A Descriptive Case Study: Challenges experienced by health care workers (HCW) at a primary health care facility when serving deaf/hearing impaired (HI) patients

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DECLARATION

I, Shameela Orrie, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.
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Abstract

Introduction
Deaf people experience significant barriers in access to health care as well as poorer health outcomes. While there are many international and South African studies describing the difficulties deaf patients experience when accessing health care, only anecdotal evidence suggests that health care workers (HCW) also experience challenges at these encounters. These difficulties are significant as they may results in errors in medical management with significant impact on mortality and morbidity of the patient as well impacting on future encounters.
This study was intended to further the understanding of the dynamics of the encounters between HCW and deaf patient by examining the HCWs experience. In this way we may identify the intrinsic and extrinsic factors contributing to the success of failure of the task, establish if the HCW has the competencies and training to achieve the objectives, how working conditions impact on success and how HCWs adapt their communication strategies. These findings could advocate for changes to formal training HCWs receive and the planning and adaptation of services offered to give deaf patients access to appropriate and effective health care.

Methods
The study design is a qualitative, descriptive case study. Data was collected using interviews and focus groups of invited staff members at Retreat Community Health Centre (RCHC) in Cape Town. Convenience sampling was used to select participants, and interviews were conducted until saturation was reached. Data was studied and analysed using the phenomenological method.

Results
HCWs reported that they serve very few Deaf or HI clients. However, themes of language barriers; resilience; preconceptions; improvisation and innovation: interpreters and recommendations emerged. Difficulties in communication were acknowledged, but HCWs insisted that these barriers are not insurmountable.

Discussion and conclusion
A few preconceptions and gaps in knowledge and awareness were revealed. HCWs also tended to rely on escorts and other interpreters. The dominant recommendations are that HCWs should receive training in sign language (SL) and/or that SL Interpreters be available at facilities. Despite using words and phrases such as “frustrating” and “more effort”, participants concluding remarks reiterate that their experiences are positive, suggesting a notable resilience.

Keywords

Healthcare workers experience/attitudes/beliefs/knowledge

Communication
Deaf/hearing impaired/Deaf patients/clients
Access to healthcare

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Chapter 1: Introduction and Literature review

A: Objectives of the Literature Review

The objectives of the literature review were:

- To define deafness and hearing impairment and determine the prevalence of the condition
- To identify current published literature on its impact on access to health care
- To explore what is known about how health care workers experience the interaction with deaf or hearing-impaired patients
- To select literature relevant to the proposed research project by applying defined inclusion criteria.
- To critically appraise selected literature using evidence-based medicine principles to determine the quality and level of the evidence.
- To provide a context and rationale for the aims, objectives, and outcomes of the proposed research project to be conducted.

B: Literature search strategy

- The UCT Library online portal served as the base for the literature search using the following databases: MEDLINE, SA ePublications Journal Collection, Google Scholar and PubMed
- Other sources included: textbooks, web pages, reports, and census reports
- Keywords used to search for literature included: healthcare workers experience/attitudes/beliefs/knowledge, communication, Deaf/hearing impaired/Deaf patients/clients, access to healthcare

C: Inclusion, exclusion, and quality criteria

The principal researcher screened the identified literature for relevance and included peer reviewed articles, articles published in English, textbooks, and official statistical reports

English language content

D: Summary

Introduction

Deaf people experience significant barriers to health care access as well as poorer health outcomes.(1) While there are many international and South African studies describing the difficulties deaf patients experience when accessing health care, only anecdotal evidence suggests that health care workers (HCW) also experience challenges during these encounters. These difficulties are significant as they may result in errors in medical management with significant impact on patient mortality and morbidity.

Defining deafness

Sound is measured in loudness using decibels (dB) or frequency using hertz (Hz*)*.(2) The World Health Organisation (WHO) defines deafness or disabling hearing loss as a loss of more than 40 decibels (dB) in the better ear for those over the age of 15 years and a loss of 30dB in the better ear for those between the age of 0 and 14 years.(2) In more practical terms, **hearing loss** (HL) or hearing impairment (HI) is the partial or complete inability to hear sound, particularly sound associated with speech. These terms are typically used interchangeably.(2)

HI also takes into account clarity of sound and this is measured using a test of speech perception.(2) It covers a range of hearing losses (mild to moderate, severe and profound) and may affect one ear or both.(2) Deafness denotes a degree of impairment where the person is unable to perceive speech clearly even with amplification.(2)

It is important to note that a Deaf person (where deaf is spelled with a capital 'D') may have any level of HI or no HI but identifies as Deaf.(2) This means s/he identifies with a cultural community with its own norms, values, behaviours and official language, sign language (SL).(2),(3) This community does not see deafness as a disability.(2)

The aetiology of deafness is varied and differs between children and adults. While childhood onset deafness is less common, the consequences are often more severe.(2) HI with pre-lingual onset has worse implications for development of language and effective communication, resulting in lower levels of education attained, lower levels of employment and higher unemployment levels with worse socio-economic status and subsequent poorer health outcomes.(2)

Common **aetiologies of childhood onset hearing loss** are congenital sensorineural HI, conductive hearing loss due to otitis media, wax (cerumen) impaction, infections (Measles, Mumps, Rubella, Meningitis), genetic causes secondary to consanguinity and side effects of ototoxic drugs (e.g. Multi-drug resistant Tuberculosis [MDRTB] treatment).(3) Adult onset hearing loss (AOLH) is most often due to presbycusis and noise induced HI.(3)

Prevalence

There have been many attempts to estimate accurately the prevalence of hearing impairment globally. The values differ between studies, regions, sexes, and severities of impairment. The variation of estimates is the result of data that is not always based on randomised sampling of representative populations, use of different criteria, discriminators, and definitions. Consequently, this means the data cannot easily be compared or generalised. Nonetheless, several good reports have been published**.**

The World Health Organisation (WHO) global report by Mathers et al (2000) stated that hearing impairment (HI) was the most common sensory loss worldwide, affecting 250 million people.(4) This estimate included those with HI as a result of congenital defects, as well as HI of childhood and adult onset.(4) It also reported that adult onset hearing loss (AOHL) was the second leading cause of years lived with disability (YLD) and at a global level contributed 4.6% of total global YLD.(4) The report used the WHO definition of hearing loss (loss of 40db in the better ear) and a severity grading of moderate or worse HI (as lower levels of loss did not incur significant disability).(4)

The follow up report in 2012 confirmed the global significance of HL with an estimated world prevalence of 1.7%.(5) This means that 360 million people suffer from HL, 91% of whom are adults.(5) It is estimated that one third of adults over the age of 65 years suffer from HL.(5) The 2018 WHO report estimated 466 million of the world's population suffer from HL.(6)

In 2008 Pascolini et al. published a compilation of results estimating the global burden of HI.(7) They reviewed 53 studies found in the WHO Programme for the Prevention of Blindness and Deafness and Hearing Impairment data bank.(7) Only studies which were based on randomly selected samples from a representative population were included.(7) While it was a comprehensive overview, the authors still recommended the need for more recent and comparable epidemiological data.(7) Similarly, Tucci et al (2009) published their report based on the review of literature on the global impact of HI and other published reports, including WHO reports.(8) Of the estimated 278 million people affected by HI, two thirds were in the developing world.(8) This study also reflected the increasing prevalence of those with hearing loss as the gross national income per capita decreased.(8)

The prevalence of HI is greatest in South Asia, Asia Pacific and Sub-Saharan Africa.(5) The sub-Saharan HI prevalence was estimated at 2.2 % with most of the African region estimates' being based on a Nigerian study.(5) The analysis by Tucci et al reported the following prevalence rates for the area also using Nigeria as the representative country: an estimated 1.2 million children aged between four and fifteen years old suffered moderate to severe hearing loss while prevalence ranged from 2.2% to 9.2% in different studies.(8) In the report, the Sub-Saharan Africa prevalence rates are further divided into the Central, West, and East and Southern African areas.(5) The southern area (of which South Africa is part) has a reported prevalence of 1.9%.(5)

In 2011, the Global and Regional Hearing Impairment and Prevalence study also found HL to be the third leading cause of disability in the world.(5) The authors reported increasing prevalence with increasing age.(5) Prevalence was highest in low to middle income countries.(5)

There are not enough population-based studies to get an accurate view of the prevalence of HI in South Africa (SA). Nonetheless, one of the studies cited in The WHO 2000 report was conducted in rural Western Cape, South Africa and reported a prevalence of 2.0% of HL in those aged six to thirteen years.(9)

To assess the prevalence of HI in South Africa better, local statistics from Statistics South Africa are helpful and include the census reports (1996, 2001, and 2011), Perceived Health and Other Indications of Health in South Africa 2004 report, and the Disability and Disablement (D&D) report in the South African Health Review 2003/2004.(10),(11),(12) The National Disability Survey (NDS) 1999, Census information and Burden of Disease Estimates for South Africa 2000 are also useful.(13),(14)

The D&D report stresses that burden of disease studies are important to monitor the health of a nation and to monitor and ensure equitable service delivery to disabled persons.(12) The values reported below (Tables 1 and 2) were those from the census 1996, 2001 and NDS (1999) and South Africa's national organisation for the deaf (DEAFSA).(10),(13),(15)

Table 1: Prevalence of Hearing Loss (HL)

Census 1996	National Disability Survey	Census 2001
1.0%	0.7%	1.0%

Table 2: DEAFSA reported prevalence and range of HL

Range of HL	Prevalence
Mild	6%
Moderate	3%
Severe	1%

In total, the DEAFSA reported an estimated prevalence of HL of 10%.(16)

In 2007, Statistics South Africa conducted a community survey between census periods, sampling 1.3 million households, to assess disability using the WHO 1980 definition of disability.(17) The survey found a lower total %age of reported disability (4.0%) compared to the findings in the 1996 and 2001 Census (6.5% and 5.0% respectively).(17) HI had a total prevalence of 0.4%.(17)

The 2011 Census also addressed the question of disability, but disability was defined as "difficulties encountered in functioning due to body impairments or activity limitation, with or without the use of assistive devices."(18) Furthermore, it used different questions to assess disability which considered that people may not identify themselves as disabled.(18) The words "impairment" and "difficulties" were used. These differences have led to the consensus that these results cannot be compared to earlier survey results.(18)

3.5% of the population is believed to be suffering from some degree of HI. Table 3 shows the prevalence of different levels of difficulty due to HI:

Table 3.

Degree of difficulty	Prevalence
Cannot do at all	0.1%
A lot of difficulty	0.5%
Some difficulty	2.9%
No difficulty	96.4%

In summary, the global prevalence of hearing loss is estimated to be 1.4%, with higher levels in middle to low income countries, and higher prevalence in males than females.(5) It increases with age and decreases with increased rates of parental literacy.(5),(19) In Africa, the prevalence ranged from 0.5% in South Africa (based on one study in rural western Cape at a school) to 6.8% in Madagascar.(5) The Sub-Saharan figures reflect a prevalence of 1.9% in those between the ages of four and fifteen years old and in those older than 15 years 7.4% in males and 5.5% in females.(19) In South Africa, various sources report different prevalence rates: DEAFSA (Deaf Federation of South Africa) reports 10%, the Community Survey 0.4% and the Census 2011 3.5%.(16),(17),(18) A more contemporary study conducted in the Cape Town metropolitan area between February and October 2013 reported a prevalence of 12.35 % in those over the age of 4 years.(20)

The paucity of local data and the wide variation in results is a population research gap that needs to be addressed. This will require a standardised framework of classification of HI with consistent and comparable descriptors. The WHO Ear and Hearing survey protocol and the WHO grading criteria for hearing impairments are useful examples of standardisation.(21),(22) However, for the data to be useful, specific demographic data should be included, such as age of onset of deafness, loss in one or both ears and presence or absence of other co-morbidities.

Human Rights and access to Health

The right to health is a fundamental human right that has been enshrined in international, regional and local declarations including the 1948 Universal Declaration of Human Rights, the 1966 International Covenant on Economic, Social and Cultural Rights, the 1986 African (Banjul) Charter on Human and People's Rights and the 1996 South African constitution.(23),(24),(25),(26)

In 2000 a UN Committee issued Comment 14, describing the right to health as an "inclusive right extending not only to timeous and appropriate health care but also to determinants of health".(27) Furthermore, the right to heath contains four elements i.e. Availability, Accessibility, Affordability and Quality.(27)

Accessibility itself is comprised of four elements, namely non-discrimination, physical accessibility, economic accessibility, and information accessibility.(25) Information accessibility refers to the right to seek, receive and impart information and ideas concerning health issues and this requires effective communication.(25) Despite the extensive legislation, accessibility of healthcare services is a perennial problem for vulnerable populations in general. For the deaf/HI population, this is also a problem, the extent and details of which have been variously explored and described.

Barriers to Healthcare

There is extensive research on the difficulties experienced by deaf/Deaf persons with accessing health care services. Several common themes are found internationally and in South Africa.

The inequalities in health care experienced by deaf patients reflect the difficulties experienced by the **disabled population** in general. This population reportedly has a higher rate of chronic diseases and is less likely to receive preventative services.(28) They are disadvantaged by structural and procedural aspects (physical access, funding, transport, communication barriers) of access to health care as well as the attitudes and beliefs of health care providers.(29)

The deaf population also face similar barriers to health care as some cultural minorities do.(30) Recognition of the Deaf community as a cultural minority is advocated as they share many of the features characteristic of minority populations.(30),(31) These features are a first language that is different from the dominant culture and their own perspectives, cultural and social norms.(28),(29) This has raised discussions around the need for health care workers to be trained in cultural sensitisation to improve access to deaf populations. The deaf population often also have lower socio-economic status and lower levels of literacy and education.(31),(32)

As mentioned previously, effective communication is an essential aspect of healthcare accessibility, and is the backbone of developing a therapeutic relationship with a patient.(33) It allows access to health care information, and allows for health care to be provided with informed consent from the user.(34)

The Deaf community uses sign language (SL) as its first language. In SA, the SASL (South African Sign Language) is not recognised as an official language.(16) The DeafSA believe that access to communication and information through SASL is a basic right for Deaf South Africans and they are advocating for its recognition as an official language as well as for the provision of a regulated, sign language interpreter services.(16)

Speech reading (lip reading), written communications and use of ad hoc interpreters are not the best forms of communication between HCW and deaf clients as they can be inaccurate and ineffective and are dependent on the clients' level of education and literacy.(33),(35) It has also been reported that deaf patients gave more positive ratings to health care interactions when sign language was used.(32) This underscores the importance of "shared language" in developing a therapeutic bond.(32) Many others have recognised the integral part SLI have in delivering equitable services including health care to deaf clients.(16)

To further elaborate and answer this matter, a local study piloted and evaluated a free-to-patient district-based professional SASL language interpreter service for Deaf people using health care services in the Cape Metropolitan area.(36) The study evaluated the usage and cost of this pilot service.(34) Important findings were that firstly, most of the requests were from primary health care facility users and secondly, implementation of this service saw the number of deaf patient's health visits increase to approach the national average of visits per capita.(34) The authors claim that SLI services close the gap in health care between the deaf and hearing population.(34) However, they also acknowledge the study's limitations such as its non-randomised sample and calculations that rely on estimated numbers of SASL users.(34) Nonetheless, the findings reinforce the need for more robust data about the deaf and Deaf population in South Africa and the health care experience, particularly at primary care level.

Patients' Experiences

Feelings of frustration are often reported by deaf patients.(37),(38) Their frustrations stem from encounters where HCWs were not prepared to deal them, rushed them, used written instructions that were either illegible or incomprehensible to them and did not respect their autonomy.(30),(34),(39),(40) Distrust of HCWs may stem from negative childhood experiences and HCW attitudes where deafness is seen as something to be treated (biomedical model), which is a view the patient often does not share.(31),(32)

Some authors reported fewer HC visits by deaf patients because of fear, mistrust, frustration and lack of confidence that they will be understood while others reported more visits by deaf patients because their problems were not adequately addressed.(30),(31),(37) In both cases, this may cause a delay in diagnosis, with more advanced disease at the time of diagnosis. As a group, the deaf report lower levels of health, supported by more sick days, doctor visits and limitation of activity, as well as less satisfaction with the health services they receive.(33)

Health Care Workers' Experience, Attitudes and Beliefs

Studies exploring HCWs' attitudes, beliefs and knowledge show that barriers may be psychological, financial or system failures.(33),(38) Some providers acknowledge the communication barrier present in dealing with deaf patients.(33),(35) They experience similar difficulties with patients who do not speak the same language as they do.(30) They also feel unprepared, uncomfortable, frustrated and may exhibit avoidance behaviour.(30),(38) Furthermore, they experience less satisfaction with these encounters as good rapport is not established and even feel guilty as they feel that equal care is not provided as a result of the language barrier.(32),(38) In an article exploring the health care delivery by English and Afrikaans speaking providers to IsiXhosa speaking patients, A. Deumert shows how the language barriers prevent equitable and effective health care delivery.(34) In this study, one HCW reports that the patients thought not to be proficient in her language are left to be seen last. This avoidance behaviour further illustrates how patients with communication difficulties are disadvantaged and experience discrimination.(37)

Historically, deafness was equated with intellectual disability and this misconception is still prevalent resulting in further prejudice against deaf individuals.(31),(32) The biomedical model of disease and disability perpetuates this attitude as it defines the physiological basis of the disability but "ignores the social, political and psychosocial dimensions of disability."(41) Using this model, deafness is seen as a pathology and reinforces stereotypical views of deaf persons which include their being thought to have less intellectual capacity, autonomy, independence and decision-making skills.(39) The provider may underestimate the capabilities of the deaf patient leading to a controlling, patronising interaction.(39) Furthermore, the provider may have anxiety about engaging the patients' disability and so ignore it.(32),(42) Lastly, private providers who realise that deaf patients need lengthier consultations may be disinclined to see them because of financial disincentives.(33)

In summary, the high international and local prevalence of deafness and hearing loss means that a significant proportion of the population face serious barriers to health care. These barriers revolve around language and communication, cultural insensitivity, as well as the attitudes, knowledge, and beliefs of HCWs, and the way the health care system is structured.(41) In the studied articles it is not clear that the HCWs are aware of the barriers deaf and Deaf clients experience and if they possess self-awareness of their own attitudes and beliefs which impact on theses encounters and if they have the skills and training they need to cope.

E: Need for further research

It would be helpful to add to existing enquiries into experiences and practices in South Africa, and to reveal regional challenges, themes, and even successes, particularly at primary health level. Local data and perspectives are needed to assist with informing focused changes in the development of and delivery of services, training, and planning of primary health care delivery. Lastly, further local data can be added to the global literature, particularly where there are notable differences.

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Chapter 2: Study Protocol

Title:

A Descriptive Case Study: Challenges experienced by health care workers (HCW) at a primary health care facility when serving deaf/hearing impaired (HI) patients.

1. Introduction

Deaf people experience significant barriers with access to health care as well as poorer health outcomes.(1) While there are many international and local studies describing the difficulties deaf patients experience when accessing health care, only anecdotal evidence suggests that health care workers (HCW) also experience challenges during these encounters. These difficulties could be significant as they may result in errors in medical management with significant impact on patient morbidity, mortality as well as future encounters.

This study explored the dynamics of the encounters between HCWs and deaf patients by examining HCWs' experiences. The research findings were analysed to identify challenges, areas for development and training, and recommendations for interventions to adapt the services offered to deaf patients.

2. Literature review (abridged)

2.1. Definition of deafness

Hearing loss (HL) or hearing impairment (HI) is the partial or complete inability to hear sound, particularly sound associated with speech.(2) Sound is measured in loudness using decibels (dB) or frequency using hertz (Hz*)*.(3) HI also takes into account clarity of sound, which is measured using a test of speech perception.(2) HI covers a range of hearing loss from mild to moderate, to severe and profound hearing loss and may affect one or both ears. Normally, healthy adults are able to hear sounds from 20 dB and distinguish up to 0.2 % differences in sound frequencies.(2)

The definition of deafness/disabling hearing loss by the World Health Organisation (WHO) standard is a loss of more than 40 decibels (dB) in the better ear (the ear with the least deficit) for those 15 years and older and a loss of 30dB in the better ear for those under the age of 15 years.(2),(3)

The term Deaf also has cultural identity meanings (spelled with a capital 'D' in these instances), where a Deaf person may have any or no level of hearing loss but identifies as Deaf.(4) He or she may belong to a cultural community with its own norms, values, behaviours and language, using sign language as their official language. They do not see deafness as a disability. (2),(4)

2.2. Prevalence

The World Health Organisation (WHO) global report by Mathers et al (2000) stated that hearing impairment (HI) was the most common sensory loss worldwide, affecting 250 million people.(5) The more recent report estimated hearing loss to affect 466 million people in 2018.(6) Of those estimated to be affected by HI worldwide, two thirds lived in the developing world.(5)

One of the studies cited in The WHO 2000 report was conducted in rural Western Cape, South Africa and reported a prevalence of 2.0% of HL in those aged six to thirteen years.(4),(7) A more contemporary study conducted in the Cape Town metropolitan area between February and October 2013 reported a prevalence of 12.35% in those over the age of 4 years.(8)

The global prevalence of hearing loss is estimated at 1.4%.(9),(10) In Africa, the prevalence ranged from 0.5 % in South Africa (based on one study in rural western Cape at a school) to 6.8% in Madagascar.(7) The Sub-Saharan figures reflect a prevalence of 1.9% in those between the ages of four and fifteen years and a higher prevalence (7.4% in males and 5.5% in females) in those older than 15 years.(7)

In South Africa the various sources report varying prevalence: DEAFSA reported 10% prevalence, the Community Survey (a country wide survey conducted by Statistics South Africa between census periods, sampling 1.3 million households) reported a 0.4% prevalence compared to the 3.5% prevalence reported by the 2011 Census report.(11),(12),(13) The paucity of local data and the wide variation in results should encouraged population studies to increase the accuracy of the estimates. To do this a standardised framework of classification of HI is needed with consistent and comparative descriptors. The WHO Ear and Hearing survey protocol and WHO criteria for grading hearing impairments are some examples of standardisation but for the data to be really meaningful demographic data such as age of onset of deafness, loss in one or both ears and presence or absence of other comorbidities are needed.(14),(15)

2.3. Human Rights and access to Health

Communication is an important enabler of many international human rights, including the right to health. It allows access to health care information and provision of preventive and curative care, with informed consent from the user.(16) HCWs are ethically and legally obliged to facilitate effective communication. This can be done by using the services of sign language interpreters, visual aids or other technology and by accessing the right training to support the needs of the vulnerable deaf/HI population.

2.4. Barriers to Healthcare

There is a considerable amount of literature which explores the difficulties experienced by disabled persons in their interactions with health care services including a systematic review of access to health care for disabled people by Gibson et al (2010) and a local study by Vergunst et al (2016).(17),(18),(19),(20),(21),(22) These studies were conducted in various countries, including South Africa and several common themes emerged.

Firstly, the disabled population reportedly has a higher rate of chronic diseases and is less likely to receive preventative services.(17),(20) Secondly, they are disadvantaged by structural and procedural aspects (physical access, funding, transport, communication barriers) of access to health care as well as the attitudes and beliefs of health care providers.(17),(18),(21) Studies exploring HCWs' attitudes, beliefs and knowledge show that barriers may be psychological, financial or system failures.(23),(24)

As a subset of the disabled population, the deaf population experience similar barriers to accessing equitable health care. (17),(25) HI people as a group have many features that characterise them as a distinct community. Members of the Deaf community have a first language that is different from the dominant culture and have their own perspectives, as well as cultural and social norms.(4)

As a minority community they may suffer from discrimination and unfair treatment and they often have lower socio-economic status and lower levels of literacy and education.(17),(26) Many advocates believe that health care workers should firstly acknowledge HI people as a unique community and secondly, be trained to assist them in appropriate ways to facilitate access to health care.(27)

Communication is the foundation of developing a therapeutic relationship with a patient.(28) Effective communication needs a common language and hearing loss, especially when it occurs at a very young age, may impede speech and language development.(29) Naturally, this means that there is a language barrier that exists between deaf patients and the HCWs, which may impede the development of the therapeutic bond between the patient and carer with possibly harmful consequences.(30) While the qualitative study conducted in Worcester, Western Cape, confirmed that the communication barrier was the main obstacle to accessing appropriate healthcare, other interpersonal factors also presented challenges.(31) Here only deaf/Deaf clients were interviewed and no health care worker perspective elicited.

Some HCWs think that written communications or speech reading(lip reading) are acceptable alternatives. (31,32) However, speech reading, even in the most favourable conditions, is very inaccurate.(32) Written communication may also be ineffective depending on patients' level of literacy and education and HCWs' handwriting. (23)

The language barrier also prevents the acquisition of knowledge. Low literacy rates restrict access to health education which is often disseminated as printed material and deaf patients also report difficulties with health care materials such as appointment cards, prescriptions, signage, instructions and consent forms.(23)

The use of interpreters is full of challenges. Inappropriate use of escorts as interpreters may infringe on patients' autonomy, including confidentiality.(29) The interpreters' level of education and familiarity with medical jargon also influences the effectiveness of this type of communication. Those with pre-lingual deafness (where deafness occurred before the development of speech) and have sign language (SL) as their first language, are most disadvantaged and could potentially benefit the most from a SL interpreter service at health care services. Unsurprisingly, research shows that deaf patients give more positive ratings to health care interactions when sign language is used.(24) Those who become deaf later in life often have better speech and reading skills but acquire SL with difficulty and in this instance SL interpreter service may not be of benefit and other strategies to improve access to health must be considered.

In 2010, Deumert published a study carried out in 3 public hospitals in the Western Cape describing how the language barriers between isiXhosa speaking clients and English or Afrikaans speaking providers prevent equitable and effective health care delivery.(29) In this study, data was collected through patient and provider interviews, questionnaires and observations. It demonstrated that where there is an absence a shared language provider attitudes and beliefs impact significantly on the quality of health care delivered.(29)

Historically, deafness was equated with intellectual disability and this misconception (which leads to further discrimination) is still prevalent.(26),(33) This misconception is compounded by HCWs' subscribing to a biomedical model of deafness, which pathologises deafness in presumptuous ways that can be alienating and even harmful to deaf clients.(34)

2.5. Conclusion

In summary, international and local studies suggest that a significant part of the population suffer from disabling hearing loss and that despite protective legislation and international conventions, hearing loss contributes to significant inequalities in health care access which lead to poorer health outcomes. Major barriers to healthcare are poor communication and language barriers but the attitudes, knowledge and beliefs of HCW as well the structure of the health care system also play a role. While there is increasing awareness and concern amongst HCW and the community that this group is underserved, it is difficult to advocate for change when the scope of the problem is poorly defined. It would therefore be helpful to add to existing enquiries into the experiences and practices in South Africa in order to reveal regional challenges, themes and successes as local knowledge may reveal strategies to improve health care delivery to HI that can be integrated into the primary care setting.

3. Problem Statement

Deaf and HI patients experience difficulties when accessing health care and health care workers (HCW) may also experience challenges during these encounters. There is little research on how these challenges and difficulties manifest in a South African primary health care context.

4.1 Aims

1. To describe the experience of HCWs at a primary health care facility in dealing with Deaf, deaf and HI patients including knowledge, attitudes, beliefs and practices.
2. To provide recommendations to contribute towards the improvement of access to equitable healthcare by Deaf and HI patients by improving communication.

4.2. Objectives

1. To describe the experiences of HCWs' interactions with deaf, Deaf and HI patients.
2. To describe attitudes, beliefs and practices of HCWs regarding deaf, Deaf and HI patients.
3. To find examples of good communication strategies used by HCWs treating deaf, Deaf and HI patients.
4. To develop recommendations to improve communication between HCWs and deaf, Deaf and HI patients.

5. Methods

5.1.Study design

This was a qualitative, descriptive case study. Participants from the study population were interviewed or were part of focus group discussions. Some demographic data was collected from the participants: age, sex, occupation, background and experience. Participants were invited to share their experience with deaf/HI patients. A questionnaire was used to guide the focus group discussions and interviews. Data was recorded and later transcribed before it was analysed.

5.2. Setting

The study was conducted at the Retreat Community Health Centre (CHC), a primary health care facility in the sub-districts of the Cape Town Metro District Health Services (MDHS). This facility services a population of approximately 3500 people, just under 20% of whom are unemployed and 80% of those employed earning R3200 per month.(13)

Up to 600 patients attend the CHC per day – including those attending the Antiretroviral (ARV) and Tuberculosis (TB) clinics. The outpatient's department operates between 8am and 4 pm but the trauma unit is a 24-hour service. Healthcare services are provided by at least 5 full time doctors, clinical nurse practitioners, registered nurses and allied health care workers, supported by administrative and ancillary staff.

The study site was selected as it fulfilled the requirements of a primary care facility and data collected here would provide a community perspective and inform local primary health care training, planning and adaptation of services.

5.3. Study Population

The study population was the staff of the Retreat CHC. This included the clinical staff such as doctors, nurses, clinical nurse practitioners (CNP), physiotherapists, pharmacists and radiologists, as well as nonclinical staff such as reception staff, bookings clerks, security guards, general assistants and volunteer workers. They participated either as members of a focus group or as interviewees in semi-structured one-on-one interviews.

5.4. Sampling of Population

Convenience sampling was used to select participants from each staff category at the institution.

Invitations to participate were extended verbally or in writing to the groups at staff meetings or via clinical and operational managers. Participation was entirely voluntary. Consent to participate was obtained from individuals who chose to participate in the study. Participants were able to withdraw from the study at any time. No monetary compensation was offered but refreshments were provided. (Appendix D)

Total sample size: Two focus groups with four and five participants per group were conducted and 17 individual interviews. The first focus group consisted of 4 nurses, all female, and was held in an empty clinic room at the end of the outpatient's clinic. Two of the participants were recent graduates while 2 were experienced registered nurses. The second was a group of five doctors, 3 female and 2 male, and was held in a tearoom during a lunch hour. Time constraints and service demands of the facility prevented the researched from conducting more focus groups discussions.

The 17 individual interviewees included 4 doctors, 2 CNPs, a social worker, a radiographer, AVR clinic CNP and TB clinic CNP, nursing staff, 2 reception staff and a volunteer worker. Of this group, two doctors and one administration officer were male, the other participants were female. Their ages ranged from 22 to 56 years of age.

5.5. Data Collection

Data was collected using semi-structured interviews and focus group discussions.

The researcher followed a semi-structured interview guide with open-ended questioning and prompts to ensure that key points were not missed. (Appendix A)

The researcher conducted 17 individual interviews, in English or Afrikaans depending on interviewee preference. No interpreter service was required during this study. Data generated was recorded electronically by audio recording with a mobile phone device and by handwritten notes. Interviews varied in duration – the shortest lasting 6 minutes 24 seconds and the longest 26 minutes 54 seconds. Data from all interviews was analysed.

In-depth interviews were held with individual participants until all volunteering participants were interviewed and saturation was achieved. Saturation was deemed to be achieved when the in-depth interview data begin to yield the same categories of content as preceding interviews.

Two focus group discussions were conducted with an experienced research assistant running the first focus group discussion while the researcher conducted the second focus group discussion. A dual moderator method was used to ensure the session ran smoothly and all the topics were covered.

Consent to participate was obtained from individuals who chose to participate in the study. Informed consent included permission to record the interview or focus group discussion by audio or audio-visual device. Where the participants refused electronic recording, responses were recorded in writing. None of the participant refused audio recordings. The de-identified audio recordings were uploaded onto a computer and sent to a paid transcriber for transcription. The interview schedules had identification numbers, but the participants remained otherwise anonymous.

5.6. Methodological Rigour

The researcher employed the services of a trained, reliable, experienced transcriber to transcribe the information from the interviews and the focus groups verbatim. The transcripts were reviewed as well as the recordings to clear up discrepancies or confusion. Focus groups and in-depth interviews were used so that the data could be triangulated to enrich the analysis. *Member checking, where the accuracy of the narrative or interpretation is checked with the participants, was not feasible but detailed record of the analysis process was kept*. The entire data set was analysed. Peer debriefing as external check on the research process was conducted.

5.7. Storage of data, privacy and confidentiality

The completed consent forms, paper copies of completed, printed transcripts and audio recordings were held in a locked cupboard. The digital recordings were downloaded to the investigator's computer and the contents were password protected. Similarly, where the transcriptions of the audio tapes were typed, the paper copies were stored in a secure drawer while the digital copy was stored on computer with password protected access.

5.8. Data Analysis

Thematic content analysis is a method of qualitative research and was used in this study.

The advantage of this method is that it is an accessible and flexible method which is useful for examining perspectives, looking for similarities and differences and may lead to new insights. (35), (36)

Disadvantages of this method are that consistency and coherence of interpretation can be difficult and trustworthiness of the findings needs to be clearly demonstrated. (35), (36)

Data was read and analysed. Content analysis allowed the researcher to become familiar with the data and develop a broad understanding of the data. During this time, notes or annotations on the transcripts were made and preliminary observations drawn. More detailed examination of the data helped identify patterns in data and allow category generation (coding). Related categories were organised into themes which helped to provide an over-arching structure to the data. A set of unifying themes were developed applied to the entire data set.

Content analysis of the transcripts was performed as follows (39,40,41)

1) Each Transcript was copied and read, with brief notes made in the margins when interesting or relevant information is found
2) The notes were perused and classified in terms of the different types of information found.
3) This list was read and each item categorised in a way that offered a description of what it is about.
4) The researcher identified whether or not the categories could be linked any way and listed them as major categories (or themes) and / or minor categories (or themes)
5) The researcher compared the various major and minor categories for each transcript.
6) All of the categories or themes were collected, and each examined in detail to consider if it fits and to determine its relevance
7) Once all the transcript data was categorised into minor and major categories/themes, it was reviewed to ensure that the information was categorised as it should be.
8) The researcher reviewed all the categories and ascertained whether some categories could be merged or if some need to be sub-categorised
9) The researcher then returned to the original transcripts and ensured that all the information that needed to be categorised has been categorised

6. Ethical considerations

Permission to conduct the research was sought from the facility manager of the facility, University of Cape Town (UCT) Ethics committee, and the Metro District Health Services (MDHS) research committee.

6.1. Autonomy

Informed consent was obtained from each participant. Consent was obtained in the participants' first language. Refusal to participate did not subject them to a standard of care lower than that which they currently receive at the CHC in the case of patient participants nor affect their job- or job-related performance assessments in the case of HCW.

6.2. Confidentiality

Confidentiality was always maintained and information regarding the research was only shared with those involved in the research. Those participating in focus group discussions were asked to keep the contents of the discussions confidential. Copies of the audio tapes, downloaded copies thereof, transcripts, digital and printed copies, copies of informed consent documents were held in a secure place and on my computer, which is password protected

6.3. Dissemination of information

The information collected was analysed and a report was written. This report was shared with the facility manager and available to all participants of the study. This data was used for a dissertation to be submitted as part of a Master of Medicine in Family Medicine degree. The report was submitted to a peer review journal and was published. A copy will be available on the UCT website where it may be accessed by staff and students of UCT.

6.4. Non-maleficence

While conducting the study, the researcher ensured that service delivery to clients of the CHC did not suffer because of the research. No harm came to participants or to those who decline participation or withdraw at any stage of participation.

7. Budget

Printing		**50c per sheet**	
	Letters of permission	**4x50c**	**R2**
	Consent forms	**25x5x50c**	**R62,50**
	Demographic forms	**25x50c**	**R12,50**
	Printed transcripts	**25x50c**	**R12.50**
Refreshments		**5xR100**	**R500**
Transcription fees	**8 to 10 hrs to be transcribed**	**R7.80/minute**	**R4680**
Total cost			**R5277**

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Chapter 3: Publication-ready Manuscript

Title: A Descriptive Case Study: Challenges experienced by health care workers (HCW) at a primary health care facility when serving deaf/hearing impaired (HI) patients

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Key words – deaf, hearing impaired, health care works, beliefs, attitude, knowledge

Introduction

Deaf people experience significant barriers in access to health care as well as poorer health outcomes. (1) To better understand these barriers we need to define deafness and attempt to estimate its prevalence.

The definition of hearing loss (HL) or hearing impairment (HI) is the partial or complete inability to hear sound, particularly, sound associated with speech.(2) The definition of deafness or disabling hearing loss by the World Health Organisation (WHO) standard is a loss of more than 40 decibels (dB) in the better ear for those over the age of 15 years and a loss of 30dB in the better ear for those between the ages of 0 and 14 years.(3)

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

The World Health Organisation (WHO) global report by Mathers et al (2000) stated that hearing impairment (HI) was the most common sensory loss worldwide, affecting 250 million people.(5) The follow up report in 2012 estimated that 360 million people suffer from HL while the more recent 2018 WHO report estimated 466 million of the world's population suffer from HL, confirming the global significance of hearing loss.(6),(7)

In South Africa reports vary, with the Deaf Federation of South Africa (DEAFSA) reporting 10%, the Community Survey 0.4% and the Census 2011 3.5% prevalence rates .(8),(9)

The inequalities in health care experienced by deaf clients reflect the difficulties experienced by disabled people in general. They are disadvantaged by structural and procedural aspects (physical access, funding, transport, communication barriers) of access to health care as well as the attitudes and beliefs of health care providers.(10) It is therefore important to explore the attitudes and beliefs of HCWs towards deaf and HI patients and encourage them to recognise the deaf/HI as a community with specific needs.(11)

Language is an important enabler of the right to health. It allows access to health care information, preventive and curative, and allows for health care to be provided with informed consent.(12) Furthermore, language is essential to developing a therapeutic relationship with a patient, yet the language barrier between deaf patients and hearing health care workers is one of the main challenges to health care access.(13),(14)

Those patients who have sign language (SL) as their first language are most disadvantaged and could potentially benefit the most from a SL interpreter service at healthcare facilities. It has been reported that deaf patients gave more positive ratings to health care interactions when SL was used than not.(13) However, while interpreters are helpful in overcoming language barriers, inappropriate use of escorts as interpreters may rob a patient of his or her autonomy and/or right to confidentiality.(15) A. Deumert demonstrates this in a study exploring the health care delivery by English and Afrikaans speaking providers to IsiXhosa speaking patients.(16) This underscores the importance of "shared language" in developing patient rapport.(13)

Historically, deafness was equated with intellectual disability and this misconception (which leads to further discrimination) is still prevalent today.(17),(18) This misconception is compounded by HCWs' subscribing to a biomedical model of deafness, which pathologises deafness in presumptuous ways that can be alienating and even harmful to deaf clients.(19)

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

Methods

Convenience sampling was used to select staff members of the Retreat Community Health Centre (RCHC). An invitation to participate in the study was extended to all the staff – clinical and non-clinical. Those who elected to participate could take part in individual interviews or be part of focus groups discussions. Informed consent was obtained from all participants. No participants left in the middle of the data collection. Seventeen individual interviews and two focus group (FG) discussions were conducted, and audio recordings of data was collected. The audio recordings were later transcribed before data was analysed. The two data collection methods helped to triangulate the data. While transcripts and recording were checked for discrepancies and vagaries, member checking was not done due to time constraints.

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

Results

The first focus group consisted of 4 nurses, all female, and was held in an empty clinic room at the end of the outpatient's clinic. Two of the participants were recent graduates while 2 were experienced registered nurses. The second was a group of five doctors, 3 female and 2 male, and was held in a tearoom during a lunch break.

The 17 individual interviewees included 4 doctors, 2 CNPs, a social worker, a radiographer, AVR clinic CNP and TB clinic CNP, nursing staff, 2 reception staff and a volunteer worker. Of this group, two doctors and one administration officer were male, the other participants were female. Their ages ranged from 22 to 56 years of age.

The content of the interviews and focus group discussions was subjected to close examination - looking for patterns or themes. Themes which emerged were those of language barriers, resilience, preconceptions, improvisation and innovation, interpreters and recommendations.

Preconceptions

Preconceptions are preconceived ideas or prejudices that inform an individual's attitudes and beliefs about something, thereby affecting their behaviour.
The HCWs identified deaf patients as disabled:

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

Over time, the societal views of disabled people have changed. In the western context, three models of disability have been described, namely the medical model, the charity model and the social model. (20) At Retreat CHC, some participants' attitudes and beliefs reflect their use of the medical model as an approach to the deaf patient. They see deafness as a condition to cure or treat, and if not treat, then a condition for which to provide "care".

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

Other participants favoured the charity model where the disabled are considered "plucky, brave, kind" and in need of "our help". HCW identify deaf, Deaf and HI patients as disabled and thus deserving of more time and consideration.

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

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

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

The social model separates the impairment from the disability.

Many HCWs at Retreat use this model. They believe that deaf patients are the same as any other patients and are treated as "normal". Their responses suggest that they understand that deaf patients' experience of the health care process will be different to that of hearing persons' and this empathy allows them to make the adjustments needed to give these patients equitable service. "Because the patient at the end of the day, you want to give them the best service. You must understand where they are coming from and help them get the best possible service. "

Other beliefs revolve around alternate communication methods – many HCW believing that lip reading/speech reading, note writing and using family members or escorts as interpreters are suitable modes for effective communication.

Innovation and improvisation

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

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

Awareness of the problem is established and once that happens they can try to "appreciate the varied experience of the deaf/HI patient" as advocated by Steve Barnett. (11)

At RCHC, deaf patients known to the facility have a stamp on their folders identifying them as deaf or HI patients. These patients will advance through the system via a "fast track".

The Retreat HCWs adopt many strategies to encourage better communication. They speak slowly and clearly, maintain eye contact, raise their voices when appropriate and speak to the better hearing ear. When these strategies fail, they try other forms of communication. For example, HCWs use written notes and instructions a frequently, despite being aware that the effectiveness of this method is dependent upon the literacy level of the patient and is time consuming. Pictures, photographs and videos were also used, and in the Focus Group discussion, a novel use of smart phones was described to illustrate a procedure to a deaf/HI patient.

The participants sometimes rely on their patients to lip read, being unaware of the intrinsic inaccuracies of speech reading. However, the HCWs were aware of other extrinsic factors that make speech reading unreliable like poor patient vision, the need to wear masks and poor lighting.

Hand gestures, signing and demonstrations are frequently used with most of the participants showing enthusiasm for sign language (SL).

A team approach was another common strategy. Participants would sensitise their colleagues to the patients' status. They would plan appointments for patients known to be deaf, Deaf or HI to coincide with those HCWs more familiar with them or better able to communicate with them. Interpreters and taking extra time were the most frequently used facilitators of communication.

"But it takes you a bit longer to consult."

Participants reported that most deaf patients came with an escort:

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

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

The Language Barrier

The patient centered approach to health care acknowledges patients’ autonomy and encourages the health care provider to gain an understanding of the disease as well as the patients’ experience of the illness.(21) To achieve this, effective communication with a common language is the minimum requirement.(16) Generally, the study participants acknowledged good communication as crucial to good health care and that there may be some difficulty when communicating with a patient who is deaf, Deaf or hearing impaired (HI).

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

“it’s a matter of just having to listen a bit more”

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

“That’s not like a language difficulty where you can’t actually speak the persons’ language. Those are a lot more common than when you have a deaf patient.”

At RCHC, languages such as Somali, Malawian, Portuguese, French are very likely to be encountered, posing potential communication challenges.

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

Resilience

Resilience is an ability to adapt and succeed in stressful situations.(24) This does not mean that a resilient person does not experience difficulty but that s/he can think and act in a way that overcomes the difficulty.

“And it was hard you know, and she spoke only Afrikaans, but I am trying really hard to explain.... but I just took my time with her.”

The staff at RCHC, like many staff compliments in South Africa work in a stressful environment with large patient numbers, chronically under-staffed and at times at risk of personal violence and abuse from clients and the community. Despite this they strive to deliver quality health care to their communities.

“So I find it not so difficult. We don’t have any problems. I mean, we manage.”

They view the Deaf/deaf/HI patient as any other client requiring their care, refusing to see the disability as a barrier.

Recommendations

After advising patients to come with an escort, the most common recommendation was that HCWs should learn SL and/or SL Is be available at the facilities.

"I find a family member that can communicate with them"

"Get people to come out and teach us things like, you know, sign language."
Prioritising patients with disabilities was also recommended.

Other recommendations conflated with previous recommendations from deaf users, including good signage, posters, electronic boards, deaf TV and mobile phone technology.

"Clear signage and lots of notes on the wall as well so we can also allow for people to read"

Discussion

This discussion will attempt to interpret the themes identified through the content analysis. It will also demonstrate the advantage of the thematic analysis method i.e. that it is an accessible and flexible method which is useful for examining perspectives, looking for similarities and differences and may lead to new insights. (25), (26)

Disadvantages of this method are that consistency and coherence of interpretation can be difficult but the trustworthiness of the findings may be demonstrated by its congruency with other bodies of research. (25),(26)

HCWs' perception or belief that deaf patients are disabled irrespective of the model of disability they subscribe to may have positive and negative results. Where disabled patients are treated differently this care sometimes means a segregated care and is an idea that has been identified in other studies.(27) This should be discouraged as our aim is to enable this group access to the existing health services.

The charity model of disability engenders positive and negative feelings such as pity, sympathy, respect, uneasiness, fear and guilt. It may inadvertently impose artificial limitations on deaf/HI peoples' abilities, and deny them equal opportunities.(20)
These positive preconceptions mean that HCWs may be more likely to engage with deaf, Deaf and HI patients empathically and attempt to communicate more holistically. The positive attitude and creative, solutions orientated approach from the HCW may also encourage the patient to respond positively.

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

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

The social model of disability is the favoured model. Using this model, the HCWs show that they understand that different people have different ways of accessing services and understand individual needs.(28)

Through their actions (heightened awareness, fast tracked, more time, checking of understanding) it may seem that deaf patients receive better treatment than hearing patients. These actions are congruent with HCWs' wish to provide equitable service to deaf patients. They understand that deaf patients' experience of the health care process will be different to that of hearing persons' and that certain adjustments need to be made to ensure this. The empathy they display toward deaf patients make the health visit a *better* experience for the deaf patient.

For patients at RCHC this starts at the reception where their folders identify them as deaf patients and with this pre-consultation knowledge, the HCW can plan the interaction, make more time and material available, and involve other members of the health care team to ensure a successful health encounter.

This "openness" to other modes of communication is common and is consistent with a recommendation made in an earlier study(19). Written notes feature strongly amongst the alternative modes of communication which is also consistent with earlier studies. In fact, Ebert et al found that writing is the most commonly used medium physicians use to communicate with deaf patients.(29)

Speech reading was another mode of communication used although HCW were unaware of the inaccuracy therein. Lieu et al. reported that only 30-45% of English can be seen on speakers' lips. (30)

HCW were very positive about sign language although very few had any skills in SL, only 2 had used sign language interpreter services and little was known about the availability or how to engage the service. It is a valuable skill as deaf patients recognise the use of basic signing as a genuine attempt by the HCW to achieve good communication, furthering the development of a therapeutic bond.(19) According to the literature, both physicians and Deaf patients consider Sign Language Interpreters (SL-Is) service the gold standard of communication with Deaf patients by physicians and Deaf patients.(15),(31)

Some participants were aware that interpreters may impinge on the autonomy and confidentiality of the patient. However, as found in other studies, using informal interpreters to overcome the communication barrier at the expense of compromising confidentiality and autonomy, was a compromise that the HCWs were willing to accept.(16)

Some HCWs reported problems such as poor accuracy of translations. Other challenges like loss of objectivity, medical jargon and entrenching the deaf patients' dependence on others in accessing health care were less well recognised. (32)

Language barrier

As society becomes more multilingual and multicultural, the likelihood of encountering a person who speaks a different first language has increased. Heap and Morgan reported that most health care encounters are conducted in English, which is not the first language of the majority of health care users.(33) A HCW is more likely to encounter a different language speaker on a daily basis than a deaf patient. It was therefore unsurprising that HCW identified foreign languages as a greater challenge than deafness

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

Awareness of potential difficulties and how awareness can improve outcomes is highlighted once again in comparing deaf patients and foreign language speaking patient encounters.

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

Resilience

As noted earlier, being resilient does not mean experiencing challenges but rather an ability to adapt and change in the face of challenges. At RCHC the HCWs recognise that these clients may have different needs and are willing to adapt and adopt numerous strategies to delivering quality health care. They are rewarded by the apparent patient satisfaction they see. They therefore demonstrate resilience in their teamwork and their comfort with asking for help.(34)

Recommendations

Given that the frequency of encountering a SASL user is so low and the investment in learning SASL so high, this would be impractical.
This view is shared by other researchers such as Reeves and Sandler et al.(35),(36) However, learning just a few basic signs, or having a board with a few common and practical signs, (as recommended by a community service registered nurse) would show Deaf clients that an attempt is being made to communicate.(37) Access to a SL Is is possible but would require educating HCWs and clients about the service and how to access it.

Limitations

This study site provided a community perspective which could inform local primary health care training and planning of services. It does however have distinct characteristics such as the population its serves, the socioeconomic climate, staff and resources available, which may make extrapolating the findings to other CHCs challenging. Another limitation of the study was that no pharmacy staff participated and medication errors and medication adherence impact heavily on mortality and morbidity. It was noted that those engaged in the focus group discussions were more forthcoming and appeared to enjoy the experience – often learning from their peers – thus it would have been useful to have conducted more focus group discussions.

Conclusion

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

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

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

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Appendices

Appendix A

Questionnaire/Data capturing Instruments:

Interview guide

• What has been your experience dealing with hearing impaired patients?
• What has been your experience dealing deaf and Deaf patients who use SASL?
• If you have not had any such experiences, do you think it would be different from a hearing patient?
• How do you feel dealing with deaf, HI or Deaf patients?
• Did you experience any difficulties?
• If so, how did you overcome the difficulties?
• How did your training help you?
• Do you have any recommendations for interactions with deaf, Deaf and HI patients?

Demographic Details:

Participant study number	
Age	
Sex	
Occupation	
Ethnicity	
Years of service	

Appendix B

Consent forms and participant information sheets

University of Cape Town
Division of Family Medicine
School of Public Health and Family Medicine

Informed Consent Form for Health care workers (HCW) at the Retreat CHC who have been invited to participate in research, "A Descriptive Case Study: An example of the challenges experienced by Health Care Workers in dealing with deaf/Hearing Impaired Patients". Interview participants.

Name of Principal Investigator: Dr. Shameela Orrie
Name of Organisation: University of Cape Town, School of Public Health and Family Medicine, Division of Family Medicine

This Informed Consent Form has two parts:
• Information Sheet (to share information about the study with you)
• Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction
My name is Shameela Orrie and I am currently enrolled in the Masters of Medicine, Family Medicine degree at the University of Cape Town. As a Master's student I need to conduct research that will improve the quality of health care service we provide to the community. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.
This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research
This study is being done to find out how HCW deal with deaf patients at this facility, how they feel about this interaction and what they recommend for future interactions.
Type of Research Intervention

This research will involve your participation in an interview lasting 30 to 45 minutes.

Participant Selection
You are being invited to take part in this research because we feel that your experience as a HCW at this facility can contribute much to our understanding and knowledge of local health practices.

Voluntary Participation
Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier. If

the interview has already taken place, you may ask that the information provided by you not be used in the research study.

Procedures
We are asking you to help us learn more about how HCW deal with deaf patients at Retreat CHC. We are inviting you to take part in this research project. If you accept, you will be asked to participate in interviews.
These are the types of questions you may be asked:
• What has been your experience dealing with deaf, hearing impaired (HI) or Deaf (people who use South African Sign Language (SASL) as their first language) patients?
• If you have not had any experiences, do you think it would be different from a hearing patient?
• How do you feel dealing with deaf patients?
• Did you experience any difficulties?
• If so, how did you overcome the difficulties?
• Recommendations?

We will not ask you to share any knowledge that you are not comfortable sharing.
During the interview, I will sit down with you in a comfortable place at the CHC. I will ask you about your experiences at the CHC especially with regards to deaf and Deaf patients. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but will be present unless you would like someone else to be there or if an interpreter is needed. The information recorded is confidential, and no one else except people involved in the study will access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The tape will be kept by me, in a safe place. The information recorded is confidential, and no one else except people involved in the study will have access to the tapes. The tapes will be destroyed after _____number of days/weeks.

Duration
The research takes place over ___ (number of) weeks/ or ___ (number of) months in total. During that time, we will visit the facility a number of times for interviewing, conducting focus group discussions and to check up on information already collected. Each interview will last for about one hour each. The group discussion will be held once and will take about one hour.)

Risks
I am asking you to share with me some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview if you don't wish to do so, and that is fine. You do not have to give me any reason for not answering any question, or for refusing to take part in the interview.

Benefits
There are no direct benefits to you for participating in the study but you will be contributing to a body of knowledge which may help other members of your community.

Reimbursements
You will not get any reward in money or kind to take part in the research. However, refreshments will be provided during the course of the interviews and focus group discussions.

Confidentiality
We will not share information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key.

Sharing the Results
Nothing that you tell us today will be shared with anybody outside the research team. The knowledge that we get from this research will be shared with you and your facility. Each participant will receive a report of the results. I will submit my report to the university (UCT) for assessment as part of my requirements for completing my studies. The report based on my findings will be given to my assessors and if suitable, will be available on the University of Cape Town's (UCT) web site where it can be viewed by students and staff of the university. It may be published in a scientific journal and will then be available to all readers of that journal.

Right to Refuse or Withdraw
You do not have to take part in this research if you do not want to. Not taking part will not affect your job or job-related evaluations in any way. You may stop participating in the discussion/interview at any time that you wish without your job being affected. I will give you an opportunity at the end of the interview/discussion to review your remarks, and you can ask to change or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Who to Contact
You may contact me, Shameela Orrie (orrsha003@myuct.ac.za or 0741867686), my supervisor, Dr. T. Motsohi (tshepo.motsohi@westerncape.gov.za) my faculty, the Department of Family Medicine (0214066510) or the UCT Ethics Committee, Prof. Marc Blockman (0214066338). This proposal has been reviewed and approved by the UCT ethics committee, which is a committee whose job it is to make sure that research participants are protected from harm. If you wish to find about more about this committee, contact Prof. Marc Blockman: 021 4066338. It has also been reviewed by the MDHS (Metro District Health Services) Research Committee.

You can ask me any more questions about any part of the research study, if you wish to.

Part II: Certificate of Consent

I have been invited to participate in research about HCW experience, knowledge and practices regarding deaf patients. The research will be conducted at the Retreat CHC. My participation will include taking part in interviews.

I have read the research information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____
Signature of Participant _____
Date _____
Day/month/year

If illiterate:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ Thumb print of participant
Signature of witness _____
Date _____
Day/month/year

Statement by the researcher/person taking consent:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Participation in interviews

   I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

   A copy of this ICF has been provided to the participant.
   Print Name of Researcher/person taking the consent_____

   Signature of Researcher /person taking the consent_____
   Date _____
   Day/month/year

University of Cape Town
Division of Family Medicine
School of Public Health and Family Medicine

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Part I: Information Sheet

Introduction
My name is Shameela Orrie and I am currently enrolled in the Masters of Medicine, Family Medicine degree at the University of Cape Town. As a Master's student I need to conduct research that will improve the quality of health care service we provide to the community. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.
This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research
This study is being done to find out how HCW deal with deaf patients at this facility, how they feel about this interaction and what they recommend for future interactions.

Type of Research Intervention
This research will involve your participation in a group discussion that will take about 45 to 60 minutes.

Participant Selection
You are being invited to take part in this research because we feel that your experience as a HCW at this facility can contribute much to our understanding and knowledge of local health practices.

Voluntary Participation
Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier. If the interview or group discussion has already taken place, you may ask that the information provided by you not be used in the research study.

Procedures
We are asking you to help us learn more about how HCW deal with deaf patients at Retreat CHC. We are inviting you to take part in this research project. If you accept, you will be asked to

participate in focus group discussions.
For focus group discussions:
You will take part in a discussion with 4-8 other persons. This discussion will be guided by a research assistant or me.
The group discussion will start with me, or the focus group leader, making sure that you are comfortable. We can also answer questions about the research that you might have. Then we will ask you questions about dealing with deaf patients and give you time to share your knowledge. We will also talk about community practices more generally because this will give us a chance to understand more about deafness but in a different way.
These are the types of questions you may be asked:
• What has been your experience dealing with deaf, hearing impaired (HI) or Deaf (people who use South African Sign Language (SASL) as their first language) patients?
• If you have not had any experiences, do you think it would be different from a hearing patient?
• How do you feel dealing with deaf patients?
• Did you experience any difficulties?
• If so, how did you overcome the difficulties?
• Recommendations?

We will not ask you to share any knowledge that you are not comfortable sharing.
The discussion will take place at the Retreat CHC, and no one else but the people who take part in the discussion, group guide or me will be present during this discussion. The entire discussion will be tape-recorded, but no-one will be identified by name on the tape. The tape will be kept by me in a safe place. The information recorded is confidential, and no one else except people involved in the study will have access to the tapes. The tapes will be transcribed then destroyed after _____number of days/weeks.

Duration
The research takes place over ___ (number of) weeks/ or ___ (number of) months in total. During that time, we will visit the facility a number of times for interviewing, conducting focus group discussions and to check up on information already collected. Each interview will last for about one hour each. The group discussion will be held once and will take about one hour.)

Risks
I am asking you to share with me some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview if you don't wish to do so, and that is fine. You do not have to give me any reason for not answering any question, or for refusing to take part in the interview.

Benefits
There are no direct benefits to you for participating in the study but you will be contributing to a body of knowledge which may help other members of your community.

Reimbursements
You will not get any reward in money or kind to take part in the research. However, refreshments will be provided during the interviews and focus group discussions.

Confidentiality
We will not share information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key.

The following applies to focus groups:

We will ask you and others in the group not to talk to people outside the group about what was said in the group. We will, in other words, ask each of you to keep what was said in the group confidential. You should know, however, that we cannot stop or prevent participants who were in the group from sharing things that should be confidential.

Sharing the Results

Nothing that you tell us today will be shared with anybody outside the research team. The knowledge that we get from this research will be shared with you and your facility. Each participant will receive a report of the results. I will submit my report to the university (UCT) for assessment as part of my requirements for completing my studies. The report based on my findings will be given to my assessors and if suitable, will be available on the University of Cape Town's (UCT) web site where it can be viewed by students and staff of the university. It may be published in a scientific journal and will then be available to all readers of that journal.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not want to. Not taking part will not affect your job or job-related evaluations in any way. You may stop participating in the discussion/interview at any time that you wish without your job being affected. I will give you an opportunity at the end of the interview/discussion to review your remarks, and you can ask to change or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Who to Contact?

You may contact me, Shameela Orrie (orrsha003@myuct.ac.za or 0741867686), my supervisor, Dr. T. Motsohi (tshepo.motsohi@westerncape.gov.za) my faculty, the Department of Family Medicine (0214066510) or the UCT Ethics Committee, Prof. Marc Blockman (0214066338). This proposal has been reviewed and approved by the UCT ethics committee, which is a committee whose job it is to make sure that research participants are protected from harm. If you wish to find about more about this committee, contact Prof. Marc Blockman: 021 4066338. It has also been reviewed by the MDHS (Metro District Health Services) Research Committee.

You can ask me any more questions about any part of the research study, if you wish to.

Part II: Certificate of Consent

I have been invited to participate in research about HCW experience, knowledge and practices regarding deaf patients. The research will be conducted at the Retreat CHC. My participation will include taking part in focus group discussions.

I have read the research information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____
Signature of Participant _____
Date _____
Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ Thumb print of participant
Signature of witness _____
Date _____
Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Participation in focus group discussions
I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.
Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____
Date _____
Day/month/year
http://www.who.int/rpc/research_ethics/informed_consent/en/

ADDITIONAL INFORMATION FOR STUDY PARTICIPANTS

o Why is this study being done?
This study is being done to find out how HCW deal with deaf, hearing impaired or Deaf patients at this facility, how they feel about this interaction and what they recommend for future interactions.
o Why are you being asked to take part?
You have been asked to take part in the study because your health care facility was selected as the study site and you are employed here where you have contact with patients.
o How many people will take part in the study?
I am aiming to enroll at least (12) twelve participants in the study, although more or fewer may participate. A minimum of eight and a maximum of sixteen participants will be considered.
o How long will the study last?
The study will last four to six months
o What do we do to decide if you are eligible to be take part?
If you are willing to participate and are an employee who has contact with patients at the facility, you are eligible to participate.
o What will happen if you decide to take part in the study?
If you decide to take part in the study you will be requested to take part in one-on-one interviews with the principal investigator (PI) and/or take part in group discussions with fellow research participants on the same topic. You will be asked to share your experiences, thoughts, beliefs, knowledge and recommendations on the topic. The interview may last thirty to sixty minutes and the group discussions may last thirty to sixty minutes. The interviews and discussions will be recorded digitally if you agree to this or by hand written notes.
o What are the risks and discomforts of this study?
It is unlikely that you will experience physical harm during this study. You may feel uncomfortable sharing your thoughts or experiences in the group or interview. You may experience boredom or frustration depending on your attitude to the topic.
o Are there any benefits to you for being in the study?
There are no direct benefits to you for participating in the study but by taking part in the study you will be adding to a body of knowledge which may help other members of your community.
o What other choices do you have?
You have the choice to not take part in the study. Even if you agree to take part in the study today you may change your mind and stop participating at any time. You will not be punished for not taking part or withdrawing from the study.
o What will happen when the study is over?
Once all the information has been collected it will be analysed and interpreted by me. I may use a computer program to help me to do this. I, the principal investigator, may come back to the study site to check some of the findings. The results of the study will be written in a report and given to the university to be assessed. It may also be sent to be published in a scientific journal.
o Will your test results be shared with you?
No tests will be conducted.
o Will the results of the research be shared with you?
Yes. I will report the findings to the study participants at the site.

o Will any of your blood, tissue or other samples be stored and used for research in the future?

No blood tissue or other samples will be taken or stored for future use during this study.

o Will you receive any reward (money or food vouchers) for taking part in this study?

While I am grateful to you for taking part in the study you will not get a reward in money or kind.

o Who will see the information which is collected about you during the study?

The information collected from you will be seen by me, the PI, my research assistants and my supervisors. The report based on my findings will be given to my assessors and an if suitable will be available on the University of Cape Town's (UCT) web site where it can be viewed by students and staff of the university. The report will also be presented to you, the participants. It may be published in a scientific journal and will then be available to all readers of that journal.

o Who do I speak to (or contact) if I have any questions about the study?

If you have any questions about the study please ask me, Shameela Orrie, the Principal Investigator: orrsha003@myuct.ac.za cell: 0741867686

Study supervisor: Dr T. Motsohi tshepo.motsohi@westerncape.gov.za work:021 6921240

The Division of Family Medicine at the School of Family Medicine and Public Health 021 4066510

UCT ethics committee, Prof. Marc Blockman: 021 4066338

Appendix C

Official Ethics approval letter from the Faculty Research Ethics Committee and Provincial Government approvals

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9993
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_2015RP55_624
ENQUIRIES: Ms Charlene Roderick

University of Cape Town
Anzio Road
Observatory
Cape Town
7935

For attention: **Dr Shameela Orrie and Dr Tsepo Motsohi**

Re: A DESCRIPTIVE CASE STUDY: AN EXAMPLE OF THE CHALLENGES EXPERIENCED BY HEALTH CARE WORKERS IN DEALING WITH PATIENTS WHO ARE HEARING IMPAIRED, DEAF OR DEAF AT A PRIMARY HEALTH CARE FACILITY

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact **HENRY LEMMETJIES** on **(021 713 9741)** to assist you with any further enquiries in accessing the following sites:

Retreat CHC

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za)

3. The reference number above should be quoted in all future correspondence.

Yours sincerely

Signature Removed

DR A HAWKRIDGE
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 24/6/2015

CC **K GRAMMER** **DIRECTOR: SOUTHERN/ WESTERN**

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

08 June 2015

HREC REF: 067/2015

Dr T Motsohi
Public Health & Family Medicine
Falmouth Building

Dear Dr Motsohi

PROJECT TITLE: A DESCRIPTIVE CASE STUDY: AN EXAMPLE OF THE CHALLENGES EXPERIENCED BY HEALTH CARE WORKERS IN DEALING WITH PATIENTS WHO ARE DEAF /HEARING IMPAIRED AT A PRIMARY HEALTH CARE FACILITY (MMed-candidate-S Orrie)

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee received on 28 May 2015.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th June 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Shameela Orrie will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

signature removed

PROFESSOR M BLOCKMan
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637,
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH

Appendix D

Instructions to Authors of the chosen journal

Author Guidelines: South African Family Practice
The following contributions are accepted (word counts exclude abstracts, tables and references):

1. Original research (Between 1000 and 3500 words):

Format

Title page: All articles must have a title page with the following information and in this order: Title of the article; surname, initials, qualifications and affiliation of each author; The name, postal address, e-mail address and telephonic contact details of the corresponding author; at least 5 keywords. Please do not use capital letters only for headings and names but stick to the normal use of capital letters.

Abstract. All articles should include an abstract. The structured abstract for an Original Research article should be between 200 and 250 words and should consist of four paragraphs labelled "Background, Methods, Results, and Conclusions".

Keywords. All articles should include keywords. Up to five words or short phrases should be used. Use terms from the Medical Subject Headings (MeSH) of Index Medicus when available and appropriate. Key words are used to index the article and may be published with the abstract.

Acknowledgements. In a separate section, acknowledge any financial support received or possible conflict of interest. This section may also be used to acknowledge substantial contributions to the research or preparation of the manuscript made by persons other than the authors.

References. Cite references in numerical order in the text, in superscript format. Do not use brackets. In the References section, references must be numbered consecutively in the order in which they are cited, not alphabetically.

The style for references should follow the format set forth in the “Uniform Requirements for Manuscripts Submitted to Biomedical Journals"; prepared by the International Committee of Medical Journal Editors.

Abbreviations for journal titles should follow Index Medicus format. Authors are responsible for the accuracy of all references.
When citing URLs to web documents, place in the reference list, and use following format: Authors of document (if available). Title of document (if available). URL. (Accessed [date]).

The following are sample references:
1. London L, Baillie R. Notification of Pesticide Poisoning: Knowledge, Attitudes and Practices of Doctors in the Rural Western Cape. S A Fam Pract 1999;20(1):117-20.
2. FDA Talk Paper: http://www.fda.gov/bbs/topics/ANSWERS/2002/ANS01151.html (Accessed 04/10/2002)

Tables. Tables should be self-explanatory, clearly organised, and supplemental to the text of the manuscript. Each table should include a clear descriptive title on top and numbered in Roman numerals (I, II, etc.) in order of
its appearance as called out in text. Tables must be inserted in the correct position in the text.

Ethical considerations. Papers based on original research must adhere to the Declaration of Helsinki on "; Ethical Principles for Medical Research Involving Human Subjects"; and must specify from which recognised ethics committee approval for the research was obtained.

Conflict of interest. Authors must declare all financial contributions to their work or other forms of conflict of interest
The following declaration may be used if appropriate: "; I declare that I have no financial or personal relationship(s) which may have inappropriately influenced me in writing this paper.";

Submission Preparation Checklist

1. The submission has not been previously published, nor is it before another journal for consideration (or an explanation has been provided in Comments to the Editor).
2. The submission file is in Microsoft Word, Open Office or RTF document file format.
3. All URL addresses in the text (e.g., http://pkp.sfu.ca) are activated and ready to click.
4. The text is single-spaced; uses a 10-point font; employs italics, rather than underlining (except with URL addresses); and all tables and figures are placed within the text at the appropriate points, rather than at the end.
5. The text adheres to the stylistic and bibliographic requirements outlined in the Author Guidelines, MS Word®, Open Office, or RTF format using Times New Roman font size 10 and single-spacing. Headings must be in Bold. which is found in About the Journal.
6. Electronic images are saved as either jpeg or gif files. All photographs were scanned at a high resolution (300dpi, print optimised) and saved/numbered appropriately corresponding with the text.
7. All tracking changes in the document must have been accepted before sending to SA Fam Pract.
8. Have you asked a colleague or language expert to proofread your final manuscript?
9. All supplementary files such as survey instruments or scanned photographs are separated from the main text and will be uploaded as supplementary files.
10. In the case of a research paper, prior approval has been obtained from a research ethics committee, and this fact is declared in the methods section of the manuscript.