who had medical expertise was critical for positive birth experiences. One participant recalled a stressful experience where she ended up asking her first interpreter to leave: *“I got there and the interpreter was lousy. All the times before this it was good but this time I just needed to know if my water broke. But then they had to do a non-stress test but it seems that something happened and the interpreter was so lousy it was going right*

over my head so I was very [upset].” (First birth, age 33). The participant’s doula, who was hearing and sign-fluent, was willing to interpret until another interpreter arrived.

While interpreters are important for access to information, some mothers reported that interpreters sometimes went beyond their role by providing support. One participant’s interpreter provided reassurance: *“I know for sure that having the interpreter was comforting in the moment. ...she held my hand.”* (First birth, age 37).

Self-advocacy

Self-advocacy was a common facilitator and almost all participants (n=39) noted the particular importance of self-advocacy for deaf women. Sometimes participants’ self-advocacy involved requesting interpreters at appointments or doing research on healthcare providers that would accommodate them: *“I feel really comfortable with [my] doctor. I’m lucky that I asked my friends [for doctor recommendations] because before that from my experiences [with other doctors], it might’ve not been that positive.”* (First birth, age 43).

Many participants noted the particular importance of self-advocacy for deaf women: *“A lot of deaf pregnant women don’t know what their options are. They think they go to the doctor and that’s the option they’re given.”* (First birth, age 43). Other participants spoke of standing up for themselves: *“Don’t feel like you have to give up your needs ... Tell them anything, don’t be scared. Back [yourself up] too.”* (First birth, age 37) Another participant said, *“There will be frustrating times when some doctors don’t listen, but you have to stand up for yourself. You have to make yourself clear, what you want, and what your expectations are.”* (First birth, age 32).

However, self-advocacy was difficult to sustain at times. For instance, this first-time mother recalled that she was unable to fully advocate for herself during hectic moments before

and after birth: *“I think I was too tired and exhausted to ask again ‘what did you say?’”* (First birth, age 41).

Discussion

Main findings

This is the first in-depth qualitative study exploring the prenatal, perinatal, and postnatal healthcare experiences of deaf women. Our findings revealed that inaccessible communication, difficulty obtaining health information, and healthcare provider selection were common challenges. However, when clinics provided on-site interpreters and study participants received accessible health information, they described more positive pregnancy and birth experiences. All participants noted the importance of self-advocacy in ensuring a positive birth experience.

Strengths and limitations

The majority of our sample was highly educated, which may contribute to having a high level of self-advocacy, and thus more positive birth experiences and an underreporting of experiences of less-educated and more disenfranchised deaf women. Additionally, most participants were white, and deaf women of color may experience additional barriers not fully captured in our sample, including the intersectionality of race and disability. As data collection relied on participant self-report, recall bias may be present, however participants were able to provide detailed narratives suggesting accurate recall. Further work is needed to explore intersectionality factors to understand how other forms of social marginalization adversely affect pregnancy and birth experiences for deaf women. To meet this need, we would recommend further diversifying the

research team, instill a longer community engagement timeline, including one that incorporates a community-based participatory research and a lengthier recruitment period.

Despite these limitations, this is the first study to conduct qualitative interviews with deaf women in their primary language of ASL, which provides context to better understand any future quantitative data and addresses a critical knowledge gap around deaf women's pregnancy and birth healthcare experiences.

Interpretation in light of other evidence

There are barriers unique to deaf women who primarily communicate in ASL, mostly due to inconsistent access when obtaining health information or communicating in healthcare settings. As a result of patient-provider communication breakdowns, some participants reported relying on peers to address gaps in information; this finding is consistent with previous research indicating deaf individuals are more likely to rely on deaf peers than healthcare providers for health information and support.³¹⁻³³ When deaf patients reported getting in-depth health information from their healthcare providers, an important facilitator was interpreters with healthcare-specific interpreting experience, highlighting the importance of healthcare providers' provision of effective communication with qualified interpreters in healthcare settings.^{3-5,22,34}

Despite the establishment of the Americans with Disabilities Act (ADA) over 30 years ago, significant healthcare accessibility issues persist for deaf individuals.¹⁴ Inconsistent or absent provision of sign language interpreters impedes healthcare access for deaf individuals due to clinics' financial concerns or a lack of awareness of communication access mandates in the ADA.^{35,36} In one study, only 17% of deaf signers received an interpreter for their primary care appointments.¹³ Other studies have shown that being deaf affects health communication,

resulting in provider frustrations and inadequate healthcare delivery due to an inadequate health history.^{7,10,12} Providers often focus on trying to “fix” deafness rather than treating the person, resulting in persistent general mistrust of the medical community among deaf people.

Furthermore, continued language and communication barriers contribute to social and healthcare marginalization for many deaf individuals.^{11,23,37} These barriers are further exacerbated by limited health literacy: Deaf individuals are nearly seven times more likely to have inadequate health literacy compared to their hearing peers,⁶ affecting their access to health information. These factors highlight the significance of participants’ reports of inaccessible communication and challenges with obtaining health information.

Most deaf people are born into non-signing hearing families, which has downstream implications for their health literacy, including how to navigate reproductive healthcare and how they experience pregnancy. If deaf women grow up in households that are not fully accessible, they may miss out on incidental learning opportunities in settings such as car rides or at the dinner table.³⁸ Increased access to accessible communication will foster the relationship between the deaf patient and her healthcare provider, and increase the number of ways deaf women get health information. When deaf patients have access to medical information in ASL at healthcare appointments, it will supplement information gained in written English elsewhere.³⁹

Coupled with a need for consistent provision of accommodations, there is a need for more training among healthcare providers so that the deaf community can have more local, deaf-friendly choices, rather than having to choose between traveling long distances for culturally competent providers or local but inaccessible providers. Some study participants were faced with the latter choice, raising concerns about the potential for adverse health outcomes. Training is imperative for all healthcare providers to ensure effective communication and quality care to

address existing health gaps that many deaf individuals face.⁴⁰ Training on how to care for deaf patients should be built into medical school curricula, with ongoing efforts to educate and assist providers through continuing medical education credits and resources. One successful training program is Deaf Strong Hospital at the University of Rochester School of Medicine and Dentistry, which aims to help first year medical students understand the experience of deaf individuals navigating the healthcare system with limited or no access services.⁴¹⁻⁴³ The training also incorporates topics such as working with interpreters, caring for deaf patients using appropriate deaf cultural and linguistic norms, and the difference between cultural and disability models.^{44,45}

Lastly, it is necessary to eliminate ableism and audism among healthcare providers. While disabled patients often experience ableism - discrimination and prejudice that excludes and devalues people with disabilities⁴⁶- many deaf patients experience ableism from healthcare providers in the form of audism, or discrimination based on hearing status.^{23,47-50} Audism can be experienced as a dismissal of needs by refusing to provide interpreters or in-depth health information, an experience of many in our sample. Efforts to self-advocate can be futile when faced with audism, whether providers' bias is implicit or explicit. Training for healthcare providers could contribute to increased sensitivity for non-English speaking communities and thus improved experiences, satisfaction, and outcomes for deaf patients.

Conclusions

Deaf women experience unique perinatal care challenges, including inaccessibility, but this study finds that their pregnancy experiences are more positive when provided opportunities for better provider-patient communication. Further research should focus on best practices for

implementing systematic changes needed to ensure accessible perinatal care, education, and services for deaf women. This can include steps such as healthcare provider and staff training opportunities, improved enforcement of legal mandates of the ADA and increased advocacy and support for healthcare systems to implement accommodations.

Disclosure of interests

There are no relevant conflicts of interest declared. Completed disclosure of interest forms are available to view online.

Contribution to authorship

MiM and MoM designed the study and obtained funding. MiM, MoM, LS and JC developed the study materials and the thematic framework for the qualitative analysis. LS and MH oversaw implementation of the study recruitment and data collection. JC, TP, and MC carried out the data collection. TP and SA were responsible for the writing up of the paper and all authors contributed feedback and edits.

Details of ethics approval

Ethical approval for the study was obtained from the Institutional Review Boards of the University of Michigan (date of approval 03/21/2018; Reference no: HUM00137504), and the Rochester Institute of Technology (date of approval 01/24/2018; Reference no: 00010413).

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This paper has a Video Abstract presented by Jenna Stewardson, Deaf Health Lab's Research Program Coordinator at the NTID Research Center on Culture and Language.

Table 1. Sample characteristics (n = 45).

Age, years	
Mean (range)	35 (22-44)
Race	
White	27 (60%)
Black or African American; Asian; American Indian or Alaska Native	8 (18%)
Bi-racial/Other	7 (16%)
Did not disclose	3 (7%)
Hispanic/Latina	13 (29%)
Household income	
Less than \$80,000	29 (64%)
More than \$80,000	16 (36%)
Highest level of education	
2-year college degree or less	16 (36%)
4-year college degree	8 (17%)
Graduate degree	21 (47%)
Marital status	
Single	16 (36%)
Married	29 (64%)
Family size	
One child	18 (40%)
Two or more children	27 (60%)
Birth Discussed	
1 st child	32 (71%)
2 nd child	6 (13%)
3 rd or later child	7 (16%)
Delivery type	
Vaginal	29 (64%)
Cesarean Section, planned	10 (22%)
Cesarean Section, emergency	6 (13%)

Table 2. Themes, codes, and definitions for barriers and facilitators to a positive perinatal healthcare experience for deaf women.

Theme	Code	Definition	Sample Quote
Communication Accessibility	Barrier: Inconsistent communication access	Women face challenges in accessing American Sign Language interpretation for communication with their providers	<i>“He didn’t explain until after they finally got an interpreter.”</i>
	Facilitator: Communication accommodations	Provider-patient communication facilitated with provision of effective accommodations	<i>“The appointment runs smoothly [with an interpreter already scheduled].”</i>
Communication Satisfaction	Barrier: Limited health information shared	Healthcare providers do not share adequate health information	<i>“I finally understood later on [from a deaf friend who explained more].”</i>
	Facilitator: In-depth health information shared	Healthcare providers share sufficient health information	<i>“...very willing to give me more time that I need instead of cutting me off.”</i>
Healthcare Provider and Team Support	Barrier: Healthcare provider selection issues	Women need to change healthcare providers	<i>“...I was happy to drive back and forth but I imagined doing that just to be ignored and told no.”</i>
	Facilitator: Additional team support	Doulas or interpreters go beyond their role to support the birth experience	<i>“I know for sure having the interpreter was comforting in the moment...she held my hand.”</i>
Self-advocacy	Self-advocacy as a facilitator	Women advocate to have their needs met	<i>“There will be frustrating times when some doctors don’t listen, but you have to stand up for yourself.”</i>

