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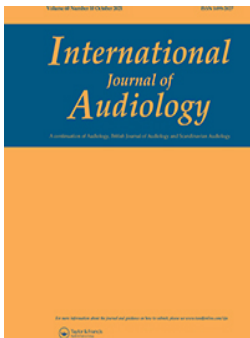
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Exploring the lived experiences of British Sign Language (BSL) users who access NHS adult hearing aid clinics: an interpretative phenomenological analysis

Celia Hulme^a , Alys Young^{a,b}  and Kevin J. Munro^{c,d} 

^aSocial Research with Deaf People (SORP), School of Health Sciences, University of Manchester, Manchester, UK; ^bCentre for Deaf Studies, University of the Witwatersrand, Johannesburg, South Africa; ^cManchester Centre for Audiology and Deafness (ManCAD), School of Health Sciences, University of Manchester, Manchester, UK; ^dManchester University Hospitals NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, UK

ABSTRACT

Objective: To explore the lived experiences of culturally Deaf British Sign Language (BSL) users who access adult hearing aid services.

Design: Semi-structured qualitative interviews were conducted in BSL by the Deaf researcher and analysed using an Interpretative Phenomenological Analysis (IPA) approach.

Study sample: Eight Deaf BSL expert informants who were experienced users of NHS adult hearing aid clinics.

Results: Participants expressed dissatisfaction about audiology staff's lack of Deaf awareness and did not feel valued as Deaf signers. Participants' motivations for hearing aid use primarily concerned audibility rather than speech. Mismatch of perspectives on 'hearing' between audiologists and Deaf patients are discussed in the context of culturally sensitive services. Inadequate or uncertain linguistic access during appointments is considered in light of patient agency.

Conclusion: This is the first study to explore culturally Deaf signers' specific experiences of adult hearing aid services in the UK and their experiences of hearing aids. There are numerous reasons why Deaf signers wear hearing aids, but access to spoken language is not a priority. Limited Deaf awareness and cultural competence in adult hearing aid services can result in patient frustration and disempowerment. Suggestions for improvement in the Deaf signing patient experience are offered.

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British Sign Language; audiology; hearing aids; patient experience; cultural competence



Introduction

Approximately 350,000 new adults per year are fitted with hearing aids (The British Irish Hearing Instrument Manufacturers Association 2019) under the National Health Service (NHS). The UK National Health Service (NHS) is a socialised health care system, which is free at the point of delivery. Patients are referred to NHS audiology services by their General Practitioner (Primary Physician). Within that large population of adult patients who wear hearing aids, Deaf people who are British Sign Language (BSL) users are a cultural-linguistic minority distinct from those who lose their hearing later in life or are predominantly spoken-language users. BSL is a language in its own right, distinct from English (Sutton-Spence and Woll 1999), and has been recognised as an indigenous language of the UK since 2003 (Smith 2003). Overall, it is estimated that there are 87,000 BSL users in the UK (BDA 2018). The actual number of Deaf signers who use hearing aids or cochlear implants is currently unknown, but it is thought to be low (Dammeyer, Lehane, and Marschark 2017). However, the number of Deaf signers who as adults are choosing to use a hearing aid and/or cochlear implant has been growing in recent years (Harris and Paludneviene 2011). It is assumed that this rise is accounted for by a new generation who have benefitted from early identification of deafness in childhood and had better access to sound at an earlier age. However, hearing

aid use does not necessarily signal rejection of either BSL or cultural affiliation with the Deaf community.

The seemingly growing engagement of Deaf signers with audiology services is an interesting shift because traditionally many culturally Deaf people have rejected hearing aids, seeing them as a symbol of oppression (Ladd 2003; Lane 2005). This is because audiology services are generally regarded as having a restorative purpose based on a deficit model of hearing, i.e. the primary purpose is to increase audibility and intelligibility of speech. This is a world view that is very different from how Deaf signers view their deafness as a component of their cultural-linguistic identity (Ladd 2003; De Clerck 2017). Deaf culture is both transnational in facets common to making signing communities and distinct with features specific to particular nations (Hualand, Kusters, and Friedner 2016) each with distinct cultural behaviours, points of view, traditions, and priorities. To be Deaf is thus readily seen as a cultural attribute that transcends notions of bodily/sensory deficit (Ladd 2003; Woodward 1972; Padden and Humphries 1988). Professional discourse that seeks to restore, cure, or eradicate hearing loss can be seen as rejecting, diminishing, or disallowing that identity (Young and Temple 2014).

In recent years, Deaf people have called into question the quality of audiology services from their views. Most of these concerns are anecdotal accounts, such as the examples found on

CONTACT Celia Hulme  celia.hulme@postgrad.manchester.ac.uk  Social Research with Deaf People (SORP), School of Health Sciences, University of Manchester, Manchester, UK
OSF: <https://doi.org/10.17605/OSF.IO/N7UYM>

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“Limping Chicken” (www.limpingchicken.com), a popular online blogging online forum for Deaf signers. Withey (2014) and Swinbourne (2017) both recounted, in negative terms, professionals’ lack of knowledge about BSL and how their choice of words conflict with how Deaf people view their deafness, identity, and everyday life. An unwillingness by some medical practitioners to consider deafness in light of cultural identity is also identified (Iezzoni 2006). Such patient feedback is at odds with NHS Audiology services priorities to provide a patient-centred (Grenness et al. 2014), individualised, and equitable service to all that is linguistically and culturally sensitive (NHS England 2016b).

The research literature on Deaf people’s interactions with audiology services is sparse.

Butler and Martin (1987) surveyed the US Deaf community’s knowledge about, need for, and opinions on audiology services. However, the study relied on ratings of pre-determined areas of importance rather than allowing the possibility of different perspectives to emerge from within Deaf people’s own experience as a qualitative inquiry might have. Also, the study is over 30 years old; it is unclear to what extent the findings are still relevant. A recent study by Cue et al. (2019) exploring participants’ narratives on what it is like to be D/deaf¹ contained some references to reasons for hearing aid use. Examples included “soothe”, “communicate”, and “provide comfort” although the meaning of these descriptors is not expanded on. Moreover, it is not clear whether participants were sign language users. More broadly, studies of culturally Deaf peoples’ access to health services consistently find that Deaf people experience poorer health as a result of misdiagnosis, underdiagnosis, and lack of communication access (Emond et al. 2015). Healthcare services are generally designed to favour those who use spoken language and written English, which may effectively hinder Deaf sign language users’ self-management of health conditions (Pollard and Barnett 2009).

Culturally responsive audiology services and practices have been the focus of some research with specific communities internationally. Cross et al. (1989) outline five elements that make a service culturally responsive: (1) valuing diversity, (2) having the capacity for cultural self-assessment, (3) being conscious of the dynamics when cultures interact, (4) having institutionalised cultural knowledge, and (5) having developed adaptations to service delivery reflecting an understanding of cultural diversity. Examples of such responsiveness include collaborations between audiology services and the Inuit (Billard 2014) and Aboriginal and Torres strait communities (Children’s Health Queensland Hospital and Health Services 2017a, 2017b). They employed health workers from their respective communities to be specialist link workers to improve access, uptake, and interaction with services. Also, Spanish Hispanics in the US (Reel et al. 2015) and Korean American older adults (Choi et al. 2019) have worked with audiology services to develop linguistically and culturally appropriate assessments and resources. No study on cultural competence concerning minority language users and hearing services has included Deaf adult signers.

In summary, there is a lack of research evidence internationally about the experiences of Deaf sign language users who access adult hearing aid services or how services ensure effective engagement. Studies of cultural competence and audiology services related to other minority communities are not necessarily directly relevant. Therefore, the current study aimed to explore the first-hand experiences of Deaf signers in England who are current hearing aid users, focussing on their motivations for

wearing hearing aids and their experiences of audiological services. It is a first step towards informing a national survey on culturally Deaf access to and uptake of hearing aid services in England.

Methods

Methodological approach

The exploratory qualitative research design is driven by Interpretative Phenomenological Analysis (IPA) (Osborn and Smith 1998). The phenomenological component permits focus on culturally engendered meanings. The idiographic element gives due attention to the individuality of experience, not just the generalisable or collective. Finally, the double hermeneutic practice acknowledges the cultural-linguistic positioning of the lead researcher (Author One) who is also a Deaf BSL user and hearing aid wearer. This enables the researcher to build a reflexive epistemological stance within the study materials accounting for and incorporating her own Deaf personal and professional experience (Swinbourne 2017; O’Brien and Kusters 2017).

Sampling and recruitment

An expert informant approach underpinned sample selection (UCLA 2012). The expert was understood in this case to mean Deaf BSL users aged 18 years or over, currently wearing one or more hearing aids, and who regularly attends NHS Adult Hearing Aid services in England. Former hearing aid users and current cochlear implant users were excluded from the study.

A purposive sampling approach (Patton 2002) directed the choice of expert informants to ensure a diversity of age, gender, family background, and socioeconomic status. Following approval through the University of XXXXX ethical review board, ten participants were initially contacted either by text messaging, email, or video conferencing. Two declined to take part in the study. All participant information and consent materials were available in BSL and with additional clarification provided live before the interview. All participants were volunteers and no payments were made.

Data collection method

Data were collected using individual semi-structured interviews guided by a prompt sheet containing open-ended, non-directive questions to encourage free narrative responses as required for IPA (Smith and Osborn 2003). They were asked questions about their personal history of using hearing aids, general experiences of audiology, how often they attended and how they communicated with staff and vice versa. Six of the interviews took place in the participant’s home, one in a Deaf club and the other on the university campus. All interviews were conducted face-to-face in BSL by the researcher (no interpreter present or required) and recorded using a video camera as BSL is a visual, non-written language. Each participant was interviewed once and interviews lasted on average 90 min.

Participant characteristics

All the participants (four male, four female) were culturally Deaf fluent BSL users between the ages of 30 and 76 years. Five were

in paid employment (three full-time and two part-time), two were retired and one was a full-time career. One, a migrant to the UK, had always worn hearing aids since arriving in the UK 10 years ago, but in their country of birth could only wear hearing aids during school hours. Six described themselves as White British, one as Black African, and one as Asian British.

To set some context for the results section, a brief “pen portrait” follows for each of the participants interviewed in this study. All participants’ names have been changed.

Amelia is in her early 50s and has worn hearing aids since childhood. She says they make her feel “grounded and safe”. She uses a BSL/English interpreter for communication when attending the clinic.

Arnold is in his late 70s and stopped wearing hearing aids when he left school and returned to hearing aids 55 years later because of improved technology. He wears them to hear background noises. He relies on his wife, a BSL user, for communication when visiting the clinic.

Emily is in her mid-40s and stopped wearing her hearing aids when she was 16 years old and returned to hearing aids 15 years later to hear her children. Emily mainly uses her hearing aids to assist with lip-reading and background noises. When communicating at the clinic, she uses spoken language (her own voice) and lipreading.

Idris is in his early 30s. He is originally from an African country and he grew up with limited access to hearing aids, only being allowed to wear them at school. Since moving to the UK he wears hearing aids all the time and uses them to listen to music, watch TV and assist with lipreading. He uses an interpreter for longer appointments but not for drop-in sessions.

Jack is in his early 70s and says he threw away his hearing aids after leaving school for “political reasons” and due to “peer pressure”. He returned to hearing aids over 40 years later to address his tinnitus. He uses lipreading and spoken language for communication when the attending clinic.

Kate is in her mid-40s and has always worn hearing aids since childhood. She uses them to communicate with her children, assist with lipreading and hear background noises. She uses lipreading and spoken language for communication at her clinic with the same audiologist she has had since she was a child.

Leon is in his early 30s. He has worn hearing aids since childhood and is very proud to wear them. He uses them to listen to music, watch TV and hear his voice. He has an interpreter for longer appointments but not for drop-in visits to the clinic.

May is in her early 40s. She wears her hearing aids to hear background sounds, helps her lipread her children, for health and safety purposes at work, and shows that she is deaf. When she attends her clinic, she uses spoken language/lipreading to communicate.

Data analysis

Data were collected in BSL and translated from the source language (BSL) to written English and uploaded to QSR NVivo 12. The translation was carried out by the researcher who is a native BSL user and also bilingual in BSL and English. All participants were assigned pseudonyms to maintain confidentiality.

The data were analysed using a six-step process framed by Smith (2009). Step 1: close reading and re-reading the transcript engendered detailed descriptions of the participant’s unique experience first. Step 2: the double hermeneutic concept was applied meaning the lead researcher from her own point of view described how she understood participants’ experiences (Smith

2009). Step 3: the interpretative and reflexive comments were used to identify emergent themes. This was an iterative process as each time a new theme emerged, the transcript was reviewed again to identify potential new themes. Many themes were generated and Step 4 consisted of abstraction to identify patterns between themes and group them into super-ordinate themes. Step 5 repeats Step 1 to Step 4 for subsequent transcripts. Finally, Step 6: patterns across all eight transcripts were identified. The reporting of the study here conforms to the COREQ Equator Network Standards (Tong, Sainsbury, and Craig 2007).

Reflexive statement by the lead researcher

I am a culturally Deaf BSL user who wears one hearing aid and have done so since childhood. Both the personal and professional aspects of my identity and experience have given me specific insights into the data which I acknowledge I have interpreted from within a framework of “Deaf ways of knowing” (Ladd 2003; Swinbourne 2017; Young and Ackerman 2001; Holcomb 2010). By this I mean my sensory, linguistic, and cultural experience of the world cannot be separated from the interpretations I bring to my own and others’ experiences and how knowledge is constructed. I acknowledge that participants’ life experiences are likely to differ from mine because of the multiple and intersecting aspects of identity. Nobody is “just Deaf”. However, I do perceive myself as being the same (Bowland, Wilson, and Winiarczyk 2015) as the participants in several ways because we have a common cultural identity and share mutual experiences. I occupy both an insider and an outsider position. Insider status brings disadvantages because I may know them professionally or socially in other contexts potentially resulting in them being less open during interviews whether for reasons of privacy or assumptions that some things do not require explanation because “we” understand. This may result in less probing data (Friedner 2016). However, being an insider can also offer added advantages arising from trust and openness with someone perceived as similar and who will understand the data from a shared vantage point (Swinbourne 2017). As a professional researcher, the IPA approach enabled such potential biases to be addressed through the deliberately reflexive stance within the data analysis at all stages ensuring rigour and transparency in the inferences drawn from the data (Hammersley 2007).

Results

The IPA analysis process resulted in four overarching themes and nine sub-themes.

1. Hearing aid – what for?

In this theme, the motivations and rationalisations of participants’ hearing aid use are set out within three sub-themes.

1.1. Why reject hearing aids and why come back to them?

Three of the eight participants were returning hearing aid wearers, having initially rejected them once they left school. In each case, the motivation to resume hearing aid use was different and arose from choices within their adult lifestyle compared to how they felt as children.

After leaving school Emily was immersed in a signing environment at home, college and socially. Quite simply, she did not feel that hearing aids fitted into her adult lifestyle.

“When I left school, I had to go to audiology myself which was a nuisance ... Another reason is that it was noisy at college, the sound was not useful and what was the point in wearing them? Oh, my family are Deaf and sign so no sounds at home and those are the reasons why I put them away”. (Emily)

Jack’s negative experiences of his Deaf school’s approach to hearing aids led him to against their use, which was reinforced by peer pressure.

“The teacher used to force us to wear them. We were angry, the teacher had microphones, they would put their hands over their mouths and start talking. ... My friends used to say, ‘we are leaving school very soon and can’t wait to throw our hearing aids away, we don’t want them’. I followed what they did and threw my hearing aids away”. (Jack)

Although Arnold shares a similar experience as Jack, his main reason for not continuing to wear hearing aids was because all he could hear was “white noise” and they did not afford any benefit.

Their reasons for return to hearing aid use were very different. Emily, 15 years later, wanted to hear her baby’s first cry. Arnold, 55 years later, learned about technological advances in hearing aids. Jack, who had suffered from tinnitus for many years, tried on his wife’s hearing aids out of curiosity and found that they helped his tinnitus.

1.2. Why wear hearing aids?

It is perceived that hearing aids are primarily used to access spoken language but for participants, this was a low priority. Rather what was important was the benefits of access to sound in different ways and how they felt. All remarked that they wear hearing aids for awareness of audible background noises, which makes them feel comfortable and safe.

“When they shout ‘Mum’ or when I’m outside, I feel a little bit safe hearing something”. (Kate)

“I can hear voices in the background, but I do not understand what is being said, but knowing that someone is there, this makes me feel comfortable”. (Amelia)

Similarly, because hearing aids for some enabled the monitoring of the volume of their own voice, this could result in feeling more confident and more in control.

1.3. Understanding hearing aids

What hearing aids are for, can also be considered in terms of the extent to which someone may understand hearing aids can do. In this respect knowledge and interest varied considerably. Idris and Leon, who use interpreters at their appointments, displayed the most knowledge about their hearing aids whereas Jack and Arnold were surprised to learn that there is more to know, but they were not interested in exploring further. Conversely, Amelia, Kate, Emily, and May showed eagerness to improve their knowledge but felt they are restricted because there are no BSL resources explaining audiograms, how hearing aids work, and their programmable settings.

2. Who knows best

This theme addresses the cultural and medical juxtaposition between Deaf people who have lived experiences of wearing

hearing aids and audiology staff who prescribe and fit hearing aids. These are set out within two sub-themes.

2.1. Self-management

Participants’ experiences of being allowed to manage their own hearing aids varied. This was interpreted as an indication of professionals’ low expectations of their capability, perhaps because they were Deaf, rather than variations in standard clinic practice. Emily and May were expressly told that they could not take responsibility for replacing their own tubes despite wearing hearing aids since they were born. They have to attend clinic drop-in sessions to get their tubes replaced professionally:

“They refused to give the tubes to me, they would not let me sort it out myself, I felt like a little girl. I have grown up with hearing aids, I know how to change them!” (Emily)

“Yes, I can do it myself, I am used to it and have lived with it all my life. They said no”. (May)

Amelia, Idris, Leon, and Kate were able to replace their own tubes.

2.2. Sees the ear not the person

Several participants had experiences where they felt their ears were seen but not their wants, needs, and preferences as individuals. For example, Emily was sitting in the waiting room with her interpreter when her audiologist was overheard saying:

“What is the point in her [me] having a hearing aid, she’s profoundly deaf. Ohh, it was not nice overhearing that. I can imagine her thinking you sign; you don’t listen to voices or speak. She does not understand my life or how I communicate” (Emily).

In May’s case, when receiving her new hearing aids, she could not understand why her preferences for sound comfort took second place to technology protocols:

“Sometimes the sound is very loud, and it startles me when it is turned on. I throw it off to show them that it is too loud. They say it is normal. I moan about it and tell them to turn it down, but they say they can’t because of the computer”. (May)

By contrast, Idris and Leon, both in their early 30 s, stood out as participants who are very involved in their hearing aid management. They both insist on interpreters at their review appointments to ensure they have maximum access to information. Both displayed not just more technical knowledge about their hearing aids’ capabilities but also more assertion that their preferences should be met.

However, most of the participants, who did not routinely use interpreters when visiting the audiology clinic, were not aware of the capabilities of hearing aids and the choices they might have in relation to settings and programmes:

“Not really, not 100%. I know the on/off switch, and that the ‘beep’ noise means the battery is flat”. (May)

“I just found out today [through this interview] that there are so many things that could be adjusted in my hearing aid. My god, I could go back and say I want that and that”. (Amelia)

Consequently, few participants described self-management, agency, or patient activation tactics to enhance their hearing aid experience.

3. Always the same

This theme illustrates participants’ outlook towards and experiences of their hearing aid services. The general perspective is

that barriers have always remained the same since their early adult years. These are set out within two sub-themes.

3.1. Inequality of access

The majority of the participants described feelings of disempowerment caused by a lack of autonomy. Barriers were immediately faced before stepping into the hearing aid clinic:

"The letter has a phone number. That is no good to me. You always have to use the phone for an appointment, it's no good! ... I have to use my son to make the phone call for me". (Arnold)

Consequently, this created a reliance on others to make contact on their behalf. However, May is an exception as her hearing aid clinic recently provided her with an email address, which has afforded her independence and equality, which she appreciates.

Most of the participants reported that no one in the clinic could sign:

"They can't sign. I talk for them. I could complain, but the complaint process is too long, it feels a long way". (Jack)

"I do wonder if they understand my Deaf voice". (Idris)

They felt they had to use their "Deaf voice", lipread or resort to using pen and paper or say nothing other than point to their appointment letter. This was important because it made participants feel disempowered and not valued as patients.

Under UK law it is the health provider's responsibility to arrange for and book an interpreter, if required, for a patient and a provider to communicate. However, for most participants, this was rarely straightforward and they said they lacked confidence that the clinic will arrange this:

"I remind them in case they do not book. Last time I did not say anything, and no interpreter was booked". (Amelia)

Based on their experiences in other areas of healthcare, it is, in their view, just not worth the stress, inconvenience, and uncertainty of insisting on an interpreter being pre-booked.

3.2. Cultural competency

Another recurring issue that, in participants' opinions, had never really changed was the lack of cultural competence they experienced in-clinic visits.

Lack of a culturally appropriate layout of seating in the waiting area led to participants mistrusting the patient calling system as explained by Jack:

"I have a specific seat on a wall so that I can see staff coming in saying my name" (Jack).

Most did not feel confident that staff would come to them if they sat where they could not see or hear, thus missing their allocated consultation.

Most reported that their audiologist displayed very little Deaf awareness and made little attempt to communicate with them directly as expressed by May and Jack:

"They do not explain anything, they put the headphones on me very quickly without saying anything. Everything is so quick; I don't know what is happening next. ... It makes me feel very small. It would be nice if they explained". (May)

"They work on the tube, but they don't look at me or communicate with me. I give them my book for batteries, they sign it and say bye. That's it". (Jack)

4. Hearing discourse

This theme considers participants' sense-making in relation to their Deaf identity and use of hearing aids. Discourse with a capital "D" in this sense means the Deaf person's understanding of "hearing" based on their literacy linked with ways of acting, interacting, feeling, thinking, and believing. Participants in this section refer to "hearing" as a person's status rather than a sensory ability.

These are set out within two sub-themes.

4.1. Identity and hearing

For all of the participants, sign language is prominent and core to their identity. Being Deaf has a linguistic and cultural meaning to them, which generally was not acknowledged in their visits to audiology. Consequently, being Deaf in an environment that is concentrating on "hearing" could be disconcerting because participants' Deaf identity and how "hearing" and deafness were discussed were at odds.

In Amelia's experience, being asked about what she could hear by others or asking herself why she was going to the hearing aid clinic could be very confusing. On the one hand, she goes to the hearing aid clinic to focus on her hearing. On the other hand, she is quite sure she is Deaf in the cultural-linguistic sense.

"I have got some hearing. I would say... well, I have always said I'm Deaf, that's it. I'm Deaf, I would not say that I'm hard of hearing, I'm not profoundly deaf, I'm just Deaf". (Amelia)

Here she uses "Deaf" to imply identity not deaf to imply a degree of hearing loss.

The same kind of mismatch of perspectives was evident in the course of the research interview as well. All Deaf people who wear hearing aids have some degree of hearing. However, when questioned in the interview about their use of hearing aids and what they can hear, the discussion was unnatural because talking about personal use of hearing aids is not usual practice in the Deaf community. Also, many did not understand how the noun "hearing" could apply to them when asked what they can hear, as they see themselves purely as a culturally Deaf person and are more used to using "hearing" as an adjective to mark others identities. "I am Deaf, she is hearing".

4.2. Understanding hearing and deafness from the audiological point of view

Jack and Idris had a real interest in learning about their hearing abilities from the perspective of audiology and hearing aids. They, and some of the other participants, when referring to audiograms, referred to the typically hearing baseline on an audiogram as "the good line" and described themselves as below the "good line".

Idris asked about his line on the audiogram:

"Are they good? They said it was OK". (Idris)

When Jack wanted a specific hearing aid and his audiologist said:

"Your hearing is not good enough for that type of hearing aid". (Jack)

Jack interpreted this as being "bad" rather than not suitable. These were both adults who as children, had experiences of others portraying their hearing abilities as being good and deafness as a problem and by extension, the individual not being acceptable.

Discussion

This is the first study to explore and elicit culturally Deaf signers' experiences of hearing aids and audiological services in the UK. The data will inform a future survey to identify what makes an effective hearing aid service for Deaf signers. The findings provide a rich understanding of lived experiences, some of which mirror existing literature and some of which was rather unexpected.

Deaf identity and hearing

The use of "deaf" to imply a sensory attribute (hearing loss) and "Deaf" to mark a cultural identity distinguishes different populations and is well-accepted in the literature. All the participants who have been interviewed use sign language and view themselves as visual cultural-linguistic beings (Ladd 2003; Padden and Humphries 1988; Young and Temple 2014; Hauser et al. 2010). For them, being Deaf is not a statement of audiological status, it is a way of life (Ladd 2003); a way of being and knowing which are influenced by their community, interactions, and relationships (Derrida 1976; Friedner 2016; Young et al. 2019). All participants described themselves from a Deaf identity perspective rather than from an audiological perspective in terms of how much they can hear and what technology they might use (Holcomb et al. 2019). For example, Amelia described herself as "just Deaf" with no references to how much she can hear and the fact she wears hearing aids.

However, this study contributes to the debate on the recognition of Deaf identity from another perspective that participants were confronted with – what is the place of "hearing"? From the interviews, it was evident that all participants viewed "hearing" as an identity label (e.g. "she is hearing") that marks a status, not as a sensory function ("she can hear"). Consequently, to ask them about their hearing made little sense as they would rarely think about their hearing in the sense which an audiology professional would use that term.

The scarcity of discussion around hearing aids and what people in the Deaf community can hear contributed to some confusion around "hearing" during the study interviews. The lack of accessible information for Deaf people to support health literacy in general (Children's Health Queensland Hospital and Health Services 2017a, 2017b; Reel et al. 2015) and hearing aid services in particular also does not assist with meaningful participation during clinic sessions or full understanding of hearing support options available to them. It is not usual to provide patient information in audiology services in signed languages. Liaison workers between audiology services and linguistic-cultural communities, such as those established with some first national peoples to promote patient activation overseas are not considered with respect to Deaf signing communities (Choi et al. 2019; Osborn and Smith 1998; O'Brien and Kusters 2017; UCLA 2012; Patton 2002). The current study's recognition of the roots of the mismatch of discourse concerning "hearing" as an identity marker or as a sensory function, is significant for building more effective services and interactions between audiologists and Deaf patients. To see the encounter about hearing as one that is cross-cultural potentially opens up new avenues for more effective professional/patient interaction. Also, as more Deaf people engage with hearing technologies, the challenge is how this might be integrated into Deaf people's self-identity and the identity/ies of the Deaf community (Dammeyer, Lehane, and Marschark 2017).

Hearing aids from deaf people's point of view

We have demonstrated that access to and development of speech are not necessarily primary motivations why culturally Deaf people may wear hearing aids. Instead, a mixture of contextual/environmental functional uses linked to everyday life and emotional/psychological benefits were important and not unconnected to each other. For example, participants report hearing aids to be beneficial for improving the audibility of hearing background noises, such as traffic, TV noise and generally being aware of people talking, as well as assisting with lipreading. Furthermore, this shows that providing audibility is important, but for reasons of speech is not necessarily at the top of the list. At the same time the feeling that this additional access to sound engendered was positive; such as feeling safe, confident, and in control. The finding points more to the importance of connectedness with the soundscape rather than necessarily to improvements in language and communication. For example, maximising a sound signal to best understand speech is perhaps of less relevance than being able to hear footsteps behind you when you cannot see a person. From a Deaf person's world view, grounded in a visual interaction with the world (Bahan 2008; Lane, Pillard, and Hedberg 2011), the functional use of hearing aids for when visual connectedness does not work, makes sense. An awareness of this perspective could assist in conversations about the range of features available for hearing technologies that might be more beneficial to some Deaf patients. As outlined by May and Jack (3.2), such conversations do not necessarily routinely happen, nor is there recognition that this is needed.

Culturally competent practice

Services provided by the NHS should be equitable, responsive to the diverse needs of patients, and be culturally inclusive (Cue et al. 2019). According to our participants' narratives, they did not experience cultural competency from their hearing aid services. For example, most hearing aid services did not facilitate an environment in which the patient's first language, BSL, could be used. The lack of consideration for people who use languages other than English is highlighted in the reviews on health workforce cultural competency by Jongen, McCalman, and Bainbridge (2018). However, these studies paid scant attention to linguistic differences, highlighting that language access may not be considered an important aspect of cultural competence.

Idris and Jack reported having to use their voice to communicate with hearing aid service staff. This is a very different position from that of confidently bilingual Deaf people who might deliberately choose to speak in specific contexts; what Napier et al. (2019) refer to as "Deaf Contextual Speakers" (DCS). In Napier's et al. study, Deaf professionals were making deliberate choices to do so either to assert their presence or because they do not trust the interpreter to get the message across. In our study, participants were by contrast disempowered by what they saw as no choice other than to try to speak. The Public Sector Equality Duty 2011 (Public Sector Equality Duty 2011) is a UK legislation for public bodies to follow to promote equality and eliminate discrimination. They must proactively provide means of accessible communication in public services remains paramount and from September 2020 all public services are required to publish an accessibility statement (Cabinet Office: Government Digital Service 2020). An assumption that somebody may be able to get by if it seems they can lipread or speak is a breach of patients' rights to their preferred language and is therefore unacceptable (NHS England/Primary Care

Commissioning 2018; NHS England 2016a). As a result, it is essential for hearing aid services and staff to review their cultural competence practices with sign language users.

Limitations

A limitation is the small sample size. Findings based on eight expert informants might have limited generalisability as their views may not be fully representative of the diverse range of Deaf signers who wear hearing aids. The age range of the participants, the youngest recruit was 30 years old, is also a limitation. The younger culturally Deaf generation's hearing priorities and use of hearing aids may be different arising from their lifestyle, political landscape, and the era in which they grew up. Another limitation to the study is that a membership check during analysis was not conducted. The first author is a sign-bilingual, but no independent verification of her translation was carried out. However, the study's strength is that it is the first that has engaged with the Deaf community about hearing aids from a culturally Deaf perspective led by a Deaf researcher.

Conclusion

Discussions around key themes of understanding own deafness and "hearing", lifelong use of hearing aids against medical expertise, motivations of hearing aid use, and attitudes towards hearing aid services yielded valuable new evidence of cross-cultural mismatches in assumptions and interactions about "hearing". Although there were some examples of good practice in audiology services meeting Deaf people's needs, the cultural-linguistic identity of Deaf signers was not prominent resulting in Deaf people reporting disempowerment and lack of autonomy. There is scope for further consideration of Deaf patients, hearing aid service staff, and service management to build a more culturally sensitive and tailored service. Furthermore, this study, with a rich data source, will contribute to survey design and development that is aimed at Deaf signers who wear hearing aids.

Note

1. Cue et al. (2019) defines d/Deaf by following the naming conventions advanced by Woodward (1972) under which the word *deaf* is capitalized or not depending upon whether audiological status (*deaf*) or cultural and linguistic affinity (*Deaf*) is being discussed.

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ORCID

Celia Hulme  <http://orcid.org/0000-0002-5657-4543>
 Alys Young  <http://orcid.org/0000-0001-8551-5078>
 Kevin J. Munro  <http://orcid.org/0000-0001-6543-9098>

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