

No Direct Communication: How Being Deaf Overshadows Challenges of Aging with HIV in Palm Springs, California



Alejandra Cabral¹, Michelle Didero², Philip Rubin³, Jeff Taylor³, Christopher Christensen³, Poorna Kushalnagar⁴, and Brandon Brown⁵

UCLA Fielding School of Public Health¹; UCLA David Geffen School of Medicine²; HIV+ Aging Research Project- Palm Springs³; Department of Psychology, Gallaudet University⁴; UC Riverside School of Medicine⁵.

BACKGROUND

- Globally, Deafness affects 432 million adults and is the most common sensory deficit in the world
- Older people living with HIV (PLWH) experience more comorbidities than those without HIV
- Little research is available about the experiences of people aging with HIV, especially Deaf people
- We aimed to ascertain challenges of and resiliencies for living as an older Deaf person with HIV

METHODS

- In Spring 2019 in Palm Springs, California, we conducted a focus group of Deaf older (55+)PLWH and their Deaf nonmedical caregivers
- Questions included major health issues experienced by Deaf PLWH and important resiliencies for allowing people to age successfully with HIV
- Both facilitators were Deaf, and one was a PLWH. The session was video-recorded, then transcribed by Deaf researchers from Gallaudet University
- Data were analyzed systematically using the rapid and accelerated data reduction technique (RADaR)

RESULTS

- **Self-Reported demographic information:**
 - White, Mean age 60 years, 71% male
- **Major issues reported by Deaf PLWH:**
 - Social Isolation and poor mental health
 - Communication barriers due to poor health literacy, lack of medical visual aids, and sparse information available in ASL
- **Resiliencies to age successfully with HIV**
 - social support
 - medication adherence
 - meditation
 - watching videos in ASL

Scan  for ASL Poster Presentation



RESULTS



Important issues that impact Deaf older PLWH:

There is no direct communication. Granted, there is communication through third party, meaning, interpreters, parents or a dependent [but] within [the health care] field, we need more people trained with sign language...so they can provide direct communication to clients. That does have an impact on mental health and emotional health. (51 year old white man living with HIV)

When the doctor informs a Deaf patient that s/he has HIV, s/he usually comes to my office upset and confused about the diagnosis... It's an experience that happens repeatedly for them... there is a real lack of education here. (78 year old white woman caregiver)

I have two languages, ASL and English. I can navigate through the Internet and type words in a search box. But many Deaf people may not be able to do this because they don't know what word to type... We have access to ASL on YouTube, but where to find the right information is hard. (51 year old white man living with HIV)

Resiliencies that help people age successfully with HIV:

I have HIV, but I mentally resist the notion of "being sick." I love myself, and love other people - I do my homework, eat good food, refrain from drinking and smoking too much, same for drugs. It's all about mind control. That's my perspective. (73 year old white man living with HIV)

I think that the seeking help process involves self-awareness and having the realization that I need help for mental health and/or psychological health. (68 year old white woman living with HIV)

I have been on medication for 30 years and I stay on schedule, thanks to my partner who feeds me and makes sure I take my medicine. We go out for walks as part of exercising because it helps with immune system and blood flow. It helps keeps my energy up. (63-year-old white male living with HIV)

CONCLUSION

- The focus group discussion often reverted to issues solely pertaining to being Deaf
- Deaf PLWH experience serious barriers to quality health care because of poor communication
- Communication barriers may exacerbate social isolation and poor mental health in Deaf PLWH
- Deaf PLWH need:
 - More health information resources in ASL
 - Improved standards for medical ASL interpreters
 - Health care providers who can directly communicate with patients in ASL
- Social support was a common resiliency factor
- This study emphasizes the intersectional identities of PLWH must be kept in mind, as other identities such as being Deaf may greatly impact aspects of aging with HIV

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Steering Committee and Patient Partner Advisory Board



Contact Alejandra Cabral, UCLA PhD student: acabral@g.ucla.edu