Deaf People Aging With HIV Face Communication Barriers

Focus group shows health care systems' inability to communicate with HIV-positive deaf people is impacting care and quality of life.

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What does healthy aging look like for deaf people living with HIV? Well, it starts with access—something they may lack because English, and especially written English, isn't their first language, according to focus group data published in the Journal of the Association of Nurses in AIDS Care.

Medical student Michelle Didero, of the University of California at Los Angeles, and a team led by Brandon Brown, PhD, of the University of California at Riverside, held a focus group with three deaf people ages 55 and over living with HIV in Palm Springs, California. The group also included four caregivers and community organizers. Most were white and had a college education.

Among other things, the focus group showed that:

- English was a second language, after American Sign Language (ASL), and participants preferred to communicate via ASL interpreters, not written English;
- Some participants had limited proficiency in reading English, rendering many websites, news sites and other written health information inaccessible and exacerbating the knowledge gap they experienced as they age with HIV;
- Some had experienced interactions with health care providers who weren't competent in communicating with deaf patients, leading to misunderstandings;
- Without culturally competent communication, participants were less able to advocate for themselves in health care settings.

Providers' inability to communicate via ASL, other cultural competency gaps and the participants' own lack of knowledge about healthy aging and their health can dampen quality of life for aging deaf people with HIV. Study participants stressed a need for more health care providers who can

directly communicate via ASL as well as improved trainings and higher qualification standards for ASL interpreters assisting with health care visits. They cited partner support, diet, medication adherence, meditation, exercise, art and seeking help as factors that improved their quality of life.

"Our focus group showed being deaf may have a greater impact on individual well-being than the ailments associated with aging with HIV," Brown said in a press release. "In future research, we hope to better understand experiences of aging with HIV while deaf among diverse subpopulations. We need to include people who are deaf or hard of hearing from all ethnicities in research to understand their health concerns and their needs. Simply by working closely with deaf persons in research, I understood far better the challenges the DPLWH [deaf people living with HIV] community faces. Without such interaction, it is hard to grasp what difficulties this group faces daily."

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