

The impact of unilateral hearing loss on adult life

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Background for the article:

There is a need to improve awareness and to better understand the impact and struggles of people who have unilateral hearing loss (UHL), the audiologists who treats them, and those who work, live and socialise with them. With better awareness comes better understanding, so health professionals can refer them rather than dismiss them. Moreover, better understanding can fuel motivation and allow the person with UHL to be more proactive about managing the condition while reducing anxiety.

Introduction

Unilateral hearing loss (UHL) has been defined as a 3FA tone average (PTA) above 20 dB HL or thresholds above 25 dB HL at 2 or more frequency above 2 kHz in the affected ear (Center, M. D. H. 2005). UHL in adults has an estimated prevalence of 7.2% of the overall population, with only 2% of people with UHL using a hearing aid or device (Golub et al. 2018).

Some of the effects of UHL have been established in the literature, including difficulties to understand speech in background noise and reduced spatial awareness (Firszt et al 2017, Lucas et al. 2018).

In this research, we wanted to explore individual perspectives of the impact of UHL on their daily lives and the difficulties that they encounter in order to provide a better understanding of the unmet needs of this population.

Method

A small 6-person research team at the National Acoustic Laboratories, Sydney, Australia, explored this area using two qualitative approaches.

Firstly, semi-structured interviews were conducted in person or via phone/ Skype with 14 adults who had unilateral hearing loss. They were either invited to participate from a volunteer research database or responded to a flyer invitation to participate. All interview participants provided written or verbal consent prior to taking part.

Secondly, an open-ended survey consisting of questions that complemented those asked in the interviews was designed to capture responses from a wider audience. An invitation to complete the survey was posted on public forums specific to UHL, such as the Action on Hearing Loss forum and relevant Reddit threads.

The interview and survey questions were grouped into six main categories: participant's background information, awareness and the causes of UHL, the impact of UHL, treatment decision-making (in this case treatment refers to the use of a hearing device of any type), the implications of treatment or no treatment, and suggestions and needs. Information from interviews and surveys were combined and main themes identified, which are discussed below.

Results/Demographic

Fourteen adults with UHL participated in interviews and 80 adults responded to the survey including 17 from the Australian Hearing database, 51 from reddit and 12 from the Action on Hearing Loss forum. Participant ages ranged from 18 to 71 (mean = 34.9) at the time of the interview/survey. Among these participants, 53% were located in the United States/Canada, 31% were from Australia, and the other 16% were from other countries, e.g. Netherlands, Vietnam, India. The causes for the UHL were diverse including meningitis, head trauma/accident, absence of auditory nerve, tumor, otosclerosis, microtia/atresia, meniere disease, virus, mumps, noise exposure, and measles. Among these participants, 44% of them reported currently using a hearing device, and 32% of them reported that hearing loss was identified since birth.

Trends, Themes & Stories

Trends

Responses from the interviews and surveys presented a clear difference between the experiences of those with congenital and acquired UHL. Those born with UHL were more likely to have developed excellent coping mechanisms (i.e. placement, lip reading), and perceived less impact on their quality of life. These congenital UHL respondents also trended towards finding devices to be an annoyance or hindrance, and many who were prescribed devices chose to discontinue their use, often deciding that they were coping fine without them. For example, one congenital UHL participant said "Nothing is particularly frustrating. Having been unable to hear in one ear all of my life, I just deal with it."

In contrast, those with an acquired UHL reported that it had a greater impact on their quality of life. They commonly described experiencing panic at the onset of hearing loss, and because of this they were quick to seek treatment. They also had to deal with grief, having lost the functional benefits of binaural hearing and potentially losing elements of their former lifestyle. Most respondents struggled with adjusting to the change and with accepting the consequences of their condition. Acquired UHL participants commonly reported having tried contralateral routing of signals (CROS) hearing-aids, and less commonly implanted devices such as bone anchored hearing aid (BAHA) and cochlear implants (CIs). While some participants gained benefit from CROS in some scenarios, these devices tended not to provide much benefit with speech understanding in high-noise situations or with localisation, the two primary hearing-related issues for this population.

There were a number of participants who reported having tinnitus, and more often than not, this was a major problem for them. For example, one participant stated, "the tinnitus is worse than the hearing loss and has affected me more negatively than the hearing loss itself."

A total of 29 themes/situations were identified in which participants experienced difficulty because of their hearing loss. The themes are further divided into three categories: (1) functional impacts, (2) psychological impacts, and (3) social/behavioral impacts.

Functional Impacts

The two most commonly reported functional impacts were difficulty listening in noise and poor localisation. Participants reported having the most difficulty in loud environments and when there were lots of sound sources. One respondent stated, "Conversations can be unbearable, especially in loud

places," and another added, "I find it hard to listen when large groups of people are together and talking over each other." Many participants reported difficulty recognizing the direction from which sounds came from, often perceiving that all sound sources originated at their good ear. For example, one participant said, "I have a hard time telling what direction sound comes from if I can't see the source of the noise."

Respondents noted that they had difficulty hearing sounds on their poor side, such as one who said, "Scenarios where I need to hear someone on my deaf side are extremely frustrating and sometimes totally impossible." Some respondents also mentioned having auditory blind spots, including a subject who said, "I feel almost like I'm blind on the left because I have no sense of someone being there and certainly can't hear them." There were also a wide range of scenarios in which people reported functional difficulties, including listening while in a car, enjoying music, and playing sport and video games. One positive theme was that participants reported better sleep, as there was less background noise with their good ear pressed against the pillow. However, this was also seen in a more negative light with respect to difficulty being woken up from sleep, which may be important in an emergency.

Participants also reported experiencing fatigue from the increased cognitive load required during activities such as conversation in loud noise. This was described by one participant as follows: "By the end of the meal, my brain is usually exhausted from trying to hear everyone."

Psychological Impacts

Most interviewees and survey respondents indicated that their mental health was impacted by their hearing loss. People expressed emotions such as fear in various ways. One example of this was the perception that the person's safety, or the safety of those around them, might be at risk due to their hearing impairment. One respondent stated, "I'm concerned about being in a situation where someone I love is in danger and my directional hearing affects it." Participants were also afraid of losing hearing in their good ear and the potential further consequences of such a loss. Others feared familiar or social abandonment due to the perception that their UHL made them a burden or annoyance to those around them. One participant voicing this fear said, "I fear my good ear getting bad and all my friends and family slowly dropping me out of their lives." Those with an acquired hearing loss also expressed panic, especially if the loss was sudden.

Participants also expressed feelings of anxiety, often over how others might judge or perceive them. One subject said, "I wish I could feel less anxious about being judged for misunderstanding or not hearing people," while another remarked, "anxiety over thinking that others think I'm ignoring them." Another participant expressed general anxiety relating to their hearing loss: "I think it has created a lot more anxiety in me overall my whole life. I think the anxiety comes from lack of ability to place sound, so I'm not as comfortable as other people are in noisy situations,"

Some participants expressed having a poor perception of themselves, in which they felt like they were a burden to those around them, or felt anxious and self-conscious about their difficulties communicating. One participant described it as follows: "I can't understand when they say things to me until I ask them to speak clearly and at me. It hurts me to think that they think negatively of me because of it."

It was clear that participants' hearing loss weighed heavily on them, resulting in feelings of depression and feelings of disconnection with the world around them. Participants reported feeling isolated from

others and actively isolating themselves by avoiding social situations. The difficulties encountered by participants in daily communication reduced the attractiveness of social gatherings. For example, one participant stated, "I think the social isolation is the worst. I very rarely socialise in noisy environments as it's just too stressful and difficult." Some people noticed that their hearing loss had changed their behaviour; one responded, "I became an introvert, and don't go out much."

Participants commonly encountered frustration throughout their daily life, particularly in social situations. One participant reported frustration at having "to ask people to repeat themselves more often than most people," while another at "having to constantly tell people who try to talk into my deaf ear that I can't hear out of it and then explaining why." Yet another respondent simply stated, "I have been frustrated with my disability all my life." In some cases, the frustration described by participants included strong elements of distress, such as one person who said, "It makes me feel broken, like I can't get simple instructions at work".

Social/Behavioural

Most participants mentioned having problems with communication in social situations, resulting in feelings of disconnection from the world around them. In some cases, these problems caused the individual to isolate themselves by avoiding social situations. Furthermore, participants reported engaging less in communication with their close family and friends due their difficulties. Participants' hearing loss also affected their relationships with family in other ways; one participant described arguments that occur with his wife relating to his hearing loss: "I've been married for over 15 years, and I still get into arguments with my spouse because I missed something she said. I have an expectation that she would understand by now; she has an expectation that I can hear."

Participants reported missing important information while in communication but also more trivial information such as jokes, which left them feeling as though they were missing out. As a result, participants often had to ask people to repeat themselves; this was a source of frustration for the participant and they also perceived it as being frustrating for those around them. This perception of frustration meant that participants were discouraged from communicating their needs to others. One participant stated, "People think I'm ignoring them when really I can't hear. People forget that I'm hard of hearing. People get easily frustrated that I can't hear them." Participants suggested that societal awareness of UHL was generally poor, and perhaps those around them tended to become frustrated due to a lack of understanding and empathy. They felt that the "invisibility" of hearing impairment was a significant contributor to this, preventing those around them from relating to the difficulties they encounter during daily life.

One of the more commonly reported themes in this study was stigma. Participants reported having a strong perception of stigma, particularly in the workplace, where they did not want others to know and judge them for their hearing loss. This often affected participants' behaviour such as wearing devices. For example, one participant said, "I only wear it on weekends. I don't want my work to know about my disability." Another participant noted, "I fear that if I have a hearing aid, people will automatically assume that I am fully deaf or incompetent to perform my job." A more general comment from one of the interviewees was, "I try not to mention it to people, unless it's really obvious."

Coping mechanisms

Participants developed various coping mechanisms in response to the difficulties encountered because of their hearing loss. Participants recognised that in some cases, coping mechanisms were applied through conscious effort, while in other cases they had adapted without conscious thought. Those with congenital UHL tended to develop coping mechanisms more easily and naturally than those with acquired UHL. There were a variety of coping mechanisms identified, including strategies to improve communication ability in noisy environments such as lip reading, sign language, and tilting their head to favour their good ear.

Other coping mechanisms required proactive action, such as positioning themselves in a corner of a room, or positioning themselves to have important sound sources on the side of their good ear while walking or at a table. More proactive coping mechanisms included communicating their needs with those around them, and moving to a quieter location before engaging in conversation. The perception of stigma was a barrier to some coping mechanisms, as participants preferred not to disclose their hearing loss to others or felt uncomfortable requesting those around them to repeat themselves while in conversation. As a consequence, another coping mechanism exhibited by participants was pretending to understand, to avoid the awkwardness of repeatedly asking someone to repeat themselves. Personality appeared to have an effect on the use of coping mechanisms and participant outcomes, with extroverted individuals being more likely to disclose their HL to others and generally more comfortable being proactive about their hearing loss, and thus were likely to have more positive outcomes than introverted individuals.

Participants also mentioned using closed captions while watching television and using assistive smartphone applications/settings. Finally, some participants visually identified their deaf ear by wearing an earbud or having a tattoo, to encourage those around them to position themselves beside their good ear before engaging in conversation.

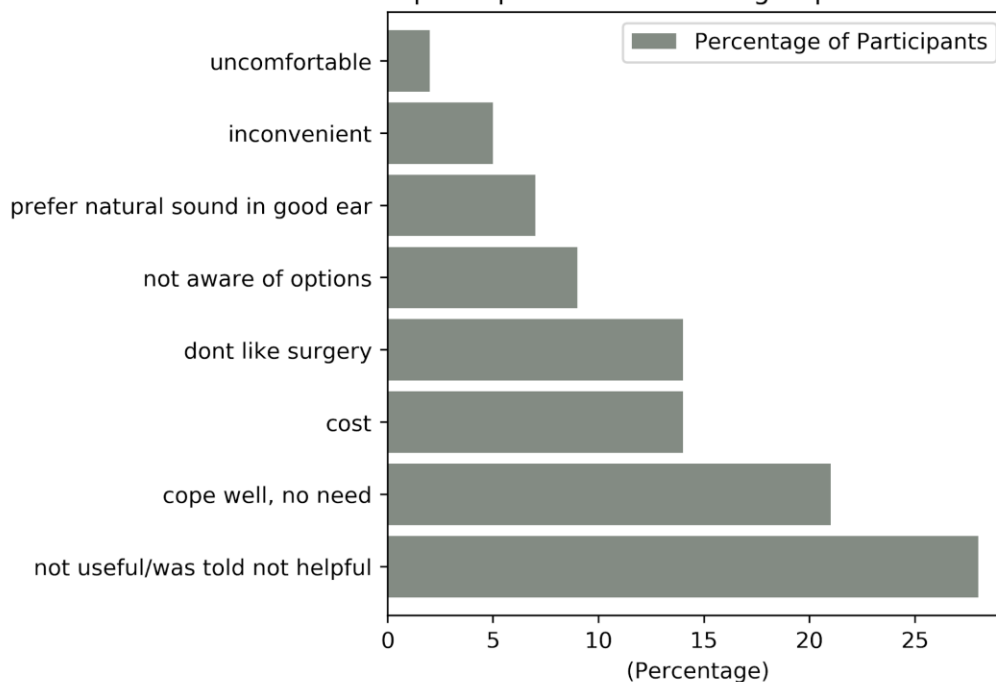
Technology/devices

Concerns of the untreated group

Table 1 shows the main reasons for participants in the untreated group not choosing devices. Most participants (28%) reported that they did not use a hearing device because they thought that it was not useful or because they were told that it was not helpful. About 21% of the respondents reported they were coping well enough that they had no need to use a hearing device. The cost linked to the hearing rehabilitation and the invasiveness of the treatment were another two main reasons (14% each) for not using a hearing device. This is especially true for people who don't have any reimbursement available. Participants were reporting, "I do not like the idea of a surgical solution that leaves a lasting cosmetic impact. Waiting for technology to get smaller/better," or telling that it "seems intrusive for someone with a working ear". Some participants were just not aware that rehabilitation options existed (9%).

A social stigma or negative perception about their hearing loss from others was also a common reason for not getting/wearing a device; a respondent told us: "I had anxiety in young age, victim of bullying and harsh comments. I gave up on wearing them due to these things."

Mains reasons for participants in untreated group not choosing devices (N=50)



Comments from the treated group

Considering the treated group, adults with UHL reported variable degrees of benefit with hearing devices (Table 2). In general, half of the participants fitted with a BAHA or CROS system reported being relatively satisfied with their hearing aids. However, while some enjoy using them--“great, made a big difference from the first aid fitted. I would wear 12 hrs a day and only take it out at night”--others report dissatisfaction with currently available technology.

A reported issue with the CROS system is its poor performance in noisy environments--“at parties or loud spaces it doesn't offer much benefit”--and that it does not help localise sounds. Another complaint from the user was the negative effect of noise routed from the bad ear to the good ear, which affects the overall sound quality for the listener. Some of the comments from the CROS users included, “*I use it whenever I am outside the house and most of the time provides significant help,*” “*it is definitely better than nothing,*” “*Useful in one-on-one or more intimate settings,*” and, “*useful in relatively quiet situations.*”

The BAHA users' satisfaction ranged from ‘very satisfied’, because it decreased listening effort, to ‘dissatisfied’. Some of the positive comments from the BAHA users included: “*being able to converse with people in public more easily,*” “*I got my energy back and I am able to to be more active. I can also now hear lyrics to songs,*” “*it helped my tinnitus,*” and, “*it helps a lot with sound location, anytime I am in public and I find it incredibly useful.*”

Some of the comments from the hearing aid users included, “*it's amazing and worth it. It just takes time,*” “*I use whenever I am out of the house, especially for loud and crowded places. It's incredibly helpful in normal situations,*” and, “*It makes hearing easier and conversations much easier to pick out of background noise. A standard hearing aid helps considerably. Outside of the house I use it ~80% of the time.*”

There were only two CI users in the treated group. One of them had a trial with a hearing aid, a CROS and a BAHA, and they took the decision of cochlear implantation due to the lack of benefit using these devices. Although both of these participants were very satisfied with the CI option, more evidence of the outcome is needed.

Some comment from people using bluetooth features are, *“The bluetooth features are incredible,”* and, *“It uses a lot of the battery.”*

Table 2. Satisfaction with the different devices used by adults in the treated group.

| | N | Satisfied | Helpful but with some issues | Ok | Dissatisfied |
|------------------------------|---|-----------|------------------------------|-----|--------------|
| CROS | 6 | 50% | 31% | 19% | |
| Hearing aids | 1 | | | | |
| | 1 | 27% | 45% | 18% | 9% |
| BAHA | 7 | 57% | 14% | 14% | 14% |
| Others/ remote microphone | 4 | 50% | 25% | | 25% |
| CI | 2 | 100% | | | |

People’s wishes

As part of our exploration, we put forward two questions to tap into people’s wishes for the future: 1) What would you like to see or be using in the next 5-10 years to help your hearing?, and 2) If you could change/improve one thing that is related to your hearing loss, what would it be?

New technology such as real time audio captioning using Internet of Things devices were mentioned multiple times. People also mentioned, “dreams of bionic implants to restore near perfect hearing,” and, “hair cells generation”.

Related to the themes and trends we have just discussed, the call for better awareness was made multiple times: *“If I could change/improve one thing that relates to MY hearing loss, I would say better public understanding,”* *“I would like more recognition in society that single sided deafness can be hard to deal with. I’ve never really had anyone understand how it’s a challenge in my life,”* or simply the wish for *“Compassion and empathy from other people”*.

One respondent who struggled with anxiety around their hearing loss also expressed, *“I wish I could feel less anxious about being judged for misunderstanding or not hearing people.”*

Conclusion

It is important to understand the demographic limitations of the current study in terms of participant recruitment from an internal database for interviews and from online forums for surveys. Nevertheless, the relatively large age spread across participants and the wide variety of etiologies provides a good overview of the issues faced by adults who have a UHL.

Importantly, our analysis showed that the impact of UHL varies among individuals. While 1/5th of the people who took part in the study reported that they were coping well in general, the majority of the participants reported a significant impact of the condition on their social life and on their wellbeing.

Another trend that we identified was the different perceptions regarding the burden of impact between people who suddenly acquired UHL - who reported stress, anxiety and difficulties - and people born with UHL, who have better adapted and reported a larger variety of coping techniques.

The most common treatment reported for UHL was a CROS aid. Some UHL patients used BAHAs and reported good benefits. Overall however, our exploration found that these two devices do not seem to address localisation or speech in noise understanding adequately. The inconvenience of the hearing devices (including the cosmetic features of the device), and the invasiveness of some of the treatment options are barriers to use or continued use and may outweigh the perceived benefits.

Another emerging treatment option is CI. *However, there is limited evidence and information on the outcomes of this treatment for UHL* - or the current evidence has not permeated through to general knowledge as yet. As for other treatment options, the invasiveness and the cost of getting a CI is a clear barrier that many people cannot overcome to consider this as a viable treatment option for them.

Lastly, we found that the psychological impacts of UHL are significant and varied, becoming the main focus within our exploration of this population's experiences. Most importantly there is a need to improve awareness and to better understand the impact and struggles of people who have unilateral hearing loss (UHL), the audiologists who treats them, and those who work, live and socialise with them.

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