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Deaf children's experiences of healthcare and the need for professional sign language (SASL) interpreters in South Africa

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In memoriam

This report is dedicated to the principal investigator, Dr Marion Heap, whose untimely passing in August 2019 has left an indelible mark on the Deaf community in South Africa.

"To live in hearts we leave behind is not to die" ~ Thomas Campbell

Rest in Peace

* * *

Summary

Deaf children face significant communication barriers in their access to quality equitable healthcare. Availability of South African Sign Language (SASL) interpreters is one method to overcome these barriers. This mixed methods study aimed to describe the need for professional SASL interpreter services for Deaf school children and explored their healthcare and communication experiences with and without these services. Quantitative data was collected through a retrospective case log of 481 requests for interpreters and a cross-sectional survey of 27 Deaf children. These data informed a set of qualitative in-depth interviews with 13 Deaf children. Results indicate increased access to SASL interpreters over time, but an ongoing need for Deaf children to be informed about their rights to access these services. A focus on developing agency through knowledge and understanding about their healthcare and sensitizing family, healthcare providers and school networks towards the strong emotions associated with receiving care should support Deaf children's access to equitable healthcare going forward.

Introduction

Effective patient-provider interactions rest foremost on successful communication between both parties. In South Africa, more than 80% of healthcare consultations occur across language barriers (Penn, 2007). These barriers remain a persistent challenge affecting equitable access to quality healthcare for all (Beukes, 2009; Claassen, Jama, Manga, Lewis, & Hellenberg, 2017; Deumert, 2010; Haricharan, Heap, Coomans, & London, 2013). Deaf children are a particularly vulnerable minority group whose healthcare needs are serious and regularly underestimated. Language barriers in this population represent an extreme case challenging healthcare providers' (HCPs) routinized approaches for addressing spoken language gaps (Drennan & Swartz, 2002). However, research with Deaf children (and adults) is sorely lacking, particularly in multicultural, multilingual South Africa. This is due, in part, to the 'hidden' nature of the Deaf population and difficulties in accessing children for research and healthcare projects (Alderson, 2007; Lambert & Glacken, 2011; McKee, Schlehofer, & Thew, 2013).

Deaf children form part of the Deaf community, a cultural and linguistic minority group that uses sign language as the primary method of communication (Barnett, 1999; Ubido, Huntington, & Warburton, 2002). In South Africa, the human rights of Deaf children are enshrined in the Constitution which states that all people have a right to access healthcare free from discrimination based on race, gender, sex, disability and language and that children have a direct entitlement to be provided with basic health care (Constitution of the Republic of South Africa, 1996). South Africa has also ratified the United Nations Conventions on the Rights of the Child (1989) and the Rights of Persons with Disabilities (2006), committing to the equitable and informed provision of healthcare for these vulnerable populations.

In South Africa, estimated prevalence of hearing impairment in children varies widely, from 0.6% of all newborns to 11.4% among children 0 to 3 years old in urban Cape Town (Maluleke, Khoza-Shangase, & Kanji, 2019; Ramma & Sebothoma, 2016; Swanepoel, Störbeck, & Friedland, 2009). Hearing impaired children who become members of the Deaf community use South African Sign Language (SASL) as their first language and are typically referred to with an uppercase "Deaf" as opposed to the lowercase "deaf" which refers to the physical/audiological absence of hearing (Haricharan et al., 2013). In 2018, the South African government recognised SASL as an official home language in the education system (Law for all, 2018; Timeslive, 2018). Deaf children attending Deaf schools are now able to learn through the medium of SASL. This is an important step towards recognising Deaf culture and SASL as part of South Africa's diverse cultural and linguistic landscape. Most members of the Deaf community are born deaf or become deaf as children. Up to 90 percent of Deaf children are born in hearing households, creating cultural and linguistic barriers within families between Deaf and hearing family members (Barnett, 1999).

These barriers extends to the health system where predominantly hearing HCPs are not sensitized to Deaf culture and unable to communicate using sign language with their Deaf patients (Haricharan et al., 2013; Kritzinger, Schneider, Swartz, & Braathen, 2014; Sadler et al., 2001). As a result, Deaf children are exposed from an early age to healthcare services that are unable to meet their unique linguistic and healthcare needs. This has significant consequences for their health. Studies have shown how negative and traumatic early experiences with HCPs decrease Deaf people's willingness to interact with the health system (Gichane, Heap, Fontes, & London, 2017; Richardson, 2014; Ubido et al., 2002). In a recent literature review of healthcare access among Deaf people, Kuenburg and colleagues (2016) highlight how persistent miscommunication with HCPs leads to strong feelings of fear, mistrust and frustration that last well into adulthood. Moreover, poor access to health information, low levels of health literacy and avoidance of care interact with communication barriers leading to misperceptions, misdiagnoses and suboptimal healthcare outcomes for Deaf people (Richardson, 2014; Steinberg, Wiggins, Barmada, & Sullivan, 2002).

Despite a plethora of policies supporting the rights of Deaf children in this setting, progress towards equitable healthcare access remains slow (Alexander, 2004; Beukes, 2009; Proudlock, 2014). An anthropological study conducted between 2003 to 2006 identified the serious language barriers faced by Deaf people accessing the public health domain in the Western Cape Province of South Africa (Heap, 2003; Heap & Morgans, 2006). In response, the first free-to-patient professional SASL interpreter service was piloted in 2008 at an out-patient clinic in Cape Town. This pilot demonstrated that, for Deaf South Africans, the right to effective health care is closely linked to language and can be achieved through providing Deaf patients with professional SASL interpreters (Haricharan et al., 2013). During 2013 and 2014, a district-based free-to-patient professional medical SASL interpreter service was piloted and costed. The service drew its first request for a Deaf child in May 2013. By the end of the year, 98 requests had been made from one school. By August 2015, over 350 requests were reported. Increasing requests for interpreters by Deaf children raise the questions: what are the language barriers of Deaf children; how do we address them; and what is the need for professional medical SASL interpreters for this population? This study sought to answer these questions by exploring the healthcare and communication experiences of Deaf children in one setting in the Western Cape Province and describing the need for interpreter services in this setting. The study forms part of a broader research project focused on developing appropriate ethical research methodologies for Deaf children and determining the need for SASL interpreter services.

Methodology

Study design

This study followed a sequential mixed methods design. Mixed method designs are useful strategy for collating and triangulating diverse data to motivate for changes in public health service planning and delivery (Gugsa, Karmarkar, Cheyne, & Yamey, 2016; O'Cathain, Murphy, & Nicholl, 2008; Pluye & Hong, 2014). Quantitative data was collected through 1) a retrospective case log recording Deaf children's requests for SASL interpreters from May 2013 to August 2016; 2) a cross-sectional survey conducted in May 2017 with Deaf children (n=27) between the ages of 13 and 18 years and 3) a set of qualitative in-depth interviews with a selection of 13 Deaf children between 14 and 18 years of age in March 2018. Data provided detailed information about the healthcare experiences of Deaf children, their use of and need for SASL interpreters. Together, results generated an interactive model identifying key individual and social areas to promote Deaf children's access to and experiences of healthcare.

Ethical considerations

The study builds on long term research and service relationships with the Deaf community in Cape Town (Haricharan et al., 2013; Heap, M. Haricharan, H, Cassidy, A. London, 2012; Heap & Morgans, 2006). Permission to conduct the study was obtained from the University of Cape Town's Human Rights and Ethics Committee (Reference 127/2015), the Western Cape Department of Education, the School Governing Body, principal and staff. Due to the particularly vulnerable nature of the study population, a study oversight committee was created to act as guide and ombudsman for the project. The committee comprised of people experienced in ethical research with children, language and interpreting and included representatives from the Deaf community.

Recruitment

The study was conducted in one of six Deaf schools in the Western Cape Province. Children were recruited for the survey and in-depth interviews following a rigorous process of informed consent. Parents were contacted via the school and provided with written information about the study and a request for signed consent to approach their child. Study information and consent forms were made available in SASL, English, isiXhosa and Afrikaans, the most common languages of our study population. A follow up telephone call or home visit was conducted with each consenting parent to ensure study information was understood. Only those children whose parents provided written consent were invited to participate. Research assistants fluent in SASL discussed the project and process of informed consent with each child. A printed consent form in the spoken language of their choice was provided and each child was asked to sign their name if they were willing to participate. Only those children who provided signed consent were included in the study. To ensure anonymity and maintain confidentiality, reference numbers were assigned to all participants in both the survey and in-depth interviews.

Data collection & analysis

Case log data was extracted from children's recorded requests for interpreter services at the participating school. Access to this data was facilitated by the school nurse and stored in a password protected MS Excel document on a secure server. Data extracted included the number of requests made, reasons for requesting an interpreter and facility to be attended. No identifiable data was recorded. Quantitative case log data was analysed descriptively and informed survey development and in-depth interviews.

Surveys were conducted via individual face to face interviews in a private room at the school, following parent and child consent. Due to limited consent responses, surveys were completed with 27 children only, representing 12% of the students at the school in 2017. Survey interviews were conducted by first language SASL users familiar to the children and the school. Survey questions were piloted in 2016 with seven children and collected basic demographic data, including age, gender, household size and school grade. Questions were also included about history of deafness, illness episodes, most recent healthcare communication experiences, preferences and recommendations for improving healthcare for Deaf children. Survey data was collected electronically using a tablet device. Data was transferred to a password protected MS Excel document on a secure server and deleted from tablets. Due to the small sample size, survey data was limited to descriptive analysis using Excel.

In-depth interviews were conducted in a private room at the school, using fluent SASL users. A semi-structured interview guide prompted questions about children's healthcare experiences with and without a professional interpreter as well as recommendations to improve access to healthcare for Deaf children. Interviews were video recorded with consent of the participating child and parent, translated into spoken English and transcribed. Participants were assigned a reference number and all videos, audio files and written transcriptions were de-identified as far as possible. Interview data was stored in a secure server and password protected. Transcriptions were reviewed iteratively and thematically coded using inductive coding in Nvivo 12 Pro. Common themes were cross-referenced with quantitative data to inform the final study findings and discussion reported below.

Results

Case log findings

Case log records from the participating school totalled 481 requests for SASL interpreters between 2 May 2013 and 16 August 2016, representing about 12 requests on average per month. These requests covered a wide range of services that extend beyond healthcare to social support and court attendance. Table 1 indicates the distribution of reasons for logged requests for SASL interpreters during this time. There is a significantly disproportionate number of requests for interpreters to attend mental health services (n=297; 61,7% of total requests) highlighting the social and psychological vulnerability of Deaf children in this setting. Mental health service requests included facilities that address general psychological support (n=246; 51,1%), drug rehabilitation (n=34; 7,1%), trauma counselling (n=5; 1,0%). Interpreter requests for general health services were also disproportionately skewed towards hospital-based appointments (n=56; 11,6%) versus appointments at primary healthcare (PHC) facilities (n=11; 2,3%). Two possible reasons exist for this. Firstly, Deaf children (and adults) may place a higher value on the use of more specialised health services at secondary and tertiary hospitals and view interpreters as more important at these levels to promote their understanding. Therefore, they are more motivated to request interpreters when accessing these services. However, a more likely reason is that Deaf children tend to access more specialised levels of care often bypassing PHC services as their first point of entry into the health system. This trend has been observed in high income countries where limited access to PHC services, negative prior experiences at this level and low levels of health literacy have resulted in Deaf adults seeking more specialized levels of care more frequently (Barnett, 1999; Kuenburg et al., 2016; Sheppard, 2014). Further research is needed to confirm if Deaf children's access to healthcare in South Africa follows similar trends.

Table 1. Case log requests for SASL interpreter services between May 2013-August 2016

Request types		
State services	**N=89**	**18,5%**
Court/Legal services	1	0,2%
Department of Social Development	10	2,1%
School events	78	16,2%
Mental Health services	**297**	**61,7%**
After-school sexual health promotion programme	12	2,5%
Drug rehabilitation	34	7,1%
General psychology services	246	51,1%
Trauma counselling - rape crises	5	1,0%
General Health services	**67**	**13,9%**
Primary healthcare clinic/community centre	11	2,3%
Secondary/tertiary Hospital	56	11,6%
Unknown facility	**28**	**5,8%**
Total	**481**	**100,0%**
Average number of requests per year	**120**	

Survey results

Cross-sectional survey results involved 27 respondents, including 19 female (70,4%) and 8 male Deaf learners between the ages of 13 to 18 years. Table 2 shows basic demographic data, history of deafness and illness episodes reported. More than half of learners were born deaf (n=16; 59,3%) and those not born deaf all became deaf before six years of age. Reasons for deafness were mostly unclear, although 12 (44,4%) learners reported being “very sick”. Hearing aids were worn by 20 learners, indicating that at least 74% had interacted with the health system, likely over repeated visits for diagnostic testing, hearing aid fitting and maintenance. Learners reported no Deaf parents and few extended Deaf family members (n=6; 22%). Most learners (n=21; 78%) reported a recent illness episode ranging from flu-like symptoms, to headaches, dizziness and musculature complaints. One learner reported a recent history of tuberculosis (TB). The most common facilities attended for these complaints included the hospital (n=10; 29,4%) and clinic (n=7; 20,6%) This finding corresponds with case log requests above and strengthens the evidence that Deaf learners access more specialized levels of care as a first point of entry into the health system.

Table 2. Basic sociodemographic data, history of deafness and illness episodes for Deaf survey respondents

	N=27	%
Gender		
Male	8	29,6%
Female	19	70,4%
Age		
13-14 years	9	33,3%
15-16	14	51,9%
17-18	4	14,8%
Household size		
1-4 people	10	37,0%
5-8 people	13	48,2%
9-12 people	2	7,4%
Unknown	2	7,4%
Primary caregivers		
Both mother & father	15	55,6%
Mother	8	29,6%
Father	2	7,4%
Other (aunt/uncles)	2	7,4%
Born deaf		
Yes	16	59,3%
No	9	33,3%
Don't know	2	7,4%
Reasons for deafness		
An accident	1	3,7%
Very sick	12	44,4%
Born deaf	7	25,9%
Don't know	7	25,9%
Wear hearing aid		
Yes	20	74,1%
No	5	18,5%
Unknown	2	7,4%
Wear glasses		
Yes	12	44,4%
No	15	55,6%
Unknown	0	0,0%
Facilities attended for illness		
Treatment at home	6	22,2%
Treatment by school nurse	4	14,8%
Pharmacy	3	11,1%
Doctor	4	14,8%
Clinic	7	25,9%
Hospital	10	37.0%
Communication with HCP		
Mother helped	18	66,7%
Father helped	6	22,2%
Sibling helped	1	3,7%
School Nurse helped	2	7,4%
Through writing	1	3,7%
Preferred method of communication with HCP		
Interpreter	16	59,3%
Parent	6	22,2%
Sibling	3	11,1%
Nothing/Writing	2	7,4%

Deaf learners’ experiences of communicating during healthcare appointments varied widely. Most reported that their hearing parents were the primary communicators with HCPs (n=24; 89%) and that mothers were more frequently in attendance (n=18; 67%). One learner reported writing to communicate directly with the doctor and her mother present. Ratings of these communication exchanges indicated only five (18,5%) children who thought communication was "good," 18 (66,7%) who rated it as "okay" and two (7,4%) who indicated it was "bad." Table 3 highlights the main reasons behind these ratings. Apart from familiarity with parent's communication style, all reasons listed are notable barriers. These findings indicate that communication exchanges with HCPs are largely unsatisfactory for Deaf children, despite the heavy reliance on hearing parents acting as primary interpreters. As one learner noted: "I need to know what the doctor say(s) and I need interpret(er) to explain because mother can't explain (to) me."

Table 3. Reasons communication rated as good, bad or okay

Reason	Good	Bad	Okay	Don't know	Total N=27 (%)	%
Familiarity with parent's communication style	3		5		**8**	**29,6**
No interpreter		1	1		**2**	**7,4**
Parent's signing attempts unsuccessful			4		**4**	**14,8**
Nurse is unable to sign well			2		**2**	**7,4**
Speech is too fast			1		**1**	**3,7**
Unable to hear what is said	2		1	2	**5**	**18,5**
Unable to understand what is said		1	3		**4**	**14,8**
Adult unresponsive to requests for healthcare			1		**1**	**3,7**
Total	**5**	**2**	**18**	**2**	**27**	**100,0**

When asked about their preferred method of communicating with HCPs, learners showed a strong preference for the use of interpreters (n=16; 60%) followed by parents (n=6; 22%) or siblings (n=3; 11%). This is despite the fact that none had accessed the free SASL interpreter service available to them during their last healthcare experience. Recommendations for improving healthcare for Deaf children once again highlighted the need for more interpreters with 19 (70,4%) learners suggesting this. Additional recommendations included: improving the signing skills of parents and HCPs, improving Deaf children's communication skills, increasing quality of care and decreasing waiting times at health facilities. This highlights both the specific and common healthcare needs of Deaf children in this setting.

In-depth interviews

In-depth interviews were conducted with 13 Deaf learners between the ages of 14 to 18 years of age. Prior use of interpreters was reported by only two learners, meaning that interview findings mostly reflect Deaf children's experiences of healthcare without an interpreter. Table 4 displays the profiles for each Deaf learner participant across key categories. As for case log and survey findings, participants reported healthcare experiences that were mostly hospital-based (8/13) and facilitated by their mother (9/13) or father (4/13). Similarly, awareness of needing an interpreter was common (5/13), despite its low usage in this group. Exploration of learners' healthcare experiences revealed five broad interrelated themes, described below.

Table 4. Participant profiles for in-depth interviews

Interview code	Sex	Age	Grade	Prior use of SASL Interpreter	Parent attending HCP interaction	Site of HCP interaction
Interview 001	Female	14	8	No	Mother	Clinic
Interview 002	Female	15	8	No	Mother	Unknown
Interview 003	Female	14	8	No	Father	Hospital
Interview 005	Male	17	Technical	No	Mother	Hospital
Interview 007	Female	16	10	No	Father	Private doctor
Interview 008	Female	17	10	No	Mother	Unknown
Interview 009	Female	16	10	No	Father	Clinic
Interview 012	Female	14	8	No	Mother	Hospital
Interview 013	Female	15	9	No	Mother	Hospital
Interview 016	Male	17	10	No	Mother	Hospital
Interview 018	Male	14	Technical	Yes	Mother	Hospital
Interview 019	Female	17	Technical	Yes	Father	Hospital
Interview 021	Male	18	Technical	No	Mother	Hospital

Feeling like an outsider

Deaf learners universally reported experiences where they were excluded from or outsiders to communication exchanges about their own healthcare. The following example describes what happened when a Deaf male learner was seen at hospital for a broken arm:

Interviewer: *Was your mother doing all this?*
Interview 005: *No, the doctor.*
Interviewer: *Then how did you understand the doctor?*
Interview 005: *No, I did not because I am Deaf.*
Interviewer: *Oh, because you are Deaf?*
Interview 005: *Yes, they were talking with my mother not me.*

These experiences were similar, irrespective of age, gender or grade, and led to feelings of disengagement and silence. Worryingly, one learner reported how these exclusionary interactions were experienced as "*just normal*" (interview 013) and another how healthcare experiences were boring with time better spent on her phone:

Interviewer: *How do you feel about the communication when you and your mom are in the doctor?*

Interview 012: *It's boring because I don't understand them, so the best way is to talk on the phone.*

Interviewer: *Talk on the phone how?*

Interview 012: *I mean ignoring them and chat in my phone.*

Keeping quiet in spite of fear

Keeping quiet despite strong feelings of fear and sadness was also commonly reported across interviews. At times, it was unclear if these feelings were related to the experience of being ill or receiving healthcare. For example, when one learner was asked about receiving an injection she responded: "*Yes, it's scary but I never spoke to them about it. I just keep quiet"* (interview 005). Another learner with a history of TB reported her sadness, but once again it was unclear if this was due to her diagnosis or the lack of an interpreter:

Interview 008: *My mother was talking to the doctor and the doctor said I had TB. He showed us an x-ray. The doctor told me that am sick and I was sad. I didn't have an interpreter with me.*

Female Deaf learners, in particular, reported choosing to "keep quiet", potentially reflecting the intersectionality of gender, Deafness and childhood healthcare experiences in this setting.

Making sense of healthcare experiences

Deaf learners shared various healthcare experiences and their attempts to make sense of what was happening to them. One young learner describes his confusion over multiple healthcare visits for different reasons:

Interview 018: *…They told me I need a pump for my lungs. I accepted it. And then I went home. Later I went with my father to Red cross for hearing test. Four people tested me and told me that my left ear is better, but my right ear is deafened. Then I had to get an implant. I asked what does that mean? Then they said don't worry. Then, when I got home, I had a problem with breathing and I fell down... They diagnosed me with a lung problem and then they helped me breathe. And then my mom and dad gave me something. And then later the doctor gave me something for my lungs, tested my lungs. I don't know what happened but it was bad and the doctor gave me a mask and an injection and then later on I felt better and went home to rest. That all.*

Most Deaf learners demonstrated limited understanding of their healthcare experiences, often unable to say what diagnosis, treatment or medication they had received. Limited understanding was exacerbated by keeping quiet and perpetuated feelings of exclusion. Children’s requests for clarity to understand their diagnosis and subsequent medication prescriptions were mediated by parents who summarised what HCPs had to say either during or after appointments. In both cases where interpreters were present (interview 018 and 019), sufficient understanding was undermined by the interpreters’ lack of familiarity with SASL, highlighting the need for appropriately trained interpreters familiar with local sign language and context.

Hearing family members as gatekeepers to care

As for the survey above, all Deaf learners described how their hearing parents, particularly their mothers, were central to accessing and understanding healthcare. In this way, parents act as gatekeepers determining when, where, how and how much healthcare and health information their Deaf child receives:

> *Interviewer:* *I mean, after telling your mother. What did she do?*
> *Interview 001:* *She will be quiet or we go tell the Doctor.*

Children’s extended family also supported access to care by providing transport or acting as mediators when parents were unavailable. Hearing family support networks are undoubtedly vital, but not always sufficient to provide comprehensive healthcare for Deaf children, as the following exchange demonstrates:

> *Interview 016:* *I was sitting and the doctor stood in front of me, trying to communicate with me and I couldn’t understand. Then my mother took over and explained to me.*
> *Interviewer:* *So, you could understand everything clear?*
> *Interview 016:* *Some.*
> *Interviewer:* *How is your mothers signing? Can she sign?*
> *Interview 016:* *Yes.*
> *Interviewer:* *Perfectly?*
> *Interview 016:* *No, a bit.*

These findings confirm survey ratings of communication and emphasize the need for parents to receive adequate SASL training and support, and timely access to qualified interpreters for their Deaf children.

A need for agency

Agency refers to the sense of control we feel over our actions and their consequences (Moore, 2016). For Deaf learners in this study, reports indicate a limited sense of agency and a passive acceptance of healthcare experiences that happen *to* them rather than with or for them. The following exchange shows how a lack of communication and differential power dynamics between a hearing HCP and Deaf learner leads to reduced agency and passive acceptance of an injection:

Interviewer:	*Tell me do you have any communication with the doctor during this process.*
Interview 012:	*No*
Interviewer:	*He just injects you*
Interview 012:	*I just look away and give him the arm.*

Interestingly, most learners demonstrated sufficient agency to initiate help-seeking when sick by asking their parents for medication or to be taken to the doctor. Although, agency appeared to shift during the healthcare experience with few learners seeking minimal clarity about procedures, diagnoses or medication:

Interview 005:	*Sometimes I ask my mother and she will say is for your health and that's all.*

This quote again highlights the important role of parents in translating healthcare information in ways that promote or limit Deaf learners' understanding and, consequently, a sense of agency about their own healthcare. Agency is further impacted by inaccessible or unclear communication between hearing Parents and HCPs that perpetuates feelings of exclusion or "outsider-ness" for Deaf learners who do not share the same hearing culture. However, keeping quiet and disengaging during healthcare interactions may also demonstrate agency as learners become bystanders to their own healthcare. Despite relatively good awareness of the need for an interpreter to improve healthcare experiences (5/13 interviews), no learner had previously requested one. Learners' agency to request interpreters could be enhanced by improving their knowledge about interpreter services and their right to access them.

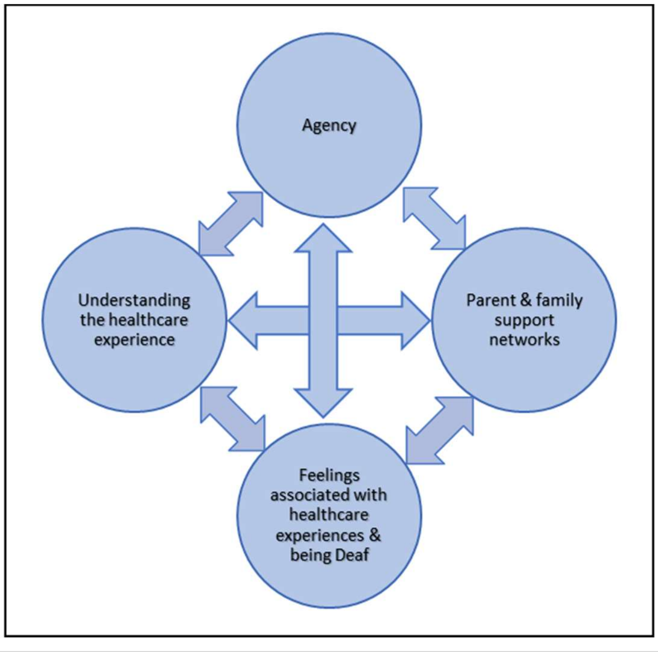
Discussion

This study draws on diverse datasets to explore the healthcare experiences and use of SASL interpreters among Deaf school children in the Western Cape Province. Case log data provide preliminary evidence of interpreter service requests and demonstrates the important social and psychological needs of its users. Ongoing monitoring and evaluation of these requests will offer valuable insights into Deaf children's healthcare needs and support funding efforts, scaling and sustainability of interpreter services for this vulnerable population. These data also highlight the disproportionate use of secondary and tertiary hospital services over primary healthcare facilities among Deaf children, a finding confirmed during the cross-sectional survey and in-depth interviews. Increased use of emergency and specialised services has been reported in Deaf adults in other settings and linked to low levels of health literacy, communication barriers, limited access to health information and negative childhood experiences that lead to avoidance of primary healthcare services (Barnett, 1999; Kuenburg et al., 2016; Sadler et al., 2001). One study reports the experience of a Deaf teenager who sought care for acne and, for unknown reasons to her, received a pelvic exam. The fear and confusion caused by this event prevented her from interacting with any HCP for a further 25 years (Sheppard, 2014). Further research is urgently needed to determine if Deaf children's access to primary healthcare services in South Africa follows similar trends and for similar reasons. Moreover, primary healthcare services among Deaf children should actively be promoted to prevent the escalation of preventable disease and curb healthcare costs. Proposed methods of promoting these services include: increasing the availability of sign language interpreters, providing SASL training to primary HCPs, implementing accessible communication technologies, adapting health information into accessible formats for Deaf people, developing opportunities for more Deaf people to become HCPs and incentives for current HCPs to become sign language proficient (Claassen et al., 2017; Kuenburg et al., 2016; Sadler et al., 2001).

Cross-sectional survey findings build on case log data by demonstrating, albeit with a small sample size, that SASL interpreter use remains low among Deaf school children. This is despite the availability of free interpreter services for learners, a strong preference for these services and recognition that hearing parents are helpful, but insufficient translators of healthcare information. These latter findings are supported by in-depth interviews and have been recognised by others (Barnett, 1999; Haricharan et al., 2013; Richardson, 2014). There is a need to increase Deaf children's understanding and awareness about the availability of local interpreter services as well as their rights to access these services. An important caveat to the provision of interpreter services is the need for adequately trained interpreters who are familiar with SASL and sensitized to the needs of local Deaf children. Ideally, interpreters should serve as linguistic and cultural bridges between Deaf patients and their HCPs (Barnett, 1999; Benjamin, Swartz, Hering, & Chiliza, 2016). As demonstrated in in-depth interviews, inadequately trained interpreters are unable to transfer vital healthcare information, leading to suboptimal understanding by Deaf children and potentially compromised quality of care. However, access to adequately trained sign language interpreters remains a challenge, both in South Africa and internationally (Claassen et al., 2017; Gichane et al., 2017; Haricharan et al., 2013; Kuenburg et al., 2016). Policy and community awareness initiatives that promote the development and professionalisation of SASL interpreters should be encouraged to increase the pool of interpreters currently available in South Africa. In 2017, the Western Cape Provincial Department of Health assumed financial responsibility for providing interpreters in healthcare, signing a memorandum of understanding with Folio, a private language and translation service. To access this service, Deaf children and adults send a text-based message to the Folio support team who clear the request with the Department of Health and book an accredited SASL interpreter for the patient's appointment (L. Spies, personal communication, November 14, 2019). Thus far, these services are only available to Deaf people in Cape Town. However, they represent a historical breakthrough in a country where professional interpreter services are lacking and no professional interpreter posts currently exist within state healthcare departments.

However, the provision of interpreters alone is not a panacea to improving healthcare access for Deaf children. This study goes a step further to explore why Deaf children's use of SASL interpreters remains low in this setting. Combined study findings give rise to four interrelated themes that demonstrate Deaf children's healthcare experiences with and without interpreters (Figure 1). Themes represent important individual and social areas that influence Deaf children's experiences of and access to healthcare beyond the use of interpreters.

Figure 1. Individual and social areas influencing Deaf children's experiences of and access to healthcare



Agency is a complex sociocultural construct closely linked to language, health literacy and the availability of social support (Ahearn, 2001; Hunter, Franken, & Balmer, 2015). For Deaf children in this study, agency varied from actively seeking assistance through parents and family support networks to passively receiving healthcare that was rarely understood. This led to strong feelings of fear, sadness and frustration associated with healthcare experiences. Deaf children's responses of "keeping quiet" further excluded them from engaging in their healthcare, inhibiting their understanding and reducing their sense of agency. Despite the active participation of parents and family support networks in facilitating access to HCPs, communication barriers between hearing HCPs, parents and Deaf children prevented adequate understanding of healthcare procedures, diagnosis and treatments. This led to further frustration and reduced agency. These mutually reinforcing issues concur with findings from a recent study of Deaf adults' access to healthcare in Worcester, South Africa (Kritzinger et al., 2014). This study found that communication barriers for Deaf people rarely occur in isolation. Additional interpersonal factors, including a lack of independence, over-protection by family members, a non-questioning attitude, and poor familial communication interact with communication barriers in ways that further limit access to healthcare. Such factors have a compounding effect on Deaf people's knowledge of their own medical history, their feelings and attitudes towards health services and their confidence in engaging more proactively with HCPs. The normalisation of exclusion may explain why the majority of children (2/3) were prepared to report the quality of care as "OK" since patient satisfaction is known to be a function of expectation based on past experience (Berkowitz, 2016; Gill & White, 2009).

This study recognizes that providing sign language interpreters alone will not necessarily make health care more equitable or accessible for Deaf patients (Kritzinger et al., 2014). Consequently, policies and programmes that promote equitable access to healthcare for Deaf children should consider comprehensive approaches that create awareness and access to interpreter services, but also focus on developing children's' agency, knowledge and understanding about their own healthcare and rights as patients. Furthermore, HCPs and family support networks should be sensitized about the strong feelings and emotions associated with healthcare as well as the specific vulnerabilities and need for empowerment of Deaf children in this setting. Realising the right of access to health care and the right of Deaf children to basic health care services requires more than just providing services but ensuring that services are non-discriminatory and provide adequate informational accessibility, which is not possible without a comprehensive set of policies and programmes (Du Toit et al., 2018).

Conclusion

Language barriers remain a “deeply entrenched structural feature of the public health system” affecting access to and quality of healthcare services (Deumert, 2010, p. 54). This study highlights the urgent and ongoing need for interpreter services to overcome these barriers for Deaf schoolchildren in South Africa. To the authors’ knowledge, this is the first mixed methods study providing evidence about Deaf children’s healthcare experiences in South Africa and their use of SASL interpreter services. The study focused on one Deaf school in the Western Cape and does not claim to be generalisable outside this context. However, due to the paucity of literature for this ‘hidden’ population group, it provides an important baseline for further action. It adds to calls for policy changes that allow for the creation of posts providing professional medical SASL interpreting services. Moreover, it describes the need to foster Deaf children’s understanding, knowledge and sense of agency in advocating for their own rights as patients. Sensitizing family support networks, caregivers, HCPs and school staff towards the often-strong feelings and emotions attached to healthcare and the particular vulnerability of Deaf children in this setting should facilitate a shift towards more sensitive and engaged healthcare experiences. Only when those most vulnerable among us have full and equitable access to the healthcare that they need, can we say that no-one has been left behind and the Sustainable Development Agenda for good health and well-being has been achieved.

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