Deaf and Dementia: The Fight for Adequate Healthcare Service

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Dementia, defined as a severe loss of memory and cognitive abilities typically with age, has become one of the most common syndromes in elderly adults, affecting over fifty-five million people across the globe. Once diagnosed, the individual is typically neglected by society, tossed in the corner by themselves where they spend the rest of their life. This illness is extremely common, and there is no known cure. However, knowing the signs of dementia and being able to recognize them in yourself or your loved ones as soon as they appear can make a huge difference.

Detecting the signs of early onset dementia becomes difficult when you are not aware of what they look like, and this is exactly the issue for the Deaf community. The Deaf community and its members have remained vocal about issues within healthcare and accessibility services for decades now. It is an internationally prevalent issue, and it directly affects millions of Deaf people. In this paper I will explore the issues of healthcare accessibility within the Deaf community, how these issues make themselves present in terms of Deaf individuals with dementia, and proper steps to be taken in order to eradicate these issues.

In order to delve into the issues that come with being Deaf and having dementia, one must consider the personal identities tied to both aspects. Looking first separately at the personal identities of Deaf people and the personal identities of individuals with dementia can give insight into the parallels between them. Being a member of either of these groups means having your citizenship questioned by a society that wants to discard of you, simply for not fitting into the box it has deemed as “normal.” In the medical sense, Deaf people have experienced this categorization of “anti-normal” since the minute they gained their d/Deaf identity (Ferguson-Coleman, 2016). The medical system is constantly attempting to “cure” Deaf individuals by giving them devices assisting in hearing. Hearing people with dementia, however, “already have established identities (with which, of course, they may have had their own internal/external battles with over the years), which are then ignored/misunderstood by those around them, therefore diminishing their personhood, and in turn, their citizenship. Their experience of this ignorance is therefore a learning curve in how this can be challenged, whereas Deaf people may perhaps be more resilient or immune to these challenges, as they have occurred for much of their lifetime” (Ferguson-Coleman, 2016).

Fighting against this ignorance and spreading awareness of the lived experiences of those with dementia means changing the language in which we use to talk about it. It is important to steer clear of terms like “victim” or “sufferer” when referring to individuals with dementia, as these terms reaffirm a separation between dementia patients and society as well as neglect the social aspect of dementia, emphasizing the medical aspect - much like the negatively medical approach to being Deaf. “Once a person receives a diagnosis of dementia, it has been observed that they are spoken about in the past tense, as if their personality and values are immediately diminished and they have become victims of the condition” (Ferguson-Coleman, 2016). This idea has been described as “Prescribed Disengagement”: the neglect of one’s social and work lives to maintain an assumed life of receiving 24/7 care after being diagnosed with dementia. The issue of language regarding dementia has become so prevalent that “prior to the Alzheimer’s Disease International Congress in Australia in 2009, people with dementia created their own charter of acceptable and unacceptable terms to use about them” (Ferguson-Coleman, 2016). In terms of the Deaf community, this idea of separation from society on the basis of “medical knowledge” makes itself evident in every Deaf person’s life. The medical approach to Deafness completely eradicates the social and cultural wonders within Deaf communities, as well as focusing on the “loss of hearing” aspect rather than the aspect of gaining Deafhood. This completely contrasts the Deaf way of perceiving Deafhood, with the example of the term “fully Deaf,” which “is a positive statement implying a person is fully embedded within Deaf culture, with a strong Deaf identity and is a fluent sign language user.” (Ferguson-Coleman, 2016). Adjusting the language we use to refer to individuals who are Deaf or individuals with dementia will ensure steps to eradicating stigmas regarding these two groups. For example, using phrases such as “living with dementia” as opposed to “victim of dementia” would decrease the negative ideas associated with those who have it. “The use of negative language can also create a culture of fear to which people will respond with preconceived assumptions” (Ferguson-Coleman, 2016).

Media plays a huge role in diminishing these negative connotations, as well. However, there is very little media written or produced by people with dementia, yet there are plenty of examples of media written about the experience of living with dementia perceived by familial or professional caregivers. (Ferguson-Coleman, 2016). The same could be said about the Deaf community. Much of the popularized media or research about the Deaf experience is written and conducted by hearing individuals, and the input from actual Deaf people is often overlooked or outright ignored by the majority hearing society. These two groups have been denied the right to speak for themselves regarding their own lived experiences. In the case of those diagnosed with dementia, “organisations take the helm in speaking for them, not with them, and do not provide a platform from which they can represent themselves" (Ferguson-Coleman, 2016). Conveying dementia through media with a negative, fear mongering approach reinforces the idea that those with dementia are "perceived as less of a citizen than their peers and unable to express their views or choices" (Ferguson-Coleman, 2016).

Understanding the ways in which personal identities of individuals within these two groups manifest and alter themselves in response to societal ostracization, we can begin to understand the social magnitude of being both Deaf and living with dementia, especially in a medical sense. Various studies conducted by Emma Ferguson-Coleman, Alys Young, and John Keady on Deaf individuals living with dementia highlighted and confirmed what those in the Deaf community have been communicating for decades: access to healthcare services for Deaf people is grossly inadequate and, in consequence, detrimental to the health and wellbeing of these individuals. They interviewed various focus groups of Deaf individuals not living with dementia and focus groups of those living with it. Among their findings were several common themes. Those not living with dementia were asked of their preferences for care should they develop it, and those living with dementia were asked of their caregiving preferences. The individuals with dementia "could give clear evidence of autonomy and agency in that they did not wish to be supported by hearing professionals who cannot use sign language" (Ferguson-Coleman, 2016). According to a qualitative study with eighteen Deaf individuals over the age of sixty-five, the majority of them divulged that they have difficulty fully understanding what their general practitioner discusses with them, due to communication breakdowns as a result of language and cultural barriers (Ferguson-Coleman, 2016). One participant in the study recounted a personal experience of communication breakdowns in which they received simply a “thumbs-up” from their nurse regarding their health status after an operation, only to be made aware later on by their family that they had almost died during the operation (Ferguson-Coleman, 2016).

Ferguson-Coleman, Young, and Keady also studied the potential language and communication changes for a Deaf person living with dementia. When interviewing several Deaf individuals who have been living with dementia for some time, they found subtle changes in language communication, but overall expression was the same. Eye contact is extremely important within Deaf culture, as breaking eye contact with a Deaf signing person is equivalent to disengaging all forms of communication. It has been somewhat assumed that eye contact of Deaf individuals living with dementia is worse / lacking; however, this was not the case with the individuals studied by Ferguson-Coleman, Young, and Keady. They found that all participants maintained steady eye contact, just as they would have done prior to their dementia diagnosis. The only times eye contact was broken was when the participant wished to cease conversation about certain topics, emphasizing a clear autonomy that media tends to strip from those living with dementia. “Eye contact control and its uses amongst Deaf people with dementia in this study came up many times as means of expressing agency, control and personal opinion” (Ferguson-Coleman, 2016).

They also studied aspects of facial expression and the use of signing space among the individuals they interviewed. They found that some participants had lost a fair amount of animation in terms of facial expression, which in signed languages such as BSL and ASL, makes receptive comprehension more difficult. However, this decline of the use of facial expression cannot be directly attributed to dementia; many individuals tend to become more monotonous with their language as they age. As far as the use of signing space, some individuals that were interviewed had adapted a completely new method of utilizing their signing spaces, whether it be moving the location of one hand or enlarging the signing space, while some had not changed the signing spaces they used prior to being diagnosed with dementia (Ferguson-Coleman, 2016). Understanding that dementia does not overtly cause major and debilitating changes to the language and communication of Deaf people is critical for fighting against the stigmas of dementia as well as promoting a better understanding of what dementia actually is and does to an individual.

Unfortunately, a better understanding of dementia is necessary across the globe, as many Deaf communities internationally continue to face a lack of education in terms of recognizing signs of various illnesses and what to do when faced with such illnesses. “According to recent reports, less than half of people with dementia living in the United Kingdom (UK) are formally diagnosed with the condition. Strategies to combat the under-detection and under-reporting of dementia are also central to each of the 24 National Dementia Plans that are currently available across Europe with a recent World Alzheimer’s Report going as far as to suggest that the provision of a diagnosis of dementia should be seen as a human right” (Ferguson-Coleman, 2014). Getting a diagnosis early can lead to better service and a better quality of life for the individual living with dementia. However in order to diagnose, one must recognize the signs and know when to send themselves or their loved ones to the doctor. Studies have shown that Deaf people unfortunately “tend to seek health-related support much later in the progression of illnesses than the average” (Ferguson-Coleman, 2014) due to improper and inadequate service towards language barriers by healthcare professionals. Those working in healthcare in English-speaking countries tend to assume, as most hearing people do, that signing is merely a preference for Deaf individuals rather than a native language, and they showcase this wrong assumption by carrying out health visits in spoken or written English (Ferguson-Coleman, 2014). What these professionals fail to recognize is that for many Deaf people, English is not a first language, and they are not comfortable with their English literacy in terms of medical information directly affecting their personal lives. This often results in miscommunication, misdirection, and misunderstandings of the information given to Deaf patients by healthcare professionals.

Additionally, most offices do not offer proper interpreting services for signed languages. Many Deaf people use hearing family members as their own interpreting service due to a lack of interpreters provided by the healthcare systems. And when they do offer interpreters, it is not uncommon for the Deaf patient to still walk away from the appointment with misinformation, as many interpreters are not medically trained enough in order to properly express the medical terminology and diagnoses needed to fully understand an illness or condition and how to go about living with it.

In a study conducted of three groups of culturally Deaf BSL users, including individuals over the age of sixty not living with dementia, professionally employed Deaf people with educational and vocational qualifications aged eighteen to sixty, and various members of Deaf clubs aged eighteen to sixty, it was found that the majority of Deaf people know a small amount of valid information regarding dementia

(Ferguson-Coleman, 2014). These three diverse groups of Deaf individuals all shared similar ideas of what they believed dementia to be like; their responses of the main features of living with dementia as “poor memory, having to repeat information, starting but not completing tasks and sometimes not being sure where they were. Most people understood that there was no cure and most believed that there was nothing anybody could do to prevent it, likening it to a diagnosis of cancer” (Ferguson-Coleman, 2014). Their responses also enforced common myths and misunderstandings of the experience of living with dementia, with phrases like, “We have to be careful, the police say be careful of somebody, don’t approach them because this person is a risk to the community and I don’t know if that’s because they are mentally ill or if they have dementia” (Ferguson-Coleman, 2014). This mindset embedded by society reinforces the harmful idea that individuals living with dementia are not to be trusted or viewed as people with basic human rights. The responses in the study also confirmed that many Deaf people possess uncertainties regarding “what actually happens as a consequence of being recognised as having dementia.” They made statements such as: “That’s what happens with hearing people, they get sent to hospital, but I’m not too sure what happens with Deaf people…” (Ferguson-Coleman, 2014) Those conducting the study chose to make it very clear that the individuals interviewed in the study were not upset by their lack of knowledge and understanding of dementia at the hands of a faulty healthcare system; they claimed to have expected such a thing, as it has become normal for Deaf people to be excluded from conversations regarding health conducted by a predominantly hearing system. As a result, Deaf communities are left to fend for themselves when detecting dementia and other conditions in themselves and in their loved ones. “If the community in which one is most embedded is not equipped to recognise and respond to early signs of dementia then how might an individual know if others do not tell them?” (Ferguson-Coleman, 2014).

The individuals in the study, particularly the group of elderly Deaf people aged sixty-five and above, shared concerns about an alarming facet of reality in regards to aging. They claimed that aging can many times incline a person to want to spend more time by themselves, rather than constantly socializing themselves. In the Deaf community, socialization is absolutely critical for maintaining the deep and secure bonds that exist between members of the community. It is not uncommon for a member of the Deaf community to be aware of events happening to another member of the community across the world, as communication within the community travels fast and socialization is essential. However, with aging, these desires to continually socialize may diminish, leaving the elderly Deaf person at a much higher risk of medical concerns (Ferguson-Coleman, 2014). If you are living alone and neglecting to socialize often, how can you perceive the signs of early on-set dementia in your own body? Deaf people already face tremendous language barriers in all healthcare settings, and it is even more dangerous to isolate when spending time with friends or community members who share your language communication can assist in detecting the signs of dementia. “It was suggested that this was very different from hearing people’s experience where even if they lived alone; there were still many others who could communicate with them in everyday life and many more opportunities for someone to raise a concern. By contrast, Deaf people were left with the worry of: how would I know because there would literally be nobody to tell me as the surrounding everyday environment (‘the hearing world') would not offer this support?" (Ferguson-Coleman, 2014) Following the trend of the previously mentioned interview study, the individuals in this particular study maintained that they have experienced numerous accounts of "being misunderstood by their doctor, of not really being sure that they could trust their doctor to correctly diagnose problems, and of leaving consultations not being fully sure they had been understood" (Ferguson-Coleman, 2014). The Deaf way of communicating through signed languages includes the importance of an abundance of visual orientation, use of role playing and scenarios, and contextualized explanations as opposed to linear, word-for-word translations (Ferguson-Coleman, 2020). Healthcare professionals who understand this and can utilize it are rare and typically out of reach for Deaf patients, affirming that "accessible information resources that are effective are not universal" (Ferguson-Coleman, 2020).

Unfortunately, the lack of knowledge and understanding surrounding dementia has also led to cases of a lack of empathy from the Deaf community experienced by some Deaf individuals living with dementia and their Deaf caregivers (Ferguson-Coleman, 2020). In a study of a Deaf carer interviewed within a focus group, another Deaf carer interviewed alone, and another Deaf carer interviewed in the company of two close friends, conducted entirely in BSL/ISL with no interpreters present in order to promote trust, all participants recounted experiences of various hearing family members acting as interpreters for doctor's visits. The participants agreed that they trusted their family to interpret more than they would trust a certified hearing interpreter, but this leads to consequences medically. The majority family members who act as interpreters are not nearly qualified enough to properly interpret medical information, as some of the interpreters are mere children. This can lead to an oversimplification of medical information, or words and phrases that are crucial to understanding the information presented to the patient are left out due to an inability of the interpreter to properly sign the medical information. Even when healthcare facilities provide adequate interpreting, oftentimes the Deaf patient still walks away with questions unanswered. In the case of this particular study, one participant claimed that he “struggled with understanding the information being given to him, regardless of the fact it was in BSL, and was not given enough time to ask questions about what has been said” (Ferguson-Coleman, 2020).

This theme of inadequate access to healthcare services can be seen in Deaf communities across the globe. “In the United States, it is reported that deaf patients experience fear, mistrust, and frustration in health care encounters while research in Brazil discusses a ‘scenario of incommunicability’ among the different social actors which makes it difficult to exchange information and allow professional treatment for deaf patients” (Kuenburg, 2016). Deaf individuals in the Netherlands and South Africa report similar experiences when interacting with their general practitioners. “In the Netherlands, a study examining communication quality between 26 GPs and 32 of their Deaf patients found that only 13% of doctors and patients evaluated their patient–GP communication as good, whereas in 39% of cases the communication was rated moderate or bad. U.S. physicians surveyed Deaf and hearing patients and reported significantly greater difficulties in communication with Deaf patients and that Deaf people are less likely to trust them and understand diagnosis and treatment” (Kuenburg, 2016). In the United Kingdom, it was discovered that 44% of Deaf patients regarded their last meeting with their health center to be difficult, whereas only 17% of the general population claimed the same (Kuenburg, 2020). Practitioners internationally also possess a gross misunderstanding of Deaf culture, leading them to believe that lip reading and written words are effective means of communication with Deaf patients (Kuenburg, 2020). Even for Deaf individuals who have spent their entire lives lip or speech reading, spoken language is not an overall effective means of communicating, and signed languages are often much preferred. “Note writing” in doctor’s appointments also leads to “deficits in health literacy and limited ‘fund of information’ deficits. Researchers argue that treating a native signer, who might not necessarily be fluent in the local written language as if it was his/her first language, can cause serious communication problems” (Kuenburg, 2020).

Furthermore, even the most educated members of the Deaf community show poor health literacy, as is the case for the general population. Considering this, it is absolutely imperative that language barriers be taken seriously in a medical circumstance. “Among a sample of 203 deaf adults in the United States, over 60% could not list any stroke symptoms, whereas in hearing adults only 30% are not able to list any stroke symptoms; only 49% of the deaf sample could list chest pain/pressure as a heart attack symptom, whereas 90% in a U.S. population-based survey could do so” (Kuenburg, 2020). This directly displays the adverse effects of a system neglecting to adhere to the needs of an entire population of people. Because healthcare providers neglect their duty to provide adequate services to those with differing language communication, there now exists a population of individuals unequipped with knowledge that could very well at some point save their lives or the lives of their loved ones. These studies and findings work together to display a horrible phenomenon that across the globe, in many different Deaf communities. “Both under- and over- diagnosis is likely to occur because of the inability of clinicians to communicate directly with Deaf people, there is a lack of culturally and linguistically appropriate screening/diagnostic instruments, and Deaf people experience poor access to health prevention and promotion services in general” (Young, 2014).

While it is becoming more and more universally accepted that significant healthcare inequalities and poor access to health information exist for Deaf people, there is still not much public information regarding dementia in this respect (Young, 2016). There is evidence of media released in BSL information about dementia, but there is no evidence to support increased awareness or effectiveness in communication and understanding of dementia across major Deaf populations (Young, 2016). While there is good evidence to support the idea that Deaf populations and their idea of dementia are inadequate, as highlighted in the previously mentioned study, there is yet to be empirical evidence of this trend stretching across entire Deaf populations nationally, or internationally, specifically regarding dementia (Young, 2016). It is obvious, however, that language barriers promoted by healthcare professionals with the use of written communication promote this separation between patient and doctor that is all too familiar within the Deaf community. “It is not just lack of linguistic access that creates barriers to effective engagement with information but also a lack of cultural equivalence in supporting access to information. The language(s) we prefer are also an assertion of our cultural identity(ies)” (Young, 2016).

These issues discussed in this paper beg the question of: what now? Knowing the information that has been presented regarding the complete and total disregard of the culture within Deaf communities by their healthcare providers elicits the dilemma of how to properly combat it. Because this is an international, systemic level of oppression and ignorance, there is no simple solution to remedying it. However, there are ways in which steps can be taken to break down barriers and eradicate ignorance over time, the biggest measure to take being spreading awareness. The more people know about an issue, the more pressure is placed on people in positions of power to actually make a difference. On the individual level, these issues cannot be fixed. However, on the community, national, and international levels, there are many possibilities of progression. The NAD argues that a good first step for "ensuring better health care access for deaf individuals is the establishment of a strong relationship between the primary care provider and the patient. A strong primary care provider-patient relationship has been demonstrated to be critical to improving chronic disease management while reducing inappropriate and unnecessary health care services." "Research demonstrates that in hospital settings, effective communication can result in shorter lengths of stay, fewer hospital readmissions, fewer emergency room visits, better treatment adherence, better medical follow-up, fewer unnecessary diagnostic tests, better healthcare outcomes, and better patient health care satisfaction" (NAD, 2022).

While these benefits are ideal, many Deaf patients do not receive such care due to a lack of access to services and a mistreatment of the language barriers between patient and physician. Because of this, the NAD argues that it is crucial for members of the Deaf community to know their rights as emphasized through section 504 of the Rehabilitation Act of 1973, Title II and Title III of the Americans with Disabilities Act, and Title VI of the Civil Rights Act of 1964 (NAD, 2022).

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