Short Communication

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HIV/AIDS and the Deaf and Hard of Hearing: A Call to Action

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It is becoming increasingly clear that the deaf and hard of hearing (DHH) have been, by and large, overlooked concerning both HIV/AIDS prevention messaging and research related to their potential uniqueness regarding knowledge, attitudes, and practice. In general, life-long disability creates "barriers to health and rehabilitation services, education employment, and other aspects of economic and social life" [1-4]. These disability barriers are magnified for the DHH community more so than other disabilities (perhaps aside from mental disability) because the DHH are often confined to their own signing or speaking groups because of frequent social discrimination and ostracism, and many have diminished reading and speaking ability, in addition to hearing limitations. This means that broad public service messages on HIV in the form of printed literature, television and radio spots, and public exhibitions may not be effective. Indeed, it has been found that broad public prevention messages are not reaching them, nor are those messages always in the proper format. This has resulted in the fact that the DHH generally have lower HIV knowledge than their hearing counterparts [5].

Just a few years ago, Chinese colleagues Chu Tianxin, Xu Qiang and I (2011) did a very preliminary, though the first of its kind on the mainland, investigation of HIV/AIDS knowledge and associated behaviors among workers at a specific factory in Beijing. This factory made it a practice to hire DHH individuals, and, as a result, offered an easily accessible convenience sample group of DHH (n = 190) and quite similarly situated hearing workers (n = 146) for contrast. The differences in HIV knowledge and prevention between the two groups were statistically significant ($p<0.05$).

The myth that somehow the DHH community does not engage in high risk behaviors was debunked. Within the DHH group of 190, eleven of the responders engaged in non-marital sex, while only two of the responders reported always using a condom. Two DHH members reported MSM (men who have sex with men) activity… one reported never using a condom, and the other reported only occasional condom use. Nine DHH responders reported drug use, and seven of these reported heroin injection. Three DHH responders reported an unspecified sexually transmitted disease, and eleven reported hepatitis, with four of this specifically reporting Hepatitis B Virus.

Concerning knowledge of modes transmission and non-transmission of HIV, the broader DHH group also displayed greater misunderstanding than the hearing group. As well, those in the DHH group reported lower levels of condom use. Troublingly, nearly half of the DHH respondents were unaware of the fact that the national "Four Frees and One Care" policy in China, established in 2003, provides widely available free testing and treatment.

Are these findings typical within other countries, both developed and developing, around the world? If they are typical, they mark a major public health oversight of an important population subset that must be addressed as soon as possible. This is not simply good for broader prevention, but essential from the perspective of a right to the highest possible level of attainable health that we all should enjoy. Unfortunately, focused and concentrated global research in the DHH community is still lacking.

I would like to call colleagues to action in addressing this deficiency, and would encourage HIV & Retrovirus to consider, after an appropriate time for investigation, an issue, or a significant proportion of an issue, dedicated to all aspects of HIV/AIDS within the global DHH community. This call is begging for a multi-disciplinary approach that involves Medicine, Public Health, and the Social Sciences that will begin to map out the specific needs of this unique subgroup. HIV/AIDS study among the elderly was similarly neglected until it became evident that the disease was spreading rapidly among older individuals around the world (National Institute on Aging, 2015; Emlet, 2006). Focused study on the DHH community globally might prevent a similar consequence [6-8]. A myriad of questions might be asked, but certain areas of inquiry immediately come to mind:

Are general HIV/AIDS prevention and control messages reaching the DHH community? If not, why?

Does the DHH community need a specialized message? If so, what, and in what format?

Does being deaf or hard of hearing impact health efficacy and health seeking behavior related to HIV/AIDS?

How do some in the DHH community network within the men who have sex with men and intravenous drug injection risk groups?

What is the impact of possible social isolation and ostracism on educating the DHH community concerning the disease?

Concerning those in the DHH community already carrying the virus, are there unique drug compliance issues? If so, how should they be addressed?

What are the misconceptions about the DHH community in terms of sexual and other risk behaviors that may complicate education, diagnosis, and treatment?

Such research is not easy. Something as simple as identifying those in the DHH community in any given area presents its challenges. As well, there is a distinct paucity of research to build upon; yet, this fact also begs for innovative and widespread research to be commenced that will rectify this gap globally. Given the seminal nature of this area of inquiry, even basic case studies and ethnographies within DHH communities around the world related to HIV knowledge and behavior would begin to establish a foundation for later quantitative research. As general prevention messages become more and more effective for the broader population, it is incumbent upon us to not inadvertently let the global DHH community slip through the cracks. I hope that colleagues will strongly consider this call to action.

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