



Health Care

“I just answer ‘yes’ to everything they say”: Access to health care for deaf people in Worcester, South Africa and the politics of exclusion



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ABSTRACT

Objective: To explore whether there are other factors besides communication difficulties that hamper access to health care services for deaf patients.

Methods: Qualitative methodology using semi-structured interviews with 16 deaf participants from the National Institute for the Deaf in Worcester and 3 Key informants from the Worcester area, South Africa. **Results:** Communication difficulties were found to be a prominent barrier in accessing health care services. In addition to this interpersonal factors including lack of independent thought, over-protectedness, non-questioning attitude, and lack of familial communication interact with communication difficulties in a way that further hampers access to health care services.

Conclusion: These interpersonal factors play a unique role in how open and accepting health services feel to deaf patients.

Practice implications: Health care services need to take cognizance of the fact that providing sign language interpreters in the health care setting will not necessarily make access more equitable for deaf patients, as they have additional barriers besides communication to overcome before successfully accessing health care services.

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1. Introduction

It is well established that deaf¹ patients face particular challenges regarding communication with healthcare providers, and this is probably a key reason why deaf people use health care services differently from the general population [1]. Tamaskar et al. [2] found that deaf and hard of hearing people were more likely than others to avoid health care providers because of, among other factors, lack of communication and lack of available interpreters. This is consistent with other reports that deaf people see doctors less often [3,4].

Steinberg et al. [1] examined the accessibility to health care for deaf people (mainly American Sign Language (ASL) users) and found

that they had both positive and negative experiences. The positive experiences were found in situations where medically experienced interpreters were used, where health care providers used sign language and where providers made an effort to improve communication. The main barrier was found to be problems with communication, which elicited feelings of fear, mistrust and frustration with the health services. Patients felt afraid of the consequences of miscommunication between themselves and their health care providers, and this often led to patients harbouring feelings of mistrust towards providers and towards the services as a whole. Deaf interviewees, furthermore, felt that some providers did not respect their intelligence, motivation and desire to be actively involved in their health care understanding and decision-making [1,5].

Communication barriers experienced by deaf people operate as a constant throughout their lives in a hearing world, and at a range of levels, including the individual, interpersonal and systemic levels, all of which come into play in health care communication [6]. In busy health care settings where there is a culture of rapid diagnosis, treatment, use of services and minimum interaction time with the patient, access for deaf people is further compromised [6]. When dealing with hearing personnel who do not speak sign language, deaf people need longer appointment times in order to be understood and to understand treatment

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¹ The term ‘deaf’ is commonly used to refer to the physical condition of hearing impairment, and the capitalized ‘Deaf’ to refer to membership of a cultural and linguistic minority, commonly of people who speak sign language. As the term ‘deaf’ is more comprehensive, we use this uncapitalized term throughout this article, taking due regard of the fact that deaf people as a group do face cultural and linguistic exclusion.

options and decisions. Where health services do plan for the extra time needs, deaf patients may feel unusually stressed and through not wishing to be burdensome may try not to be demanding. Paradoxically, this understandable response on their part may contribute further to communication failures which may in turn further hamper or discourage subsequent attempts in accessing health care services in a timely manner [7].

Looking at the interpersonal level it appears that previous communication failure experienced by deaf people, in all their relationships, clouds their perception of communication and generates feelings of for example, shyness and insecurity. These interpersonal factors lead in turn to a lack of ability/will to enter into better communication with others therefore in some instances just distancing themselves completely. This has problems in successfully accessing health care services and appropriate treatment.

All the above issues take on a greater salience in low and middle-income countries where services are fewer, and personnel more stretched in terms of their patient loads. Health care services in South Africa, for example, are characterized by long waiting times and shortage of both staff and medication [8]. Those that are hit hardest by this situation are the most vulnerable population groups and amongst them disabled people [9–12].

Despite these facts, the vast majority of research on access to health care for deaf people has been conducted in wealthier countries. In this article we contribute to filling this evidence gap by reporting on barriers and facilitators to health care services and health care information experienced by deaf people in a small town in South Africa. The data were collected as part of a larger study on access to health care for people from vulnerable populations in four African countries, known as the Equitable project (for more information see www.equitableproject.org).

2. Methodology

2.1. The study site

Worcester is a small town situated 96 km outside of Cape Town in the Western Cape province of South Africa. Worcester has historically provided comprehensive services for deaf children and adults through a number of organizations including the National Institute for the Deaf (NID), the organization through which we recruited study participants. The NID is one of the oldest and largest non-profit organizations, dating back to 1881, and the only facility in South Africa and Africa that provides all services from early childhood to old age for deaf people.

In this study we selected participants from the following NID departments:

- Lewensruimte which provides deaf adult care in a mini-village setting comprising of group homes and workshops catering for deaf adults with multiple disabilities.
- Shalom old age home which was opened in 2009 and which provides social and 24 h support/health services to elderly deaf people.
- The NID College which provides further accredited education, occupational and skills training for deaf students throughout Africa in a variety of study fields including: hospitality, construction, welding, and office administration.

2.2. Study design

Because this was an exploratory study, a qualitative approach was used to collect in-depth descriptive data. Two semi-structured interview guides, one for deaf health care service users and one for

key informants identified through purposive sampling, were used to facilitate the interview process and to ensure that similar topics were covered during interviews but also allowing the participants to express their own views and experiences [13].

2.3. Participants

Participants comprised both users of health care services and key informants. The *user* population of this study were deaf people living and/or working at departments or workshops of the NID in Worcester. *User* participants had to be deaf or hard of hearing and working and/or living at one of three NID departments in Worcester. Hard of hearing participants were those participants who had a hearing loss and could understand us and have a conversation without the help of an interpreter, although they were still offered interpreter services. Participants also had to have used formal health care services over the course of their life, preferably in Worcester. The *key informants* were persons who had knowledge about the health care services provided in Worcester, the deaf population of Worcester and the area of Worcester (see Table 1).

2.4. Data collection

Both interview guides were designed to elicit an hour to an hour and a half, face-to-face interview. Before conducting the interview an explanation was given to each participant about the aims and objectives of the study, the interview process and the confidentiality of the data that would be recorded. Every participant signed the informed consent document.

All interviews were conducted in the preferred language of the participant with the assistance of trained interpreters, where needed. Interpreters were trained interpreters from the NID and therefore bound by confidentiality.

Table 1
Sample characteristics.

Feature of respondents	Number of respondents
Hearing status and other impairments	
Hard of hearing	3
Deaf	10
Deaf and mild intellectual disability	2
Deaf, blind and intellectual disability	1
No known impairment	3
Sex	
Female	10
Male	9
Age group (excluding 3 key informants)	
20–34 years	8
35–49 years	5
50–64 years	1
65+ years	2
Use of an interpreter (excluding 3 key informants)	14
Country of origin	
Outside of South Africa	4
South Africa	5
Unknown most probably South African	10
Which institutional division (excluding 3 key informants)	
Lewensruimte	8
NID College	6
Shalom Old Age Home	2
Participant type	
User	16
Key informant	3

2.5. Data analysis

The digitally recorded interviews (recording of interpreters' voice) were transcribed for analysis purposes. The data analysis was conducted with the use of Atlas.ti version 6 Software. The study utilized both inductive and deductive coding, in line with thematic analysis as discussed by Fereday and Muir-Cochrane [14]. Deductive coding was used as a starting point to create a codebook based on interview topics to provide a detailed account of certain aspects in the data [15]. Inductive coding was used while analyzing the data to elicit themes from within the data itself providing further rich description of topics for discussion [15].

2.6. Ethical considerations

The EquitAble study, to which this smaller study contributes, has been rigorously reviewed and approved by the Health Research Ethics Committee (HREC) at Stellenbosch University. The vulnerability of the people we worked with was acknowledged and the potential benefit to the local community of our research was emphasized. We also obtained permission from the head of the NID as well as each individual department head.

3. Results and discussion

Unsurprisingly, communication factors were found to be at the core of participants' difficulties in accessing appropriate health care. What was clear though was that these issues did not occur in isolation. As we shall show, for our participants, interpersonal factors combine with communication challenges in a mutually reinforcing negative cycle. Shyness, insecurity, and lack of independence (consequent of living an institutionalized/sheltered life) all seem to be important. Communication failure seems to lead to a loss of a sense of security in the health system; this loss may lead to shyness in initiating communication, as we shall show.

3.1. Interpersonal factors

This section looks at a number of interpersonal factors both arising from the characteristics of the deaf person or a feature of their relationship with others, bearing in mind the interrelationships with each other and communication failure. The factors described include lack of independent thought, overprotectedness, non-questioning, and lack of familial communication.

3.1.1. Pervasive disempowerment

One key informant described some deaf people in Worcester as lacking independent thought, being very strong in their beliefs but merely accepting new information without questioning, unless it goes against these beliefs:

But it was very interesting, for me, the way that many of the deaf people here just accept everything and just go on and just say, oh, okay, no, that's fine. If it's a hearing person telling me that, they must be correct because the hearing people know everything. They go and talk to each other, but they never question anything – and that's exactly the same thing when they come to the hospitals.

This is corroborated by our interviews with participants, where in individual interviews we found that many participants accepted medication the provider prescribed or procedures carried out, without questioning or attempting to understand what was transpiring. The bulk of participants at some stage during the interviews acknowledged that many times they exit a consultation with no idea of diagnosis or reasons for medication.

This is compounded by communication problems and increases the chances that deaf people will lack knowledge of their own medical history:

Sometimes they talk to me, but I cannot always understand, then I just answer "yes" to everything they say. I went to the hospital, did my writing, sat across from the doctor and he said, so what is the problem? And I wrote something, and he then sent me to have an injection – but I don't know why. But I don't know if I had an illness ... or why ... I don't know. ... they don't ask what is my medication for, why this and what that. They don't ask anything. They go there and they just accept the treatment that they are given, and then they say, no, that's fine. It's fine. ...

From the health care providers' point of view it would be very difficult to pick up this miscommunication and lack of understanding if the patient does not acknowledge their lack of understanding. This is different to the experience of one of the hard of hearing participants who has the confidence to ask the health care personnel when he does not understand a diagnosis, procedure or treatment. Consequently, he has a good understanding of his own medical history, illnesses and necessary treatment protocols:

No they do not always explain to me exactly what is going on, you know when I ask the doctor then he will explain ... That's how I know so many things.

3.1.2. Overprotection and lack of familial communication

Overprotection and lack of communication between family members are regarded by one of our key informants as one explanation for this lack of assertive engagement in health care on the part of some deaf people. Overprotection by concerned parents and a pattern of parents' speaking on behalf of deaf children is described:

I think, as they grow up, they never do anything on their own. If they don't live in a hostel, their parents are overprotective and do everything for them. If they live in a hostel, there is always somebody that goes with them, and those people aren't professional as they should be. So they will go with them to the hospital and the child would sit, and they would say, okay, he has a headache and he complains of a stomach ache, and-and-and. What is it? The doctor says, no, it's da-da-da-da, and he needs to take this a few times a day. And they say, okay, come home and we'll give you these pills. Then they go home. And that's just the way he grows up. And when he is finally on his own and he has to be independent, and he has to go to the hospital to the doctor on his own, it's the same. I stay quiet and my mother talks to the doctor and my mother tells me what they are going to do.

Unfortunately in many cases the parents themselves have not learnt to communicate effectively with their deaf children and health information is not passed on to the patient and, furthermore, the correct health information does not necessarily get relayed to the health care provider:

Maybe, it's their parents' responsibility, but then the parents can't communicate with them either. We have one boy here who says he doesn't want to go home in the holidays because he can't talk to anyone there. So the others say, no, they are lucky because they stay close to their friends, so they just visit their friends constantly. I mean, they don't understand their parents.

3.2. Interpersonal factor and their effect on access to health care

All these factors (lack of assertiveness, non-questioning, overprotective environment, lack of familial communication) have

a snowball effect on people's knowledge of their own medical history, not to mention family medical history. Not one participant could conclusively tell us what lead to their deafness. Participants felt that it was not their place to ask these questions of their parents:

It is not for me to ask or tell my mother. I have never thought about how to ask or tell her. . .

I was born hearing. One year old, I was sick – something about my ears. A long time I was sick, and then I became deaf. One or two years old – I don't know. . . . No, I don't know what the name is. Father explained to me that I became deaf, but that is all I know. I became deaf, but I don't know what the name of the disease is.

Issues around shyness, lack of confidence or fear of appearing ignorant were other reasons provided for participants' reluctance to ask a provider to repeat themselves or explain in a more accessible manner. The education system, parents and interpreters all foster relationships which over protect the deaf person and inadvertently through previous learned experiences lead to feelings of insecurity and shyness in independently accessing health care services:

They are either too shy or not confident enough, or afraid to show their ignorance. I don't know, but they just don't say, I'm sorry? I don't understand. Please explain? Maybe, we should even make a set of flash cards: I don't understand. Please explain. The words are too difficult. Use other words. But they just don't do it.

Failed previous experiences at communication with family members and community members also affect participants' access to timely health care services independently. One participant attempted to access the health care services independently only after receiving instructions from her sister. Previous experiences of being ridiculed have made her extremely shy to try and communicate in other settings (she has limited speech):

Last year at home. . . I went to the hospital for teeth take out. My sister go to work I went alone to hospital, I felt very shy, how can I communicate so I went back home, so the next day my sister went with me to the hospital and the sister . . . she said that she was shy so the sister explained everything it was better. . . . I stayed alone long time and I waited until five o'clock and I told the doctor please change the date because I am alone, I feel afraid of the doctor so they made a new appointment so I went home, my sister asked why I was so late until five o'clock, it's for the doctor he need the sister with me I cannot go alone. . . . I was confused, the people they was many pregnant women how did I know which one was the dental problems and the pregnant problems so I felt afraid. . . . Some people maybe talk I don't understand my voice so I was shy I am always shy so when I go to sister if I know which person is the nurse then I know, OK next time I can remember, I know the sisters I will feel better.

Participants also feel isolated, ashamed and confused when they cannot simply ask someone at the health care facility a simple question like the correct queue to stand in. This may lead to non-utilization when services are needed, because of feelings of being misunderstood, or treated as intellectually inferior. Participants were also concerned that they would reveal their ignorance about their health conditions, and they had concerns about possible errors in diagnosis and treatment.

Maybe if a problem happens then I cannot explain to the doctor otherwise a mistake could be made.

The doctor sometimes prescribes pills without explaining what the pills are for and the pills do not even always work.

I think, sometimes, unnecessary illnesses or bad stuff can happen because they never questioned him.

And people look at you and think you are different and think you don't understand anything but if I can communicate in sign language then other people would see that I am quite smart and capable like others.

As a result of communication failures, participants perceive that health care services misuse deaf people, that providers fear deaf people, do not listen to the concerns of their deaf patients, and find it easier to simply ignore deaf patients and not provide them with all the information that they need. One deaf participant reported that providers actually spend less time explaining to deaf people than they do to hearing people. In addition she felt that in the private sector doctors were simply after the deaf person's money when they know that they suffer socio-economically:

The doctors and nurses don't always understand me. Many deaf people feel that the hospital staffs don't treat deaf people appropriately. Deaf people do not always get the information they need. . . . Some doctors are afraid of the deaf, they are afraid to communicate with deaf patients. The doctors do not always understand what the deaf say. Yes . . . the staff must also consider the deaf patients. The staff should explain to the deaf patients what is going on. Sometimes doctors and nurses treat you as if you're not even there. It makes you feel bad. You're sick and you would also like to know what is wrong with you. . . . The doctor just wants money from us deaf people, and we have no money because we get small salaries.

The doctor does not want to spend too much time with the deaf and he was very curt. Doctors give ordinary people more time. . . . when I was younger I always went to the doctor and chatted a lot, but now the doctor does not want to chat. You can see that the doctor does not have any more time for the deaf. The doctor is impatient with the deaf. Long ago, the doctor helped me a lot more. The doctor just answers anything. He does not even hear what you say. It's important for the doctor to show respect to the deaf. Deaf people do not have the money just to go to another doctor.

Unfortunately one finds that many health care providers are not trained in using interpreters and as a result they end up talking directly to the interpreter and not to the patient. This makes the consultation similar to one when a parent brings a child to see the doctor, and may lead to feelings of exclusion and infantilization.

After discussing communication problems with the participants it appears that many participants would still feel apprehensive about independently accessing health care services, seemingly because of previous experiences that cloud their memories. This is explicitly stated by the next participant (see quote below) who would still feel scared accessing health care services independently even if interpreters were provided at facilities. The isolation she feels by not being able to read lips and therefore being totally reliant on some unfamiliar person's interpretation would still make her feel uncomfortable in accessing health care services independently:

There must be sign language interpreters at the hospital, but I will still be afraid to go alone . . . , afraid because I cannot read lips.

4. Conclusion

4.1. Conclusion

The results of this study, as with other studies, indicated that communication problems in different forms constitute most

significant factors affecting access to health care services for deaf participants [1,5,16], but that there are additional factors arising from a history of exclusion and disempowerment which has resulted in an internalization of being excluded and disempowered. These factors, as shown in this analysis include lack of adequate communication within the family, not being addressed directly by health care providers, and giving deaf people a sense of being excluded. Even if the best possible interpreting services were to be available in health services, deaf people who have grown up in exclusionary and discriminatory contexts (in all probability, most deaf people in the world) have additional barriers to navigate. Many will have a history of being rebuffed and belittled; some will have learned to depend on others to mediate between them and services, including health services. There is no question that in low and middle-income contexts in particular, there is an urgent need for provision of interpreting services. But what is also needed (and this is a more subtle and complex challenge) is a process of engagement with deaf users of services to assist them to expect more, not to silence themselves in these contexts, and to expect and demand the same access to health care that others enjoy. As urgent as the need for interpreters is the need for evaluated participatory interventions to assist deaf users of services to feel comfortable enough to engage assertively with the health system.

The data we have from this study are limited and we had few participants in a particular context. We require more data to make stronger recommendations on these issues. What is clear, though, is that regarding the need for interpreters as simply a technical issue which can easily be solved may be somewhat naïve. There are broader issues of disability politics at play here, and these political issues have consequences for the everyday lives of deaf people.

4.2. Practice implications

Sign language interpreting is essential when dealing with patients who are deaf and speak sign language. It is also important for clinicians to be aware of the fact that patients who are deaf may have difficulties asserting themselves and demanding the services they deserve. It is essential to create an open and accepting atmosphere in the clinical setting. The responsibility to address these communication barriers should be addressed by both the facility and deaf people through discussion and consultation.

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