Perceptions of parents of children with hearing loss of genetic origin in South Africa

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Abstract

More than 80% of people with hearing loss (HL) live in low- and middle-income countries. Up to 90% of deaf children are born to hearing parents, leading to novel parenting, communication, educational, and psychosocial experiences. Half of congenital pre-lingual HL is genetic, with a relatively high recurrence risk that may lead to specific challenges for parents of affected children. Currently, little is known of genes implicated and causative mutations for most populations who have HL in Sub-Saharan Africa, as well as genetic counseling services needs for this population. Therefore, this study aimed to explore parents' perceptions and understanding of the genetic etiology of their child's HL, in order to inform policies and services. In-depth qualitative interviews were conducted with 11 parents of children who have non-syndromic HL of putative genetic origin. Data were analyzed through the framework approach. Three salient themes emerged, namely comprehension and understanding of the cause, in which most parents were unable to identify the potential hereditary cause of their child's HL; responsibility and blame; and their perception of genetic counseling and testing. Most of the participants had positive attitudes towards genetic testing, describing that it may provide answers and that the information gained would be helpful for the future. The data could assist in understanding the challenges faced by parents, in the absence of genetic testing, emphasizing the need for accurate genetic testing to support counseling services to parents of children with HL in an African Setting.

Keywords Genetic hearing loss · Parents · Genetic counseling · Genetic testing · Qualitative research · South Africa

Introduction

More than 80% of people with hearing loss (HL) live in low- and middle-income countries (Murray et al. 2015). Given that 90% of deaf children are born to hearing parents, who may have little or no experience with deafness, diagnosis may be followed by novel parenting, communication, and educational

and psychosocial challenges, as the family adapts to a new reality (Jackson and Turnbull 2004). In response to the diagnosis, parents have previously expressed intense emotions coupled with fear, uncertainty, and grief (Jackson et al. 2008).

The etiology of HL is complex, but it is thought that approximately half of congenital pre-lingual HL is genetic. Isolated, or non-syndromic hearing loss (NSHL), accounts for approximately 70% of genetic HL and is highly heterogeneous (Smith et al. 2014). Mutations in the gap junction protein beta-2 (*GJB2*) gene remain as the leading cause of autosomal recessive prelingual HL in most populations of European and Asian ancestry, accounting for approximately 50% of cases (Chan and Chang 2014; Denoyelle et al. 1997; Kelsell et al. 1997). Despite on-going research into the molecular basis of hereditary HL in black African populations (Lebeko et al. 2015; Lebeko et al. 2016; Wonkam 2015), genetic testing for HL in SA is largely uninformative. Without confirmatory genetic diagnosis, accurate and informed genetic counseling may not be optimally provided to the parents of deaf children in our many sub-Saharan African settings.

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Research from other countries suggests that there may be a paucity of knowledge related to the cause of genetic HL among hearing parents. In a recent survey study conducted in Russia, 91 parents of deaf children were asked what they presumed the cause of their child's HL to be, prior to delivery of a positive *GJB2* genetic testing result. The majority of the participants (78%) attributed their child's HL to non-hereditary causes, particularly if they did not have a family history of HL. The authors suggest that when delivering positive genetic test results, parents may have preconceived opinions on the cause of their child's HL and that increasing genetic awareness will assist in acceptance of these results and their implications (Solovyev et al. 2017). In Portugal, a study by Rodrigues and colleagues showed the value of genetic counseling in this regard. Surveys completed by 44 parents of children with *GJB2*-related NSHL showed that prior to a genetic counseling session, only 13.6% of the parents knew that there was a genetic cause for their child's HL, compared to 84.1% post-counseling. Additionally, after the session, 93.2% were able to correctly recall the recurrence risk (Rodrigues et al. 2013). This study highlights the important role that genetic counseling may play in assisting parents to understand the mechanism behind their child's HL as well as the risk for recurrence.

In previous studies, without knowing the cause of their child's HL, parents have experienced guilt, blame, helplessness, and uncertainty regarding inheritance and possible recurrence risks in future pregnancies (James et al. 2006; Rodrigues et al. 2013). Parker et al. conducted a survey, administered to parents of deaf children, to determine what parents and families wanted from a clinical genetics service. Of the 130 respondents, 12.3% expressed interest in their genetics provider addressing issues of self-blame (Parker et al. 2000). Opinions regarding genetic testing for HL has also been investigated in other settings, such as the USA (Brunker et al. 2000), the UK (Middleton et al. 2010; Middleton et al. 2001), and Nigeria (Adedokun et al. 2015) and has recommended taking into account the views of hearing parents, deaf parents, and/or the deaf community, to improve clinical practice.

Despite the growth in the genetics/genomics field worldwide, genetic services are insufficient in SA, as they are in other African countries and in many mid- and low-resource settings (WHO 2010). At present, only three urban centers in SA offer a comprehensive service including diagnosis, genetic counseling, and care for those affected by genetic conditions (Beighton et al. 2012). With limited resources and a shortage of trained professionals, most of the South African population are without access to clinical genetics services (Greenberg et al. 2012). As research continues and the search for appropriate testing for HL in Africa is developing, it is imperative that we acknowledge the perspectives of affected families, in order to adopt genetic counseling practices that are of local

relevance, with the aim of suitably assisting newly diagnosed deaf children and their families.

Therefore, the aims of this study were to (1) explore experiences and perceptions of parents of children with congenital or pre-lingual non-syndromic HL of potentially genetic origin, on the cause of their child's HL in Cape Town, and (2) investigate the role for genetic counseling services and parents' perspectives in this setting.

Methods

Population and sample

Between December 2015 and May 2016, we recruited parents from two sites in Cape Town, South Africa: a well-established school for deaf children and the pediatric genetics clinic at Red Cross War Memorial Children's Hospital (RCWMCH). We contacted potential participants through letters sent via the school, coordinated by the school nurse or by telephone in the case of those from RCWMCH.

Inclusion criteria

Participants were included if clinically consulted and examined by a medical geneticist, ascertaining in the absence of appropriate genetic testing that the child's HL was of a putative non-syndromic genetic origin, based on family history of HL and exclusion of potential environmental causes. These included meningitis and other infections, prematurity, or other perinatal co-morbidities. Six parents, whose child attended the school for the deaf, that hosts weekly and term boarders, aged 4–18 years from various areas of the Western Cape province of SA, participated in this study, as did five parents of children who have previously attended the pediatric genetics clinic at RCWMCH.

Of 41 potential participants contacted, we interviewed 11. Two declined, six agreed, but were not available for interviews, and 22 did not respond.

Interview guides

To gauge information about perceptions of the cause of HL, the study instruments were developed collaboratively by the research team that included two genetic counselors (SAG and NL), a public health specialist who completed a PhD on hearing loss (SM), and a medical geneticist (AW) with a research interest in the genetics of HL in Africa. The participants completed a short questionnaire to gather socio-demographic information. The primary researcher (SAG) then conducted in-depth interviews using a semi-structured English language question guide, developed by finding issues of importance in the literature. Questions were purposefully open-ended to

allow the participants to fully express their viewpoints and experiences. In addition to questions that related to the genetic aspects of HL, over half of the interview guide's questions encompassed various areas with which HL may affect a parent's life so that a holistic understanding of their experiences may be gained.

Data collection

We conducted interviews in the parents' preferred language in a location convenient for the participant. We completed nine interviews in English, one interview in isiXhosa, and one interview South African Sign Language (SASL). An interpreter assisted the primary researcher in the isiXhosa and SASL interviews. After the consent process, the interviews were digitally audio-recorded.

Data analysis

Interviews were transcribed verbatim and imported into NVivo10 (QSR International). Each of the participants were assigned an alphanumeric code (e.g., P1–P11), and when participants made reference to their child, using his or her name, their child was given a letter of the alphabet corresponding to their parent's numeric code (e.g., A–L, excluding I). We conducted thematic content analysis to identify themes in the data using the framework approach. This approach includes familiarization with the data, indexing of all transcripts, coding, charting, mapping, and interpretation of the emerging themes (Smith and Firth 2011). The first author coded the transcripts, and the second author independently verified the codes. To ensure validity, discrepancies in codes, and emerging themes were discussed between the authors.

Results

Sample demographics and social characteristics

A summary of the sample's demographic and social characteristics is described in Table 1. The ages of the participants' children are included in Table 2. All of the women interviewed had at least one deaf child. Three participants had a family history of HL. Two of the participants were from the same family, participants 6 (deaf mother) and 10 (hearing mother), and their relationship is depicted in the pedigree provided (Fig. 1). Participant 9 had another child with HL. The children of the remaining participants were all the first in the family to have been diagnosed with HL.

As we explored the understanding and perceptions of the participants in relation to their child's putative hereditary HL, several themes emerged. The themes reported here are the most salient that emerged from the analysis: (1) comprehension and

Table 1 Participant characteristics

Category of participant		
<i>n</i>	11	
Mean age (SD)	35.8 (8.6)	
Category of participant	<i>n</i>	%
Gender		
Male	0	0
Female	11	100
Race ^a		
Black African	3	27.3
Mixed ancestry/colored	8	72.7
Home language ^b		
English	5	45.5
Afrikaans	4	36.4
IsiXhosa	3	27.3
SASL	2	18.2
Marital status		
Single	5	45.5
Married	5	45.5
Engaged	1	9.1
Employment status		
Employed	7	63.6
Unemployed	4	36.4
Household monthly income (Rand)		
0–3000	5	45.5
3000–7000	3	27.3
7000–10,000	2	18.2
> 10,000	1	9.1
Family history of HL		
Yes	3	27.3
No	8	72.7

SD standard deviation

^a Historically, the South African Apartheid government influenced deaf education by segregating learners according to race. In the 1930s, the school used in this study was only allowed to accept “colored” learners. Since the demise of the apartheid regime, deaf education in SA remains segregated and racial discrimination is particularly apparent in South African Sign Language studies (Reagan et al. 2006)

^b Totals do not add up to 100% as some participants are bilingual in their home environments

understanding of the cause of their child's HL, (2) responsibility and blame, and (3) their perception of genetic counseling and testing.

Comprehension and understanding of the cause of their child's hearing loss

Participants had varied views on the cause of their child's HL. Seven of the 11 participants were unable to identify the cause

Table 2 Age of participants' child

Participant number	Age of child (years)
P1	5
P2	17
P3	6
P4	6
P5	6
P6	13
P7	11
P8	12
P9	8
P10	15
P11	3

of their child's HL or attributed it to an environmental etiology, such as participant 3 attributing her child's HL to recurrent ear infections:

"Every time he got an infection in the same ear, continuous in the same ear ... When I took him to the clinic they only give me antibiotics and [pain medication], and that only made it worse."

Those who did not know the etiology at all reported, "I don't know" (P1 and P9) and "I still have no answer" (P8).

The remaining four participants mentioned genetics in their response to the cause of their child's HL. Two of which had been seen previously at the genetics clinic at RCWMCH (participants 5 and 11), and the further two participants with a family history of HL were able to accurately identify the cause of their child's HL to be "in the family" (P6) or "because of the genetics" (P10). Family history was seen to not necessarily be a determining factor as to the identification of a possible genetic

cause of HL, as participant 9, who has two deaf children, was unable to identify the potential hereditary origin of her children's HL.

When the seven participants who reported a non-genetic explanation of their child's HL were asked whether they thought that their child's HL could potentially be explained by a genetic cause, several were skeptical. They interpreted that genetic etiology must mean familial history:

"I don't think, because in my family there is no one. We don't have no one. He is the first one actually who is deaf" (P3).

Another participant revealed:

"It was devastating. You know he is your first born, you don't know where this came from because there is no one in the family that is deaf" (P8).

One of the participants explained that she does not understand how her child's HL can be genetic because it is not associated with a syndrome, like other children at her child's school. She noted that there are children with Down syndrome at her child's school:

"When I am looking at the kids [at the school], some of them have like Down syndrome, some of them are deaf with the Down syndrome but with E she is only deaf, she has nothing else" (P5).

Participant 10's family history meant that she understood the hereditary nature of her daughter's HL but had misunderstandings regarding recurrence risk, as illustrated in the following quote:

"I spoke to my eldest ones. I said to them, you must understand now it is running through the family, so I don't think you must have more children if you are not ready for a deaf child. But the doctor said [at the hospital] it is mostly the girls. Yes. Running in the girls". (P10)

Fig. 1 Pedigree showing the relationship between participants 6 and 10. Shaded circles (for females)/squares (for males) represent those with hearing loss (HL) in the family

Responsibility and blame

The participants that experienced uncertainty regarding the cause of their child's HL sought to find an explanation, two taking responsibility by attributing it to the stress they experienced during pregnancy and one participant questioned whether it was her fault, experiencing self-blame, "I was questioning in my mind. What happened to this child from the start? Or is it me maybe?" (P4).

One of the participants explained that knowing that there is genetic cause for her child's HL would ease guilt, as no one would be to blame:

Interviewer: "You said before that you felt guilty..."

P5: "[Yes], because I did think it was my fault because I was like giving birth and I was giving up because my body couldn't take it anymore, that's why I was feeling guilty."

Interviewer: "But you wouldn't feel guilty if it was a genetic cause?"

P5: "No, no!"

Interviewer: "Why not?"

P5: "I don't know (pause) probably because I will feel it is not my fault and I don't want to blame anybody at all."

Participant 5 is saying that with a definitive genetic etiology, she would no longer blame herself for her child's HL. Relatedly, participant 8 explains that blame is counterproductive to acceptance and adaption to having a deaf child:

"From my point of view, you can't help for your genetics I think. You didn't form yourself and if there are two people who are put together with some genetic default and you have a deaf child and you are the cause, I don't think that you can blame the other because you didn't know. But... if there was deafness in the family maybe you could have had yourself tested, things like that you know, precautions." (P8)

The participants who mentioned feeling responsible or blaming themselves for their child's HL were without a family history of HL. In the absence of a known cause, they assumed this responsibility with the ensuing guilt having negative effects on the participants.

Perception of genetic counseling and testing

For various reasons, all the study participants voiced interest in pursuing genetic testing. Participants 11, however, stated that it "would not change anything" for her deaf child but would be useful for the option of prenatal genetic testing in the future. In contrast, participant 6 (a deaf mother), hoped for a deaf grandchild one day as it would be "expanding the family." Four of the participants' children reportedly underwent previous genetic testing, either through another tertiary hospital in Cape Town or through RCWMCH. Participant 11 describes the perceived usefulness of the test and the return of results:

P11: "She did a genetic test at [another hospital], and they did one here [RCWMCH]."

Interviewer: "And did you get the results back?"

P11: "Yes! But they say they can't test, I don't know what you call it, all the genes. They said the most common deaf genes they tested."

Interviewer: "Did you get a result back?"

P11: "No! That's the thing, they can't figure out where her deafness comes from. Because it might be in one of her other genes they can't test for or might just be out of the blue. Or maybe it's like I have two percent of deaf genes and her father have three percent and those mix and then becomes five percent."

There are two points to note in participant 11's response. First, she identifies the limitations of genetic testing in our setting and secondly the heterogeneity in HL. However, she incorrectly reports on the percentages of genes. This illustrates either a lack of recall of genetics concepts or a misinterpretation or misunderstanding of the information provided during her post-test counseling. Participant 2 explained that her son's genetic testing came back "normal," which further fueled her confusion. She may not have been properly informed about the limitations of testing for hereditary HL, especially in the South African setting.

Participants without a family history of HL were generally unprepared for the diagnosis, making them possibly more likely to seek testing to answer their questions regarding the cause of their child's HL. However, in this study, even those with a positive family history of HL, and those who had undergone previous testing, were interested in further testing. When queried about why they thought that testing would be useful, participants explained that they wanted to "learn more" (P1), that it would provide "peace of mind" (P3), and that by having a definitive diagnosis, they would be able to make appropriate choices with regard to their own recurrence risk and risks for their children's future offspring.

Discussion

To our knowledge, this study is the first of its kind in South Africa, in its attempts to examine parents' perspectives of their child's hereditary HL. Several participants experienced misunderstandings in relation to the hereditary and putative genetic cause of their child's HL. As a consequence of these misunderstandings, feelings of guilt and blame ensued. Most of the participants had positive attitudes towards genetic testing, describing that it may provide them with answers and that the information gained would be helpful for the future.

The eight participants in this study who had no previous family history of deafness were generally surprised at the diagnosis of HL in their child. Conversely, when there was a family history of HL, as with participants 6 and 10, they were able to correctly identify their children's HL as hereditary.

Participant 9, however, who has two deaf children, was unable to assign the potential genetic cause of her child's HL.

As with previous research, parents may present with information seeking behavior and struggle without a definitive cause to attribute to their child's HL (Parker et al. 2000; Steinberg et al. 2007). Although public awareness of genetics is increasing, parents may have different understandings, preconceived ideas, and misconceptions about hereditary traits. Words and concepts such as genetics, genes, and DNA have become popularized through media and television but much of it remains poorly understood in our setting (Greenberg et al. 2012), just as it is elsewhere in the world (Condit 2010; Etchegary et al. 2009; Lanie et al. 2004). Given that most basic genetics concepts are only taught in Grade 12 Life Sciences (Department of Basic Education 2011), it is understandable that many of these concepts are difficult to recognize and retain for the majority of the South African public, especially for the population over a certain age who would not have had access to this during their schooling. As only six of the 11 participants finished high school, the fact that Life Sciences is not a mandatory subject and may not have even been available during their time, many of the participants in this study would not have had access to basic genetic concepts in their schooling and were therefore unable to recognize this as a potential cause of their child's HL. Furthermore, unequal access to higher education and marked social disparities in SA means that there is less dissemination and comprehension of genetics concepts resulting in a large proportion of families affected by a genetic disorder left unable to explain why this is happening in their family (Greenberg et al. 2012).

Some participants ascribed personal responsibility to their child's condition. Feeling personally responsible often provides parents with the illusion of control (Kessler et al. 1984). An expected event, such as the diagnosis of HL in a child, could shatter a parent's world of normalcy and understanding. Parents may grapple with the existential question of "why did this happen?", leading to a search for the agent responsible, which can often mean assuming personal blame or feelings of guilt (Weil 2000). In this study, some of the parents expressed feelings of guilt and blamed themselves for their child's HL. These attributions of blame and parental feelings of guilt are important factors to take into consideration when dealing with genetic conditions and should be addressed in the genetic counseling consultation. Kessler et al. encourage the genetic counselor to make use of tactics that may alleviate a parent's feeling of guilt. These include using the genetic counselor's authority in their professional role to tell the parent that it is not their fault, normalizing the parent's emotions, reframing their feelings of responsibility, and limiting their liability (Kessler et al. 1984). The role of genetic counseling to address and manage blame and guilt in hereditary HL has been previously examined (James et al. 2006; Parker et al. 2000; Rodrigues et al. 2013).

It has been identified that when deafness is familial, it is usually assumed that the child's HL is the same as that of the similarly affected family member and therefore parents do not pursue genetic testing (Kaimal et al. 2007). This was not the case in this study. Participant 6, a deaf mother, expressed interest in testing for its potential to identify a child with HL, which would be favorable for her. Some may see the deaf trait as something unfavorable, but a large part of the deaf community (those who culturally identify as being deaf) wishes to make their population larger and will seek genetic counseling and advice on how to use genetic testing, such as prenatal diagnosis or preimplantation genetic diagnosis, to ensure that they pass on the deaf trait to their offspring (Emery et al. 2010; Middleton et al. 2001). This is an important factor to be aware of as a genetic counselor working with the deaf.

One of the participants in this study had undergone genetic testing and genetic counseling, and she was able to correctly identify her child's HL as hereditary but was still unable to explain genetics, how it related to her child's HL, and the risk for recurrence. This again highlights the need for appropriate genetic counseling and the provision of resources, both pre- and post-testing, so that genetic information may be well-understood and retained. Indeed, all the participants in this study had positive attitudes towards genetic testing, in the hope that it would provide them with answers and that the information gained from testing would be of use in the future. This is a valuable finding as genetic testing for HL in the South African setting is under scrutiny. Rich diversity and extreme genetic heterogeneity means that further research into the genetic basis of HL in African populations is crucial before testing will be useful and widely available, but here, we show that there is a definite need and desire for this testing by those families affected by HL.

Study limitations

We acknowledge several limitations in the present study. Firstly, most of the interviews were conducted in English. Although not necessarily the participants' first language, the offer for an interpreter was only taken up by two participants. In these interviews, informal interpreters were used, teachers' aids working at the deaf school. Although it is not ideal to use a lay interpreter, it is common practice in the South African setting to make use of lay persons due to a lack of available trained interpreters (Kilian et al. 2010).

Secondly, purposive sampling does lend itself to ascertainment bias. The views of those unwilling to participate, unable to attend the interview, or less communicative are not included. Only a small proportion of those contacted for involvement made themselves available for an interview (response rate 27%). This lack of engagement by many of the parents may be explained by a number of factors. First, many of the children who attend the school are there as boarders, either

weekly or for the term, and their homes far from the research site, making it difficult for parents to travel for the interviews. Although an offer was made by the researcher to travel to the parents for the interview, none of the potential participants took up this offer. Second, the nature of this research may cause parents to not be interested in being interviewed, as their experiences of their child's HL may be unfavorable, and they may not wish to discuss these matters. Furthermore, as previously reported, many South Africans are faced with burdens (van der Spuy and Pottas 2008) and therefore cultural, economic, and linguistic barriers prevail between researchers and their proposed subjects (Benatar 2002). Lastly, those interviews that were conducted at the school may have influenced the participants' candor, as they may have felt that the researcher had an association with the school and that perhaps their answers would influence the care of their child.

Despite these potential limitations, the study has provided unique insight into parents' experiences with HL and perceptions regarding genetic testing that deserve to be replicated in additional settings in Africa, in order to ultimately improve genetic counseling and care of people living with HL and their families.

Practical implications

This study is the first undertaken in the South African setting to employ qualitative methods to examine the parental experience of hereditary HL in the child. This small sample illuminated novel issues related to the context of a selected setting in Cape Town and is potentially relevant to other mid- to low-resource countries.

This research illustrates the need for referral to genetics services in our setting. Through the genetics services, a thorough clinical examination, and when it becomes appropriate and available, genetic testing of newly diagnosed congenital/prelingual HL means that parents may be provided with genetic counseling, information, and referral to supportive services as indicated. Furthermore, the experiences and perspectives of parents of children with hereditary HL are valuable for genetic health care professionals, with the aim of better service delivery to meet the specialized needs of these families.

Research recommendations

A recommendation for further research in this field includes examining the child or adolescent's view of what has caused their HL and what they have experienced in relation to their deafness. As research is ongoing to determine the molecular basis of HL in black South African populations, testing may become available and guide the clinical diagnosis of many children whose families do not have a definitive cause for the child's HL. Results will need to be fed back to the families and may present interesting findings with regard to their

potentially altered understanding of the cause of their child's HL. A qualitative approach would be most suited to this.

In this study, only a small proportion of parents contacted for involvement made themselves available for an interview. Future studies may want to address the reasons why parents may be unwilling to participate in genetic research for HL. In the clinical setting, Kaimal et al. (2007) encourage genetic healthcare providers to be aware of the questions and attitudes of parents that attend a genetics consultation. They recommend educating parents and other healthcare professionals about the usefulness of a genetic evaluation, genetic counseling, and possible testing for children with HL (Kaimal et al. 2007). Further, there is a need for governmental involvement in increasing public awareness of HL, as well as further studies on the value of community engagement in the field of hereditary HL. It is important that research respects the communities involved, building trust between researchers and the communities, which may assist in participants' willingness to be involved in research (Tindana et al. 2015).

Conclusions

This study has obtained some valuable findings with regard to the attribution of causality, understanding of genetics, and opinions of parents of children with putative hereditary HL. By understanding how parents perceived the cause of the child's HL, the need for services, such as genetic testing and genetic counseling that provide parents with an explanation of the mechanism behind hereditary HL, is explored. As we increase our understanding of the molecular basis of HL in African populations, qualitative research affords us insight as to the potential value of developing genetic testing for HL to be utilized in the pediatric setting. If parents did not engage with the potential benefits of having a genetic diagnosis, they would not make use of this service and the ongoing research would not make it off the bench and into the clinic. This was not the case in this research, as these parents showed interest in genetic testing, promoting the significance of ongoing molecular research. Even in the absence of comprehensive genetic testing at this time, we evaluated that there is a definite need for genetic counseling in this population to increase genetic knowledge, provide supportive counseling, and advise on approximate recurrence risks based on family history so that parents of deaf children do not go underserved purely because testing is limited.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Research involving human participants All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (University of Cape Town's Human Research Ethics Committee) and with the Helsinki Declaration of 1975, as revised in 2000.

Informed consent Informed consent was obtained from all participants included in the study. The study was approved by the Faculty of Health Sciences Human Research Ethics Committee at the University of Cape Town (HREC 699/2015).

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