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RESEARCH

Challenges experienced by healthcare workers in managing patients with hearing impairment at a primary health care setting: a descriptive case study

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Background: There has been little research on the experiences of healthcare workers (HCWs) with deaf/hearing impaired (HI) clients. Anecdotal evidence suggests that HCWs experience challenges, but little is reported on how they manage these challenges. Interactions with and care of deaf/Deaf and HI patients by clinicians has yielded several questions around communication and assessment strategies, as well as comparative quality of health care for deaf/Deaf and HI clients. This research was intended to further the understanding and knowledge of these aspects of health care of deaf/Deaf and HI clients.
Methods: The study design is a qualitative, descriptive case study. Data were collected using semi-structured interviews with individual HCWs and focus-group discussions with groups of participants. Participants were invited staff members at Retreat Community Health Centre (RCHC) in Cape Town. Convenience sampling was used to select participants, and interviews were conducted until saturation was reached. Data were studied and analysed using the phenomenological method.
Results: HCWs reported that they serve very few Deaf or HI clients. However, themes of language barriers, resilience, preconceptions, improvisation and innovation, interpreters and recommendations emerged. Difficulties in communication were acknowledged, but HCWs insisted that these barriers are not insurmountable.
Discussion and conclusion: A few preconceptions and gaps in knowledge and awareness were revealed. HCWs also tended to rely on escorts and other interpreters. The dominant recommendations are that HCWs should receive training in sign language (SL) and/or that SL interpreters be available at facilities. Despite using words and phrases such as ‘frustrating’ and ‘more effort’, participants’ concluding remarks reiterate that their experiences are positive, suggesting a notable resilience.

Keywords: attitude, beliefs, deaf, hearing impaired, healthcare workers, knowledge

Definitions

Hearing loss (HL) or hearing impairment (HI) is the partial or complete inability to hear sound, particularly sound associated with speech.[1]

The definition of deafness/disabling hearing loss by the World Health Organisation (WHO) standard is a loss of more than 40 decibels (dB) in the better ear for those over the age of 15 years and a loss of 30 dB in the better ear for those between the age of 0 and 14 years.[2,3]

A Deaf person, where deaf is spelled with a capital ‘D’, may have any level of HI or no HI but identifies as Deaf and belongs to a cultural community using sign language as their official language.[1,4]

Introduction

The prevalence of HI globally has not been studied extensively despite the WHO global report by Stevens et al. stating that hearing impairment (HI) was the most common sensory loss worldwide, affecting 250 million people.[5] The estimated global prevalence of hearing loss is 1.4%.[4,5] In South Africa reports vary, with the Deaf Federation of South Africa DEAFSA reporting 10%, the Community Survey 0.4% and the Census 2011 3.5% prevalence rates.[6,7]

The inequalities in health care experienced by deaf clients reflect the difficulties experienced by disabled people in general. They are disadvantaged by structural and procedural aspects (physical access, funding, transport, communication barriers) of access to health care as well as the attitudes and beliefs of healthcare providers.[4] It is therefore important to explore the challenges encountered by HCWs while rendering service to deaf and hearing-impaired patients and to provide solutions to circumvent these problems with the aim of improving their quality of care.[8]

Language is an important enabler of the right to health. It allows access to healthcare information, both preventive and curative, and allows for health care to be provided with informed consent from the user.[9] Furthermore, language is essential to developing a therapeutic relationship with a patient, yet the language barrier between deaf patients and hearing healthcare workers is one of the main challenges to access to health care.[10,4,5]

Those patients who have sign language (SL) as their first language are most disadvantaged and could potentially benefit most from a SL interpreter service at healthcare facilities. It has been reported that deaf patients gave more positive ratings to healthcare interactions when SL was used than not.[11] However, while interpreters are helpful in overcoming language barriers, inappropriate use of escorts as interpreters may rob a patient of his or her autonomy and/or right to confidentiality.[12] Deumart demonstrates this in a study exploring the healthcare delivery by English and Afrikaans speaking providers to IsiXhosa speaking patients.[12] This underscores the importance of ‘shared language’ in developing a bond.[13]

Historically, deafness was equated with intellectual disability and this misconception is still prevalent, resulting in further bias and prejudice against deaf individuals.[8,10,13] The biomedical model of deafness, which regards or treats hearing impairment as abnormal, is often held by HCWs. This model may not allow the HCW to appreciate the patient's health agenda in the consultation and allows the patient's autonomy to be undermined.[2,8,13] Furthermore, the provider may have discomfort with engaging the patient's disability and so ignore it.[4,13]

In summary, the high international and local prevalence of deafness and hearing loss means that a significant proportion of the population face serious barriers to health care. These barriers revolve around language and communication, as well as the attitudes, knowledge and beliefs of HCWs, and the way the healthcare system is structured. It would be helpful to add to existing enquiries into experiences and practices in South Africa, and possibly to reveal further regional challenges, themes and even successes.

Convenience sampling was used to select staff members and informed consent was taken. No participants left in the middle of the data collection. Seventeen individual interviews and two focus-group (FG) discussions were recorded. The two data collection methods helped to triangulate the data. While transcripts and recording were checked for discrepancies and vagaries, member checking was not done due to time constraints.

A few categories were created prior to coding, i.e. experiences, attitudes and beliefs, knowledge and recommendations. Data were coded according to what was happening (process of care), what healthcare workers (HCW) were doing, what they believe, their attitudes and what they recommend. Other codes were created for pieces of data that reflected ideas not covered by these codes. Both authors looked at the coding sheet and made adjustments and changes. The relevant data in the source material (transcripts) were grouped accordingly. The groups were then analysed, and emerging themes identified.

Results and discussion

Themes which emerged were those of language barriers, resilience, preconceptions, improvisation and innovation, interpreters and recommendations.

Preconceptions

Preconceptions are preconceived ideas or prejudices that inform an individual's attitudes and beliefs about something, thereby affecting their behaviour.

The HCWs identified deaf patients as disabled:

> 'Deaf, blind, whatever. I think we are all the same, but is just one has a disability that affects the other in a certain way than the other one.'

Over time, the societal views of disabled people have changed. In the Western context, three models of disability have been described, namely the medical model, the charity model and the social model.[14] At Retreat CHC, some participants' attitudes and beliefs reflect their use of the medical model as an approach to the deaf patient. They see deafness as a condition to cure or treat, and if not treat, then a condition for which to provide 'care':

> 'It depends on the cause of the deafness, because if it has a cause that has a solution we solve the problem, then the problem goes away.'

This care sometimes means a segregated care and is an idea that has been identified in other studies.[15]

Other participants favoured the charity model where the disabled are considered 'plucky, brave, kind' and in need of 'our help'. It engenders positive and negative feelings such as pity, sympathy, respect, uneasiness, fear and guilt. It may inadvertently impose artificial limitations on deaf/HI people's abilities, and deny them equal opportunities:[14]

> 'I don't feel differently about deaf patients, but it is different because you see it as a handicap, automatically you feel more compassionate, more sensitive. See them as special.'

While the perception that deaf patients are 'good' may result in the deaf patient receiving better treatment, it may also lead to a paternalistic relationship between the HCW and client, ultimately impairing the patient's autonomy in the consultation.

Problems also arise when the patient fails to fulfil the stereotype constructed by the HCW. Examples include the 'angry patient' or the patient who is demanding, rude and non-adherent with treatment. The patient behaves outside the preconceived model and does not receive that preferential treatment, leading to an unsatisfactory encounter.

The social model separates the impairment from the disability.[14] Using this model, the HCWs show that they understand that different people have different ways of accessing services and understand individual needs.[14]

Many HCWs at Retreat use this model. They believe that deaf patients are the same as any other patients and are treated as 'normal'. However, from their actions (heightened awareness, fast tracked, more time, checking of understanding) it seems that deaf patients receive better treatment than hearing patients. These actions are congruent with HCWs' wish to provide equitable service to deaf patients. They understand that deaf patients' experience of the healthcare process will be different from that of hearing persons' and that certain adjustments need to be made to ensure this. The empathy they display toward deaf patients make the health visit a *better* experience for the deaf patient:

> 'Because the patient at the end of the day, you want to give them the best service. You must understand where they are coming from and help them get the best possible service.'

Innovation and improvisation

The study participants are aware that communication is paramount in providing good health care. Once they realise that verbal communication is ineffective, they have shown inventiveness and resourcefulness in ensuring effective communication despite the obvious barriers:

> 'Other ways and means to even to cross the language barrier where we are able to effectively communicate, because I mean in essence that is all part of service delivery.'

Awareness of the problem is established and once that happens they can try to 'appreciate the varied experience of the deaf/HI patient' as advocated by Steve Barnett.[16]

At RCHC, deaf patients known to the facility have a stamp on their folders identifying them as deaf or HI patients. With this pre-consultation knowledge, the HCW can plan the interaction, make more time and material available, and involve other members of the healthcare team to ensure a successful health encounter. These patients will advance through the system via a 'fast track'.

The Retreat HCWs adopt many strategies to encourage better communication. They speak slowly and clearly, maintain eye contact, raise their voices when appropriate and speak to the better hearing ear. When these strategies fail, they try other forms of communication. This 'openness' to other modes of communication is common and is consistent with a recommendation made in an earlier study.[17] For example, HCWs use written notes and instructions frequently, despite being aware that the effectiveness of this method is time consuming and depends on the literacy level of the patient. In fact, Ebert et al. found that writing is the most commonly used medium physicians use to communicate with deaf patients.[18] Pictures, photographs and videos were also used, and in the focus-group discussion a novel use of smart phones was described to illustrate a procedure to a deaf/HI patient.

The participants sometimes rely on their patients to lip read despite being unaware of the intrinsic inaccuracies of speech reading. Law et al. reported that only 30–45% of English can be seen on speakers' lips.[19] However, the HCWs were aware of other extrinsic factors that make speech reading unreliable, such as poor patient vision, the need to wear masks and poor lighting.

Hand gestures, signing and demonstrations are frequently used with most of the participants showing enthusiasm for sign language (SL). This is a valuable skill as deaf patients recognise the use of basic signing as a genuine attempt by the HCW to achieve good communication, furthering the development of a therapeutic bond.[17] According to the literature, both physicians and Deaf patients consider sign language interpreters (SL-Is) as the gold standard of communication with Deaf patients.[3,18]

A team approach was another common strategy. Participants would sensitise their colleagues to the patient's status. They would plan appointments for patients known to be deaf, Deaf or HI to coincide with those HCWs more familiar with them or better able to communicate with them.

However, interpreters and taking extra time were the most frequently used facilitators of communication:

> 'But it takes you a bit longer to consult.'

Participants reported that most deaf patients came with an escort:

> 'A lot of the time a family member comes in who can sign and who can interpret for you and then that makes it a lot easier.'

Professional SL-Is were rarely used. Only two interviewees reported using them. Most interpreters were informal, i.e. family members or friends. Escorts were initially seen as a support for the deaf patient, helping the patient navigate the healthcare system and being an interpreter. However, it also became apparent that the escorts provide valuable support to the HCWs themselves. In fact, HCWs actively seek them out, because their presence makes the HCWs feel more comfortable and satisfied with the encounter.

Some participants were aware that interpreters may impinge on the autonomy and confidentiality of the patient. However, as found in other studies, using informal interpreters to overcome the communication barrier at the expense of compromising confidentiality and autonomy was a compromise that the HCWs were willing to accept.[12]

Some HCWs reported problems such as poor accuracy of translations. Other challenges like loss of objectivity, medical jargon and entrenching the deaf patients' dependence on others in accessing health care were less well recognised.[20]

Language Barrier

The patient-centred approach to health care acknowledges patients' autonomy and encourages the healthcare provider to gain an understanding of the disease as well as the patients' experience of the illness.[21] To achieve this, effective communication with a common language is the minimum requirement.[12] Generally, the study participants acknowledged good communication as crucial to good health care and that there may be some difficulty when communicating with a patient who is deaf, Deaf or hearing impaired (HI).

Nonetheless, as previously stated the HCWs did not identify this difficulty as an insurmountable barrier and cited many examples of where it was overcome. This finding is in contrast with studies of deaf patients where communication difficulties were noted to be a very large barrier to accessing health care:[22]

> 'It's a matter of just having to listen a bit more'

In fact, the HCWs rank language barriers between them and patients who speak other languages as a greater problem. Difference in language is a widely acknowledged, major barrier to effective communication and access to health care.[23]

Somehow, it seems the HCWs' preconceptions and beliefs allow them to identify deaf, Deaf and HI patients as disabled and thus deserving of more time and consideration:

> 'I don't feel differently about deaf patients, but it is different because you see it as a handicap, automatically you feel more compassionate, more sensitive. See them as special.'

The responses further suggest that they believe that deaf patients are more patient, follow instruction better and are better patients:

> 'They sit quiet and not like other patients that moan. They wait their turn .... They don't mind. I think it's in their nature to be very humble, very quiet .... So they are very humble. I just love them.'

These positive preconceptions mean that HCWs may be more likely to engage with deaf, Deaf and HI patients empathically and attempt to communicate more holistically. The positive attitude and creative, solutions-orientated approach from the HCW may also encourage the patient to respond positively.

As society becomes more multilingual and multicultural, the likelihood of encountering a person who speaks a different first language has increased. Heap reported that most healthcare encounters are conducted in English, which is not the first language of the majority of healthcare users.[24] An HCW is more likely to encounter a different language speaker on a daily basis than a deaf patient:

> 'That's not like a language difficulty where you can't actually speak the person's language. Those are a lot more common than when you have a deaf patient.'

At RCHC, languages such as Somali, Malawian, Portuguese and French are very likely to be encountered, posing potential communication challenges. As a result, some HCWs regard the need for foreign-language interpreters as higher than the need for sign language interpreters:

> 'I … it would be nice to have a sign language interpreter, but the demand is bigger for the foreign languages.'

The lack of good interpreter services leads to HCWs experiencing more frustration due to time constraints and decreased work efficiency. They may also be less willing to provide the extra time to patients whom they do not see as being disabled.

Yet another factor is that of the increased awareness the HCWs generally have regarding deaf patients. At RCHC, the folders of deaf patients are marked and these patients are easily identified, thereby allowing the HCW to prepare and anticipate. In contradistinction, folders are not marked with the patients' preferred languages.

Resilience

Resilience is an ability to adapt and succeed in stressful situations.[25] This does not mean that a resilient person does not experience difficulty but that she/he can think and act in a way that overcomes the difficulty. The staff at RCHC, like many staff complements in South Africa, work in a stressful environment with large patient numbers, chronic under-staffing and at times are at risk of personal violence and abuse from clients and the community. They view the Deaf/deaf/HI patient as any other client requiring their care, refusing to see the disability as a barrier. Concurrently, they recognise that these clients may have different needs and are willing to adapt and adopt numerous strategies to delivering quality health care. They are rewarded by the apparent patient satisfaction they see. They therefore demonstrate resilience in their teamwork and their comfort with asking for help.[26]

Recommendations

After advising patients to come with an escort, the most common recommendation was that HCWs should learn SL and/or SL-Is be available at the facilities. Given that the frequency of encountering a South African sign language (SASL) user is so low and the investment in learning SASL so high, this would be impractical.

This view is shared by other researchers such as Reeves and Sadler et al.[27,28] However, learning just a few basic signs, or having a board with a few common and practical signs (as recommended by a community service registered nurse) would show Deaf clients that an attempt is being made to communicate.[29] Access to an SL-I is possible but would require educating HCWs and clients about the service and how to access it. Other recommendations concurred with previous recommendations from deaf users, including good signage, posters, electronic boards, deaf TV and mobile phone technology.

Conclusion

Even when words and phrases such as 'frustrating' and 'more effort' are used, the concluding remarks reiterate that HCWs' experiences are positive. While their positive attitude may be interpreted as a type of indifference, it can also be seen as being rooted in the resilience these HCWs have developed while working in a chronically under-resourced and over-burdened setting.

Nonetheless, this exploration of HCWs' attitudes and beliefs reveals a few preconceptions and gaps in knowledge and awareness. Their behaviours and strategies also reveal a reliance on escorts and other interpreters with little consideration or appreciation of the challenges of loss of confidentiality and autonomy, inaccuracies in translation and entrenching dependence. Therefore, HCWs at RCHC may benefit from further education on the subtler challenges of interpreter use, available resources and how to access them, as well as training in disability awareness and ethnography.

Lastly, more robust local prevalence studies would be useful, as well as studies of deaf, hearing-impaired and Deaf clients' experiences with accessing health care at RCHC.

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