
Pregnancy Outcomes and Disparities for Deaf and Hard-of-Hearing Mothers

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(Part 1 of 2 · [read Part 2](#))

Deaf and hard-of-hearing women are more likely to visit the emergency room and stay in the hospital during pregnancy or around the time of childbirth for reasons unrelated to delivery, our researchers at the Lurie Institute for Disability Policy found in a national study.

“We need to think about how we can design a healthcare system that is patient-centered and truly accessible,” says Dr. Michael McKee, a medical doctor and researcher at the University of Michigan Medical School who is himself deaf. Co-principal investigators, McKee and Dr. Monika Mitra of the Lurie Institute for Disability Policy are leading the first systematic investigation of pregnancy experiences and outcomes of deaf and hard-of-hearing, or DHH, women in the United States. Mitra is the director of the Lurie Institute for Disability Policy at Brandeis University and an associate professor at Brandeis’s Heller School for Social Policy and Management.



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The research is part of a five-year National Institutes of Health–funded study of deaf and hard-of-hearing women’s outcomes and experiences across the perinatal period: pregnancy, childbirth, and beyond.

NOTE: *What’s the difference between “Deaf” and “deaf”?*

Deaf and hard-of-hearing people sometimes use the terms “deaf” and “Deaf” to describe themselves. “Deaf” with a capital “D” suggests an identification with Deaf culture, language, and identity, whereas “deaf” with a lowercase “d” is more neutral. For example, a Deaf person may have attended a school for DHH students. Many people use one or the other exclusively, but a person might use “deaf” in one context and “Deaf” in another.

Before our team started this study, very little research into this topic had been conducted. A **preliminary study** for the current project led by Mitra and McKee had found disparate outcomes for DHH women. That result contrasted with the only other similar study at that time, a retrospective cohort study using data from Washington State. All other studies of this population—and there were very few—were not systematic. Mitra calls the lack of research on these women’s perinatal experiences “shocking.”

The current study, now in its fifth year, has already produced **notable findings**.

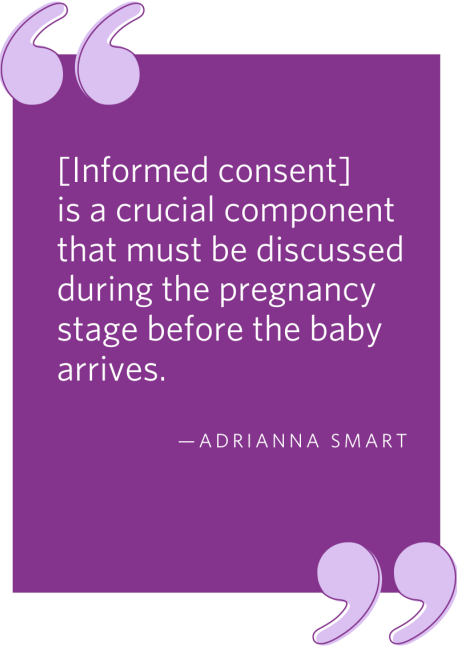
According to the study’s findings, deaf and hard-of-hearing women were more likely to have severe chronic medical conditions than hearing women, including preexisting and gestational diabetes, preeclampsia, eclampsia, and placental abruption.

NOTE: Preeclampsia and eclampsia are conditions related to high blood pressure, which can often be dangerous. Placental abruption occurs when the placenta separates from the uterus.

Deaf and hard-of-hearing women were also more likely to have complications during pregnancy and adverse birth outcomes compared with their hearing counterparts—including low or very low birth weight, less healthy newborns, and preterm birth.

McKee points to several factors that may contribute to these findings. These factors include communication breakdowns, lack of accommodations (e.g., communication supports such as interpreters), inadequate provider training, and additional health risk factors linked to hearing loss. The study underway will help researchers understand the factors involved and how they interact. Ongoing study analyses are looking at differences in hospital use among DHH women compared to other women. Additional research will be necessary to examine causal pathways more closely.

Adrianna Smart, a Deaf advisory board member with two preteen children, emphasizes that many deaf and hard-of-hearing women who are pregnant or are considering pregnancy do not have enough information on pregnancy and childbirth. Smart stresses how important it is for doctors and other healthcare providers to understand this concept and take steps to provide clear and comprehensive information about healthcare procedures and options available. They must take extra time with deaf and hard-of-hearing women and,



[Informed consent] is a crucial component that must be discussed during the pregnancy stage before the baby arrives.


—ADRIANNA SMART

because interpreters typically interpret only what is said, doctors and other healthcare professionals must not assume that interpreters will fill in any communication gaps.

Even when deaf and hard-of-hearing women do receive written information, they may not understand everything they read because their families or teachers may not have taught them about perinatal health, healthcare, or their rights. This understanding is especially important when healthcare rights involving informed consent are involved. “This is a crucial component that must be discussed during the pregnancy stage before the baby arrives,” says Smart.

Unfortunately, many women don’t know that they have the right to make their own choices about childbirth. Smart wants deaf and hard-of-hearing women to know that they have the right to plan their preferred options, such as when a cesarean section might be performed, with their doctor or midwife. Smart herself discovered only seven months into a pregnancy that, though she had been encouraged to plan for her baby’s arrival by doing things like preparing the baby’s room, she had not been told to make plans for birthing, breastfeeding, or postpartum care. Without the proper information, she had also been overlooking her own needs for nutrition, exercise, and rest.

There is much that can be done now, McKee advises, some of which is or should already be part of medical practice for this population. He says that healthcare providers must identify deaf and hard-of-hearing women as a group needing extra support: “We should be flagging these individuals as higher-risk women, similar to what we do for other health conditions or older women.”



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Healthcare providers can start by improving patient–provider communication. Effective communication with providers—or the lack thereof—affects how deaf and hard-of-hearing women use healthcare, adhere to treatments, and make decisions about the risks they may incur. Clear, accessible communication can increase their trust in—and satisfaction with—the healthcare they receive.

One of our goals for this study is to create recommendations for clinical practice. These will help providers better care for deaf and hard-of-hearing women. For example, recommendations can help practitioners notice cues that patients may not understand a treatment plan or other advice.

McKee also wants DHH women themselves to know that, although the burden of improving healthcare provision does not fall on them, there are still some things they can do now that may improve their pregnancy experience and outcomes. For example, DHH women who might want to become pregnant or who are pregnant can advocate for accessible communication, seek out information on reducing risks that affect pregnancy, and look for a healthcare provider with experience caring for DHH patients.

The beginning phase of the project focused on analyzing secondary quantitative data from two sources: the Massachusetts Pregnancy to Early Life Longitudinal data system and the Healthcare Cost and Utilization Project National Inpatient Sample for 2007–2016. Informed by findings from data analysis, we conducted qualitative interviews with deaf and hard-of-hearing women to learn more about their pregnancies, the kinds of care they received while they were pregnant, and ways that clinicians can improve care for pregnant DHH women. We are currently analyzing data we collected in a national survey of deaf and hard-of-hearing women about their pregnancies, and conducting qualitative interviews with clinicians, doulas, and interpreters.

Our qualitative interviews, survey, and secondary quantitative analysis will allow us to understand what deaf and hard-of-hearing women need during

pregnancy, how DHH women interact with their providers, and how researchers and practitioners can ensure that these women can receive accessible healthcare before, during, and after pregnancy.

Disclaimer

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