Deafness and hearing loss in higher education

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Abstract

Hearing loss and deafness affect more than 5% of the world's population. Although hearing loss and deafness are invisible disabilities, they significantly impact individuals. In this chapter, I draw on my personal experiences as an academic with hearing loss and a researcher of ableism in academia to reflect on what it means to be hard of hearing, deaf and Deaf in higher education.

Introduction

June 2019.

I am an invited guest speaker talking on the topic of ableism in academia. I have held this talk on several occasions already, I know what I am going to say, and I am so attuned to what comes next, that I can include performative elements. Today, I find myself lingering a little bit longer than usual on the topic of conferences. I have already pointed out how difficult it is to navigate the lunchtime buffet if you have disabilities.

"Let's continue imagining. Here we are now with everyone else eating our food, and we would like to network with other conference delegates. But that won't be possible!"

I pause for effect, and pointing to the person signing furiously to my left, I finally add,

"Because the Sign Language interpreters are on their lunchbreak. Again, a shift in attitude is required. We tend to see the sign language interpreters to be there for the person who is deaf; but in reality, they are here because people like me cannot sign. The barrier is not the deafness, the barrier is **my** lack of language."

After the entire talk, a number of attendees approach me to have a quick chat, ask questions and to thank me. I am happy talking and explaining. I am in my element; until the deaf delegate and his British Sign Language interpreter come up to me. I greet them both, saying hello and thanking the interpreter for his help. I am utterly embarrassed. Apart from hello and thank you, I can say nothing. I had formal education in English, French, Latin and Spanish as foreign languages, so I get by in most European languages comfortably, but any language really quickly because I understand how the structure works and from there, I pick it up. I manage to hold mini-conversations and order food etc. in foreign languages even if I don't have any formal teaching, like I did in South Korea two years ago. And yet, I cannot speak BSL at all. I do speeches and presentations on ableism in academia, but I cannot communicate in BSL. I can lipread, and I can make sure I speak properly so others can lipread off me, but that is it.

I express my embarrassment and shame, but the deaf attendee and the interpreter are both cheerful. They are just grateful that someone has made it plain and clear in public how challenging it is to be a deaf academic.

According to the World Health Organization (2020), hearing loss and deafness affect more than 5% of the world's population, and they are on the increase. Estimates predict that by 2050, 1 person in 10 will experience disabling hearing loss (World Health Organization, 2020). The figures should be shocking, as they mean that in our children's generation 10% of all children and adults will be having a disabling hearing loss of more than 30 or 40 decibels, respectively (World Health Organization, 2020). For now, it may feel easy to forget or ignore the issues in our anglophone, Euro-Western centric society, as the largest proportion of people with hearing loss live in low- and middle-income countries, especially South Asia, Asia Pacific and sub-Saharan Africa and are over 65 years of age (World Health Organization, 2020). In our "bury your head in the sand" attitude we can push aside any concerns about hearing loss, because we are still young, anyway; until we are directly affected by the consequences. A person with disabling hearing loss as defined by the World Health Organization (2020), for example, will not hear anything that is quieter than 40 decibels. 40 decibels is the sound in a library or equals the bird calls in your garden. If you do not experience hearing loss, imagine a life without hearing breathing, whispers, rustling leaves, or not hearing the bird calls and nature sounds in a quiet rural area or an ambient urban environment (IAC Acoustics, n.d.). For full disclosure, according to the latest hearing test in

January 2019, at the time of writing, my hearing loss stands somewhere between 70 and 90 decibels in both ears, with some frequencies being less affected than others. My hearing loss is defined as somewhere between severe and profound (World Health Organization, n.d.). To paint a full picture, the 70 to 90 decibels equal the noise levels between a vacuum cleaner, a food blender and a Boeing 737 at one nautical mile before landing (IAC Acoustics, n.d.).

As I will highlight, hearing loss and deafness significantly impact individuals. In this chapter, I draw on my personal experiences as an academic with hearing loss and a researcher of ableism in academia to reflect on what it means to be hard of hearing, deaf and Deaf in higher education. In the next section, I outline the contentions around the use of language and their importance within and amongst people with hearing loss and deafness, before exploring in more detail what it means to be a hearing impaired, deaf or Deaf academic. I then reflect on the fluidity and changeability of hearing loss and the impact hearing loss may have on individuals, which leads into a very personal conclusion.

I commence each section with descriptions of a critical incident or situation to locate the theorisations, factual accounts and literature within my personal story. The extracts in this chapter all come from diary and journal entries, which I have kept over the years as part of my endeavours to make sense of my experiences, to practise reflexivity and to use writing as a method of inquiry (Richardson, 2000, 2003). The neatness of the write-up in this chapter is deceiving. In reality my writing is messy, nonlinear and includes sketches, symbols and images, because in line with writing as a method of inquiry I experiment with form and content to extrapolate meaning. In effect, I think with stories (Frank, 2013). The process of

thinking with stories means not to reduce them to content and then analyse them, but to take them as complete, let them affect your own life, joining with them, becoming immersed in them. The end goal is to develop empathy and resonance to truly experience and feel nuances and meanings and to let the story lead in particular directions (Frank, 2013: 22-25, 158-161). My approach to thinking with my own stories, is possible, because the writing, rewriting and retelling do not happen immediately, but are layered upon the originally recorded story, so that I am distanced enough to experience the stories as new to let them lead my thinking, and I hope yours, the reader's, too.

Hearing impaired, deaf or Deaf?

January 2019.

I sit inside the turquoisy-green sound booth. I don't know if this one has holey walls, or doesn't. The booths are all different, but the same, no matter where you are having the hearing tests done. Having been hard of hearing from birth, I have so many hearing tests throughout my life, I could actually be an audiologist myself, by now.

We start with the easy one, headphones on and you listen out for the beeps. If you hear a beep, you click the button. Over the years, I have become quite adept at making this a reaction game. How quickly can I press the buzzer this time? Right ear done.

After a while, my concentration span starts to drop, and I am starting to hear beeps, where I am not even sure if they are in my head or in my ears at all. Again, I am used to that. I am really quite smug about this whole episode. Left ear done.

Next, it's the bone conduction test. That one is always tricky for me. The audiologist puts that special headset over my head, places the oscillator on the bone behind my ear, and off we go.

I can tell that I am not doing well, but that's ok. Some fluctuations always happen. You just need a lapse of concentration, perhaps be a little more tired than usual, or have a cold. Even if you aren't showing any signs of a sneezing or sniffles, your hearing may already be affected. Also, the oscillator wasn't positioned very well. The audiologist opens the door to the booth and explains that we have finished our test. I am surprised. I tell her that I don't think this was the best test, and that the oscillator wasn't placed very well. "It was placed just fine". "I would like to repeat that test". "We do the left ear now."

Beep, buzz, beep, buzz. The booth door opens and I am done.

But I am not.

I am still confused. I haven't had the bone conduction for my right ear. Maybe the oscillator wasn't positioned very well. In fact, I know it wasn't, because I couldn't feel the pressure I usually feel. And also, if I don't press the button for a specific frequency, then the audiologist just needs to increase the volume. Some back and forth between the audiologist and me follows.

In the end, I get the audiologist to repeat the bone conduction for my right ear. Headset on, oscillator on that bone, booth door closed, we are off again. I wait for the beeps. There are none.

At one point, I can feel vibration on the bone behind my right ear, but I cannot hear the sound. I know that I should be able to hear that beep, the vibration is there, but the sound is not. The sound just is not there. No matter how much I concentrate, the sound is not there.

It is at this point that I realise I am deaf. I am in shock. As the audiologist opens the door to the booth, I break down in tears.

A person who is not able to hear the full range of frequencies and/or sound intensities, is described as having hearing loss according to the International Statistical Classification of Diseases and Related Health in its 10th revision (ICD-10, 2019). However, in wider society and amongst the general public more labels or descriptions are in use to describe the physicality of not being able to hear. The terms most commonly in use are: hearing loss, hearing impairment, being hard of hearing, being deaf and being Deaf. I have had hearing loss since birth, and as such, I always identified as being hard of hearing, not deaf. Organisations and associations use clearly defined signifiers to differentiate between the labels. The most commonly applicable description of hearing loss is that of the World Health

Organization, which categorises hearing at 26 to 40 decibels as slight/mild hearing loss, with hearing at 41 to 60 decibels as moderate, hearing at 61 to 80 decibels as severe and hearing at 81 decibels and above as profound (World Health Organization, n.d.). Within these broad categories, the World Health Organization uses the terms "hard of hearing" to describe anyone with a mild to severe hearing loss and "deaf" for people with profound hearing loss (World Health Organization, 2020). As a result of medical conditions throughout my life, my hearing loss deteriorated over the years, to the point where by January 2019, I had entered the "profound" or "deaf" category. Firmly rooted in a socio-medical view of hearing loss, I experienced biographical disruption (Bury, 1982), when I realised that I would now no longer be hard of hearing, but deaf. I worried about the consequence of further hearing losses and not being able to communicate through Sign Language, and I found the prospect of cochlear implants as a solution worrisome and frightening, rather than reassuring. For me, hearing loss or being hard of hearing was one thing, being deaf quite another. The British charitable organization Action on Hearing Loss, formerly called the Royal National Institute for Deaf People uses the terms "hearing loss" and "deafness" (Action on Hearing Loss, n.d.); as does the charity Hearing Link (Hearing Link, n.d.), although it prefers "hearing loss". But there are many other organisations that specifically focus on deafness, such as for example the British Deaf Association (British Deaf Association, n.d.) and the National Deaf Children's Society (National Deaf Children's Society, n.d.).

Merely perusing the websites of these organisations highlights the particular philosophical, theoretical outlook the associations take and the cultural and societal importance choices of words have. Unlike all of the other organisations named above, the British Deaf Association uses Deaf with a capital D (British Deaf Association, n.d.). That minor distinction between using or not using the capital D brings into awareness a veritable gulf of differences between identities and identifications. How hearing loss is described is not linked to the underlying cause and has nothing to do with medical diagnoses or clinical descriptions. It has everything to do with how the person defines themselves. A person who experiences hearing loss may still see themselves as primarily the person with the hearing loss second. A Deaf person, however, aligns themselves with an entire culture and society with its own values and beliefs. They do not see their deafness as an impairment or disability, but as a different and specific way of life emphasising the positive aspects and gains which they experience through the fact that they are Deaf (Ladd, 2003).

According to Ladd (2003), there are several reasons, for Deafhood to be experienced as a gain: Firstly, in ordinary circumstances, being born Deaf means to have access to and learn to speak Sign Language. Using Sign Language therefore is a particular identifier and having full command of this embodied way of communicating provides opportunities that ordinary language would not. Secondly, despite the localised differences in signs, Sign Language is considered a global language, where individuals are able to adapt quickly to understand one another, where language barriers would usually prevent internationalised conversations. Thirdly, identifying as Deaf for many means to escape the deficit-focussed interpretation of their experiences associated with the medical and social models of disability (Oliver, 1983, 2013). Instead of focussing on the "deficits" of not being able to hear, on the missing ability of the body and on the social barriers that need to be overcome, which would turn their narratives into a tragedy, Deaf people emphasise and embrace their particular being-in-the world, are proud and joyful of belonging to and being part of the Deaf culture (Ladd, 2003; Holcomb, 2012). Naturally, as within every culture and society, not everyone whole-

heartedly agrees and there are disputes and contentions within Deaf culture, too (Padden et al., 2009).

The medical and social models of disability require of society to remove the barriers of being non-hearing, which means that support systems like hearing aids or cochlear implants are put into place. A cochlear implant is a two-part device, of which one part is surgically implanted under the skull and the outside part is worn behind the ear. Despite its invasive nature, cochlear implant surgery is considered a safe and successful intervention with a relative lack of major complications (Kiringoda and Lustig, 2013). For adults who undergo the cochlear implant surgeries, hearing and quality of life improve significantly (Gaylor et al., 2013; Snels et al., 2019), but the results amongst children and infants is less clearly defined with hardly any evidence for significant performance differences where audiometry perception/speech perception is concerned (Vlastarakos et al., 2010). In relation to actual lived experiences studies highlight that individuals need to work through a process of acceptance and getting used to a new life after the cochlear implant surgery before they are able to express increased wellbeing and life satisfaction (Mäki-Torkko et al., 2015). What the cochlear implants do, is move a person from a life without any auditory stimulation to a life with sound with variable results, as the individuals need to (re)learn to cope with new sensory inputs and a different way of life (U.S. Food and Drug Administration, 2018). And it is exactly this aspect of the cochlear implant, and indeed hearing aids, that Deaf culture takes issue with. The Deaf community argues that this different way of life and the new sensory inputs invades a person's identity, what is essentially the core of a Deaf person, what makes the Deaf person Deaf (Blume, 2009), and which contradicts the socially constructed sensory experience of the Deaf (Valente et al., 2011). If hearing loss and

deafness are such individual experiences, what then does it feel like to (not) hear in higher

education?

What it means to (not) hear in the academy

December 2019.

It's 10.55 am. The meeting starts at 11, but I am already by the door of the meeting room. I am always the first or amongst the first to arrive. How many colleagues know or have noticed that I make sure to be early to have a choice of where I will be sitting? I always move into the room to sit with the window to my back. Working with the sun and daylight, rather than against it, means that I can see people's faces to lip-read. The next criterion is a new one. It's got to be the seat that is most centrally located along the side of the table, so that I have roughly equal distances between everybody. Since I've had my Bionic Woman¹ bionic ears, this is important, because I can then adjust the settings via the App on my smartphone that will Bluetooth the information to my bionic ears.

Over the years, I've observed colleagues doing things to help their hearing: tilting their heads to one side, or cupping their hands around an ear to guide the sound more closely into the ear, the low-tech and immediate ear trumpet.

I'm grateful for my bionic ears, and certainly wouldn't want to trade places, here.

Embedded in the above cited record from my diary is the question of disclosure of hearing loss in higher education. In response to my own question, many of my colleagues do not know that I have hearing aids. In fact, most of my social contacts do not. While growing up, my parents always made a point that having hearing loss and needing hearing aids are not important and are effectively not any different from needing glasses. My non-disclosure here is not an issue relating to stigma (Cienkowski and Pimentel, 2001; Erler and Garstecki, 2002; Iler et al., 1982), the fear of being stereotyped or potentially being faced with ageism (Southall et al., 2010). For me, my hearing loss and the fact that I use hearing aids just have

¹ *The Bionic Woman* was a TV series in the 1970s, where the protagonist Jamie receives a bionic ear via a cybernetic implant. With that bionic ear, Jamie can hear at low volumes, unusual frequencies and over uncommonly long distances (Wikipedia, n.d.).

not ever been important enough to warrant a mention. Deafness has only recently become a concern for me: from that dreadful bone conduction test in January 2019.

For others, however, admitting to be hard of hearing or needing hearing aids may well be requiring a kind of personal commitment and a public statement, that so many academics are not able or willing to make in relation to their needs, as it would make them appear vulnerable and weak (Brown and Leigh, 2018). The full truth of hearing loss in academia is simply not known. Research confirms the connection between hearing loss and academic achievement showing that being only minimally hard of hearing has a significant impact on academic performance and behavioural developments (e.g. Tharpe et al., 2009; Qi and Mitchell, 2012). Indeed, education and academia are still "hearing worlds" (Brooks, 2011), and so children and young adults with hearing loss may potentially not progress in the same way that hearing children and young adults do (Woodcock et al., 2007).

In any case, there is definitely a lack of representation of the Deaf in academia, given that 5% of the world's population is categorised as having hearing loss (World Health Organization, 2020). Although developments in relation to increased equality and inclusion have resulted in more students with disabilities and learning difficulties being able to access higher education, it is estimated that only 8% of students in higher education in the United States who have hearing loss have disclosed their hearing loss (Richardson et al., 2004). If such a high percentage of non-disclosure of hearing loss amongst students is anything to go by, and we compare this to the wider issues of disclosure of disabilities in academia, then we can only assume that there will be many academics who have not yet "come out of the hard of hearing closet" (Burke and Nicodemus, 2013, n.p., Section 2). Indeed, social

conventions and own perceptions of what constitutes one's normal self, favour nondisclosure (Lingsom, 2008), resulting in the concealing behaviours described above.

The extract also shows that I have clearly developed particular strategies to create an environment that is particularly conducive to my way of working. I make sure that I can see colleagues' faces to lip-read and that I can take advantage of the room layout to gain the most of acoustics in a room. The use of visual cues of non-verbal communication, the strategic positioning in a conversation, having preferred rooms to be able to move towards students and colleagues in teaching or meeting situations, dominating a conversation to minimise needing to listen to others, avoiding particular kinds of situations and events are all typical strategies to cope with hearing loss (Tidwell, 2004).

Where Deaf people and British Sign Language users in academia are concerned, the reality of academic work is quite different. As I recorded in the initial diary entry from June 2019, the Deaf need the support of a Sign Language interpreter, because the vast majority of us working in academia do not sign. Based on official statistics, it is estimated that there are only 151,000 British Sign Language users in the entire UK, 58%, of whom are Deaf, which leaves us with a meagre 64,000 hearing people able to use British Sign Language (British Deaf Association Sign Language Week, n.d.). Of course, arrangements and adjustments can be made, but booking a Sign Language interpreter is no easy feat. Then, there are the kinds of informal conversations along corridors, in lifts, on the staircases or over lunches and coffees after formal meetings that are often more important for community building and social networking. In such situations, the hard of hearing struggle, as the background noises make it more difficult to hear and they will worry about appearing less competent when they give "wrong" answers (Tidwell, 2004). The Deaf will most likely be excluded entirely, because the Sign Language interpreter will only have been booked for the time of the formal gathering.

The ableist attitude that pervades the academy, also means that many academics are insensitive and unreasonable. Generally, these behaviours are genuinely unintentional and not malicious, but just highlight the lack of awareness within the academy. For example, we have all attended that conference talk, where the speaker asked "You can hear me without microphone, can't you?". This simple question puts the burden of adjustment and arrangements onto the person with the hearing loss. It requires an enormous amount of courage to raise your hand in a room full of strangers to then admit publicly that you actually cannot hear the speaker. The issue of disclosure has already been mentioned, but this puts disclosure at quite a different level.

Finally, the extract highlights my relationship to my hearing aids. For many individuals, the hearing aid is a stigma symbol (Goffman, 1990/1963), which results in individuals avoiding to address issues of hearing loss. Amongst those who do use hearing aids, there are different experiences. If more advanced technology is used in a hearing aid the wearer's overall satisfaction and quality of life improve more significantly than in less advanced devices (Williams et al., 2009). But there are hearing aid users who state that the devices are not helpful for particular situations or that the individuals prefer a quieter and calmer environment with less noise and stimulation (Lockey et al., 2010). I am clearly excited about my latest hearing aids, to such a point that I refer to them as my bionic ears, as I am fully aware of the deficit I experience when I do not have them.

Conclusion

July 2019.

Freshly out of the shower, I try to brush my hair. The tangles of my natural curls requiring more attention that I would like. I cannot put my hearing aids in², so I start brushing without. But as I do, I realise how much I usually rely on hearing the brush pull its teeth through my tangled curls. Not hearing means, I cannot judge at all, which section of hair I need to deal with. Do I brush over the same part? Do I move further up or down that same strand? Do I move on to a different section altogether? Not hearing, I lose my ability to brush my hair.

Most literature and people talk about senses compensating for the loss of one. But not hearing does not suddenly equip me with X-ray vision, or at least 20/20 vision. I don't gain the superpower of smell or taste. The only sense that's heightening is the sense of danger.

With the narrowing of my auditory field, my heartbeat quickens, my body tenses and muscles tighten, I become nervous and agitated. My body is in fight or flight mode triggering anxiety and panic. And all that in the safety of my bedroom trying to brush my hair without my hearing aids in.

The impact of hearing loss can be significant, in that being excluded from conversations may result in withdrawal, social isolation and loneliness. Not being able to access aspects of the world, may also result in losses regarding academic achievement. If the hearing loss occurs in early ages, then speech may also be delayed or otherwise affected (World Health Organization, 2020). The stark reality is that the employment rate for those who are deaf or hard of hearing is 65%, which compares to 79% of people with no long-term health issue or disability (Hearing Link, n.d. a). Within academia, being hard of hearing, deaf or Deaf sits alongside other disabilities and chronic illnesses, in that it often does not get reported or that those who are hard of hearing, deaf or Deaf drop out of the academy. It is through my

² My hearing aids have custom-made ear pieces that are inserted into the ear canal. When I have ear infections or colds, the ear canals become swollen, which makes them too narrow to fit the hearing aids.

work on ableism in academia that I have realised and recognised the importance of telling

the story of the unheard "unhearing".

Epilogue

March 2020.

Sitting on the sofa in the living room. Bluetoothing Van Morrison's "These are the days" from his 1989 Avalon Sunset album into my bionic ears. I listen intently to the guitar opening, waiting for the drums to come in. Feeling emotional.

I have heard this song many times before, but this is the first time I listen with my bionic ears. This is the first time, that I don't just simply hear the main melody of the guitar, but the accompanying chords. It's the first time that I hear the flam on the drums. I am amazed. I have always liked this song, but here are notes that I have not ever heard before.

"These are the days", Van Morrison's voice rings in my ears. I can actually make out the individual words and understand them.

This clarity of speech, this beauty of sound. I've had my bionic ears for a few months now, and I've been listening to more music and podcasts and I've been watching more films than ever before. I realise I have a life-time of music, podcasts and films to catch up.

Reflection questions

Are there any hard of hearing, deaf or Deaf colleagues in your professional networks? If not,

why do you think this is?

How do you feel about communicating with the Deaf?

Which assumptions may you make when you start a lecture or conference presentation? For

example, do you automatically clip on a microphone or do you present without one?

Recommendations

Awareness and empathy: The key element for supporting deaf colleagues is to show awareness and empathy. Information is available freely on internet and also provides insights into what can be done to support communication with the hard of hearing.

Sign Language training: As part of increasing awareness of the challenges of the Deaf, learning Sign Language may be a first step. Most taster sessions and introductory lessons start out with a general overview of the development of British Sign Language, deaf awareness and a brief insight into Deaf culture. Ideally, the burden for Sign Language training would not lie with individuals but with institutions, offering courses as part of professional development for staff, in order to ensure that we are all able to at least exchange some general pleasantries, when we meet Sign Language speakers.

Support and encouragement: Many individuals who need hearing aids struggle to come to terms with the situation. Others get aids fitted, but then struggle to get used to the devices. In such cases, the best you can do is to be supportive of these individuals and encourage them to seek advice from their audiologists. Getting new hearing aids and starting to wear them is a significant event, even if you had hearing aids before. Just like every car make and model is different, and has its own quirks, every set of hearing aids is different. The brain needs time to adjust and (re)learn sounds and stimuli. This is why there are often longer gaps between audiology appointments. But that does not mean, you cannot ask to be seen in additional appointments, if you need help and guidance. Additionally, just as not every mechanic is equally good at fixing every car, and instead may have preferences for specific makes and models, audiologists also vary in technical skills and specialist knowledge about

what is available on the market and what would suit particular kinds of "hearers". Hearing aids need to be fitted and moulded to the ear, but they also need to be suitable for the wearer's lifestyle. This is why it is vital that there is a good relationship between the audiologist and the hearing aid user. Being supportive and encouraging may therefore take the form of suggesting to find a different audiologist, just as you would suggest to find a new mechanic or plumber.

Basic rules of communication: Some minor behavioural adjustments on your part, may make life unbelievably easier for your hard of hearing and deaf colleagues. When you communicate or present, make sure that everyone in the room has a clear view of your face, as many people are lip-reading to support their hearing.

Ensure that you use microphones when they are available. Do not assume that nobody will need them. If there is a situation, where you are asked a question by someone who does not have a microphone, repeat the question, before answering it.

If you are aware of someone being hard of hearing, deaf or Deaf, make sure you have their attention before starting to speak.

Give others time to respond. Sometimes, individuals take a little longer to make sense of what was asked of them.

Finally, and most importantly, however, if your conversational partner asks you to repeat

what you have just said, continue speaking at the same speed, just louder. Talking at the

same volume, just more slowly does not help at all – they are deaf not stupid.

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