


RESEARCH ARTICLE

Maternal medicine

Experiences of pregnancy and perinatal healthcare access of women who are deaf: a qualitative study

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Abstract

Objective: Women who are deaf experience higher rates of reproductive healthcare barriers and adverse birth outcomes compared with their peers who can hear. This study explores the pregnancy experiences of women who are deaf to better understand their barriers to and facilitators of optimal pregnancy-related health care.

Design: Qualitative study using thematic analysis.

Setting: Semi-structured, individual, remote or in-person interviews conducted in the USA.

Sample: Forty-five women who are deaf and communicate using American Sign Language (ASL) and gave birth in the USA within the past 5 years participated in the interviews.

Methods: Semi-structured interviews explored how mothers who are deaf 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: Barriers and facilitators related to a positive experience of perinatal care access among women who are deaf.

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 women who are deaf were able to use ASL interpreters, they had more positive pregnancy and birth experiences. Self-advocacy served as a common facilitator for more positive pregnancy and healthcare experiences.

Conclusions: Healthcare providers need to be more aware of the communication and support needs of their patients who are deaf, especially how to communicate effectively. Increased cultural awareness and consistent provision of on-site interpreters can improve pregnancy and birth experiences for women who are deaf.

KEY WORDS

antenatal care, maternity services, qualitative research

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This paper has a Video Abstract presented by Jenna Stewardson, Deaf Health Laboratory Research Program Coordinator at the NTID Research Center on Culture and Language available at: <https://vimeo.com/761853406>.

1 | INTRODUCTION

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

Although women who are deaf experience poorer pregnancy and birth outcomes than women who can hear,^{3,4,18,19} the factors contributing to these disparities are unclear. During pregnancy, women who are deaf have elevated risks of gestational diabetes, hypertension and pre-eclampsia, and they are significantly more likely to experience preterm birth, low birthweight infants and caesarean delivery than their peers who can hear.^{18,19,24,25} With the higher rates of adverse pregnancy and birth outcomes, coupled with an increased risk for inaccessible and inadequate health care, an in-depth study was needed to understand the pregnancy experiences of women who are deaf. To address these gaps, we conducted a qualitative study with mothers who are deaf 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 women who are deaf and their infants.

2 | METHODS

Ethical approval for this study was obtained from the authors' Institutional Review Boards. The Perinatal Health Framework

for Women with Physical Disabilities was adapted for use with women who are deaf as a group with a sensory disability.²⁶ As part of a larger study on the pregnancy experiences and outcomes of women who are deaf and hard of hearing,¹⁹ interviews with 45 women who are deaf 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. Members of the deaf community 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 21–50 years of age and have given birth within the past 5 years in the USA. Participants were recruited by a mix of purposive, convenience and snowball sampling via email, social media and in-person recruitment at community events. To maximise diverse representation, study flyers and social media graphics were distributed widely, targeting organisations serving people who are deaf, including those within different ethnic communities.

2.1 | Data collection

From May 2018 to November 2019 the research team conducted 90-minute-long semi-structured qualitative interviews in ASL with 45 participants who are deaf. 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 via 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 and 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.

2.2 | Analysis

Interview transcripts and information from the background survey were uploaded to the web-based qualitative analysis application Dedoose v8.3.35, 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 frequency of code application.

3 | RESULTS

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

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 subthemes, (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 examples of a lack of self-advocacy acting as a barrier in our sample; the challenges experienced can be attributed more to unsuccessful self-advocacy or larger healthcare systemic issues, as demonstrated by the barriers included in other themes. Table 2 summarises these barriers and facilitators with codes and their definitions.

3.1 | Communication accessibility

3.1.1 | 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, as a result of 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 years). Inconsistent access to on-site interpretation led to poor

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	
1st child	32 (71%)
2nd child	6 (13%)
3rd or later child	7 (16%)
Delivery type	
Vaginal	29 (64%)
Caesarean section, planned	10 (22%)
Caesarean section, emergency	6 (13%)

continuity of care 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 years). In this case, delayed access to interpretation resulted in limited health information, adding to the mother’s stress and confusion during an unplanned delivery.

3.1.2 | Facilitator: communication accommodations

When healthcare providers accommodated participants’ communication needs, 28 study participants reported

TABLE 2 Themes, codes and definitions for barriers and facilitators to a positive perinatal healthcare experience for women who are deaf

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	'He did not explain until after they finally got an interpreter.'
	Facilitator: communication accommodations	Provider-patient communication facilitated with the provision of effective accommodations	'The appointment runs smoothly [with an interpreter already scheduled].'
Communication satisfaction	Barrier: limited health information shared	Healthcare providers do not share adequate health information	'I finally understood later on [from a deaf friend who explained more].'
	Facilitator: in-depth health information shared	Healthcare providers share sufficient health information	'... very willing to give me more time that I need instead of cutting me off.'
Healthcare provider and team support	Barrier: healthcare provider selection issues	Women need to change healthcare providers	'... I was happy to drive back and forth but I imagined doing that just to be ignored and told no.'
	Facilitator: additional team support	Doulas or interpreters go beyond their role to support the birth experience	'I know for sure having the interpreter was comforting in the moment ... she held my hand.'
Self-advocacy	Self-advocacy as a facilitator	Women advocate to have their needs met	'There will be frustrating times when some doctors do not listen, but you have to stand up for yourself.'

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 years). Having an interpreter to facilitate communication and minimise the burden placed on the patient who is deaf became especially important when participants were in labour: '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 labour].' (first birth, age 35 years).

In addition to the ease of arranging interpretation for appointments, healthcare providers' perceived cultural competency for their patients who are deaf 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 years).

3.2 | Communication satisfaction

3.2.1 | 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 realised: '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 years). For other mothers, health information gaps became apparent in retrospect, as 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 years).

3.2.2 | 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 had 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 years).

3.3 | Healthcare provider and team support

3.3.1 | 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 years).

Other mothers did not, or could not, consider deaf-specific criteria: 'No [I didn't look for someone who already had experience working with women who are deaf] 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 years). However, this meant that 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 years).

3.3.2 | Facilitator: additional team support

The 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 years). The participant's doula, who was hearing and sign-fluent, was willing to interpret until another interpreter arrived.

Although 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 years).

3.4 | Self-advocacy

Self-advocacy was a common facilitator and almost all participants ($n = 39$) noted the particular importance of self-advocacy for women who are deaf. 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 years).

Many participants noted the particular importance of self-advocacy for women who are deaf: '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 years). 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 years). 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 years).

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 years).

4 | DISCUSSION

4.1 | Main findings

This is the first in-depth qualitative study exploring the prenatal, perinatal and postnatal healthcare experiences of women who are deaf. 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.

4.2 | Strengths and limitations

The majority of our sample was highly educated, which could contribute to having a high level of self-advocacy, and thus more positive birth experiences, and to an under-reporting of the experiences of less educated and more disenfranchised women who are deaf. Additionally, most participants were white, and women of colour who are deaf 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 marginalisation adversely affect the pregnancy and birth experiences of women who are deaf. To meet this need, we would recommend further diversifying the research team, instilling a longer community engagement timeline, including one that incorporates community-based participatory research, and a lengthier recruitment period.

Despite these limitations, this is the first study to conduct qualitative interviews with women who are deaf in their primary language of ASL, which provides context to better understand any future quantitative data and addresses a critical

knowledge gap around the pregnancy and birth healthcare experiences of women who are deaf.

4.3 | Interpretation in light of other evidence

There are barriers that are unique to women who are deaf who primarily communicate in ASL, mostly through 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 that individuals who are deaf are more likely to rely on peers who are deaf than on healthcare providers for health information and support.^{31–33} When patients who are deaf 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 ADA over 30 years ago, significant healthcare accessibility issues persist for individuals who are deaf.¹⁴ The inconsistent or absent provision of sign language interpreters impedes healthcare access for individuals who are deaf as a result of the financial concerns of clinics 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 as a result of obtaining 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 people who are deaf. Furthermore, continued language and communication barriers contribute to social and healthcare marginalisation for many individuals who are deaf.^{11,23,37} These barriers are further exacerbated by limited health literacy: individuals who are deaf are nearly seven times more likely to have inadequate health literacy compared with their peers who can hear,⁶ affecting their access to health information. These factors highlight the significance of the participants' reports of inaccessible communication and challenges with obtaining health information.

Most people who are deaf are born into non-signing hearing families, which has downstream implications for their health literacy, including how to navigate reproductive health care and how they experience pregnancy. If women who are deaf 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 will increase the number of ways women who

are deaf get health information. When patients who are deaf have access to medical information in ASL at healthcare appointments, it will supplement the information gained in written English elsewhere.³⁹

Coupled with a need for the 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 travelling 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 the existing health gaps that many individuals who are deaf face.⁴⁰ Training on how to care for deaf patients should be built into medical school curricula, with continuing efforts to educate and assist providers through continuing medical education credits and resources. One successful training programme 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 individuals who are deaf navigating the healthcare system with limited or no access services.^{41–43} The training also incorporates topics such as working with interpreters, caring for patients who are deaf 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. Although 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 reported by many in our sample. Efforts to self-advocate can be futile when faced with audism, whether the 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 patients who are deaf.

5 | CONCLUSION

Women who are deaf experience unique perinatal care challenges, including inaccessibility, but this study finds that their pregnancy experiences are more positive when provided with opportunities for better provider-patient communication. Further research should focus on best practices for implementing the systematic changes needed to ensure accessible perinatal care, education and services for women who are deaf. 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.

AUTHOR CONTRIBUTION

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 the implementation of the study recruitment and data collection. JC, TP and MC carried out the data collection. TP and SA were responsible for writing the article and all authors contributed with feedback and editing.

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CONFLICT OF INTERESTS

None declared. Completed disclosure of interests form available to view online as supporting information.

DATA AVAILABILITY STATEMENT

Due to privacy and ethical restrictions, the data will not be available for sharing.

ETHICS APPROVAL

Ethical approval for the study was obtained from the Institutional Review Boards of the University of Michigan (21 March 2018, ref. no. HUM00137504) and the Rochester Institute of Technology (24 January 2018, ref. no. 00010413).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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