

Communication Strategies Utilized by People with NF2 and Hearing Loss

Amanda Bergner, MS CGC

Johns Hopkins University

Background: The hallmark of neurofibromatosis 2 (NF2) is bilateral vestibular schwannomas (VS), which cause hearing loss (HL) that progresses to deafness typically beginning in early adulthood. Incomplete auditory rehabilitation following the onset of HL can lead to significant interruption in communication across multiple spheres of life, increasing the likelihood of social isolation and depression. There is little known about the strategies for communication utilized by people with NF2 and HL, or the adequacy of these methods.

Methods: A 14-question online survey was posted on Instant.ly from May-September 2013 and advertised to individuals with NF2 and HL through NF2 support groups with an online presence and several NF2 clinical centers in the United States. Survey responses were collected and analyzed.

Results: 187 participants from 5 continents completed the survey and were eligible for inclusion in data analysis. The mean age of respondents was 39 years. The average duration of HL at the time of the survey was 13.6 years (SD=9.6). Most individuals reported using a combination of strategies for communication. The majority (125/187) utilize lip reading. 41% (76/187) use manual signing, such as a formal sign language, cued speech, fingerspelling, or “homemade” signs. Only 4 respondents rely solely on a formal sign language to communicate. 14% (27/187) use written language to supplement their communication. Despite the numerous strategies employed, 95% of respondents report ongoing communication difficulties in one or more daily settings (e.g. workplace, school, home, restaurant, phone).

Discussion: Auditory rehabilitation in the NF2 population is currently inadequate even in the context of improved rates of hearing preservation following surgery, moderate success with medical therapies, and amplification options including hearing aids, cochlear implants and auditory brainstem implants. Importantly, the uptake of sign language as a primary means of communication in the NF2 population is very low. This information can assist medical teams in providing more comprehensive care for people with NF2 by assessing the adequacy of communication strategies being employed and referring for auditory rehabilitation as needed. This data also speaks to the need to develop alternative methods of enhancing communication as a means of improving overall quality of life.

Full List Authors: Amanda Bergner, MS CGC, Johns Hopkins University; Jennifer Smart, PhD, Towson University.