

NEW MEASURE TO SCREEN DEAF WOMEN FOR PERINATAL DEPRESSION

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Background

Approximately 1 million women in the U.S. have profound hearing loss and use American Sign Language (ASL) as their primary language.^{1,2} Many providers are unfamiliar with the unique linguistic and cultural needs of the Deaf community, therefore Deaf women experience major obstacles to receiving effective physical and mental healthcare. For example, failure to provide ASL interpreters or translations from written English is a common communication barrier that prevents Deaf women from receiving health-related treatment and information.

Although Deaf and hearing women become pregnant and give birth at the same rates, Deaf women do not receive the same level of prenatal healthcare as their hearing peers due to the communication barriers noted above.³ Compared to hearing women, Deaf women attend fewer prenatal care appointments, receive

less information from their doctors, and are less satisfied with their prenatal care.³ Reduced quality of prenatal healthcare can lead to higher rates of negative mental health outcomes compared to women who are not Deaf.^{4,5}

One such negative health outcome is perinatal depression—depression that occurs during pregnancy or up to one year after giving birth. Perinatal depression is a serious mental health issue that affects women from all backgrounds. If it is not treated, perinatal depression can be detrimental to both the mother and baby, making it important to screen, assess and treat all women for perinatal depression so that they can be linked with appropriate treatment. In 2015, the *Edinburgh Postnatal Depression Scale (EPDS)* was recommended as a gold standard depression screening tool. Unfortunately, the screening tool is often ineffective when used with Deaf women due to low health literacy rates among members of the Deaf community.⁶

What We Did

As a first step to address this communication barrier, Drs. Melissa Anderson, Kelly Wolf Craig, and Nancy Byatt were awarded a UMCCTS Pilot Project Program grant for their 1-year project – **Creating the Capacity to Screen Deaf Women for Perinatal Depression**.

The primary goal of this project was to translate the EPDS from written English to American Sign Language (ASL). Using the new ASL EPDS, the team aimed to recruit 50 Deaf perinatal women from across the United States to conduct depression screening interviews.

Translation Methods

Translating the EPDS: The research team worked together to translate the original EPDS from English to ASL using a three-step process:

1. A **forward translation** from English to ASL was conducted by a Certified Deaf Interpreter (CDI). A CDI is a Deaf person who is a certified interpreter, ASL is their native language, and they are fully integrated in Deaf culture.
2. The next step involved a **back translation** from ASL to English, which was conducted by a second CDI.
3. The final step was an **equivalence comparison** of the original English measure and back-translated English measure. Any inconsistencies between the versions were resolved together by members of the research team.

After the translation process was complete, the final translation was filmed for the purpose of documentation and interviewer training.

Recruitment and Data Collection

Recruitment occurred over a six-month period. Recruitment efforts included the development and dissemination of a recruitment flyer written in plain English, as well as numerous video blogs (vlogs) posted on Facebook. The Deaf Community Advisors (DCAs) also conducted outreach efforts by calling and emailing Deaf service agencies nationwide.

Following informed consent, each woman participated in a one-time, 30-minute videophone interview. The interview included demographic questions and the 10 questions from the ASL EPDS. All videos were taped for quality assurance.

The research team used an ASL script during the interviewing sessions.

The research team included a principal investigator, two co-investigators, one volunteer intern, and two Deaf Community Advisors (DCAs). DCAs are Deaf community members who are involved in all stages of the research process to ensure that the research questions, methods, and sharing of results are aligned with Deaf culture, language, and values.

By following an ASL script, the research team conducted interviews in ASL with pregnant women in the Deaf community. The research team chose to use interviews for multiple reasons: (1) if the team decided to use a survey, the screening questions and response options would have to be filmed and then embedded into the survey as video clips; (2) additionally, the team wanted to have more flexibility in presenting the survey items before creating a final, crystalized version of the survey.

Preliminary Findings

The team successfully recruited, enrolled, and collected data from 36 Deaf perinatal women. The average ASL EPDS score among these Deaf women was 5.6 (out of a maximum of 30 points). This average is similar

minimal symptoms of depression; 30.6% reported **mild** depression; 5.6% reported **moderate** depression; and none reported **severe** depression.

There are a few possible reasons why there were no reports of severe depression in the sample. Some participants reported that they had experienced severe depression in previous months, but not in the past week (the required response period in the EPDS). Some participants may have been afraid to disclose depression, embarrassed or ashamed to look like a “bad mother”. It is also possible that recruitment efforts did not reach Deaf perinatal women with severe depression – perhaps these women were not active on Facebook, not connected with Deaf service agencies, or not motivated to participate in a research study.

Another finding during the study came from the translation process and consideration of Deaf women with a range of sign language skills. It was noted that one of the participants had experienced severe language deprivation during her childhood and presented with language delays in ASL. The Likert scale options in the questions presented

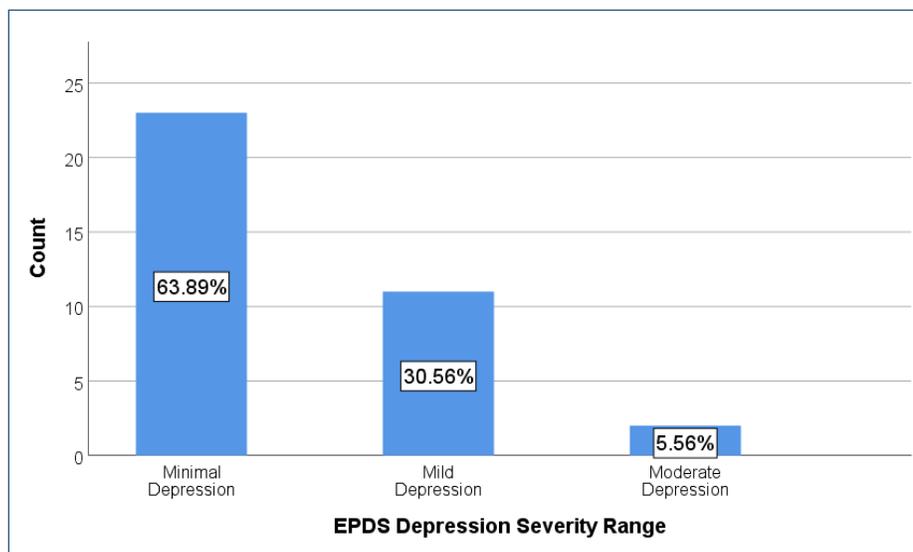
a “yes” or “no” answer rather than picking an answer like: “a lot of time” or “only sometimes”. Even with this initial barrier, the interview team was able to adapt a gestural system in order for this participant to understand the question options. However, planning for similar situations will need to be taken into account when considering how to develop a final, crystalized video version of the ASL EPDS.

Next Steps

The team’s long-term goal is to disseminate the ASL EPDS across the country, so that it can be used by any healthcare providers who work with Deaf perinatal women. To prepare for this dissemination, more exploratory research is needed with Deaf perinatal women and with healthcare providers to determine the best ways to introduce the ASL EPDS into typical healthcare settings.

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to EPDS scores among community samples of hearing women. 63.9% of Deaf women in the sample reported

a challenge to this participant when trying to provide an answer. It was easier for the participant to provide

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The project described is supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant UL1TR001453. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. Contact Person: Melissa Anderson at melissa.anderson@umassmed.edu with questions.

