

Exploring the barriers and facilitators to health care services and health care information for deaf people in Worcester

by
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Declaration

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ABSTRACT

The Deaf community face similar access barriers to health care services and information as do other linguistic minority groups. Amongst others, this includes limited access to English communication, misunderstanding of medical terminology, irregular contact with health care professionals of the same language and cultural background and the need to overcome the challenges experienced by using others as interpreters in a health care setting. Barriers to the written and spoken word limit access to health care information as deaf people cannot overhear conversations, have limited access to mass media and present with low literacy rates. The South African Constitution stipulates that every citizen has an equal right to health care services and should not be unfairly discriminated against, on the basis of language. Unfortunately, despite what is written in the Constitution, the reality is that many South Africans are denied equal access or receive compromised access to health care services because of language barriers. The lack of access to interpreters at health care facilities across South Africa inhibits patients from expressing themselves correctly and limits the providers' professional ability to make a correct diagnosis and provide relevant information.

The current study explores the barriers and facilitators to accessing health care services and health care information for people who are deaf in a relatively well-resourced setting. A sample of deaf participants from the National Institute for the Deaf in Worcester were interviewed to gain an understanding of problems experienced with accessing health care services and health care information. Participants reported communication and socio-economic factors as barriers to accessing health care services. The main barrier to accessing health care information was considered to be the inaccessibility of the mass media. Recommendations were made by participants on ways to improve access to health care services and health care information for the deaf population of South Africa.

Keywords: Health care acces, Health care information, Deaf, Worcester, Barriers and facilitators to health care services.

OPSOMMING

Die dowe gemeenskap ervaar soortgelyke struikelblokke as ander linguistiese minderheidsgroepe met toegang tot gesondheidsdienste en inligting. Dit sluit onder andere in beperkte toegang tot Engelse kommunikasie, wanbegrip van mediese terminologie, ongereelde kontak met mediese dienspraktisyne van dieselfde taal en kulturele agtergrond, en die uitdaging wat oorkom moet word om ander mense te gebruik as tussenganger en tolk in 'n mediese situasie. Hindernisse met geskrewe- en spreektaal beperk die toegang tot gesondheidsinligting. Dowe mense kan nie na gesprekke luister nie, het beperkte toegang tot massamedia en vertoon oor die algemeen 'n laer geletterdheidsprofiel. Die Suid Afrikaanse Grondwet stipuleer dat elke burger 'n gelyke reg tot gesondheidsdienste het en verbied onregverdig diskriminasie op grond van taal. Ten spyte van die Grondwet is die realiteit dat baie Suid Afrikaners nie gelyke toegang het nie en 'n laer vlak van mediese dienslewering ervaar as gevolg van taalprobleme. Die ontoereikende beskikbaarheid van tolke by gesondheidsfasiliteite reg oor Suid Afrika beperk die vermoë van pasiënte om hulself behoorlik uit te druk. Dit beperk daarom ook die mediese praktisyne se vermoë om 'n korrekte diagnose te maak en relevante inligting rakende die diagnose aan die pasiënt oor te dra.

In die huidige studie is die struikelblokke en fasiliteerders vir toegang tot gesondheidsdienste en inligting ondersoek vir dowe mense in 'n relatief goed toegeruste omgewing. 'n Steekproef van dowe deelnemers is by die Nasionale Instituut vir Dowe in Worcester geselekteer. Deur middel van onderhoude is die probleme wat ondervind word met toegang tot gesondheidsdienste en gesondheidsinligting geïdentifiseer. Deelnemers het kommunikasie en sosio-ekonomiese faktore as struikelblokke tot die toegang van gesondheidsdienste geïdentifiseer. Die grootste struikelblok met toegang tot mediese inligting was die beperkte toegang tot massamedia. Voorstelle is deur die deelnemers gemaak vir die verbetering van die toeganklikheid tot mediese dienslewering en gesondheidsinligting vir die dowe populasie in Suid Afrika.

Sleutelwoorde: Toegang tot gesondheidsdienste, Gesondheidsinligting, Dowe, Worcester,
Struikelblokke en fasiliteerders tot gesondheidsdienste.

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CHAPTER ONE

INTRODUCTION

Disabled people are a marginalised grouping within society and as such, their experiences with health care systems across the world are not readily understood (Hwang et al., 2009; Scheer, Kroll, Neri, & Beatty, 2003). As a group they also present with multiple complex medical and non-medical needs, yet very often receive below par health care (Hwang et al., 2009). Previous studies indicate that people with disabilities receive less of certain preventive services or different preventive services to the general population (Diab & Johnston, 2004; Kroll & Neri, 2004; Tamaskar et al., 2000), experience poorer access to needed services (Fouts, Andersen, & Hagglund, 2000; Kroll, Jones, Kehn, & Neri, 2006), report a greater degree of dissatisfaction with services that they do receive (Iezzoni, Davis, Soukup, & O'Day, 2002) and are less likely to utilise primary preventive services even though they are at higher risk for secondary conditions and just as likely as the general population to partake in risky health behaviour (Kroll et al., 2006).

Of particular importance are the many barriers, ranging from structural to procedural, that have been found to hinder disabled people from accessing quality health care and preventive services (Bachman, Vedrani, Drainoni, Tobias, & Maisels, 2006; Hwang et al., 2009; Kroll et al., 2006; Scheer et al., 2003). Although many of the perceived barriers to health care for disabled persons are on par with those of the general population, the consequences of these barriers appear to be more severe for this grouping (Scheer et al., 2003), and therefore an understanding is needed of barriers that are specific to disabled people in order to achieve equal health care for all.

Overall, people in South Africa experience significant socio-economic, structural and cultural/linguistic barriers to quality health care (Levin, 2006c; Pillay, 1999). Many studies have found that language barriers are experienced as a severe barrier to health care services in the linguistic

minority groups of South Africa (Crawford, 1999; Levin, 2006a; 2006b; 2006c; Penn, 2007; Schlemmer & Mash, 2006).

Deaf people who use sign language as their first language, regard themselves as being a linguistic minority facing similar access barriers to those people of linguistic minorities: limited access to English or Afrikaans based communication, misunderstanding of medical terminology, irregular contact with health care professionals of the same language and cultural background and overcoming the challenges experienced by using family members, co-workers, carers or friends as interpreters in a health care setting (Folkins et al., 2005; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006; Tamaskar et al., 2000).

Communication barriers are a challenge experienced not only by people who are deaf or hard of hearing but also by providers when it comes to communicating within a health care setting (Bachman et al., 2006; Iezzoni, O'Day, Killeen, & Harker, 2004). This poses a particular problem to access and quality of health care services, as primary health care depends heavily on effective communication between patient and health care provider to ensure that health care services are safe, timely, efficient and patient centered (Iezzoni et al., 2004; Law, Bunning, Byng, Farrelly, & Heyman, 2005). Access to health care information is also limited by barriers to written and spoken language as deaf people cannot overhear conversations, have limited access to mass media and present with a low average reading level of grade three or four (Jones, Renger, & Firestone, 2005; Zazove, Meador, Reed, Sen, & Gorenflo, 2009). Communication in health care settings currently falls below par (Iezzoni et al., 2004), which may be one of the main reasons why deaf people use health care services differently from the general population (Steinberg et al., 2006). Tamaskar et al. (2000) found that their deaf and hard of hearing participants were more likely to avoid health care providers because of lack of communication, lack of available interpreters and other factors. This is consistent with other reports that deaf people see doctors less often (Barnett & Franks, 2002). Despite the fact that communication

plays a vital role in correct diagnosis and health care management, little attention is given to providing medical students with the necessary skills to communicate with people that have a hearing loss (Barnett, 2002).

1.1 Research problem and rationale

Section 27 (1) (a) of the South African Constitution states that everyone has the right to health care services, followed by section 27 (2) which obliges the State to take reasonable measures within its available resources to achieve these rights (Constitution of the Republic of South Africa Act, 1996). However, a question that arises is whether equal health care can be maintained when South Africa has 11 official languages according to section 6 (1) of the constitution?

Furthermore, although sign language is not recognised as one of the official 11 languages in South Africa, it is explicitly recognised under section 6 (5) which refers to the establishment of the Pan South African Language Board which must ‘promote, and create conditions for, the development and use of...’ sign language (Constitution of the Republic of South Africa Act, p.1245, 1996).

Section 9 of the Constitution relates specifically to equality, touching on issues of unfair discrimination directly or indirectly by, amongst others; race, disability, culture and language (Constitution of the Republic of South Africa Act, 1996). Therefore, health care access should not be undermined by any unfair discrimination with regards to language differences. Unfortunately, despite what is written in the Constitution, the reality is that many South Africans are denied equal access or receive compromised access as a result of language barriers (Pillay, 1999). The lack of access to translations and interpreters (facilitators) in the health care services of South Africa inhibits the patient from expressing themselves correctly and limits the providers professional ability to make a correct diagnosis, or provide relevant information, which may result in some patients receiving sub-standard treatment from a facility, leading to unfair discrimination on the grounds of language which goes against the South African Constitution (Pillay, 1999).

The Deaf population falls within at least two categories which may experience unfair discrimination i.e. disability and linguistic minority and despite the fact that the Government has the responsibility to provide equality in public services, currently there are many users of South African Sign Language (SASL) but a low number of professional interpreters (Heap & Morgans, 2006). The current study, located within a broader study (refer to section 3.1), evolved to explore the barriers and facilitators to accessing health care services and health care information for people who are deaf in a relatively well-resourced setting.

1.2 Outline of the study

The study will be set out as follows: Chapter 2 will be a literature review focusing on issues of health, equitable access to health care services and health care information, but also touching on relevant issues around deafness, language barriers experienced in South Africa and SASL.

Chapter 3 will focus on the methodological aspects, for example: study aims, setting, design, instruments, participants, procedure, data analysis, consent, ethics and interpreter issues relating to this study.

Chapter 4 will run through the results of the study, providing extensive quotes to corroborate findings. Finally, Chapter 5 will discuss the study results with reference to similar findings in the literature, also highlighting limitations of the current study and findings that are unique to our study setting.

CHAPTER TWO

THEORETICAL OVERVIEW AND A REVIEW OF THE LITERATURE

Before reviewing relevant literature this Chapter will briefly look at global and South African prevalence rates of disability, after which it will focus on the issue around deafness/Deafness and the Deaf community. This will be followed by a review of facilitators and barriers to health care services and health care information experienced by people with disabilities and the deaf population. As a result of the differences between the language spoken in health care facilities around South Africa and the language spoken by the majority of primary health care patients, I will briefly look at general language barriers experienced in South Africa and then focus on SASL and interpreters.

Although issues of race, gender and class could play a role in the patterns of marginality experienced by the deaf population, they were not discussed in this study as the participants were all recruited from the National Institute for the Deaf which provides equal support to all its residents irrespective of their race, gender or class. This would however be different for the larger EquitAble project as participants were recruited from the larger Worcester community.

2.1 Disability in South Africa

It has been estimated that approximately 10%-12% of the world's population are disabled, which is in line with the 10% estimate made by the United Nations (Mont, 2007). This is however quite a contentious issue as reported figures vary greatly from one country to another, for example, Kenya reports a figure of 1% and New Zealand a figure of 20% (Loeb, Eide, & Mont, 2008; Mont, 2007). It has been found that developing countries tend to report lower prevalence rates than do developed countries and even within countries big variances are often found. Some of the reasons for these differences are reportedly due to differing definitions of disability, methodologies of data collection and study design which make comparing prevalence rates very difficult (Loeb et al., 2008; Mont, 2007).

In the 2001 South African Census, people living with disabilities which prevented them from full participation in life activities, was estimated at 5% of the total population (Statistics South Africa, 2005). The Western Cape and Gauteng provinces of South Africa reported the lowest prevalence rates of disability with 4.1% and 3.8% respectively. Of the 2 255 982 people living with disabilities, 20% suffered from hearing impairment, which was the third highest reported disability behind visual and physical disability (Statistics South Africa, 2005). The latest reported extrapolated figures for South Africa are those from the Community Survey conducted in 2007. This report indicates that the overall disability prevalence in South Africa has decreased to 4%, with the Western Cape still reporting the second lowest disability prevalence figure, this is in line with reports that low income African countries report prevalence rates of under 5% (Loeb et al., 2008; Statistics South Africa, 2007). Mont (2007) argues that the lower prevalence rates in low income countries could be a truer reflection of the severe disabilities found in these countries.

An estimated 179,792 people in the Western Cape were reportedly living with disabilities and of this total the hearing impaired were estimated to be around 14,604 people which was the third lowest category ahead of intellectual and communication disabilities (Statistics South Africa, 2007). The Community Survey for 2007 indicates that there were 649 hearing impaired people living in the Breede Valley Municipal area, which is where our study site of Worcester is situated. This number represents 0.36% of the total hearing impaired of South Africa. This figure excludes 458 people who are included in the multiple disability category and 7,668 people who are included as a disabled group under the institution category, which is not defined.

Mont (2007) warns that it is often impossible to get an accurate prevalence figure for disability from a census as it is difficult to include enough questions on the full wealth of human functioning, especially within the social model which includes the interaction with the environment.

The conclusion of the 2001 Census report draws our attention to the fact that these prevalence figures may be on the lower side, as a result of the formulation of the disability question, which in that census potentially excluded those people living with disabilities but who can carry out normal daily activities (Statistics South Africa, 2005). Over the years the definition of disability used to collect census and survey information has changed (Statistics South Africa, 2007):

- In Census 1996, respondents were asked to indicate whether or not there were any people with serious disabilities living in the household. Serious disability was however not clearly defined and was subject to the respondents perception of seriousness.
- In Census 2001, disability was defined as a physical or mental handicap lasting or expected to last for at least six months. In order for the person to be classified as disabled the disability would have to prevent the person from executing daily activities independently and from full participation in life activities.
- During the Community Survey 2007, the disability question was split into three distinct questions and respondents were asked to indicate which disability they had. If they indicated that they lived with a disability then they had to indicate the type of disability and the intensity of the disability. The intensity of the disability was related to the extent the disability prevented the person from full participation in life activities.

The prevalence figure for disability in South Africa is therefore not comparable over the years, as a portion of the change could be as a result of different disability definitions and not a true indication of differing levels in disability.

2.2 Deafness

In the literature of deafness and Deaf culture a common distinction is made between “deaf” and “Deaf” (Heap & Morgans, 2006; Reagan, 2008). The audiological condition, resulting in lack of

hearing is commonly referred to as being deaf; this definition is closely linked to the medical model's definition which includes a person having a hearing impairment when compared to 'normal' peers (Chong-Hee Lieu, Sadler, Fullerton, & Stohlmann, 2007; Steinberg et al., 2006; Williams & Abeles, 2004).

Deaf, denoted with a capital letter, on the other hand refers specifically to a distinct cultural group which uses the local sign language in their daily lives and is more in line with the social model's definition which considers deafness as a problem located within society and not the individual. (Chong-Hee Lieu et al., 2007; Jones et al., 2005; Steinberg et al., 2006; Stibbe, 2004; Taegtmeier et al., 2009; Williams & Abeles, 2004; Yousafzai, Edwards, D'Allesandro, & Lindström, 2005). On the other hand, Young (1999) would refer to Deaf in terms of the cultural-linguistic model, which does not put emphasis on deafness but rather on language use and cultural identity, viewing Deaf people as not having a hearing impairment but as having their own natural language and characteristic values, attitudes and traditions.

While this is the most commonly used distinction in literature, it is complicated by the fact that a person can be deaf without being Deaf (Reagan, 2008). The use of sign language as your main form of communication is a necessary but not sufficient indicator of membership in the Deaf culture. This is why elderly persons who become deaf later in life are generally not considered to be part of the Deaf culture as they do not use SASL (Heap & Morgans, 2006; Reagan, 2008). It is recognised that this distinction is over simplified and in no way tries to undermine the complexities within each and between each definition.

For many people, with no exposure to the Deaf culture, the definition of deafness is straightforward and within the medical model as defined above, it is seen as a hearing loss which is easily classified as a disability (Williams & Abeles, 2004). This creates an on-going debate where many members of Deaf communities do not consider themselves to be disabled, but rather see themselves as a linguistic

minority (Chong-Hee Lieu et al., 2007; Taegtmeier et al., 2009; Williams & Abeles, 2004; Yousafzai et al., 2005). This view on disability can have far reaching consequences within some staunch Deaf communities which reject all people who accept the medical definition of deafness and are very critical of cochlea implants, campaigning heavily against them being provided to children (Williams & Abeles, 2004). The smaller subgroups within the Deaf culture, those with multiple disabilities, face an added burden as very often their other special needs are not met within these Deaf communities (Williams & Abeles, 2004).

The deaf population can be further divided into subgroups; depending on the degree of hearing loss, language preference, education and integration into either the Deaf culture or hearing world (Reagan, 2008). Barnett (2002) defines a few subgroups within the deaf population; hard of hearing are those people who can still derive useful information from speech, whereas deaf people receive no useful information from sound. Deaf people who communicate orally could either be late-deafened adults or orally educated deaf. Late-deafened adults are defined as those people who have had the opportunity to adjust their communication over a time period while progressively losing their hearing (Barnett, 2002). Orally educated deaf people are referred to as those that have been deaf since childhood but have attended schools which have emphasised speech reading and speaking skills (Barnett, 2002).

The differences on the continuum between deaf and Deaf and all the subgroups can complicate research further and that is why in this study where our main focus is on barriers and facilitators to health care services and health care information and not the difference in definitions of deafness, we focus on deaf people in Worcester, which include those that are Deaf, deaf and hard of hearing. No distinction has been made between those deaf people who are pre-lingually deaf or late-deafened.

2.3 Health

The World Health Organization's (WHO) definition of health, as "a state of complete physical, social and emotional well-being, and not merely the absence of disease or infirmity" has remained

unchanged since 1948 (WHO, p.1, 1946). Despite this positive definition of health, much of the literature is still focussed on pathology and the absence of disease (Levin & Browner, 2005; McMullin, 2005). This more negative definition can be productive in measuring the physiological traits of health but excludes any other alternative meanings of health (McMullin, 2005).

As far back as 1979, researchers realised that beliefs around health and illness are of significance to almost everyone, even though they could be vastly different across cultures (Idler, 1979). At that stage, a distinction was drawn between disease and illness. Disease was indicated by its pathological abnormalities and could be observed, measured, recorded, classified and analysed according to clinical norms. This definition of disease is similar to the now coined medical model approach to health, that through diagnosis a person's health can be compared to the norm and from there the degree of good or bad health can be determined (Tighe, 2001). Illness, on the other hand, was considered as a social phenomenon focussed on the human experience of disease. This human experience included behavioural changes and feeling sick, which are linked to the person's social context (Idler, 1979). This definition of illness correlates nicely with the now more commonly used term, social model of disability and health (Tighe, 2001). Even though a distinction was made between disease and illness, and is now made between the medical and social models, Tighe (2001) found that her participants' perception of health was a complex issue made up of elements from both models.

By 1987 it had become fashionable to associate health with quality of life and at this stage Ware (1987) looked at what should be included in instruments that were meant to measure health by reviewing the concepts of health. He argued that health was multi-dimensional and made up of distinct components. For health to be measured at a certain point in time, one would have to measure each component separately. He went back to the definition of health as defined by the WHO and the

dictionary and proposed five distinct dimensions that make up health: a) physical health, b) mental health, c) social functioning, d) role functioning and e) general perceptions of well-being.

A special issue of *Social, Science and Medicine* was published in 2005 to broaden the focus of the concept health; although it was difficult for researchers to move their focus away from absence of disease, important issues were raised (Levin & Browner, 2005). Izquierdo (2005) for example found that despite improvements in health shown by the Matsigenka over the past 20-30 years (using biomedical indicators) the Matsigenka considered their health and well-being to have deteriorated over the same period. This discrepancy points out the problems in defining and measuring health, without considering cultural beliefs and perceptions. Physical health was only considered to be one component of health and well-being for the Matsigenka which is broadened to include, amongst others positive and nurturing social relations, happiness and providing for the family.

For the highland Maya in Mexico, physical health and well-being in part is considered in terms of 'vital warmth' (Groark, 2005). 'Vital warmth' points to the warmth that is needed to preserve vitality and vigour.

McMullin (2005) found that Hawaiians distinguished between being healthy and being a healthy Hawaiian. When asked about being healthy they would allude to the Western version of absence of disease, followed by eating habits and exercise, but further in the interview they would refer to being a healthy Hawaiian which included maintaining balance and family relations, understanding ones culture and ancestry and the ability to eat and prepare foods that come from the island.

The reason why many researchers probably opt for the biomedical definition of health is that it can cross borders, while cultural understandings of health are culturally specific.

Recently, the concept of 'healthworld' has been coined by Germond and Cochrane (2010) based on the word *bophelo* which was learnt while doing research in Lesotho. The word *bophelo* allows for six overlapping concepts of holistic health and well-being: the person, the family, the village, the nation,

religion and the earth. Based on this, healthworld is used to explain the complexity of health beliefs and behaviours and to denote the concept of health which should include both social and religious contexts. Healthworld focuses on a person's concept of health, health seeking behaviour and conditions of health, which should be considered in the health care services of a heterogeneous society like South Africa.

2.4 Health care services

Pillay (1999) offers an all-encompassing description of health care services based on the WHO definition of health as defined above. Based on this definition, the term health care services used in the South African Constitution should include all prevention, diagnostic and treatment services which are needed to ensure a person's overall well-being (Pillay, 1999).

In Africa, different socio-economic groups are covered by different services and funding, resulting in health care which is provided on an ability-to-pay approach (McIntyre et al., 2008). Political change in South Africa, since the end of apartheid, has enabled the health services to make strides towards Pillay's definition of health care services by attempting to correct the inequalities of the past. This has been achieved by removing user fees for maternal and child primary health care, as well as the disabled and elderly, aiming to re-orientate services toward primary health care and building 1300 new clinics (Chopra et al., 2009). Despite concerted efforts from the government we still find large inequalities. Currently, domestic individuals and companies are the main funders of health care in South Africa, and although all primary health care services are free for all (since April 1996), user fees at public sector hospitals are applied according to an individual's income bracket (Cummins, 2002; McIntyre et al., 2008).

2.4.1 Equal access to health care

Health is considered a priceless possession (Tighe, 2001) and in 2005 the World Health Assembly called for equitable health in all health systems, defined as “access to adequate health care for all at an affordable price” (McIntyre et al., 2008).

Depending on the framework utilised, equity and access will include and/or exclude differing elements. Although this concept is readily used throughout literature it remains relatively vague and as such health care providers may not have the correct understanding of its relevance to their work and how it can be improved to create better satisfaction and utilisation of services by disabled persons (Sowney & Barr, 2004).

Sowney and Barr (2004), using Walker and Avant’s framework, conceptualise equity to access, as entering and benefiting from a service in which you have confidence. The dictionary definition of equity highlights fairness, which implies that something is evenly proportioned, right and just. It also refers to all people having the same access and receiving the same benefit from health services; including physical access, subsequent care and treatment. Access, refers to the opportunity to reach a service and enter that service. Accessibility to a health care facility would therefore mean that the service is easily available in terms of distance, time and attitude. Both dictionary definitions of equity and access include the word ‘right’ which Sowney and Barr (2004) conclude to mean having the same right to access health care and receive the same range and quality of services as other people.

The current study forms part of a larger EquitAble study (which will be discussed in Chapter 3) which measures accessibility to health services using, as a central tool, the comments from the United Nations Committee on Economic, Social and Cultural Rights from 2000. Good services to health care are considered to have four elements: accessibility, availability, acceptability and quality.

Accessibility is broken down into four essential components: non-discrimination, physical accessibility, economic accessibility and information accessibility. Accessibility refers to the need for

health facilities, goods, services and information, to be physically and economically (affordable) accessible without discrimination.

In simpler terms, Scheer et al. (2003) define access as the use of services relative to the patients need for care, while barriers are those factors that prevent a person from using a service when it is needed.

2.4.2 Barriers and facilitators to health care services

Factors causing barriers to health care are not independent but interdependent, as very often it is a combination of factors which inhibit access to services. Some of the interdependent factors experienced by disabled persons are environmental, structural, communication and delivery process barriers and although these barriers may not be unique to disabled persons, they are exacerbated for this population (Scheer et al., 2003; Yousafzai, Dlamini, Groce, & Wirz, 2004). For example while long distances or topography can be an access barrier for the general population of an area, for a wheelchair user this barrier is experienced as being so much worse as it is very difficult/impossible to use a wheelchair without help in a very hilly environment.

2.4.2.1 Communication barriers and facilitators

Communication barriers appear to be the most commonly expressed barrier by both linguistic minorities and deaf people. It should be clear from the definition of health services above that effective communication is essential, both for the patient who needs to express themselves in terms of symptoms, complaints etc. and for the health care provider who must be able to explain treatment protocols, preventative options and make diagnosis in treating any condition that may be affecting the patient's physical, emotional or social well-being (Pillay, 1999).

Iezzoni et al. (2004) found that their participants' problems with communication centred around 6 themes: a) conflicting views around being deaf or hard of hearing, b) differing views on effective communication strategies, c) risks posed by miscommunication (e.g. medication safety), d)

communication problems during consultations and other procedures, e) difficulties with facility environment and interacting with office staff and f) telephone communication, when required to choose a number from a list on the telephone message.

Law et al. (2005) highlighted issues of inclusion, process of communication and continuity, as concerns experienced by their participants who experienced communication difficulties when interacting with health care services:

- Inclusion, included aspects around access to health care services and information, which should be experienced as open, respectful and equal by all patients. This includes physical access and access via communication (Law et al., 2005).
- Process of communication as alluded to by Law et al. (2005), included the way in which health issues were handled and the need for agreement between patient and provider around the message that needed to be communicated, being deeper than just eye contact, interest and attentiveness but also including the patients feeling around whether they could interact effectively to communicate their message. Other themes included under the process of communication were: time, problems with interpretation, mediating role of the caregiver, skilful communication and self-awareness.
- Continuity related to the relationship between both parties for health maintenance and effective use of health care services. This relationship is critical in the timeous access of health care services and any treatment protocols (Law et al., 2005).

Steinberg et al. (2006) looked specifically at the accessibility to health care for deaf people who mainly use American Sign Language (ASL) and found that deaf people had both positive (facilitator) and negative (barrier) experiences. The positive experiences were found in situations where medically experienced interpreters were used, when health care providers could use sign language

and when providers made an effort to improve communication. The overarching barrier was found to be problems with communication, which elicited feelings of fear, mistrust and frustration appearing in their descriptions of the health care service encounter. They felt afraid of the consequences of miscommunication between themselves and their health care providers, and this combination often led to patients' harbouring feelings of mistrust.

Quality of health care communication was found to be another problem as it caused poor understanding between health care provider and patient (Steinberg et al., 2006). In the absence of interpreters, providers very often turned to alternative inadequate forms of communication (Iezzoni et al., 2004; Steinberg et al., 2006):

- Speech reading (lip reading) was one of the most common alternative methods used, but was found inadequate in circumstances where face masks were used by health care professionals or situations where more than one health care professional was present for a procedure, observation or consultation. Other incompatible factors included hurried speech, not facing the patient while speaking, or having a foreign accent. Speech reading is a difficult process in itself as only 30% to 40% of the spoken English language is visible on the lips.
- Written communication was also found to be lacking because of the vocabulary used and the handwriting of health care professionals. Differences between syntaxes of the English language and ASL were also found to be a challenge for deaf patients. This is not surprising as the median level of deaf high school graduates in the United States is grade four or five. The Deaf Federation of South Africa estimates that the functional illiteracy rate of deaf and hard of hearing people in South Africa is 75% (Van Rooyen, 2009).

In addition to the above, Iezzoni et al. (2004) found that deaf interviewees felt that some providers did not respect their intelligence, motivation and desire to be actively involved in their health care understanding and decision making.

The most common way to overcome these communication barriers within a health care setting is the use of interpreters. Interpretation as defined by Pillay (1999) is the act of receiving a message in one language and sending it in a different language, making sure that the exact message is conveyed.

The deaf participants in the Steinberg et al. (2006) study, experienced positive attitudes toward health care services when communication was facilitated by a medically certified interpreter. Folkins et al. (2005) participants also recommended that the single most important improvement to health services, for them, would be the provision of not only interpreters but high level certified medical interpreters. What must be remembered however when working with interpreters is that all interpreters may not be formally trained and therefore not all people that are fluent in sign language will necessarily be qualified to work as an interpreter (Williams & Abeles, 2004). Health care staff that had some knowledge of ASL were also found to be better than nothing and the use of visual aids and extra time taken for explanations was also found to be helpful (Steinberg et al., 2006). Although family members can be utilised as interpreters, deaf individuals often felt that their privacy was being breeched and that they were excluded from their own health care decisions (Bat-Chava, Martin, & Kosciw, 2005; Steinberg et al., 2006).

Levin (2006b) recommends that interpreters be more widely and readily available and doctors be trained in working with interpreters during consultations. Doctors should furthermore be required to learn basic linguistic skills in the indigenous language of the area where they work (Levin, 2006b; Schlemmer & Mash, 2006) and be aware that medical jargon may not be readily understood by lay people with communication problems (Levin, 2006c; Mayer & Villaire, 2004). The deaf participants in the Steinberg et al. (2006) study echoed these recommendations by also suggesting that interpreters be used on a more regular basis and that providers learn some basic sign language.

To be able to implement the above recommendations it is important for medical students to be taught the subtleties of working with patients with hearing loss and to recognise the different communication

preferences that are associated with differing degrees of hearing loss, this will improve quality of service and reduce mutual frustration (Barnett, 2002).

2.4.2.2 Structural - Environmental barriers

Working within the guidelines of the health services framework Kroll et al. (2006) distinguished between structural-environmental barriers and process barriers (next subsection).

Structural –environmental barriers refer to conditions in the physical, social and economic environments, including facilities, equipment and insurance coverage which create inaccessible services (Kroll et al., 2006). For physically disabled patients, structural-environmental barriers are particularly salient as both the interior and exterior characteristics of the facility can create access problems (Kroll et al., 2006). These problems relate to disabled parking bays, ramps, doorways, doors, cramped waiting areas, inaccessible weight scales, examination tables, equipment (e.g. mammogram equipment) and unavailability of transport which is substantiated by a group of cerebral palsy patients (Kroll, Beatty, & Bingham, 2003). To improve health care services for the physically disabled it is important to improve physical access to facilities and equipment by constructing ramps, making disabled parking available, providing adjustable equipment and examination beds, to name but a few (Kroll et al., 2006).

One of the major environmental barriers experienced by independent disabled persons was transportation (Scheer et al., 2003). The use of public transportation is not always an option when the provider's offices are not close to the transport facility or when other health conditions may prohibit the patient from walking any significant distance. It may also be that these services are unreliable and patients miss appointments as they cannot control the timing of the transportation services. Scheer et al. (2003) also found that many patients would delay visits to health care services, often putting their health in jeopardy, as they did not find the facility accessible.

2.4.2.3 *Process barriers*

Process barriers refers to the interaction between provider and patient, which takes place within the health care setting, including lack of provider knowledge around issues of disability, lack of respect and lack of skilled assistance at facilities (Kroll et al., 2006).

Lack of provider knowledge and timeliness of services (including appointments) were also found by Scheer et al. (2003) to be relevant process barriers. Participants found that providers lacked knowledge on how to comprehensively treat a disabled person and struggled to look beyond the person's disability and treat the actual health concern of the patient (Kroll et al., 2003; Kroll et al., 2006; Scheer et al., 2003). As with other linguistic minorities Crawford (1999) and Levin (2006a) participants also felt that: a) providers did not readily understand the nuances of the Deaf culture and language, including the fact that grammar and syntaxes differ between sign language and English and b) interacting with office staff was a challenge, particularly waiting on your name to be called (Iezzoni et al., 2004). In addition to the above barriers, participants in Kroll et al.'s (2006) study experienced lack of sensitivity, courtesy and support during examinations.

Timeliness of services is always a contentious issue when it comes to primary health care services in any country, whether the patient is disabled or not and is an issue that relates to accessibility.

Consideration needs to be taken of the time it takes to reach the service, the actual waiting time between arriving and leaving the facility and time spent waiting for referrals (Sowney & Barr, 2004).

Law et al. (2005) indicate that the main concern from their participants with limited communication and their caregivers, was the issue of time. They felt that leaving little time for the consultation process could lead to indirect or direct negative outcomes for the patient. In another study participants found that they did not receive timely access to needed care by having to wait for appointments to be scheduled, conflict between job hours, hours of needed transportation and availability of providers and

insufficient time provided to attend to the full range of patients' needs (Kroll et al., 2006; Scheer et al., 2003).

To create a more disability sensitive environment, both physically disabled persons and deaf people, recommended that providers be educated about the medical needs, assistance needs and communication needs of the disabled (Kroll et al., 2006; Yousafzai et al., 2005). Deaf people felt that in addition, providers need to be educated about the sociocultural aspects of being Deaf (Iezzoni et al., 2004).

2.5 Health care information

In order to maintain a healthy lifestyle, one needs to have access to health education, health promotion and preventive services (Sowney & Barr, 2004). People with disabilities face inequalities in accessing health care information, with this kind of information being limited in Deaf communities and often information that is considered rudimentary in the general population is lacking in the deaf population (Barnett, 2002; Yousafzai et al., 2004). This area of health care has been neglected in the past but has found new fervour as a priority area, with the shift of responsibility for one's health to the individual.

Collaboration is needed within primary health care services to develop, deliver and evaluate health education programmes, making them more accessible to disabled persons and their specific needs (Groce, Yousafzai, & Van der Maas, 2007; Sowney & Barr, 2004). Consideration needs to be taken of those minority groups within the disabled grouping, such as the deaf, learning disabled etc. who have special requirements when it comes to the dissemination of this kind of information. These programmes should be easily accessible, timely, non-discriminatory, address gaps in knowledge, designed in the appropriate language and format and promote confidence in health care providers (Folkins et al., 2005; Pollard, Dean, O'Hearn, & Haynes, 2009; Sowney & Barr, 2004). Some suggestions are that the material must rely more on visual tools for example: pictures, video, role-

playing than written text and messages should be communicated by deaf peers (Bat-Chava et al., 2005).

2.5.1 Access to health care information

Where do deaf individuals get their health care information? Deaf and hard of hearing participants are less likely to receive preventive information from their health care providers or the media and more likely to receive information from the Deaf community (Tamaskar et al., 2000). Due to tightly knit Deaf communities, deaf individuals often get their health care information through the so called 'grapevine' (Bat-Chava et al., 2005; Groce et al., 2007). While this may be an effective means of information transfer, it is an informal source of information which is not always accurate and can lead to misinformation and gaps in knowledge (Bat-Chava et al., 2005; Groce et al., 2007). This informal information is reinforced by regular repetition from within the community and is very difficult for hearing individuals to challenge and correct (Groce et al., 2007). Despite the fact that very often information passed on in this fashion may not be accurate, Bat-Chava et al. (2005) found that in New York State, participants living in urban areas with large Deaf communities were more exposed to health care information about HIV/AIDS than other deaf participants.

One of the potential reasons for this tightly knit community could be the fact that approximately 90% of deaf children are born to hearing parents and struggle to acquire a language at home; therefore they choose to rather be associated with the Deaf culture where they receive support, than with their home hearing culture (Morgans, 1999).

2.5.2 Barriers to health care information

For many years, the focus of health care information has centred on the lack of access to HIV/AIDS knowledge, which can be considered a human rights issue (Yousafzai et al., 2004). Research undertaken in the developed countries of America and Europe indicate that deaf individuals lack access to this information, resources and services as a result of problems with communication, low

literacy rates, low educational level and close networks within the Deaf community (Bat-Chava et al., 2005; Folkins et al., 2005; Groce et al., 2007; Pollard et al., 2009). Groce et al. (2007) found that in Nigeria similar patterns existed, where there was a significant difference between knowledge around how HIV/AIDS is spread and access to accurate information between deaf and hearing individuals. Another area of concern is the lack of health care information among the deaf population with regards to cancer and cancer prevention interventions (Zazove et al., 2009).

As with access to health care services, communication and language appear to be the main barrier to accessing health care information (Bat-Chava et al., 2005). As deaf individuals rely on sign language as their primary means of communication, overheard conversations and mass media (radio and television) are generally inaccessible to them (Barnett, 2002; Groce et al., 2007).

Low literacy rates are another concern within this population, as even educated deaf individuals present with lower literacy rates than their hearing counterparts, this impacts on the understanding of diseases, instructions on medicine bottles and access to educational health information in magazines, newspapers and captioned television programmes (Bat-Chava et al., 2005; Groce et al., 2007; Mayer & Villaire, 2004). Health literacy has been referred to as the degree to which people have the ability to acquire, process and comprehend basic health care information and services in order to make suitable health decisions (Mayer & Villaire, 2004). Pollard and Barnett (2009) found that a sample of highly educated deaf people demonstrated a risk for low health literacy, therefore concluding that the general deaf population was at an even higher risk for low health literacy and associated health problems. In Nigeria, it was found that despite high literacy rates being reported, access to information via the printed media was still limited, which could indicate that functional literacy may be a problem (Groce et al., 2007). In another African country, Kenya, it was found that high levels of illiteracy and poor understanding of the official language among educated deaf people who were taught in English, lead

to poor accessibility of health care information that was presented on posters and other written materials (Taegtmeier et al., 2009).

With regards to the level of preventive health information, Tamaskar et al. (2000) found that deaf and hard of hearing individuals were less likely to believe that smoking less, exercising regularly, maintaining a healthy weight and annual check-ups were health benefits. They also concluded that deaf and hard of hearing individuals have unique traditions and beliefs, as with other linguistic minorities, which could influence their knowledge, attitudes, understanding and behaviours toward preventive medicine. These values and beliefs are a complex matter linked to the time hearing loss occurred (Tamaskar et al., 2000).

Differences between level of hearing loss and age were also found to contribute to access to health care information, with sign language users being less knowledgeable than oral deaf and hard of hearing and deaf adolescents being more informed than deaf adults (Bat-Chava et al., 2005). This could be attributed to educational level and English proficiency, with the oral deaf and hard of hearing having completed, on average, an extra three years of education with the majority obtaining a college degree.

Another area of concern for deaf people is their lack of knowledge about their and their family's medical history. From childhood onwards, conversations between their parents and providers could not be overheard and/or the family members do not use sign language so family health issues have never been communicated and they would often have lost out on vital information (Barnett, 2002).

2.5.3 Facilitators to health care information

Schools appear to be a facilitator towards accessing health care information, it seems that children have more access to health care information while attending school but once they leave school, information becomes less accessible (Bat-Chava et al., 2005; Groce et al., 2007). This was highlighted

in a Ugandan study where it appeared that disabled persons benefited from HIV/AIDS information that was provided in schools (Yousafzai et al., 2005).

In the sections above, we explored how the tight knit Deaf community can be a barrier to accessing accurate health care information, but this same feeling of community can also be a facilitator to accessing health care information. The need to belong to the Deaf community makes it important to train and support deaf individuals to become educators and outreach workers capable of providing accurate health care information through the 'grapevine' to members of the Deaf community (Groce et al., 2007; Tamaskar et al., 2000). This was reinforced in a study in Kenya, where it was found that peer led programmes were successful in engaging deaf people in health care information (Taegtmeier et al., 2009). This is promising as it creates a good option for increasing attendance at VCT sites across Africa. The only problem was that these efforts were hampered by four different signed languages being used throughout Kenya (Taegtmeier et al., 2009), this could potentially cause a similar problem in South Africa.

2.5.4 Recommendations

Educational material in written form is often produced and distributed to educate the general population about certain preventative methods, treatment protocols etc. that would benefit knowledge and understanding of various chronic illnesses (Pillay, 1999). This information will need to be adapted to more appropriate formats for those Deaf people who only communicate through sign language. In order to achieve this, one needs an understanding of the local Deaf culture (Yousafzai et al., 2005).

What remains undisputable, is that this population needs culturally and linguistically aligned material to cater for the larger deaf population; taking cognisance that needs may be different across this population i.e. between deaf and hard of hearing (Bat-Chava et al., 2005; Folkins et al., 2005).

2.5.5 Facilitators to health care information in South Africa

The Centre for Deaf Studies at the University of Witwatersrand, considers Deafness to be the single largest disability grouping in South Africa, estimating that about 500 000 deaf South Africans use SASL as their first language. Yet, this community has limited resources available to them about important issues such as HIV, health and human rights.

The Gay and Lesbian Archives (GALA) has developed an innovative new comic book called; Are your rights respected? to help the Deaf community access information about sexual violence, sexually transmitted infections (STIs), HIV and different sexualities in the Deaf community. The comic conveys the story of friends at a deaf school who try to find out about sexual health, and petition for their right to information. One of the most important messages conveyed is that they stick together after their friend becomes a victim of sexual abuse.

Very few words accompany the vibrant images depicted in the comic as every effort was made to mainly use SASL and illustrations to portray the message. It was compiled in this fashion taking into account the limitations in Deaf education, and the lower literacy rates often found among deaf learners.

GALA produced this comic as part of their Deaf Oral History Project and Outreach Programme and deaf people were involved in all steps of the process from co-ordination, use of SASL, artwork and feedback focus groups before the comic was finalized.

2.6 General language barriers to health access in South Africa

The diversity in cultures and languages within the South African context provides us with a situation where very often the health care system is mono-lingual and the patients come from within our multi-lingual society, creating communication and cultural incompatibility barriers to the health care

services that are offered (Crawford, 1999; Levin, 2006c; Penn, 2007; Pillay, 1999; Schlemmer & Mash, 2006).

The current language barrier problems experienced in health services are rooted in the political history of South Africa. With Apartheid, came suppression of indigenous languages creating a predominant English and Afrikaans environment that has been maintained in the health care services today, where most doctors are White (speaking English or Afrikaans) and most patients are Black (speaking a variety of different indigenous languages) (Crawford, 1999; Levin, 2006b; Pillay, 1999). Certain of the tertiary institutions in South Africa are attempting to correct this imbalance by introducing courses which focus on communication with patients whose language and culture are different from one's own (Levin, 2006c). These courses are not meant to be purely centred on linguistic skills but are also meant to give the students an understanding of different cultural concepts of health and illness.

Levin (2006b) found that parents of children being treated at Red Cross War Memorial Children's Hospital, regarded language and cultural barriers as more important to health care than the structural and socio-economic barriers they experienced, blaming their own limitations rather than that of the doctor. They found it difficult to understand medical terminologies, treatment protocols and diagnosis, fearing that this linguistic barrier would have a negative effect on their children's health (adherence).

Levin (2006a) and Penn (2007) further point out that medical terminology caused concern in patients who experienced difficulty in understanding terms, owing to the differences between terms Xhosa speaking patients use and those used by providers, due to culture-specific explanatory models of disease.

Schlemmer and Mash (2006), in a study of a district hospital in the Western Cape, found that significant barriers existed between Xhosa speaking patients and non-Xhosa speaking staff when it came to health care services. They documented that communication issues created an inefficient work environment, as the use of informal or unofficial interpreters interfered with other duties. It created

uncertainty with the non-Xhosa speaking staff about the accuracy of the interpretations. Other issues included lack of rights in terms of informed consent and confidentiality, negatively influenced attitudes between health care providers and patients and an overall dissatisfaction with quality of health care provided.

Crawford (1999) also draws our attention to potential access problems caused by linguistic barriers; no formally trained interpreters or use of nurses as interpreters, which could lead to errors or omissions' in interpretation, mismatched terms for illness, vocabulary differences between Xhosa and English and mispronounced Xhosa names.

Unfortunately, interpreting services are not the norm in the South African health care system and when a provider does need an interpreter they often turn to nursing staff, family or fellow patients (Crawford, 1999; Penn, 2007). This relationship may help alleviate some of the tensions in communication barriers but creates new tensions between health care staff, as the interpreting service is not well understood or defined and never evaluated (Crawford, 1999). The nurses have not received any training in performing interpreting services and the providers have not had training in using of an interpreter in the consultation process, untrained interpreters may lack certain language skills and commit errors leading to serious misrepresentations of meaning which may affect care (Levin, 2006c). In Crawford's (1999) study, a white doctor, who is fluent in Xhosa, eluded to this when he recognised the misinterpretation, mistranslation, and consequent misunderstanding that occurred on a daily basis between health care staff and patients.

Penn (2007) highlights that successful communication does not only depend on the training or experience of the interpreter but also depends on other factors including the type of interaction, illness variables and terminology, the relationship that evolves and the site of the interaction. Ultimately the care of the patient resides with the health care provider and in order to ensure good medical practice, the provider must also ensure good communication, as they overlap on many levels (Levin, 2006c).

2.7 Education and South African Sign Language (SASL)

SASL is the typical language used in Deaf-Deaf communication throughout South Africa and is linguistically different from any other spoken language in South Africa (Reagan, 2008). Although SASL is different linguistically from other languages it does not detract from the fact that it is considered a language in its own right, which is functionally capable of expressing human experiences (Reagan, 2008). Deaf people in South Africa therefore consider themselves to be a linguistic minority, with their own language and culture which parallels that of any other linguistic minorities (Aarons & Akach, 2002). Similar to estimated numbers in America for the culturally Deaf, it has been estimated that approximately 500,000 people in South Africa use SASL in their daily lives (Aarons & Akach, 2002; Williams & Abeles, 2004).

The problem in South Africa is that we already live within a complex linguistic situation and unfortunately deaf South Africans face a similar challenge which is embedded in this complexity (Reagan, 2008). Past political and social views on ethnic groups, distinguishing between White, Non-white (Coloured and Indian) and Black have played a role in the development of the educational system and the development of schools for the deaf which is closely linked to the history of sign language in South Africa (Aarons & Akach, 2002).

2.7.1 Brief overview of deaf schooling in South Africa

After South Africa was colonised the state took almost no responsibility for the education of the deaf and this responsibility fell to the church leaders of the time (Aarons & Akach, 2002). The first public school for white hearing children of Dutch descent was founded in 1663, but only in 1863, 200 years later was a public school established, by the Dominican Catholics, for deaf children of all races to be taught in signed English (Aarons & Akach, 2002; Simmons, 1994). By 1904 only two other schools for deaf children had been established in South Africa, one in Worcester and one in King Williams Town (Aarons & Akach, 2002). Worcester started to feature as a centre for deaf (and blind) children

in the year 1881 when Reverend De La Bat (Dutch Reformed Church), whose brother was deaf, opened the first school for deaf (and blind) Dutch (later Afrikaans) speaking White children (Heap & Morgans, 2006; Miles, 2004; Simmons, 1994). Over the next 50 years this school in Worcester was well established as one of the strongest schools (Miles, 2004). The main language of instruction was Afrikaans which was influenced by the British two-handed alphabet and named the Worcester Sign System (Simmons, 1994). In 1933, the Dutch Reformed Church opened another school in Worcester, for Coloured deaf children (Nuwe Hoop), with the same language policy as the De La Bat School, Afrikaans sign (Aarons & Akach, 2002).

In 1941 the first school for African deaf children opened its doors in the then Transvaal Province of South Africa. The first school for African deaf children in the Western Cape was only established in 1986, as a result of the scrapping of the Nationalist government's influx control (not allowing any African children in the Western Cape) (Aarons & Akach, 2002). By 1994 there were 18 schools catering for deaf African learners (Simmons, 1994) and by 1999 there were approximately 30 schools for the deaf around South Africa (Morgans, 1999).

2.7.2 SASL

Sign language is not universal and like other languages is developed naturally through the needs of a specific community, evolving further over time, in this way each country and even community develops its own sign language which is different to that of other countries, especially when countries are geographically and historically distinct (Aarons & Akach, 2002; Morgans, 1999). Residential schools create an optimal environment for this development to take place and from here it is spread into the surrounding Deaf communities.

Over the years these different schools' teaching medium has been influenced by the churches that were involved in their establishment, and some schools would rely on oral teaching mediums whereas others would be solely signed language and still others a combination of both (Aarons & Akach,

2002). The signed language of the communities was thus heavily influenced by the teaching medium in schools and since there is little historical history around SASL it is presumed that it was originally influenced by the Irish, British and American systems (Morgans, 1999).

As it stands we have 11 official languages in South Africa and according to Simmons (1994) sign language was developed within these groupings leaving a situation where there is no uniform sign language used in South Africa. For example, currently even within one race grouping, the white grouping, there is Afrikaans and English sign language. On the other hand Aarons and Akach (2002) feel that as deaf South Africans become more committed to the Deaf Culture, the question around whether SASL is one language or not becomes less important to deaf people. Although subtle differences in language are no longer seen as an issue in the Deaf communities, different ‘dialects’ exist across South Africa but the important issue is that, in general, different groupings within the Deaf community do not experience substantial problems in understanding each other.

2.7.3 SASL interpreters

Interpreters used in public service should be professionals who undergo standard training and are accredited by a professional board, abiding by a code of conduct and ethics (Heap & Morgans, 2006; Williams & Abeles, 2004). In South Africa the relationship between users of SASL and professional SASL interpreters is skewed. Heap and Morgans (2006) provide a breakdown of possible availability of interpreters in the South African context. There are only four interpreters that have been trained professionally and accredited by the South African Translators Institute. Another 15 to 20 interpreters have been accredited on the basis of their SASL fluency, experience and competence. Then there are an additional +/- 40 ‘grassroots’ interpreters who are not formally trained or accredited. These interpreters could include children of deaf adults (CODA’s) who are fluent in SASL or teachers of the deaf. Although these ‘grassroots’ interpreters may be fluent in SASL they are not trained interpreters and do not adhere to a code of conduct or ethics, which means there is no guarantee of privacy,

confidentiality or fee charged and they are not trained in medical terminology. Taking all these categories together, based on the estimate of 500,000 SASL users there is a ratio of 1 interpreter for every 7,812 users.

On top of this, interpreter services in South Africa are expensive and at a stage, DeafSA stipulated a minimum fee of R500, which means that a visit to a primary health care service would cost at least R500 excluding transportation to outlying areas, which is probably out of reach of many deaf South African's who generally have a lower socio-economic status (Heap & Morgans, 2006).

In summary, the deaf population face many challenges in accessing health care services and health care information, the most significant of these being communication difficulties, limited vocabulary and low literacy rates. The next chapter will focus on the methodology used in this study, highlighting interpreter issues experienced during the data collection phase.

CHAPTER THREE

METHODOLOGY

3.1 Background to the study

This small study forms part of a larger European Union funded project entitled “Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa” (EquitAble). EquitAble is a four-year collaborative research programme comprised of researchers from two European and four African countries. Each of the African partner countries represent distinct challenges in terms of equitable access to healthcare in contexts where a large proportion of the population has been displaced (Sudan); where the population is highly dispersed (Namibia); where chronic poverty and high disease burden compete for meagre resources (Malawi); and where, despite relative wealth, universal and equitable access to health is yet to be attained (South Africa).

Documentary analysis of international and country –level health policy will identify health policy aspirations and challenges; along with opportunities for alignment and harmonisation, between different stakeholders (work package 2). Intensive qualitative interview and case studies, along with behavioural observations will explore the experiences of healthcare users, non-users and providers, and feed into the development of a household survey instrument (work package 3). The extensive quantitative household survey will allow us to test models of access to healthcare, taking into account how the relationship between activity limitations and healthcare access is mediated by or interacts with, cultural, contextual and systems variables (work package 4). These work packages will constitute a much needed evidence base for health policy and practice in resource poor areas.

EquitAble also goes beyond the provision of information and addresses how to ensure that research evidence affects policy and practice: both within the EU and Africa.

In South Africa, 4 sites were chosen from three provinces: Northern Cape, Eastern Cape, and Western Cape. The sites and areas were selected to depict the high levels of inequality that is found in South Africa.

- Fraserburg (Northern Cape) – is a predominately Afrikaans rural setting with potential participants from all income levels. Disability is quite visible and the population of the area (predominately coloured) have an open attitude towards disability as ‘something that happens’ rather than a more spiritual or bewitching explanation of etiology. People with disabilities are integrated in a number of employment areas. Alcohol and the related disabilities (e.g. Fetal alcohol syndrome) is a big problem in this area. One clinic makes up the formal health care system of Fraserburg where a doctor is available every second week (functioning as GP and district surgeon).
- Madwaleni (Eastern Cape) – is a deeply rural area with many inequities, water and sanitation issues, poverty, tape worm infestations and almost each household has someone with impairment. There are high levels of mental illness (psychosis), combined with many people suffering from seizures. The Secondary hospital is embedded within the +/- 30 village system; with 8 satellite clinics around Madwaleni hospital (200 beds).
- Worcester (Western Cape) – Is classified as rural within the demographics of the Western Cape. Vast distances need to be travelled by many within the catchment area to access healthcare. It is also an agricultural area with many farm workers and therefore many related occupational injuries as well as a high prevalence of fetal alcohol syndrome as the legacy of the ‘dop system’ is still being practiced.
- Guguletu (Western Cape) – consideration was given to political reasons and the choice of an area that has not been overdone in terms of research. Guguletu is an old, established area and

has slipped off the radar screen in recent years with regards to research, as a township area, Gugulethu also has strong links to Athlone. Gugulethu also has high rates of TB.

For further information on the EquitAble project refer to the project website at www.equitableproject.org. This smaller qualitative study, which forms part of work package 3, took place in Worcester which is one of the four South African sites that were chosen for the larger EquitAble project.

3.2 Study aim

The first aim of this study was to explore the barriers and facilitators to health care services and the second aim explore the barriers and facilitators to health care information. Both aims relate to those barriers and facilitators experienced by deaf people living and/or working at departments/workshops of the National Institute for the Deaf (NID) in Worcester, which is traditionally a well-resourced area with regards to blindness and deafness.

3.3 Study setting

3.3.1 Worcester

Worcester is a rural town situated 96km outside of Cape Town in the Western Cape province of South Africa. The Western Cape is one of the most developed, topographically diverse provinces with the lowest unemployment rate in South Africa (Maart, Eide, Jelsma, Loeb & Toni, 2007). As Worcester is the largest town in the interior regions of the Western Cape it serves as administrative capital of the Breede Valley Municipal area which stretches from Rawsonville to Touwsrivier, an area of 2 995 square kilometres with a population of 146 029 (Statistics South Africa, 2005). It also acts as regional headquarters for most Provincial and Government departments, including a large secondary specialist hospital (Worcester Hospital), which services the greater Western Cape Winelands/Overberg region. It is a predominantly Coloured, Afrikaans speaking community, which is well serviced in terms of

sanitation, water supply and waste disposal, with 42% of the people employed in the Agriculture sector (Statistics South Africa, 2005).

Worcester is also well known all over South Africa as a town which caters for the deaf and the blind as the National Institute for the Deaf and Blind have been attending to the needs of the visually and hearing impaired since 1881. As the current study focused on the deaf population, the NID in Worcester was approached to take part in the study. This provided us with a sample covering many different subgroups within the deaf population as well as students from other African countries. The next subsection will provide further details on the departments chosen within the NID and a look at their policies and principles.

3.3.2 National Institute for the Deaf (NID)

3.3.2.1 Background and policies

The NID is one of the oldest (1881) and largest non-profit organisations and the only facility in South Africa and Africa that provides all services from early childhood to old age while safeguarding and promoting the interests, human rights and wellbeing of deaf people throughout South Africa and Africa. To realise this vision the NID provides a full continuum of programmes covering the whole lifespan of deaf people, for example, education, empowerment, rehabilitation, spiritual and social development, as well as providing guidance and support to parents of deaf children.

The Deaf community is often isolated as a result of communication barriers and therefore the main objective of the NID is *'to help the Deaf to help themselves, by striving to empower Deaf people to attain their full potential and take their rightful place as responsible citizens of South Africa'*

(National Institute for the Deaf, n.d.).

The NID is made up of various departments:

- Lewensruimte, provides deaf adult care in a mini-village setting comprising of group homes and workshops catering for Deaf adults with multiple disabilities,
- Two old age homes, provide deaf elderly care, in Worcester (Shalom) and Bellville (Rusoord),
- The NID College provides occupational skills training to its' students,
- De la Bat School provides early, primary and secondary education to deaf children from Grades R to 12,
- Two congregations for the Deaf in Worcester and Bellville provide spiritual guidance to the deaf community,
- Deaf Christian Ministry Africa (DCMA) is responsible for training Deaf spiritual workers,
- Centre of Knowledge, and
- The Tea Garden and Garden Centre are set up as business training units.

The NID follows a holistic approach to education, training, health and spiritual care and offers a wide variety of services, including:

- attending to inquiries from the public regarding deafness, Deaf communities in South Africa, Deaf culture, Deaf heritage and Sign Language,
- identifying and promoting Deaf awareness and other topics that affect the lives of people with hearing loss,
- identifying issues that are critical to people with hearing loss and then proceeding to set priorities, analyse policy options, make recommendations and take positions in unison with the Deaf communities, and South African and global experts,
- offering expertise in various areas such as education, rehabilitation, health care, mental health, training, accessibility and technology to Deaf people in Africa,

- administration of fundraising and funding of NID departments, and
- early identification, assessment and provision of hearing aids and assistive devices.

In this study we focused on participants and key informants from the following departments:

3.3.2.2 Lewensruimte

Lewensruimte (living space) for Deaf adults with multiple disabilities was established in 1978 as a therapeutic community which renders services and training locally, nationally and internationally to develop the full potential of Deaf persons with special needs. The idea for Lewensruimte was envisioned in 1947 when Rev. Gawie de la Bat bought a farm outside Worcester which was intended to provide training and work placement opportunities for low functioning and multiply-disabled Deaf school leavers. Although research and practice later showed that the farm could not achieve its' original goals, it opened the way to a long valued ideal when it was sold and the funds were used to establish a specialised programme for the multiply-disabled Deaf in a mini-village. In 1978 this aftercare centre was established to provide a residential and work environment for multiple-disabled Deaf adults in a protective environment.

Currently Lewensruimte provides accommodation for 65 residents in five different group homes, as well as additional accommodation in seven small flats. Each group home has a house mother who is responsible for the caring of residents, including health care.

The protective workshops provide work for the residents in for example ceramics, metalwork, handwork, and art therapy. Protective Workshops are intended to accommodate adults with limited work abilities where work is adapted to their level of functioning. Residents are first evaluated and then placed in an appropriate workshop in accordance with their aptitude, interest and choice. Some workers can deliver 50% to 80% of the open labour market production norms whereas other workers can only deliver 30% to 50% production. Every effort is made to rehabilitate and train workers to gain

greater independence and if possible to place them back into the open market.

The workshop has its own set of policies to be followed:

- Appropriate work and manufacturing activities are a human right,
- Workers have the right to access appropriate and affordable evaluation and training in order to optimise their true potential,
- Workers have the right to work according to their ability and potential, and
- Work is considered a powerful therapeutic tool to enhance quality of life.

Lewensruimte's mission is to:

- Create a therapeutic, caring community for multiple disabled Deaf adults, and
- Offer sustainable care, development and training programmes in the workshops, old age homes and Deaf community.

The philosophy followed is grounded in the Christian-reformed character of Lewensruimte and is maintained as follows:

- Religion is not an admission criteria, however
- Christian norms and ethics are maintained,
- The Deaf congregation (Worcester-De la Bat congregation) is considered the spiritual home of residents who wish to integrate. No resident will be forced to integrate with the congregation,
- Christian religious meetings will be held regularly,
- Weekly assembly is held as part of the spiritual development and maintenance programme,
- Although religion is not an admission criteria, Lewensruimte does not provide for any religion other than Christianity,

- Lewensruimte participates in the activities of the Christian community,
- Staff members are expected to respect the Christian ethos and character of Lewensruimte,
- Residents' religious beliefs are respected. Staff members must not attempt to convert residents to other religions, and
- Reasonable access will be afforded to members of other religious groups who wish to visit residents who are members of their church / faith.

3.3.2.3 Shalom Old Age Home

The NID is the only organisation in South Africa which provides social and 24 hour support/health services to elderly Deaf people. The NID services two old age homes for the Deaf. Rusoord Old Age Home for the Deaf in Bellville which was opened in 1995 and Shalom Old Age Home for the Deaf in Worcester which was opened in 2009. Our elderly participants were recruited from Shalom Old Age Home in Worcester.

Although the need for an old age home for the Deaf in Worcester was recognised many years back, the NID was not in a financial position to address this urgent need. The elderly Deaf made their voices heard which compelled the NID to start with strategic planning for an old age home on the NID campus.

Since the commencement of the building of Shalom, donors, sponsors and many hearing partners volunteered their products and services either free of charge or at a discounted rate to enable the building of Shalom to continue. The official opening of Shalom old age home took place in March 2009 and the first residents moved in, in April 2009.

Both old age homes accommodate elderly deaf people along the continuum of deafness for example: Cultured Deaf, deafened, hard of hearing, deafblind, physically disabled and multiply disabled Deaf. Staff provide daily social and support services and NID strives to establish a homely atmosphere for

the residents. The NID provides various programs and activities which are enjoyed by the residents. The NID ensures that the elderly Deaf are able to live in a secure, caring and Deaf-friendly environment.

The NID provides the following services to its' elderly deaf residents:

- Housing is provided at affordable rates to residents ensuring that they live in a safe facility where they can be part of a Deaf community and communicate in Sign Language,
- NID strives as far as possible to have all security measures in place so as to ensure the safety of residents at both homes,
- Communication systems are in place to support residents by way of lighting systems, visual posters, Sign Language communication, interpreter services etc,
- At each home a social worker is available to look after the well-being of residents,
- The ministers of both congregations are responsible for the spiritual care of residents. Staff members also provide support in this regard,
- There is a High Care Unit for the frail in Bellville, which is outsourced to a private medical organisation, that provides 24 hour services to the residents. Residents in Worcester also have access to 24 hour medical services which are provided by support services on campus,
- Residents can partake in weekly exercise programmes,
- Weekly games programmes and activities are available for residents,
- Excursions are provided every quarter including outings to: the zoo, Two Oceans Aquarium, Kirstenbosch Nature Gardens, Butterfly World, visits to dairy / wine farms, etc., and
- NID provides support to elderly Deaf persons with regard to transport and communication assistance during visits to, for example: clinics, hospitals, doctors, shops, banks etc.

3.3.2.4 NID College

NID College provides further education, occupational and skills training for Deaf students throughout Africa in a variety of study fields including: hospitality, construction, welding, and office administration.

The College provides accredited training which enables students to apply for job placements as well as have the opportunity to become full participating members of society.

3.4 Study design

In accordance with the larger EquitAble project, a qualitative approach, based within the phenomenological paradigm was followed for this formative study. Semi-structured interviews were used to facilitate the interview process and to ensure that similar topics were covered during interviews but also allowing the participants to express their own views and experiences (Bless & Higson-Smith, 2000). These interviews were conducted to gather personal recollections from deaf people regarding their experiences with regard to accessing health care services and health care information.

3.5 Instruments

Two semi-structured interview guides, one for deaf health care service users and one for health care service providers and key informants, were used to facilitate the interview process (see Appendix A & B). As discussed in previous sections (for example section 3.5.2), the deaf population has been found to present with lower literacy levels and limited vocabulary, therefore it was decided that interviews would elicit more in depth description of experiences compared to questionnaires. The semi-structured interview guides for users and providers were the same as those used in the larger EquitAble study. *Users* were conceptualised as people or households who use healthcare services within the study sites and these questions were formulated to explore the users' perceptions and experiences of their primary healthcare facility. *Key informants* were conceptualised as those people with a wealth of

knowledge about the healthcare system, and/or the site, and/or one of the vulnerable groupings in the area. The provider guide was mainly used to facilitate the interviews with key informants although depending on the role of the key informant certain aspects from the user guide were also included.

The user questions focused on: a) understanding of health, health related issues and health needs; b) issues around access to the health care facilities, including issues on patient satisfaction, transport and costs; c) the participants' understanding of vulnerability in general and their own vulnerability; d) additional questions for people presenting with a disability included questions on rehabilitation services and assistive devices. The provider guide broadly focused on a) an understanding of equitable healthcare access, vulnerability and disability; b) treatment of people with disabilities and knowledge of relevant policies and regulations; c) experiences of providing health care services at the facility, including job satisfaction, morale and challenges faced.

All interviews were digitally recorded with prior consent from participants.

3.6 Participants

Participants were made up of both users of health care services and key informants.

3.6.1 User population

The *user* population of this study were deaf people living and/or working at departments/workshops of the NID in Worcester.

3.6.2 Key informant population

The *key informants* were persons who had knowledge about the health care services provided in Worcester, the deaf population of Worcester and the area of Worcester.

3.6.3 Criteria of inclusion and exclusion

User participants had to be deaf (deaf or hard of hearing) and working and/or living at one of three NID departments (Lewensruimte, Shalom Old Age home or NID College) in Worcester. Hard of hearing participants were those participants who had hearing loss and could understand us and have a conversation without the help of an interpreter, although they were still offered interpreter services. Participants also had to have used formal health care services over the course of their life, preferably in the area and preferably public health care services, however participants that used private health care services were not excluded so as to understand whether experiences were similar between these two different types of services. Participants from the NID College were from other African countries and were also included to get an idea of whether barriers and facilitators for deaf people could be an universal experience.

3.6.4 Sample characteristics

Of the 16 users that were interviewed, seven were male and nine female. There were eight participants from Lewensruimte, six participants from the NID College, who came from South Africa, Zimbabwe, Dubai, Botswana and Zambia, the remaining two participants were residents of the Shalom Old Age home. The majority of the participants had severe hearing loss, while three participants were hard of hearing two of which did not use an interpreter during the interview process. Two of the participants were deaf and mildly intellectually disabled and one was deaf, blind and mildly intellectually disabled. In line with the larger EquitAble project the age of participants was divided into certain categories; 0-4, 5-14, 15-19, 20-34, 35-49, 50-64, 65-79, 80 and older. As six of the participants were interviewed from the NID College the main age group of the participants was between 20 years and 34 years of age. Five of the participants were aged between 35 years and 49 years, while one

participant was between 50 years and 64 years. The two participants from Shalom were aged between 65 years and 79 years.

3.6.5 Participant recruitment

As this phenomenological part of the overall EquitAble project was designed to elicit helpful qualitative information and to inform a more systematic survey looking for overall trends at a later stage, participants were recruited for this study by purposive sampling, with the help of staff at NID. Lewensruimte was approached to take part in the bigger EquitAble study and from there two other departmental heads of NID joined in with this smaller study (NID college and Shalom Old Age Home). The departmental personnel each recruited participants that they felt would be able to participate in this study and also explained to the participants broadly what the study would be about, obtaining provisional consent also informing them of a time slot for their interviews.

Three key informants were purposefully sampled for their specific knowledge of health care services in the area and the deaf population of the area. The breakdown of the key informants was as follows:

- A healthcare provider for many years with extensive knowledge of the health care system in the area and a parent of a deaf child,
- A CODA who was also one of the interpreters for our interviews, and
- A social worker and interpreter at NID with extensive knowledge of difficulties faced with the health care system, especially mental health.

In the end a total of 16 users and 3 key informants were interviewed. Details of participants are provided in Table 1.

Table 1*Study Participants*

Participant code#	Participant Type	Department of NID	Male / Female	Age category	Impairment
SA-170310-W-HU-BC	User	Lewensruimte	F	20-34	Deaf
SA-170310-W-HU-ML	User	Lewensruimte	F	20-34	Deaf, Blind and intellectual disability
SA-170310-W-HU-MM	User	NID College	F	20-34	Deaf
SA-180310-W-HU-JK	User	NID College	F	20-34	Hard of hearing
SA-170310-W-HU-JK	User	NID College	F	20-34	Deaf
SA-170310-W-HU-CS	User	Lewensruimte	F	35-49*	Deaf and mild intellectual disability
SA-170310-W-HU-CS	User	Lewensruimte	F	35-49*	Deaf and mild intellectual disability
SA-160310-W-HU-ML	User	Lewensruimte	F	50-64	Deaf
SA-170310-W-HU-ML	User	Shalom Old Age Home	F	65-79	Deaf

Table 1 *Continued*

Participant code	Participant Type	Department of NID	Male / Female	Age category	Impairment
SA-180310-W-HU-MM	User	NID College	M	20-34	Hard of hearing
SA-180310-W-HU-JK	User	NID College	M	20-34	Deaf
SA-180310-W-HU-SHB	User	NID College	M	20-34	Deaf
SA-170310-W-HU-JK	User	Lewensruimte	M	35-49	Hard of hearing
SA-160310-W-HU-ML	User	Lewensruimte	M	35-49	Deaf
SA-170310-W-HU-LM	User	Lewensruimte	M	35-49*	Deaf
SA-170310-W-HU-ML	User	Shalom Old Age Home	M	65-79	Deaf
SA-130510-W-KI-JK	Key informant		M		No known impairment
SA-170310-W-HP-SHB	Key informant		F		No known impairment
SA-270510-W-KI-JK	Key informant		M		No known impairment

Note: * reflects an estimation of the participants age. # participants code have been adjusted to maintain anonymity.

3.7 Procedure

Both interview guides used during the interview process were designed to be used during an hour to an hour and a half, face to face interview. Prior to interviews taking place, participants were informed about the study and consent was obtained, both to proceed with and to digitally record the interview.

All interviews were conducted in the preferred language of the participant with the assistance of trained interpreters, where needed.

All participants were provided with an interpreter unless they indicated that they did not wish to use an interpreter during the interview. Interpreters were either the participant's carer or staff members of the NID.

All interviews were conducted by the Worcester fieldworkers; 4 students of Stellenbosch University (3 Honours and 1 Masters), 1 international colleague from Sintef (Norway) and 2 fieldworkers from the Worcester area. All fieldworkers were trained before data collection on the interview process and the interview guides.

3.8 Interpreter issues

As was anticipated, language barriers were found to exist during the majority of the interviews as the participants' preferred language was either English/Afrikaans sign language which was unfamiliar to all interviewers and therefore interpreters were useful during these interviews.

Despite the fact that professional interpreters are supposed to simply create a conduit for the message that needs to be conveyed, Brunson and Lawrence (2002) concluded that interpreters caused a significant effect on the deaf participants' mood in a therapeutic setting. One of the reasons for this is that the participants maintain constant eye contact with the interpreter through the session and therefore are very aware of non-verbal cues from the interpreter.

Interpreters in our study were also found to be either facilitators or barriers to the interview process. At Lewensruimte the participants' carers were used as interpreters and the interviews were conducted smoothly. At the NID College there were two interpreters used, one with years of experience interpreting during class at the NID College and the other interpreter was a CODA. It was very evident during the interviews that the CODA interpreter created a more relaxed interview atmosphere

and the participants were more comfortable and more forthcoming with information. On the other hand the other interviews seemed not to run as smoothly with some disconnect between participant and interpreter. This became particularly evident in an interview which struggled at the beginning with the assistance of one interpreter, but when the CODA interpreter took over, the participant was visibly relieved and the interview proceeded more smoothly.

Most of the participants that were interviewed in these cases were participants from other African countries and because sign language differs between different countries and areas it was found that they were more comfortable with the CODA interpreter as this interpreter could easily communicate across these boundaries, whereas the other interpreter had to resort to finger spelling in certain circumstances. Another reason for their comfort with the CODA interpreter relates to the Deafness discussion in Chapter 2. CODA present a special case when it comes to Deaf cultural identity as they grow up with sign language as their first language which makes them eligible members of the Deaf culture, unlike hearing people that can sign or other deaf people who do not use sign language as their main form of communication (Reagan, 2008). This could explain the relative ease with which participants communicated with the CODA interpreter compared to the distance that was kept between participants and the trained interpreter. This phenomenon is something that may need to be considered by anyone who is doing research with deaf people and interpreters.

3.9 Data analysis

The digitally recorded interviews were transcribed into either English or Afrikaans for analysis purposes. The larger EquitAble project is committed to employing disabled persons in as many phases of the project as possible therefore these transcriptions were completed by the interviewers, as well as a visually impaired external party.

The data analysis was conducted with the use of Atlas.ti software. Emerging themes were used to categorise the data and formed the basis of our data analysis (Fereday & Muir-Cochrane, 2006).

Thematic analysis was used to identify, analyse and report themes in our data. This is a flexible approach to qualitative analysis which has the potential to provide rich and detailed data (Braun & Clarke, 2006). The study utilised both inductive and deductive coding, in line with thematic analysis as discussed by Fereday and Muir-Cochrane (2006). Deductive coding was used as a starting point to create a code book based on interview topics to provide a detailed account of certain aspects in the data (Braun & Clarke, 2006). Inductive coding was used while analysing the data to elicit themes from within the data itself providing further rich description of topics for discussion (Braun & Clarke, 2006). The themes that emerged from the data were compared to previous research in order to ascertain the extent to which themes in this study were similar to or different from what has been found in other studies (Pehlke, Hennon, Radina, & Kuvalanka, 2009). These findings will be discussed in the next Chapter.

3.10 Confidentiality and informed consent

3.10.1 Informed consent

Before conducting the interview an explanation was given to each participant about the aims and objectives of the study, the interview process and the confidentiality of the data that would be recorded. After this each participant signed the informed consent document. This signing or making of their mark on the letter of informed consent indicated that the participant gave consent freely, that the study was explained in full, that participation was understood to be voluntary and that the participant understood that they could withdraw at any stage without giving a reason. Participants were reassured that refusing to participate in or withdrawing from the study would not disadvantage them in any way. They were informed that they will not necessarily benefit directly from the project but that the data will be used to try and contribute to universal and equitable access to healthcare.

The participants were also alerted to the fact that, although the data was recorded and will be stored electronically, all personal identifying information will be removed during the transcription process to keep their participation confidential.

Consideration was taken of possible obstacles to the participants' understanding such as language, cultural differences, levels of literacy and cognitive functioning and therefore the consent form and other information was conveyed in such a way that the participants could understand it easily. All participants signed one of the two consent forms (user or provider) (see Appendix C & D).

3.10.2 Data protection and privacy

As the data collected in this smaller study will be used in the larger EquitAble study, data collection needed to follow the eight principles as stipulated in the FP7 Guidelines on Ethics, which are that the data will be:

- Fairly and lawfully processed,
- Processed for limited purposes,
- Adequate, relevant and not excessive,
- Accurate,
- Not kept too long,
- Processed in accordance with the participants rights, and
- Secure

3.11 Ethical considerations

The qualitative portion of the EquitAble study, of which this smaller study contributes to, has been rigorously reviewed and approved by the Health Research Ethics Committee (HREC) at Stellenbosch

University (see Appendix E). The vulnerability of the people we worked with was acknowledged and the potential benefit to the local community of our research was emphasised.

Professionalism is highly regarded throughout the EquitAble study and as such, it was expected of all interviewers to maintain the highest level of ethical behaviour and standards during the pursuit of this study. Joint research activity, training of researchers, work group peer review and review by the Project Management Group, all provide safeguards within the larger project to ensure that the highest ethical and professional standards are adhered to by all researchers and reduces the likelihood that ethical issues will arise.

The next chapter will provide details on the results of this study.

CHAPTER FOUR

RESULTS

The results of this study will be presented under the following broad headings: deafness, participants' understanding of health, communication barriers to health care services, structural-environmental barriers, process barriers, patient satisfaction and perception of health care services, health care information and health knowledge, recommendations to improve health care services and information, institutional support and sign language and interpreters. The results from the deaf participants and the key informants are not split in this Chapter as the responses from both perspectives overlap quite extensively and the key informant responses add weight to the experiences of the deaf participants.

In Chapter 4 I have decided to use extensive quotations to give a good flavour of the quality and range of responses. In addition, in order to preserve the idiomatic nature of talk, I have decided not to translate the Afrikaans quotations; however for purposes of publication these quotations will be translated into English.

4.1 Deafness

As indicated in the literature, there is a continuous debate around deafness, Deafness and disability. What is interesting in this study is that none of the deaf participants themselves referred to Deaf Culture or issues around disability/non disability. The key informants on the other hand were the ones to provide us with insights into the Deaf Culture in order to illustrate points around health access and understanding of health information.

The key informants reiterate the sentiment that deaf individuals prefer to be considered a linguistic minority as opposed to being considered disabled, in the sense that they do not suffer from an ailment that needs to be cured. From this standpoint we are reminded that certain fragments or people within the Deaf community do not view cochlear implants in a good light:

P: It's a very big problem, and I think it starts because there are a huge number of misconceptions amongst the deaf. Many people think that you can just put the deaf into the same group as disabled - but you can't, because they like to call themselves a linguistic minority. But there are so many things that are completely different so that you can't just lump them together and say, you know, they are just disabled.

P: ...We're a linguistic and cultural minority, why do you want to change us. Leave us. Respect us. Don't try to heal or cure us with cochlea implants.

While the tightness of the Deaf community can be positive in strengthening their position as a linguistic minority it can act as a barrier to health care services, particularly HIV testing and the facilitating of inaccurate health information that is learnt via the 'grapevine':

P: ... the deaf community is very small, so news spreads really quickly - and that is what they are all afraid of. So we do have a team from the clinic or somewhere coming here to do the testing, the boys and the girls on separate dates. But only those who are a hundred percent sure that they are safe, they will do the testing. Those that are unsure, won't do it. Because the others are sitting out there, so you come in here and they do the test, they see you are HIV-positive, and then how do you get out of that door without everyone seeing that you look a bit different now. You look a bit down. Is there something wrong? Oh, he just had a test, that means ... aah.

What has been observed by one of our key informants, is that although deaf people are very strong in their beliefs, that have been reinforced by the close knit Deaf community, they also lack independent thought and merely accept new information without questioning, unless it goes against these beliefs. This is evident in college classrooms and spills over into the health care setting, where in the individual interviews we found that many participants just accept medication the provider provides or procedures to be carried out, without even questioning or understanding what is transpiring. This lack

of independent thought and questioning in the health care setting has close links to communication problems and participants lack of knowledge of their own medical history:

P: But it was very interesting, for me, the way that many of the deaf people here just accept everything and just go on and just say, oh, okay, no, that's fine. If it's a hearing person telling me that, they must be correct because the hearing people know everything. Just this morning in class we were testing, it's a class we have called life skills where we try to develop their thinking and independent thought, so what we do, we ask them what does a butterfly use to taste. Then we say, no, a butterfly uses its feet to taste with. Did you all know that? No! No! We didn't know that. And then you just wait a little bit and then you ask, is that true? Then they go, mmm ... if you didn't ask them whether it was true, they would have believed you solidly. And as a matter of fact, it is true. None of the students in our college have gone through that exercise and said, what! Are you sure? That's ridiculous. Really? They all just said, wow, taste with their feet. They go and talk to each other, but they never question anything - and that's exactly the same thing when they come to the hospitals.

This lack of understanding could be very difficult for a health care provider to pick up and address, especially when the person does not acknowledge that they don't understand what the provider is trying to say. Issues around shyness, lack of confidence or fear to appear ignorant are some reasons provided for this reluctance to ask a provider to repeat themselves or explain in an easier manner. We again find that this misunderstanding could come down to communication problems, in that the provider unknowingly could be using more difficult terminology which is not understood by someone with a limited vocabulary:

P: They are either too shy or not confident enough, or afraid to show their ignorance. I don't know, but they just don't say, I'm sorry? I don't understand. Please explain? Maybe, we

should even make a set of flash cards: I don't understand. Please explain. The words are too difficult. Use other words. But they just don't do it.

4.2 Participants' understanding of Health

Included in our questionnaire was a question around the meaning of health, measures one would take to remain healthy and bad health or being unhealthy. Many participants found this particular question very difficult to answer and struggled to elaborate on their answers, however they did touch on some important concepts of health.

In line with the more negative definition of health, some of the participants considered health to be the absence of disease, or bad health to be the presence of illness:

P: Die inwoners het siektes en probleme.

P: Ongesondheid is as jy doof en siek is.

Social well-being of the person was also considered to be an important factor in determining good health, including a person's relationship with their family and other members of the community.

P: 'n Mens moet sport doen, met ander mense kommunikeer en baie sosiaal verkeer. Dit is belangrik om sosiaal te verkeer sodat jou gees gesond kan bly. Dit beteken as mens se gees gesond is. 'n Mens moet mekaar help. Jou familie hou jou gesond, jy moet bybel lees, sosiaal verkeer en sport doen

P: To have friends... To have support for the deaf.

One participant pointed toward anger as a key sign of an unhealthy lifestyle and acceptance of all people as an essential component of living a healthy life:

P: Die inwoners word maklik kwaad. Die inwoners raak kwaad vir sommige werkers aangesien hulle nie ook op die perseel bly nie...Toe ek hier begin werk het was almal kwaad

vir my aangesien ek 'n nuwe werker is en ek nie op die perseel bly nie. Mense moet mekaar aanvaar en dit is hoe hulle gesond sal bly.

Emotional well-being was considered by some to be representative of good health, one participant providing a detailed account of how she misses her grandmother which makes her 'unhealthy':

P: ...as jy koud, bekommerd is as jy nie meer vriendelik is nie, as ek nie gebare verstaan nie, as ek sleg slaap, as ek dink aan mense wat dood is, begrafnisse, bekommernisse, jy het dan nodig om aanmekaar te bid. Dit raak beter as jy bid. Maar dit gaan weer af met bekommernis. Slaap in die aand dan weer wakker, warm in die nag kan nie slaap nie, bene wat kramp, gaan toilet toe in die nag sukkel om weer te slaap. Drink water in die oggend, bly vaak, drink water om wakker te bly. Dan huil ek, dink terug aan ouma, familie wat ek soek wat ek nie kry nie, probleme binne in wat vir my frustreer, spanning wil nie beter raak nie, drink baie water, dis belangrik. Dink ook aan die broer en suster en baie aan ouma, sy het my groot gemaak, mis haar baie.

Some of the previous quotes have touched on the understanding of health within a religious context. There were a few participants who considered health in light of its connection with spirituality in their lives, including faith as a means to overcoming health conditions. One hard of hearing participant tells her story of how her family's faith made her hear and speak after being unable to do either as a result of her mother's illness (measles):

P (who is hard of hearing): ... but what I believe is when I was born I used to can't speak and can't hear and what I believe is that there is God, something like that, there is God but all my family they are Christians so they believe that there is God they used to pray and have faith, if it is God's will to make heal if he want me to speak and if he want me to work it is only Gods will so they pray and have faith, so the reason why I am hearing is a gift from God, if God want me to be deaf, yes I am, if God want me to be half hearing, yes here I am, ja but it is not

but maybe sometimes it is because of my mother's background, illness, like measles something like that is affected me so this is why I can understand the reasons

Participants also provided some thoughts around what a person should do to remain healthy, these ranged from drinking water, healthy eating habits, exercise, acceptance of your problems, and medication:

P: Drink water, as jy probleme het moet jy dit aanvaar en aangaan met jou lewe

P: It's important that you can work if you are healthy and take care of your health drink a lot of water and take care of your life. You must live right.

P: If I am healthy then I will wait until I get flu and then drink some tablets. I like walking a lot, resting and being active.

P: Eet gesond soos eiers en kaas. Jy moenie te veel eet nie, want dan kan jy ook siek raak. Oefening is ook baie belangrik, 'n mens moet baie gaan stap.

Despite the fact that deaf participants struggle to access health care services independently, due mainly to communication problems, some still acknowledge that an important part of maintaining your health is seeking out health care services when need:

P: Elke persoon moet gereeld dokter toe gaan, jy moet gaan stap en pille drink as jy siek is

P: Health is very important to people, to keep themselves healthy and to look after themselves healthy if you are not feeling well it's very important for them to go and see, see the doctor so that the doctor will be able to explain what the problem with their healthy so that they can be able to get better healthy.

4.3 Communication barriers to health care services

Communication is a necessity in providing quality health care to all. The results of this study indicate that communication problems are the most significant factor affecting access to health care services for our deaf participants. Communication barriers arise as the first language of participants is sign language and the language mainly used in health care settings is English or, in our study area, Afrikaans. Communication problems appear to be a general barrier for deaf people across different African countries, as the college students also reported communication to be their main barrier to health care access in their countries. Although most of the college students could use alternative forms of communication, for example writing, they still experienced a barrier to accessing health care services as providers in their countries were not proficient in English which is the main alternative language for deaf people in Africa:

P: The tribe ... they are not English. The language they speak, I don't know. I can only read English. The tribe is the Bemba tribe. They write, and I don't know the language that they are writing in.

P: ...but yes for me I am lucky because I, I can be able to hear so, so the problem is sometimes the doctor does not know how to speak English some they speak like in Zimbabwe they used to speak Ndebele, Shona because of Zimbabwe character language so with me I speak English but it is difficult...

Miscommunication can lead to, for example: feelings of being misunderstood, treated as intellectually inferior, stress, being uninformed about your health and concerns about possible errors in diagnosis and treatment.

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

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

Communication problems can create an invisible barrier between the people that are trying to communicate and as a result of this barrier, participants perceive that health care services misuse deaf people, that providers are scared of deaf people, that providers do not listen to the concerns of their deaf patients, that providers find it easier to simply ignore deaf patients and not provide them with all the information that they need in terms of treatment and diagnosis:

P: Die dokters en verpleegsters verstaan my nie altyd nie. Baie dowes voel ook dat die hospitaal dowes misbruik. Dowes kry nie altyd die inligting wat hulle nodig het nie..... Sommige dokters is bang vir die dowes, hulle is bang om met dowe mense te kommunikeer. Die dokters verstaan nie altyd wat die dowes praat nie. ...Ja, die personeel moet bietjie die dowes ook in ag neem. Die personeel moet vir dowes verduidelik wat aan gaan. Soms maak dokters en verpleegsters of jy nie eers daar is nie. Dit laat 'n mens sleg voel. Jy is siek en jy sal graag ook wil weet wat fout is met jou.

P: Ja, dokters kan nie altyd dowe mense verstaan nie, so nou is dit makliker om hulle te ignoreer.

Many of the participants have complained that providers supply them with medication, without providing any reasons or any information on dosage. They are in the lucky position that the NID provides additional support to its residents and many times providers will send the medication to the hostel/home and the sisters will have to explain to participants how to use their medication:

P: Die dokter gee ook soms pille sonder om te verduidelik waarvoor die pille is en dan werk die pille nie eers altyd nie.

P: Nee, die dokter verduidelik nie eintlik vir my nie. Hy stuur die medikasie na die ouetehuis toe en dan verduidelik die suster vir my hoe ek my medikasie moet drink.

A few participants mentioned the problem of continuity. Continuity facilitates the building of a relationship between patient and provider; this relationship can facilitate better communication as the provider becomes accustomed to the communication preferences of their patients. One participant explains how the providers in her old towns of Springs and Boksburg took the time to understand her needs better and provided her with medication that worked, now she has moved to Worcester where she does not have a relationship with a specific provider and she is misunderstood, which is evident by the fact that the providers prescribe medication which ‘does not work’:

P: I don't know the time was changed there was different maybe I come here and there is a different woman doctor next time I come then there is a person I can speak to

P: Ja, die dokters in Springs en Boksburg het my baie goed geken en al my probleme verstaan. Dit is vir my moeiliker in Worcester om mediese sorg te kry...Die pille wat die dokters in Worcester vir my gegee het, werk glad nie en die dokters ken my nie so goed nie. Toe ek in Johannesburg gebly het, het ek altyd beter gevoel, maar die dokter by Worcester gee vir my die verkeerde medikasie. Die pille laat my nou swak voel en ek is allergies daarvoor.Ek het hoë bloeddruk en die pille wat die dokter vir my gegee het werk nie, want ek het die heelyd pyn.

Owing to communication problems, most participants find waiting rooms to be particularly stressful. They cannot relax and wait for their number/name to be called as they cannot hear and many times could miss appointments. This was also a problem for one of our hard of hearing participants who found that he could not hear when his number was being called over the intercom as the person always spoke unclearly and the waiting areas are crowded and noisy. This particular participant always asks the patient next to him to listen to the numbers/name and inform him if his is called, or he

would simply ask the person what their number is and when he sees them getting up he will follow them to the relevant window. This appears to be a problem with waiting areas in general and not a difference between public and private services as one key informant relays a story of a staff member who sat at a private facility for over an hour waiting to be called only to miss her appointment:

P: Dit is vir my baie probleem ek kan nie uitmaak as iemand roep nie, dan sê ek altyd vir die persoon langs my as hulle roep E sê vir my want ek kan nie uitmaak wat hulle sê oor daai luidsprekers nie. ...as ek nou sit met 'n nommer, hulle sê mos nou nommer soveel tot soveel kom en nou praat die ou soms baie onduidelik want daar is soms so baie geraas almal die mense wat praat, echos wat die hele plek rondbons, jy kan nie uitmaak wat die ou sê nie...

P: One of our staff met the doctor, and she had an appointment at 12 o'clock, but they used an intercom system. So they called the name on the intercom at 12 o'clock and she didn't hear it. She is deaf. She can't hear that. So she was sitting there until one o'clock. She got up and she went to the lady at reception and said, listen, my appointment was for 12 o'clock. I have been sitting here since quarter to 12. It's now one o'clock. What! Didn't you hear they called you? You have missed your appointment. Hello, I'm deaf. I can't hear when you call me on the intercom. People don't make that connection immediately.

P: Wat dan gewoonlik in die hospitale gebeur is dat 'n dowe se naam sal geroep word oor die intercom, nou dink hulle die person is nie daar nie, die een wat 'n tolk het kan nog vir hom sê dis jou beurt om te gaan, maar die een wat nie 'n tolk het nie, hy wag en wag vir ure want hy weet nie dat sy naam geroep word nie want hulle gebruik 'n intercom stelsel en die dowe kan dit nie hoor nie.

Making of appointments at health care facilities is another problem area experienced by deaf participants, which again is much more problematic as they cannot hear and struggle with

communication. Participants try alternative methods like email, sms, or fax but find this does not always work, so they have to rely on other people to make an appointment for them:

P: Ek sms my skoonma dan bel sy die dokter om vir my 'n afspraak te maak.

P: Ek stuur 'n sms, 'n faks, 'n e-mail of die werk bel sommer vir my part. Dit het al gebeur dat ek ge-email het en 'n faks gestuur het, maar die spreekkamer het my nie geantwoord nie. Dan moet ek altyd iemand vra wat vir my part sal bel. Doves kry altyd laaste 'n afspraak.

P: My mother will go with me and make an appointment because it is difficult for me to go alone and communicate so she will be able to help me

In the first section of this Chapter, a key informant introduced us to the idea that deaf people often do not have the confidence to tell a provider that they do not understand what is being said during a consultation. Many of the participants have confirmed this by indicating that they often do not understand what their diagnosis is and when they do not understand what the provider is explaining they simply answer 'yes;' to their questions:

P: Soms praat hulle met my, maar ek kan hulle nie altyd verstaan nie, dan antwoord ek maar net "ja" op alles wat hulle sê.

P: I went to the hospital, did my writing, sat across from the doctor and he said, so what is the problem? And I wrote something, and he then sent me to have an injection - but I don't know why. But I don't know if I had an illness ... or why ... I don't know.

P: And that they say they come to the hospital, they don't ask what is my medication for, why this and what that. They don't ask anything. They go there and they just accept the treatment that they are given, and then they say, no, that's fine. It's fine

For some participants the use of a hearing aid would facilitate communication between patient and provider however it is found that for varying reasons deaf persons do not want to use this assistive device:

P: No. It's also, some people prefer not to use hearing aids.

P: I am tired of hearing aids because you know when deaf people say yay yay (imitates deaf sounds) it is too much noise, but it helps very well it's very good to help but if I am in the class, ja, it is good to help but I like sit in front I can hear very well, not at the back, at the back I will have problems.

P: Nee, Dit raas te veel, hou nie daarvan nie.

P: It was also the protest, you know, this nonsense about deaf people are being okay and needing to have machines to help them to hear, is nonsense....No, the school switched to sign language - so she wasn't forced. She wasn't in a context where she was forced to use a cochlea implant. She switched it off!

Despite all the problems with communication, most participants still reported that the health care staff were respectful, friendly and helpful. One participant provides an observation of how busy staff are at the Worcester Community Day Centre, running around up and down the whole day:

P: Ja, hulle was baie gaaf en behulpsaam. Die dokter het my ook baie vinnig gehelp.

P: She says they were friendly she says....she says that they very calm with her and easy because she tells them she's a deaf person and then they help her and tell her she must wait a little bit.

P: Die mense help my mooi, die hospitaal is ook skoon en netjies. ...Ja, hy het alles baie mooi aan my verduidelik.

P: maar as daai ou nog 'n wit stok in sy hand het wat erg swak siende is dan sal, het ek nou al gesien dan sal een van die pasiënte help daai persoon of die ou by die security help daai persoon om te kom dat hy 'n stoel....die verpleegsters wat daarso is, jy sien net dat hulle die heelyd op en af, orals heen en weer...

4.3.1 Alternative forms of communication

When communication problems are experienced in health care settings many providers try alternative forms of communication; the most commonly used alternative forms are writing and speech reading.

While these are valid alternative forms of communication used in many different countries, one of the biggest obstacles to using writing as a form of communication is vocabulary. As English is the second/third language of deaf people, their vocabulary is not of the highest standard, especially when it comes to medical terminology. Adding to this problem is the fact that an estimated 35 out of the 40 schools for the deaf in South Africa only provide education to a grade 7 level. In order for writing to be an effective form of communication, providers need to understand how to simplify their vocabulary to a level understood by deaf people. Despite medical terminology being a problem in writing, as a form of communication even simple terms like urinate are often not understood by deaf people:

P: ... they just rely on writing to one another but many of the deaf don't understand the vocabulary. They don't completely understand.

P: Before, when I was in Zambia, I had lots of trouble with the medical system there because it's difficult to communicate, and many of the deaf people there can't write English....The nurses often write ... but they use these big words - difficult words - and then they write to you and you don't understand. Then you just stay sick and hope you get better.

P: they write English but the problem with deaf people they are not good in English that is the truth, they are not very good English but you have to write simple English that can make them understand.

P: ... their English is not on a level where they would be able to. I mean, we have students here who have a matric certificate, right, but they can't write English. They wrote English as a subject in grade 12, but they can't write English. I mean, he writes ... just this morning, he was actually sitting here ... and he would write ... instead of saying the problem with this message is, he would say, message problem has.

P: ... But I think there are 40 schools for the deaf in the country, five in the Western Cape, and I think something like five have got secondary schools. So 35 goes up to standard 5.

P: ... And he says when he writes to them and they write back, they write all these big words that he doesn't understand. So the famous fall-back is just write to each other, but that also doesn't work....For example, my father in the hospice just writes to the nurses there. Now, they ask him ... it's maybe a little bit crude, but never mind ... they ask him to urinate in a bottle and he doesn't know what urinate means. You know, it's a general word that people know - but he doesn't know. So I tell them, just write pee, he will understand that.

Many residents at Lewensruimte (one of our study sites) are described as intellectually disabled which impacts their ability to read, write or lip-read, limiting their communication to sign language:

P: But with our people, because they are mentally disabled as well, many of them can't read and write. So the communication is very basic. They can't lip-read, so they don't understand the type of words that the people use.

Most people assume that all deaf people can lip-read but this is not the reality, speech reading is an advanced skill which is complicated by the fact that many similar words appear the same on a person's lips:

P: En mense aanvaar net almal kan lip lees, almal kan nie lip lees nie. Spraak lees is `n baie gevorderde vaardigheid, so nie al die mense wat doof is kan spraak lees nie, hy kan, nie baie dowes kan spraak lees nie. Ook baie woorde op die lippe is dieselfde soos mamma en papa, wat sê ek nou, mamma of papa. Dis moeilik, dis wat ons vir mense probeer verduidelik praat stadiger as `n persoon kan lip lees, maar meeste van die tyd skryf. Die meeste dowes kan lees en skryf, as die persoon nie kan lees en skryf nie, is dit nie omdat hy doof is nie, maar omdat hy verstandelik gestrem is. Mense dink dowes, o, niemand kan lees en skryf nie, dis nie die waarheid nie. Dowes is dieselfde as ons horende mense, die problem is meer jou verstandelik gestremde.

For those participants that rely on speech reading as a form of communication, further barriers are experienced when there is light behind the provider and when the providers speak too fast, unclear, or look down while engaging with the deaf person:

P: Baie van hulle weet nie as 'n mens gehoor probleem het nie dan kry jy so byvoorbeeld kom jy by die dokter, die dokter hy is hier by die lêer (looking down at file in front of him on desk) dan sit ek daar (opposite him) hy praat hier met die papier ek sê vir die dokter, dokter asseblief, ek kan nie jou mond sien nie, die venster wat daarso is skyn lig in dan sit ek daar, daai lig skyn vol in my oë ek kan nie eers jou gesig sien nie as hulle die venster kan toetrek, sit die lig aan en kyk na my as jy met my praat, ek kan nie verstaan wat jy sê nie, jy praat binnemonds praat duidelik asb.

P: They talk very fast. If the person talks very fast then I show them slower.

4.3.2 Dependent on support

Strongly linked to communication barriers is the need of deaf participants to have accompaniment in order to access health care services and aide communication. This dependency creates other problems for them as they have to fall in with the schedule of the other person and sometimes have to wait for an opportunity before they can visit a health care facility:

P: Kommunikasie is 'n groot probleem en daar moet altyd iemand saam gaan om te tolk. Ek moet altyd wag tot my ma tyd het om saam met my dokter toe te gaan. Ek kan nie op my eie in my eie tyd gaan nie, ek kan net dokter toe gaan in die tyd wat my ma pas.

P: Oh, he is very independent - or used to be. But going to the hospital ... I mean, if you're going to the hospital and you have a flu, that's fine, you can find a way, but if you go to hospital and you have an advanced illness, how ... it's not possible. No, no way. So my father is lucky in that he can have lots of interpreters going with him. But someone else, I don't see how ... they would never be able to do this on their own.

P: Dowes is afhanklik van ander mense. ...Dit is moeilik, want daar moet altyd iemand saam gaan.

P: Ja, want daar is nie altyd iemand wat saam met my dokter toe kan gaan nie Ek wag tot een van die susters tyd het om saam met my dokter toe te gaan.

This dependency, combined with lack of confidence on the part of the deaf person, can lead to non-utilisation of health care services when needed:

P: Last year at home (Langa), I was at the hostel but I went to the hospital for teeth take out, my sister go to work I went alone to hospital, I felt very shy, how can I communicate so I went back home, so the next day my sister went with me to the hospital and the sister explained everything and she said that she was shy so the sister explained everything it was better. ...I

stayed alone long time and I waited until five o'clock and I told the doctor please change the date because I am alone, I feel afraid of the doctor so they made a new appointment so I went home, my sister asked why I was so late until five o'clock, it's for the doctor he need the sister with me I cannot go alone... I was confused, the people they was many pregnant women how did I know which one was the dental problems and the pregnant problems so I felt afraid.

Depending on the living conditions of our participants, support is provided in the form of carers and interpreters by the staff at NID, which covers the College, Old Age Home and Lewensruimte participants. Family members and friends provide additional support when residents are off the NID grounds and some participants find support at health care facilities where they rely on fellow patients:

P: Ja, No I went with my friends mother she took me through, took me to the doctor so that she can make sure that communication is going well.

P: My mother will go with me and make an appointment because it is difficult for me to go alone and communicate so she will be able to help me...

While some residents are lucky, in that their family can communicate in sign language, other residents are in the unfortunate situation that they cannot rely on their parents or family members for support as they have never acquired the language or have limited sign language which is insufficient to provide the necessary support:

P: ...Me and my little brother, we would mostly sign a little bit, talk a little bit and write a little bit. My younger brother, he can at least do the alphabet, so if something is difficult, he can spell the word for me....I also explained that they also have problem at family at home, like communication, they don't have communication with the family, like when you wake up in the morning, just say hi, but don't explain what is happening what is happen not to make them laugh or have some fun, you know it is quiet at home with deaf people because you know why,

I seen many, many deaf children they are complaining their communication with their family is having problems.

P: The parents don't know how to sign so its difficult for the deaf children, very, very difficult so its that like, hi, simple sign language cause parents they cannot be able to sign, or something that is difficult to sign...

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

P: My home, my life I don't it is normal for me because why I am the only deaf person, communication, many communication barriers, some don't understand me different ways from Worcester, I feel in Worcester my life is OK, Ok because there is a lot of communication but it is different from home.

This dependency on support to facilitate communication is a problem for all deaf people entering the health care setting, but has been highlighted as a particularly difficult situation when it comes to psychotherapy. The therapeutic environment is interrupted in many ways by the addition of an interpreter, which unfortunately is a must in most cases, even if alternative forms of communication are considered it would be less therapeutic if the whole session had to be written between the therapist and the patient:

P: Because even with the thing of a psychologist, if they now really have this huge problem and they want to speak to a psychologist in private -they can't because there is no communication. They can't write the whole interview the whole time ... so again, interpreters must be available.

4.4 Structural-environmental barriers

4.4.1 Socio-economic factors

Socio-economic factors can have an impact on a person's overall health by creating living conditions which are not conducive to a healthy lifestyle. Accessing health care services is also made more difficult by not being able to afford transport to the facility, opportunity costs related to waiting times at primary health care facilities or cost of treatment when it is not covered by the government. Socio-economic factors also limit the choice of facilities and services a person wishes to attend, especially the choice between private and public health care services which will be discussed in the next subsection of this Chapter.

Unemployment is a significant factor in the lives of deaf people, communication problems and below par education are seen as reasons for the high unemployment rate. Communication problems challenge the whole employment process, while lack of adequate education limits the job opportunities available to this grouping:

P: ... one, deaf people don't go to college they don't like college where to have a better education, two, deaf people have no job they are always outside begging money, three, deaf people they always sit at home, sometimes, sometimes may they want money to get their way but they can't afford, five uhm they can't get a job like working wood work, sewing, but the people at work place don't accept deaf people but why because they got poor communication.

P: 90 percent of the deaf are not employed because they haven't got that schooling background and so on. So ten percent are employed.

None of our deaf participants had employment on the open market. One key informant, working at Lewensruimte, acknowledged that while they strive to empower their residents with different skills,

very few will be able to work in the open market as they are most often also slightly intellectually disabled. These residents live off their social grants and do extra small jobs for money:

P: ...So we really try and focus on development, but many of our people will never be able to work in the open labour market because of the severity of their disability. But we really try to strive that they ... if they can learn to tie their shoelaces, he can do that. If he can learn to make porridge, he should learn to do that.

P: They get pension the state pension. And she makes pretty cards, she makes pretty cards that she also sells. She loves making pretty cards.

P: I work at the ceramic section and on Tuesday and Wednesday I help a little bit and go iron by a lady in town from 11-1 work and then I'm back at Lewensruimte at 2 in the afternoon. ...The lady gives her R50 for the ironing and she gets money from here also.

One of the participants explains how his lack of economic stability and poor living conditions led to a deterioration of his health to such a point that the welfare services were forced to intervene:

P: ... dat sy besluit nee, maar sy trek nou plaas toe, dat sy daar by iemand op 'n plaas gebly het, die omstandighede daar was nogals bietjie sleg gewees, want ek het op die ou end meer soos 'n hond buite geslaap op 'n tentjie wat skaars groot genoeg was net om 'n bed te vat en in die wind en die weer moes trotseer en my gesondheid baie sleg daar onder gelê toe die welsyn se mense besluit nie maar hulle gaan my weg daarso, toe het ek mos Worcester toe gekom toe het ek eers vir 'n tydjie hier by die skool gebly terwyl hulle besig was om die papierwerk en dokters ondersoek om my keuring en alles deur te kry om die ou einde hier te kom bly.

The two quotes below give us an indication of monthly/weekly income received by two participants residing at Lewensruimte, the one participant is providing a breakdown of monthly expenses that need

to be paid from his social grant and the other indicates that she receives R80 a week for needlework, cleaning and packing of clothes:

P: Ons kry nou mos op die oomblik R1 010 ek verstaan nou April maand gaan dit weer bietjie op elke jaar mos. Nou uit daai geld uit, $\frac{3}{4}$ van dit gaan vir akkommodasie, die ander $\frac{1}{4}$ wat oorbly is gewoonlik wat ek terug kry, en daai gebruik ek, ek koop vir my toiletware, seep, daai tipe ding en dan miskien nog so paar randtjies oor vir miskien as ek ietsie by die snoepie wil koop, maar hulle het reeds gereël vir my vir polisse vir as ek eendag te sterwe kom, sodat ek begrawe kan word, daai iets soos R20 per maand, wat eintlik maar min is.

P: Doen nou naaldwerk, maak skoon ander dae, pak saam met M klere reg....Elke week dieselfde R80.

For our participants, health care services at the public primary health care facilities in the area are free, although there are different pricing models applied depending on your income, medical aid and disability status:

P: As jy na 'n staatshospitaal toe gaan dan is dit verniet.

P: Ek hoef nooit daarvoor te betaal nie.

P: ... want kyk as ek baie geld het gaan die staat in elke geval nie vir my afslag gee nie, hulle gaan my skielik spring van 'n H0 na 'n H4 toe, en sy sal vol prys betaal...

Although public primary health care services are free for persons with a disability, not all services relating to a person's disability are free, for example, the repairing and payment of hearing aids needs to be covered by the person and is not covered by the government. The courier costs to send the hearing aid to Cape Town to be fixed is estimated at R85 which is quite a substantial amount when a person is living off approximately R253 a month after accommodation. Other services that are reportedly not funded by the government include dental and optometry costs, although another

participant has indicated that although she has to pay R100 for an eye test, the glasses she receives are free:

P: ...en ek is hardhorend die wat my gehoor apparaat is stukkend, en daar is nie geld om dit reg te maak of te kyk vir 'n ander een nie. ...Ons moet self betaal, kyk hier, die staat dek nie daai nie, staat is soos tande en brille, staat help nie daar nie, ons moet self betaal. ...Net die courier geld is gewoonlik maklik R85 dan stuur hulle dit Bellville toe na daai plekke toe wat werk met die gehoorapparaat.

P: Ek moet R 100 vir die oog toets betaal en die bril kry ek verniet.

P: ... but if they go to Worcester Hospital. If they go to the Worcester Hospital for physio, they must pay - or the audiologist, they must pay. And that should be free. And if a public service child gets a cochlea implant in Tygerberg (and they do provide six or eight per annum now), it should be free.

In terms of provision of free health care to people with disabilities, one of our key informants has a problem with how it is being implemented. According to him people with chronic illnesses, in many circumstances, are also covered by the disability grant and therefore no distinction is made between the two when it comes to services that should be benefiting the disabled. He postulates that services, such as audiology and physiotherapy, at the secondary hospital should also be free for people with disabilities:

P: At the moment, they say people with disability grants. But many people with chronic disease will get on a disability grant, but they are not disabled as defined. If the intention is to give something to the people with disability, it's not being implemented correctly. So in terms of the access question, to me as a provider, that is something that is not right yet. They are being charged....Not in the primary health care sector, but if they go to Worcester Hospital. And that should be free.

4.4.2 Private vs. public health care services

In South Africa we have both private and public health care services, the private health care services are utilised mainly by the small portion of the population that has access to medical aid funding.

Although many of the participants struggle with employment and experience socio-economic factors as a barrier to accessing health care services, they still prefer using the little money they have on private health care services, instead of using the free public health care services in the area. Reduced waiting times, perceived provider knowledge, cleanliness of facilities, friendliness of staff and relaxed waiting room environments have been given as reasons to rather use private health care instead of public health care services. Communication barriers exist in both private and public health care services so in respect of access with regards to communication, both services are on par:

P: By staatshospitale moet jy altyd wag en die dokters weet nie altyd wat jy makeer nie. By 'n privaat hospitaal word jy gou gehelp en die dokters kan jou altyd gesond maak. ...Privaat hospitale is baie beter. Staatshospitale is baie vuil en daar is baie kieme, maar privaat hospitale is baie skoon en jy word vinnig gehelp...Ja, maar by die staatshospitale moet jy lank wag voordat iemand jou sal help. By die privaat hospitale word jy vinnig gehelp, maar dit is heelwat duurder.

P: Privaat hospitaal is beter, hulle help ook beter. Staatshospitale help nie 'n mens so goed nie, hulle diens is swak. Privaathospitale is net slimmer, beter. Hulle was slim om my oë te opereer.

P: I said ok fine so I sit in relaxed place where I can watch TV or read the magazine, so maybe after 15-30 min she will call my name then I go to the doctor...

P: Because it's faster and cleaner. The people are friendlier. My father broke his ankle at work, so then he went to Medi-Clinic. And he said the food was very nice, but he still can't understand the doctor. The doctor is very friendly and the doctor says hello, but he still

doesn't understand what the doctor is saying. So private and public, the same thing... Because he went for his radiation therapy and then the doctor would say, okay, he has to have ... is it four electrons by six ... or is it now ... oh, wait, let me just phone someone. You know, then you start wondering, mmm, this does not look very promising. And from what I have seen in the private, especially when I had my wisdom teeth removed, the doctor was all business: da-da-da, there is no hesitation. And I mean, that's what you look for in a doctor. You don't want a doctor who says, hmmm, aaah - you don't want that kind of thing.

What has been observed by one participant, is that having medical aid funding, does not only improve your access in terms of private medical care but also seems to improve your experience of public health care services. You would have to pay for your health care when using public health care facilities but it appears as if your visit is expedited without having to wait in long queues like the other members of the general public:

P: Ek sal miskien nou wel vir my, kyk hier, ek weet mense wat gewoonlik as privaat inkom hulle word baie mal nogals gouer gehelp, ek het dit al gesien gebeur, mense wat mediese fondse het hy gaan, ek sien nie eers dat hulle sit en wag nie, hulle stap net reguit deur na daai venstertjie wat jy hierdie, ek weet nie of jy al gesien het by die Eben Donges hulle het mos daai eerste drie venster die kant, dan is dit mos daai toonbankie wat hier is wat jy altyd eerste by aanmeld, dan is dit mos die twee vensters aan die kant, wat soos mos in die gang af beweeg daar na die kafeetjie toe gaan en so aan. Almal die mense met die mediese fonds hulle gaan almal reguit soontoe, hulle word hulle se lêer getrek en jy sien daar loop die ou. Hy sit nie in die lang tou nie, want hy weet sy mediese fonds sorg vir hom.

4.4.3 Transport

Transport problems do not appear to be a bigger barrier among deaf people than for the general population. Some of the participants indicated that they have their own car and therefore transport is

not an issue at all, others are fortunate in that the NID provides transport for them to go to the clinic or hospital, others rely on family members or friends, while others prefer to walk:

P: Ja, die suster ry met Lewensruimte se bussie.

P: as ek baie siek is sal die personeel my help, maar as ek net bietjie siek is kan ek self gaan, ek het my eie motor.

P: ...sometimes I go with my sister by car sometimes I walk if it is me I walk.

One participant experienced problems with transport when she had to go to Cape Town to see a provider, she used public transport and she experienced overcrowding and a long journey on taxis and busses:

P: Met taxi en die bus gery kaap toe....Ek het nie goed gevoel nie. Die taxi was vol, ouma moes sukkel om plek te kry, moes soek vir plek op die taxi en die bus...Ons het lank gesukkel stadig gery tot daar.

Another participant experienced transport problems, not because he was deaf but because he was living on a farm and therefore was geographically excluded. The farm was 11 to 15km from the closest town and if he wanted to access health care services he had to wait until Fridays to catch a ride with the farmer's wife. In case of emergency, he had to contact the ambulance services for transport or in one case even the police services:

P: ... soos byvoorbeeld dit is 11 of 13km van die plaas af na Tulbagh toe, 15km van die plaas af Wolseley toe, ek het later die dokter in Wolseley gesien....die vrou van die plaas eienaar die het elke Vrydag middag gaan aflewerings doen, want sy het koek gebak en dan het sy naweke haar goed verkoop, elke Vrydag middag het ek dan saam met haar gery in dorp toe, as ek dinge by die dokter moes gaan. Elke vier weke het ek mos my, het hulle mos my pille gegee en dan moes ek dan die dokter self sien, dan moes hy bietjie kyk, doen wat ever hy dan moet doen,

maar andersins as ek enige ander probleempie het dan het ek altyd moes gewag het tot Vrydag toe om dan geleentheid te kon kry, behalwe die een keer waar ek baie sleg siek was toe het hulle nie eers ambulans nie, toe reël hulle dat 'n polisie van dat die polisie van Wolseley af gery het om vir my te kom haal, om vir my te vat dokter toe.

4.5 Process barriers

Lack of provider knowledge and understanding around issues of deafness at health care facilities create access problems for deaf participants. Providers often overlook the fundamental element of being deaf - hearing loss. One would expect that in a town like Worcester, where disability is so observable, people would be more aware of the nuances of specific disabilities, but they are not:

P: ...Ja, but once again, they are just unaware. It's not everybody, but there are people who are just unaware of it. And even in Worcester, where you have people who are blind and deaf, people are still unaware. There was this one place that phoned us the other day: they have wonderful opportunities for deaf people. I said, well, that is good. What type of job is it?

Receptionist, answering the phone. Oh, you are looking for The Institute for the Blind. No, no, they specifically said I should phone the deaf.

P: Yes. Some don't know about deaf people. Some try to help, some don't.

Lack of understanding or acknowledgement of difficulties experienced by deaf people because of communication problems has some participants reporting irritation on the side of the provider when asked to communicate in a more suitable manner. Some training has subsequently taken place to equip providers with insight into the challenges of communication experienced by deaf people:

P: Die een dokter het eenslag 'n bietjie omgekrap geraak toe sê ek vir hom hulle moet onthou daar is van ons mense wat kan nie lekker hoor nie, hy moet kyk na my as hy met my praat.

Nadertyd toe het die dokter al verander en ek verstaan daar is mense wat werk daar gedoen

het bietjie die mense daar bewus gemaak het dat hulle moet onthou daar is mense wat nie lekker kan hoor nie, en kyk na die persoon as jy met hulle praat. Nie kyk na die papiere nie kyk hier, kyk daar nie praat met die papier en kan niks uitmaak wat hy sê nie.

P: Different in the sense that, yes, I think a lot has been done over the past years to try and make services accessible.

One of our key informants informed us that the home based care unit in Worcester has made big strides around issues of disability awareness and positive results have been experienced in terms of health care providers:

P: So there was a positive impact on the nurses: their knowledge improved, and their insight and awareness, in terms of what can be done for a mother with a disabled child.

4.5.1 Timeliness

Timeliness, as with the general population, is also a factor in accessing health care services for our deaf participants. As a result of communication barriers participants feel that extra consultation time is needed to provide adequate space for a successful consultation in order for the patient to fully explain their health concerns. One participant is under the impression that providers actually spend less time explaining to deaf people than they do to hearing people, in addition she feels that because of time constraints the provider does not listen attentively to what is being asked and answers with anything even if not relevant:

P: Doves het langer tyd by die dokter nodig aangesien hulle baie moet verduidelik. Die dokter het nie altyd tyd vir doves nie. As die doves langer tyd nodig het dan moet hulle meer betaal....Ja, daar is 'n groot verskil. Die dokter wil nie baie tyd aan die doves spandeer nie en hy is baie kortaf. Dokters gee vir normale mense langer tyd. ...Toe ek jonger was het ek altyd dokter toe gegaan en baie gesels, maar nou wil die dokter nie meer gesels nie. 'n Mens kan

sien dat die dokter nie meer tyd vir die dowes het nie. Die dokter is ongeduldig met die dowes. Lank terug het die dokter my baie meer gehelp. Die dokter antwoord sommer enige ding, hy luister nie eers wat jy sê nie, dis belangrik vir die dokter om respek te toon teenoor die dowes. Dowes het nie die geld om sommer na 'n ander dokter toe te gaan nie.

Other issues similar to those of the general population are waiting times at health care facilities, often without an appointment, a person can spend a whole day waiting on service, even at times with an appointment participants have reported having to wait several hours at health care facilities:

P: Baie keer moet jy die hele dag wag. Ek gaan vroeg in die oggend sodat ek nie so lank hoef te wag nie

P: She says they had to wait long. They only got back 4o'clock the afternoon she got her file at 10:00 and they had to wait wait wait for the doctor to take the x-ray photos.

P: ...As jy daar aangekom het, dit is stamp vol, jy wag vir 'n ewigheid voordat iemand jou sien, maak nie saak of jy 'n afspraak het of nie jy sal daarso sit en wag, met jou nommertjie om jou lêer te doen, maak nie saak hoe laat jou afspraak oorspronklik was nie en dan eers deur te gaan, dat jy al jou agterend al dood gesit want jy weet nooit of hulle skielik gaan roep nie, jy kan nie wegbeweeg nie want netnou kom sit iemand op jou plek. Nou eindig dit op dat jy heelyd moet gaan staan want daar was amper nooit sitplek gewees nie, daar was nou vir jou sleg gewees.

As an example, one participant provided us with a description of a day spent at the Worcester Community Day Centre for a splinter that he sustained over the weekend:

P: Van begin wat ek daar aangekom het, ek was afgelaai toe was dit 7.30 am gewees ek is op die ou einde eers nege uur se kant ingebeweeg in die gebou in, want die mense wat daarso buite wil sit by daai, in daai gang, het ek eers nege uur ingegaan. Toe is ek nou by die venster

kry jy mos daarso by daai vroultjie daar by daai klein kantoortjie sit, kry jy mos jou nommer en sê sy vir jou OK right by venster nommer soveel daar is mos A, B, C, D. Dan moet jy nog wag daarso by die groep dan kom 'n man daarso van wat met die lêers werk, en sê OK right C nommer soveel tot nommer soveel beweeg na die venster toe om in die lyn te gaan staan vir die lêers, en dan moet jy daar staan en wag tot en met jy nou jou lêer kry dan is dit alklaar amper hier 10 uur 10.30 am, dan moet jy nogsteeds van daarvanaf gaan na voorbereiding se kant toe jy gaan nog nie reguitdeur agtertoe nie, dan moet jy daar gaan sit en wag dan is dit al hier 12uur se kant teen al teen die tyd wat hulle by my verby kom. Teen daai tyd beweeg deur om agter by die dokter uit te kom dan is dit al 12.30 pm dan gaan daai mense weg vir middagete dan kom hulle 2 pm terug. Van 2 pm tot amper 3 pm se kant om te wag voordat hulle by my kon uitkom, toe eers het hulle my gestuur na dat die dokter nie self gedoen het nie, die dametjie daar by die verband kamer dat hulle daarso die dingetjie doen, en dit op patch en doen wat nodig is om te doen en vir my twee of drie pleisters gegee om saam te vat en gesê OK right hier is 'n klein bietjie salf normaalweg gee hulle nie meer salf nie, sy het vir my bietjie swart salf gegee en dan 'n paar stukkies gauze en dan 'n pleistertjie en gesê right ek moet hom net self verbind en hom skoon hou. Op die ou einde is ek eers 3.30 pm daar weg, dit vir van die oggend 7.30 am daar aantegekome het.

Some participants found that having an appointment does indeed facilitate the process once a person enters the health care facility, you may still have to wait for a couple of hours but it should be less than the whole day:

P: ...nou gelukkig reël hulle altyd voor die tyd, dat hulle reël vir my 'n afspraak dat dit makliker en vinniger is om gehelp te word, soos ek daar kom gee ek net my kaartjie in, hulle trek my lêer en ek gaan reguit deur agtertoe waar die dokter...

At the health care facility in Worcester they have a separate chronic queue to facilitate access to health care services for people with chronic health conditions:

P: Wat hulle altyd gemaak het, hulle het die mense wat kom vir kronies hulle gaan almal eenkant toe hulle het 'n venstertjie, hulle se lêers word altyd klaar, hulle weet al watter datums die mense kom, hulle gaan reguit deur hulle gaan wag hulle by daai klomp stoele by daai venstertjie, en dan soos wat jy nou deurkom dan kry jy jou lêer en dan gaan jy reguit agter dokter toe.

4.6 Patient satisfaction

Despite many of the challenges discussed in earlier sections of this chapter, some participants still feel satisfied with the service that they receive from health care facilities:

P: Ja, die diens was baie goed. ...Die suster by Lewensruimte help my gewoonlik as my probleem nie te groot is nie. As ek sieker raak dan gaan ek maar na die dokter toe by die hospitaal en hy help my dan baie mooi.

In contrast to some participants wanting more time during consultations, many participants felt that service providers spent sufficient time with them during consultations. During this time providers were said to be able to provide quality health care, show empathy and understanding around disability issues and were patient in explaining medication dosage:

P: Nee, nooit. Nee, nee dit is darem nie asof hulle 'n ou wil aanjaag nie 'n dokter doen wat sy moet doen ...Ja, daai dokter hy het baie verstaan want hy het 'n hele paar gestremde mense wat seker vir hom sien wat staats pasiënte is.

P: Ja dit was goed. ...Ja, in die oggend, middag en aand, hulle het mooi verduidelik eers eet dan pilletjies drink.

4.7 Health care information and health knowledge

When a person is responsible for your own health, it is important that you have sufficient knowledge about your medical history, your family's medical history as well as a basic understanding of health and anatomy. Together with health knowledge, it is important to have an adequate understanding of health conditions, treatment options and preventive practices.

4.7.1 Health care information

Deaf people do not acquire the same amount of health care information as the rest of the population.

The collected data indicates that deaf people do not always know about illnesses and preventive measures that hearing people take for granted, for example cancer and strokes.

In a continent with a high prevalence rate of HIV/AIDS it is inevitable that health care information will target this illness. Many participants feel that HIV/AIDS is the only illness on which information is provided and that even though the focus is on HIV/AIDS most information is superficial, centred on precautionary measures and not an in-depth discussion around issues of the illness, testing and test results. One participant speculated about why this may be the case and reported that maybe the presenters feel the deaf will not understand a more in-depth discussion similar to those provided to the blind and physically disabled. Provision is made in these education programmes for the 'don't do this or do this' but not for the why you should not do or do something. Participants have indicated that they would like information on coughs, sore throats, colds/flu, cancer, diabetes and tuberculosis:

P: Many deaf people don't know about things that hearing people take for granted like cancer or strokes. AIDS is the one thing that is preached continuously. ...It is always about AIDS. I would like more about like say cancer and different things about health you don't know about. ...With regard to AIDS they pretty much only give superficial information and not in-depth info... I don't know why? Maybe they think that's what the deaf can understand. For the blind

or physically disabled it is more in-depth and they benefit more. ...Yes. The other disabled groups seem to get more information. It is a worry.

P: And they said, no, it's fine. You are negative. I was negative, but what does that mean.

Many of the deaf people haven't got a clue about what it means. And then some of the deaf say, no, that guy has Aids. Or, that guy is positive, but they don't really know what it means.

...They explain to you about condoms and about Aids, but not really in depth. They just say, remember to use a condom. Don't have too many sexual partners - but that's it. They just give you the warnings.

P: It's like an exaggerated focus on HIV. But all the emphasis on HIV, makes it so that all the others are forgotten. So they don't realise that you can actually still get lots of other diseases. HIV is not the only thing that you can get.

P: About coughing, sore throat, cold.

E: And in my opinion, it's a lot worse than HIV. With HIV, because of your low immune system, you get cancer, and then you actually die from cancer. It's a pretty horrible disease and I think it's something that probably all of them have had some kind of contact with in their families or somewhere, but they just don't know anything about it. Nothing! ...You know, talk to them about radiation and talk to them about chemotherapy - things like that. Because I think with the more developed kids, cancer is more likely as they grow older, than Aids, and Aids is like overused. You know, something like diabetes, they have no idea what diabetes is. If you tell them the whole thing about sugar - no clue. ...But maybe cancer ... TB, once we had a man speaking about TB, but that was not very effective because after that, if someone coughed, they would all go: TB! TB!

Deaf participants are largely excluded from mass media attempts to provide health care information.

A key informant indicated that what the general population picks up automatically from television

shows, magazines and posters does not get picked up automatically by a deaf person, mostly due to their limited vocabulary. Another key informant termed this 'incidental learning' indicating that everything needs to be taught to deaf people in its entirety. It is indicated that the internet may be a favourite alternative source of information for many deaf people but as one of our key informant's cautions, a person must be vigilant against obtaining inappropriate, inaccurate information between all the other more accurate information on the internet. Each grouping within the deaf population will have their additional unique challenges but if the person is empowered they will find a way of gaining health care information. One important question that remains unanswered is, whose responsibility is it to provide this health care information? Is it the health sector, education sector or the family's:

P: I can check, if I don't have time, I can go to information on the internet or people, I know more about it.

P: That is the type of thing that you pick up from all the TV ads ... I mean, if you watch Oprah with Dr what's-its-face, then they would say, this is what you need to do to stay healthy. Or, if you read a magazine - that kind of thing - but they don't. And it always comes down to the fact that they don't have a vocabulary, and they don't take in information as automatically as we do. So maybe it's the school's responsibility. I don't know. Maybe, it's their parents' responsibility, but then the parents can't communicate with them either. So for HIV, TB and that kind of thing, it's like ... we have an HIV workshop here ... not a workshop, but like an information session ... maybe twice a year or something.

P: You know exactly by now, that with the deaf, there is no incidental learning. They've got to be taught everything. Everything. They've got to be instructed in total. There is no just picking it up through osmoses or from the peer group. ...But the deaf are often very good on the electronic side of things, these days, in getting onto Facebook, the internet or whatever. The problem with the internet, you don't know what you can trust. You could get any kind of

junk on there. But I think, generally, if they take the trouble and if they are inquisitive and if they are empowered to get access, they can easily overcome it, nowadays. ...No, deaf will obviously have an extremely limited ... the product on the table for people who are deaf ... the deaf people will be largely excluded from ... sometimes, there are certain things available, but usually not by the government - not by the department of health. They would rarely go to the extent where they would take special measures to have programmes to bring them to the same level. So obviously, they are at a disadvantage.

The data collected indicates that most participants receive health care information via school/college health care education programmes, while others have indicated that they have received health care information from hospitals with some additional education being provided at workshops and training seminars:

P: Hospitals. Sometimes workshops, training seminars.

P: In Zambia, it's basically from the school.

One of our key informants has reported that peer education would be the best source of health care information for deaf people because of the many preconceived ideas on health that are reinforced by the Deaf community. Training peer educators on the other hand appears to be a laborious process, taking the Cape Town Deaf Club almost 5 years to accredit and train two deaf HIV counsellors:

P: They understand it. They do. And they come up with some of the most ridiculous ideas, and I'm sometimes afraid that no matter how we might explain it, they still disregard it and continue on their own because they are stubborn. It takes a lot to change an idea that they've had for a long time. So I think they understand. Most of them, they know - they understand, but whether they actually do, I don't know. These preconceived misconceptions that they have are very difficult to get rid of. Very, very difficult. Sometimes I think, if we actually had someone

who was HIV-positive ... I know you get ... some of them that do talks at presentations, if you could have some of them ... if someone like that does it, that would be ideal.

P: I mean, do you know how many deaf people are HIV-positive in the Worcester area and are actually on ARV treatment? I don't know. The Cape Town Deaf Club and attic - the departmental unit for Aids training, information and counselling - I know the woman in charge, and she has been busy with, probably for the past five years, to coach and get accredited training for two deaf counsellors. ...Two. Two persons would have accredited training as an HIV counsellor, being able to work on the adherence thing and the understanding of the disease. Because, I think with HIV, the intellectual requirements are also that you must understand your disease!

4.7.2 Health knowledge

What was evident from the interviews is that many deaf people do not have a very good understanding about their own health and medical history. Many participants are unaware of how they became deaf, never asking their parents or not understanding what the explanation was:

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

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

P: Well, this particular boy, he just said he became very, very ill and he vomited. He was ill and his head ached for many, many weeks, and then after that he was deaf.

Besides not understanding why they became deaf, often deaf participants leave the health care setting without understanding what the doctor has diagnosed them with, or why they are having medication

or injections, all without questioning the fact and simply doing as the provider says. This was touched on briefly under Deaf culture where one of our key informants provided some reasons as to why deaf people do not have an understanding of their health history; lack of independence that many deaf children experience when growing up is one of the main reasons:

P: Nothing. He explained something ... with the bone there is a problem. So he only gave me pills and ointment. I don't understand, inside there is something, but he gave me only pills to drink...

P: And that they say they come to the hospital, they don't ask what is my medication for, why this and what that. They don't ask anything. They go there and they just accept the treatment that they are given, and then they say, no, that's fine. It's fine.... I think, as they grow up, they never do anything on their own. If they don't live in a hostel, their parents are overprotective do everything for them. If they live in a hostel, there is always somebody that goes with them, and those people aren't professional as they should be. So they will go with them to the hospital and the child would sit, and they would say, okay, he has a headache and he complains of a stomach ache, and-and-and. What is it? The doctor says, no, it's da-da-da-da, and he needs to take this a few times a day. And they say, okay, come home and we'll give you these pills. Then they go home. And that's just the way he grows up. And when he is finally on his own and he has to be independent, and he has to go to the hospital to the doctor on his own, it's the same. Then they just never really realise what's wrong with him. I think, sometimes, unnecessary illnesses or bad stuff can happen because they never questioned him.

In a way, communication problems lead to lack of health knowledge. One of the ways is, when a deaf person uses family members as interpreters, they run the risk of not gaining all the information about their health condition. One of our key informants indicated that when his father was diagnosed with cancer they kept this from him until all the siblings had discussed the matter. This could potentially be

seen as a human rights violation, which if medical interpreters were used in health care facilities, could be avoided. When asked whether his parents resent the fact that they are not informed completely of what happens in the consultation room around their own health, he answered that he thinks it is comfortable for the parents that there is someone else to worry:

P: My father was diagnosed with cancer last year, stage 4, and then we decided to keep it from him, which is a good thing, until the four children could discuss it first. So we just said the doctor said you are very ill, but they are working on the treatment plan now and they will let us know. And then back here in Worcester, there was a telephone conference between all the children and what we were going to do.... Ja. Then we all discussed the whole thing, and from that we can ... it might not be very ethical, but at that stage, I think, I take off my interpreter's hat and I put on my ... it's my dad, which is comfortable sometimes....No, I think they don't know anyway else. They don't know anyway else to be. That's the way it has always been....So it could be that it's comfortable to have someone else do all the worrying. I don't know. But I also think that's the way it's always been and they are comfortable with that. I'm sure there are deaf people, very independent, who go to the hospital to the doctor on their own - but I haven't met one yet. I'm sure there are.

Out of all the interviews with *users* there was only one hard of hearing participant that had a good understanding of his conditions, symptoms for diseases, preventive measures to be taken and procedures that were performed on him. Another hard of hearing participant had a basic understanding of her asthma but also seemed a bit confused at times. A reason that two of the hard of hearing participants had better knowledge of their own health could be that they can conduct an independent conversation with a few adjustments but also understand more of what is said around them:

P: Ek het jare terug, wat gebeur het is ek het bronchitis gehad, en toe het die kiem na my hart toe geslaan en een van my hart se spiere aangetas, nou wat ook gebeur het een van die are het

vernou en toe het hulle so bietjie meer as 'n jaar terug het hulle mos 'n stent ingesit om my hart aar oop te hou.... hulle kan nie rerig bevestig dat ek diabetes het of nie, maar al die simptome is daar, die water drink, die baie water afskei, die voel dat ek moeg is, seer plekke wat nooit wil gesond word, al daai tipe dinge, probleme met my oë wat ek nie reg kan sien meer nie... ek gebruik glad nie, suiker nie ek het hierdie suiker sakkies wat ek oopskeur daai blou sakkies, as ek koffie of tee drink, maar ek het ook my eie suiker pilletjies wat ek het, wat ek miskien by iemand gaan kuier dat ek dan my eie suiker pilletjies in my koffie of tee kan gooi. ...

P: ... when I was going to boarding school I used to suffer from asthma, in the winter time but its affect me especially in the winter time it affects me so I went to the doctor so the doctor say she try to explain this I got to explain to control the asthma she asked if I used a spray when I was young but I actually, I explained that I used to have that but I used to never used it for a long time, that is the last time I went to the doctor for my asthma. ...no it is going well, but I use my spray and tablets it helps to control coughing, helps to stop the coughing and control my breathing, because last year I used to suffer three to two days without stop breathing.

4.8 Recommendations to improve access to health care services and health care information

A few of the participants and key informants provided some recommendations they considered necessary to improve access to health care services and health care information for deaf people.

As much as communication barriers was the most significant factor hampering access to health care services, the use of sign language by providers and health care staff or the use of interpreters was also one of the most mentioned recommendations to improve service. Furthermore, providers should take cognisance of how to communicate with deaf people, that each person's needs may be different, realising that they need to use simple vocabulary when writing to a deaf person and be aware that medical terminology is beyond the reach of many deaf people:

P: As ek een persoon kan ontmoet wat gebare taal magtig is, want dit is belangrik vir dowes om te verstaan wat vir hulle verduidelik word. Dis belangrik dat iemand met hulle kan kommunikeer in gebare taal wat vir hulle kan verduidelik, of 'n persoon moet stadiger praat sodat 'n mens kan lip lees, of gebare taal een van die twee, dis belangrik.

P: In the hospital, they need to have an interpreter. The government needs to accept sign language. And deaf people, especially in terms of employment, need to not be marginalised or oppressed.

P: ...they need, they need to know how to be able to communicate with the deaf they need to know how to sign and communicate with the deaf, they need to know how to write simple English to communication with the deaf.

P: Yes. They need training and if they have interpreters because they don't always have people there to interpret.

As interpreters are not used in South African clinics, it was suggested that they should then at least have sign language posters in every consultation room. These posters indicate basic sign language and through pointing at the poster the provider will then be able to pick up the essence of what the patient's complaint is. This is of course not an ideal situation but at least there will be some clarity between provider and patient:

P: die ideë wat hulle het met die kaart met hulle uitgebring het ook, help nogal baie ek sien by die polisie stasie is ook. By die polisie stasie het hulle ook so kaart opgesit het, as 'n persoon wat nou doof is hy kan beduie na die kaart nou dieselfde as hulle my elkeen van die ondersoek kamers die dokters ook so kaart op het, want ek weet hulle het mos die mediese kaart op wat die basiese gebare wys, so daai persoon as die dokter agterkom maar die persoon is doof en hy beduie woes daar hy kan net vir die persoon sê wys daarso, wys vir my daar, want die persoon kan wys daar, daar, daar letterlik met die gebare wat wys en die teken waarvoor die

gebaar staan, daai persoon kan dan selfs sy naam spel vir die dokter deur net te druk op die gebare vir die dokter, wat sê aah dit is jou naam, en die dokter kan ook sien daarso maar wat is die basiese gebaar om te gebruik om vir die persoon te vra wat is jou naam? So dat die persoon kan beduie op die kaart so al het die dokter nie gegaan vir 'n gebare taal kursus nie, as hulle in 'n noodsituasie is dat daar darem 'n manier van kommunikasie is daai persoon kan verwys na die kaart toe en die dokter kan ook op die kaart volg wat die persoon beduie. ...Ek het, nee, nee by een of twee van die plekke daar in Tygerberg hospitaal het ek daar gesien maar by hulle lyk dit asof dit net 'n algemene plakkaat is, in pleks dat hulle in elke spreekkamer so iets moet hê, sodat as daar nou 'n dowe persoon aankom die dowe persoon kan net verwys na die kaart toe en daai dokter het miskien nog nie die geleentheid gehad om gebare taal opleiding te kry nie, kan hy net verwys na die kaart of dan ten minste die persoon 'n paar basiese gebare kan wys sodat die dokter 'n paar basiese dinge en dan van daar af volg op die kaart.

Another suggestion relates to a technology that already exists but can be utilised to make the deaf persons health care visit much less stressful. They recommend that electronic boards be placed in the waiting areas of clinics, hospitals and doctors' offices and instead of calling the person over the intercom they can simply flash the next person's name on the board so they can see when they are being called. There are already such electronic boards being used in Worcester Hospital but according to participants they are used solely as advertising space:

P: Daar kan by die spreekkamer flitsende bordjies wees met die pasiënte se name op en as jy geroep word om in te gaan kan jou naam net op die bordjie geflits word.

P: Ek het gesien hulle het mos hierdie borde wat hulle opgesit het, wat hulle mos die tyd wys, datum se nou advertensie flitse...soos daai toets bord, daai ding is mos gekoppel aan 'n computer, so hulle kan dalk miskien net die persoon se naam flits so by die apteek, of soos by

Eben Donges self het hulle ook die bord, dan kan hulle miskien net die persoon, wat ek gesien het by plekke dat hulle miskien nou net sê byvoorbeeld as hulle, hulle weet daai persoon dan het hulle 'n liggie wat aangaan, sê byvoorbeeld soos 'n groen liggie laat flits, ok daar brand 'n groen liggie daar gaan iemand se naam nou roep, dan kyk jy maar net vir die toets bord en hier flits jou naam op die toets bord, ah venster nommer soveel, soos wat jy gaan as jy by die bank gaan of die poskantoor of by die winkels het hulle mos die pyltjie wat flits wat sê vir jou toonbank nommer soveel, dan flits hy nou weer hier vir jou en die pyltjie wat flits en wys vir jou so 'n mannetjie wat loop dan wys vir jou die nommer van die, dat jy die kant toe of daai kant toe moet gaan.

Another recommendation was that if clinics/hospitals allow for appointments to be made they should stick to those appointment brackets and not expect the person to wait the whole day with everyone else that has an appointment for that day. The suggestion is that they have three or four timeslots during the day for appointments so that not everyone has to sit there from 8 o'clock in the morning:

P: ...maar nou kom 'n man sê byvoorbeeld hulle stuur my ek moet gaan na die x-strale, hulle sê vir jou okay right jou afspraak is ag uur, maar nou kom 'n mens daar aan dan sê hulle okay right jy kry nou nommertjie, maak nie saak of jy afspraak het of nie afspraak nie, jy kry 'n nommertjie hulle gaan soek vir jou lêer, as jy mos 'n afspraak het moet jou lêer alreeds opgaan boontoe al, omdat hulle mos van jou weet dat jy net kan aanmeld en deur beweeg sodat jy gehelp kan word, of as jy 'n afspraak het by een van die ander klinieke, soos wat ek MOPD wat hulle my mos moniteering van die hart moet doen, dat jy mos dan net aanmeld en jy wys jou kaart, dat jou lêer alreeds daar moet lê, sodat jy net van daar af reguitdeur gaan sodat hulle miskien die mense in groepe deel en sê nou right, sê byvoorbeeld dat ag uur groep, 'n tien uur groep, 'n een uur groep of 'n drie uur groep en so aan. So dat nie almal wat vir daai dag gesien moet word, almal nie opdaag ag uur en dan sit hulle met so groot bondel en

dan eindig jy op dat jy dalk sit tot 4 uur die middag voordat hulle by jou uitkom. Hulle kan dan liewerste sê OK jy is in die 8 uur groep sorg dat jy hier is tenminste 'n half uur voor jou afspraak, dat jy aanmeld en deurgaan.

Some of the participants have emphasised a need for appropriate health care information around chronic diseases to be provided to this population:

P: But in the hospital ... or, for example, talking about Aids or the various other types of illnesses, there's nothing ... no education, workshops or training. ...For example, about malaria, about Aids or various illnesses, so that you can actually know about what they all are. But currently, there is nothing.

One participant suggested the use of television as a medium to provide information to deaf people. In South Africa, DeafTV is aired on SABC3 every Sunday, this was suggested as a good platform to be utilised to expand information provided to deaf people by including contact details about clinics and providers who can communicate through sign language. As indicated, deaf people enjoy watching television and this medium will be a great way to impart health care information around chronic illnesses to deaf people in a way that is easily understandable to them. Another possible medium to use in South Africa is MXit (cellular phone), this has been indicated as a favourite past time by deaf people. The only challenge in providing information in this format is that the vocabulary needs to be appropriate, otherwise the essence of the message will be lost:

P: ... but my question is how will they know that there is deaf doctor who be able to sign? To communication, I don't know how, maybe through internet, but deaf people they cannot open the internet. Maybe I think it is best maybe you can write down the words, then you can tell through in the television, I think this is best, maybe the doctor then can see the telephone number where the hospital in different place, so if the, because I know the people love watching TV, if the write words where they can meet the doctor on the television then they can

write a text to the doctor. ...I wanted to say I think it is best to know where SABC3, maybe if you know where the deaf people, I mean like doctor who can be able to sign, maybe it will have more information and give those people from SABC3 because I seen every Sunday from 12 pm to 12.30 pm is Deaf TV programme for the deaf because all the deaf people, they give more information about job, everything so that deaf people will know where they will attend. So I think what is best if you know more information give to those people and they will explain in sign language for you people, there is a doctor this place, there is a doctor this place, that deaf people will know and then you must give them more information telephone number, this and that, they will sign everything.

P: A major thing for deaf people is MXit. Anyone who is deaf is on MXit. I know an old guy who is like 56, and he is on MXit because all his friends are. Because I mean, you can't phone someone, and SMS-ing isn't an actual chat or a conversation.

An interesting suggestion from our CODA informant was that SASL should be developed to the level of American or British sign language. Currently SASL does not cater for, amongst others, words such as condition and diagnosis which are paramount in discussing and understanding chronic illnesses. The suggestion was made that appropriate words that are missing in SASL be included in the school curriculum and then it would be easier to make a DVD of health information which can be distributed and shown at clinics in different areas. The informant did however foresee problems with this approach as the activists and purists in the Deaf community would prefer to use the languages as developed in their area:

P: So if the schools could just have ... I have always thought that if the sign language in South Africa could be developed to a level where it is in the US or the UK, it would solve so many of our problems. To give you a stupid example: we have the word subtle, and there is no sign for the word subtle. There's a sign for the word table and there's a sign for the word chair, but

there's no sign for the word condition. There's no sign for that word. There's no sign for the word diagnosis. There's a way to describe all these things, but if there were a sign, and if at school they had a curriculum for sign language where they were taught and somehow, they found a way to get all these new signs in, that would be some achievement because then you could make a DVD or video that you could send to all the hospitals, with all these signs on.... America has signs for everything. We have a deaf psychologist here from America, and he is deaf - not hard of hearing - but deaf, deaf, deaf. So he's a deaf psychologist from America, and that's not something you'd even closely be able to contemplate in South Africa. ...The deaf people don't want to. I like the American sign language because it gives me signs that I don't have. I mean, I don't have a sign for the word psychiatrist, and American sign language does, so I use that one. But the deaf people don't want to. They want to use their own signs. ...Most of the deaf people at grassroots level are fine with using American sign language or British sign language. It's the people higher up, for example, the people in the federations or the associations ... all the other -ations. ...They are the ones. They are all deaf as well, but they are the ones that are saying, no, we are South African so we have to have our own sign language. But I think, sometimes it's just for the politics of it. Because I mean, the people on the ground are still sukkeling and struggling because they don't have signs for things, and they just try and get by. But that's a very big problem that will take many, many years to solve.

4.9 Institutional support

In terms of accessing health care services and health care information, the NID provides support to all its residents in various ways. In most cases the support provided in accessing health care services is provided by the NID and not by the health care services of the area:

P: Obviously, a deaf person living in Touwsriver will struggle to get an interpreter to go to the clinic. A deaf person living in the Institute for the Deaf in Worcester, when there isn't a

visiting doctor and they've got to go to the clinic, the institution will send an interpreter along. So obviously, the person will get ... and the interpreter will hassle the nurses, you know, come and help this kid here. So people living in an institution will probably get better health care; those institutions look after their people.

The hostel mothers and sisters will be the first port of call for residents who take ill. The hostel mothers will take participants to the doctor when needed and they supervise how medication is administered to make sure the right dosage etc. is adhered to:

P: If something happens to me. If I get sick the hostel mother will take me to the hospital to get my medication and make sure I drink my medication to make me feel healthy again and go back to classes.

P: Then I tell the hostel mother then she go with me to the doctor there at the clinic.

The sisters at the institution also provide support by making residents medical appointments, accompanying them when needed, arranging pick up of medication from the various health care facilities and making sure that medication is adhered to and taken correctly:

P: Ja, die suster bel altyd vir my om 'n afspraak te maak. Ek kan nie self 'n afspraak maak nie... Nee, die dokter verduidelik nie eintlik vir my nie. Hy stuur die medikasie na die ouetehuis toe en dan verduidelik die suster vir my hoe ek my medikasie moet drink. ...Wanneer my pille op is, dan laat weet ek net vir die suster en sy gaan haal weer vir my pille.

P: You came to the sister here at Lewensruimte and asked, that her shoulder is sore and to make an appointment for her at the doctor.

P: Hulle reël dat jy by Eben Donges (Worcester hospital) en dan gaan haal hulle dit vir my, ek gaan elke drie maande soms elke vier maande kry ek 'n afspraak dan moet ek die dokter daar gaan sien, of die dokter maak plan dan sien hulle vir my hierso, hier by ons kliniek hier... ek

gaan haal dan ook nie meer by die apteek self daar nie, ek vat net my voorskrif kaart as ek van die dokter af kom, kom ek direk terug hiernatoe, gee my voorskrif kaart af by ons vir suster hierso en hulle gaan haal my pille vir my.

P: Die susters wat by die ouetehuis werk maak altyd vir my 'n afspraak. ...Die suster by Lewensruimte help my gewoonlik as my probleem nie te groot is nie. As ek sieker raak dan gaan ek maar na die dokter toe by die hospitaal en hy help my dan baie mooi.

The various NID departments also provide transport for residents to and from health care facilities as well as arranging interpreters/carers to accompany the residents to facilitate access and communication:

P: ...Except, like with E, we will drive him there, but then he is able to sit on his own in the hospital. Because he is hard of hearing, he can speak. But the moment it's a deaf person ... okay, they can help themselves; they can read and write. But with our people, because they are mentally disabled as well, many of them can't read and write. So the communication is very basic. ...Our registered nurse and the carers, it's their responsibility. So they are the people that will go to the hospitals and escort these people over there. But most of our staff can sign, so they will be the communication medium for the doctor or the psychiatrist, depending on what is needed. ...What usually happens, if somebody gets ill, then we have our registered nurse here. But let's say, she is off duty and it's after-hours, we will call her, but we will simultaneously also notify the ambulance. There's always some of our staff present when somebody gets sick. Always. Except, E will be able to go on his own. But we always assist them. And then, ja, they go from here to the GGS 40 or to the hospital, depending on what is the problem.

P: Ons stuur altyd personeel saam, maak nie saak waarnatoe nie, daar gaan altyd personeel lid saam. Daar moet altyd 'n personeel lid saam om te gaan tolk en te verduidelik.... Ons

personeel gaan altyd saam. Hier is ook 'n verpleegkundige wat half dag werk, en ook het ons die bestuurder van die groep huise wat haar assistent is, so tussen hulle twee word daar altyd gereël dat een van hulle gaan hospitaal toe, of van ons versorgings personeel. Ons het versorgings personeel wat skofte werk. Daar is altyd twee versorgers op diens. Dan het ons ook huismoeders wat dan verantwoordelik is vir as daar iets in die nag gebeur om dan hospitaal toe te gaan, maar gewoonlik gebeur dit dat ons dowe huismoeders ons het drie dowe huismoeders en twee horende huismoeders dan gaan, omdat dit dan weereens moeilik is vir die dowe persoon is om te kommunikeer. Die dokters die mense by die hospitale hulle praat te vinnig, hulle het nie rereg tyd om te gaan sit en vir die mense te verduidelik nie dis hoekom horende personeel altyd saam gaan na die hospitale en klinieke toe.

It appears that the health care services in Worcester have taken cognisance of the need for information to be provided at their clinics and have arranged a once a month meeting which deaf members of the community can attend, using an interpreter from NID to make it accessible.

Two health care professionals are currently more accessible to deaf people in the area. On a weekly basis, a doctor provides clinical services on the NID premises. A psychiatrist is also available at the Worcester Hospital once a month and deaf people from as far as Cape Town come to utilise this service. I was however unable to ascertain whether this was as a result of efforts on the part of the NID or a gesture made by the health care services in the area. These particular health care providers seem to be more accessible to deaf people as they understand deafness and a little sign language.

Despite the provision of these services the participants feel that there are only two sisters and house mothers that can help when people at the institution are ill and that the doctor should visit

Lewensruimte more times within the week/month. It also appears that the residents of NID find it more comfortable to consult with the doctor at Lewensruimte:

P: And at Worcester hospital, once a month, they have this clinic where the other deaf people in the community can go. And again, they make use of an interpreter from The Centre of Knowledge, and they will go to the department of health and interpret there for those hours that they have a deaf person there. It's quite a big issue... We have now the psychiatrist that comes to us once a month, and he is starting to pick up on the signs, but he is still ... his interaction is not that nice so that he can now have an interview all by himself. He needs our staff to assist him in the signing.

P: Soms gaan daar iemand saam met my, maar die dokter by Lewensruimte kan my ook 'n bietjie verstaan.

P: At the Worcester hospital there is a psychiatrist, who once a month has a day where we send an interpreter up (my brother, actually) and he goes for that day. Then any of the deaf patients ... or sometimes they come from Cape Town ... they come through on that day that's specifically for deaf people.

4.10 Sign language and interpreters

4.10.1 Sign language

I follow English but it is a sign language that is picked up by the deaf people. It is not an official language that is taught. It is just picked up by all the others.... Some is American sign language, some Zimbabwean, some Botswana. But all you get there is Botswana sign language. ...It signs very different to adapt to the South African sign language. ... I still remember the Botswana sign language and I come here and I have been here a few months and its not so hard anymore.

The data emphasises the fact that sign language is not a universal language and that there are many variations, even within one country. The participants at the college are from different African

countries and quite a few of them found it difficult at first when they came to South Africa as they did not understand the signing. We find these differences even between sign language used in Worcester (mostly Afrikaans) and Cape Town (mostly English), when there is a meeting in Cape Town then the NID has to send an interpreter along, as the deaf people do not understand English sign language. Despite the fact that there are different 'dialects' deaf people pick up the differences quickly and are able to communicate with people from other countries a lot quicker than a hearing person would. One of the key informants had quite a few examples around differences in sign language and interpretation:

P: It's very different. When I came here to South Africa for the first time, I had no idea what the people were saying. I didn't understand it at all. But I try my best to learn, and I have improved.

P: So if our Afrikaans-speaking deaf people go to a meeting in Cape Town, with an interpreter there, we have to provide another interpreter because our deaf people can't follow the interpreter in Cape Town because he is using English signing. Sign language is not universal. It's like you get different dialects, you get different sign language. Each country has their own sign language. So we have a lot of students here ... we had a student here who was deaf and who came from America; students from Austria; students from the Netherlands, and the signing is ... some of the things are similar, and eventually after a few days, you start to understand the basics, but signing is not universal. And even here in Worcester, the two different schools here, Nuwe Hoop and De La Bat School, some of their signs even differ. ... But in South Africa there are so many different languages, and the Xhosa-speaking person is not going to understand my signing. And even at the college, the students come from Malawi and from different countries, so they don't understand me and I don't understand them, although they can sign, but the signing is completely different. ...I had a student here now and

she was from America. She was a social work student from Gallaudet University. Profoundly deaf, and has never used her voice - only signing. Now she has arrived here. Now, this is our sign for toilets. In America, this is the sign for name! Now she would come to me and she would sign this. So I would keep showing her where's the toilet at the airport. But she was actually asking me what this person's name was. It took me a while ... oh, its name. This is the name, and you would finger-spell it.

P: And sign language differs. But I mean, if you have the basic idea, you can get yourself across to anyone. If you have the foundations right, you'll get yourself across. If you use a sign and they don't know it, you find a way. There is one doctor that I know of who is fluent in sign language, and he is in Bloemfontein. So we can fly my mother up every time she needs help! So apart from that, I don't see any other realistic way.

The use of interpreters is further complicated by the fact that sign language is not universal. You cannot simply accept that a deaf person will understand any interpreter provided; this complicates matters in a health care setting, where medical interpreters would need to sign in the preferred language of the area, aggravating the problem around the shortage of interpreters that are available, training of interpreters etc.:

P: So once again, it depends on whether they understand the interpreter. Like the interpreters on the news, not all our deaf people understand them because it's a different sign language.

Within the deaf population there is also a sub-category of people that are deaf and blind. These people all have differing communication needs; one key informant explains to us the different forms of communication, sign language, tactile sign language and finger spelling:

P: Yes, we've got a few deaf & blind people here. And again, the communication differs. You know, our deaf people can see, so we just sign. But the deaf & blind people can't see and they can't hear, so you use ... the people that are here, they have Usher's syndrome, which means

they were born deaf and became blind later in life. So they have sign language. The only thing that happens now, you start doing tactile signing, which means hands-on. You would sign, but the deaf & blind person would put his hands on mine and I would sign, so he can then follow me. So that's another way you can do it. You get different ways of deaf & blind communication. You get people that can only read finger spelling. Other people, they are totally blind, so he can't see the finger spelling, but he can feel it. But he doesn't have sign language - he only has finger spelling. So you would finger spell every letter of every word, and he would follow what you are saying. And then you have another deaf & blind person, he uses finger spelling, but with the two hands. So you would use his hand as the one, and you would make the alphabet in his hands. And then you've got the people that are tactile signing with his hands on yours, and you just do the signs like normal.

4.10.2 Interpreters

As discussed in this results chapter, deaf people are reliant on interpreters not only when accessing health care services but for many other services as well, so it is not surprising that another important issue discussed in our interviews was around interpreters and their use.

One of our African participants highlights the issue around training of interpreters and explains how there is no formal training of sign language in their country. Some hearing people are trained, but their sign language is often below par, so that deaf people don't like working with them. It was found throughout our data collection process that CODA's are the best people to use as interpreters, as sign language is their first language and they adapt much easier to different 'dialects'. One of our participants acknowledges that he had problems understanding the one interpreter used in the interview process, while in other interviews this was picked up by the flow and atmosphere of the interviews:

P: There is no official training but many that go to the university get the training there but it is not very good sign language. The sign language that the deaf use among themselves are better. People learning from a book or America the other deaf people in Botswana don't like.

P: That's why I say, the CODAs are your best interpreters, because kids of deaf adults, actually, their first language is sign language because their parents are deaf so the parents sign to them and they pick that up as well.

P: But E does ... some of the ... the other girl who was here, she sometimes doesn't understand. ...Many from the school, and a few workshops as well. But oh, the sign language ... ja, the interpreters, they study it, but it's difficult to understand them. So they sign a little bit, and they only use the easy signs. And if they don't know the sign for something, they just leave it out. So they are just using interpreting because they know they will be paid, and they don't care about making sure that we understand.

Despite the fact that deaf people are so dependent on interpreters, one of our key informants engages around the topic of interpreters and their availability, pointing to the fact that certainly interpreters in the Worcester area have other permanent jobs as well, which makes availability a challenge. Training of interpreters is also a challenge due to limited resources and the fact that government does not provide money to extend training and numbers:

P: I am used as an interpreter, and we have an interpreter at The Centre of Knowledge, but we are not ... I'm a social worker and I also interpret. A is an interpreter, but he also has another job description. E is an interpreter, but he is full-time an interpreter for the college. So we haven't really got an interpreter that ... oh yes, we have got CODAs, which is the children of deaf adults, but a lot of them are like in specific jobs, so when there is a need, all of us can't go. We are probably busy with something else, and then we see if some of the CODAs will be available so they can probably assist us. So we make use of CODAs, as well as siblings that

are fluent in sign language. That is really a great need, but there are no funds now for that. So that's why all of us, we are interpreters, but we also do something else. And if you hire an interpreter, they are quite expensive. We provide it free and so on ... actually, not for free ... let's say that it's a deaf client, I will interpret for him but I won't charge him. But let's say it's an organisation like the police that needs an interpreter, they will have to pay for the interpreter services. If I have to go and interpret in court, they have to pay for my services in the court. So that's basically how it works. ... So ja, it would be wonderful if the government could provide funding for interpreters. Up to now, the institute has to provide the services, and government doesn't support that. It does not provide funding for interpreters. You know, appoint interpreters and government will pay for that. That's a thing that really needs to be done

She goes further to touch on a very relevant topic, accreditation of interpreters. Interpreters who are not accredited and do not belong to a professional organisation, do not have any need to adhere to ethical codes around confidentiality. Using a trained interpreter is highly important in a health care setting, where assumptions made on the part of the interpreter could lead to incorrect diagnosis and treatment, the interpreter should only be a conduit of information:

P: We only have a few accredited sign language interpreters in South Africa that went for the actual training. At that stage, they chose two people from the province to go for the training, and the training was only provided in Johannesburg. So that meant that I had to leave my job for a week, go for the training, come back and again go there for a week. So I can't just stop my job here and go for the training to be an accredited sign language interpreter. But that is actually how it works here. We have these few people that can sign ... all of the staff can sign, but not all of them can be used as interpreters. There's definitely a difference. So those of us who can be used as interpreters, they will find out, listen, there's a meeting tonight. Are you

available or not, yes or no, or whatever....At The Institute for the Deaf, ja. Two interpreters at the college, and we've got one at The Centre of Knowledge, and then we've got a few CODAs who are also in specific jobs, but they can be used after-hours. There are a few of them as well. ...the interpreter should also be aware of what's going on. For instance, there was this ... it didn't happen here ... I don't know where it actually occurred, but this interpreter was signing for this deaf person at the psychiatrist. This deaf person had a psychiatric problem, and they get an interpreter who did not know anything about psychiatry. And the psychiatrist asked the deaf person "do you hear voices?" And then the interpreter did not interpret that because he assumed deaf people can't hear. So he can't hear voices, and he didn't even ask the deaf person that. So that eventually had a negative reflection on what was actually going on, because this deaf person heard voices all the time. Although he was deaf, the voices were in his head - he was hearing them. But the interpreter did not ask that because he thought this is a stupid psychiatrist. You know, deaf people can't hear, so how can he ask such a question!

In other countries and certainly also within other areas of South Africa, interpretation services are too expensive, especially for people that are struggling to keep/find employment. This then further hampers access to health care services and also does not alleviate any of the communication barriers which it is meant to do:

P: You try your best. You write. An interpreter is too expensive. I don't have money for an interpreter....Ja, communication. It's always a problem. Sometimes, I would like to get an interpreter, but they are too expensive. When the interpreter is finished, then he says, now you pay me. Then what do I do. So I just go by myself, writing. Sometimes, with the difficult words, I have to say, no, explain to me what this word means. Then they explain to me, but I still don't understand, and the person gets frustrated.

Although communication is facilitated with the use of an interpreter, much of the time participants still feel excluded from their own health decisions. Providers are not trained in using interpreters during consultations and very often make the mistake of speaking directly to the interpreter and not the patient; although this may be unintentional, it creates a feeling of isolation on the part of the participant.

P: Then many people will talk to the interpreter, but they exclude then the client or the patient who is deaf because the interpreter is now the spokesperson. And that shouldn't be, you know. They should really look at the deaf person; make eye contact...

P: I stay quiet and my mother talks to the doctor and my mother tells me what they are going to do.

In summary our results indicate that deaf people at the NID also experience communication problems as being the most prominent barrier to health care services and health care information.

Communication problems create additional problems for participants as they cannot make their own health care appointments, they are always dependent on other people to facilitate communication, they have limited vocabulary and lower literacy levels compared to the general population and many times do not have a good understanding of their own medical history. Chapter 5 will discuss the results of this study, highlighting similarities and differences to other research.

CHAPTER FIVE

DISCUSSION

The limitations of the current study will be highlighted before the discussion of the results as this is the lens through which the data needs to be considered. The results of the previous chapter will then be discussed, with reference to relevant literature. This discussion will include recommendations made by the participants on ways to improve access to health care services and health care information for deaf people and institutional support which is a theme particular to our study setting.

5.1 Limitations of the study affecting interpretation of the data

A key limitation of this study is that it focussed on a very small number of participants who live at the NID in Worcester. The results of this study are therefore not representative of all deaf people in the Worcester area or in South Africa. As indicated in Chapter 4, these participants received support from the NID in the form of transport, picking up of medication, making of health services appointments and provision of interpreters to facilitate communication in the health care facilities. This will be different to the experiences of other deaf people in the same geographical area but who do not have the same support from an institution. Despite the additional support received by our participants, the barriers experienced are similar to barriers reported in other studies, centring on communication problems and problems linked to communication.

The college students who participated in the study came from different African countries and have not had much experience with health care services in South Africa; therefore, most of their experiences are based on health care services in their home countries. The barriers experienced by these participants are similar to other residents at NID which implies that the results can be considered representative of most deaf individuals, certainly in some African countries.

Another limitation is the issue of language that arose during the interview sessions. As explained in Chapter 3, we had to use interpreters during most of our interviews and because of difficulties experienced with one of the interpreters it could have created a situation where participants may not have been able to articulate their stories fully.

A major limitation of the data obtained is that the information is based solely on self-report. This is not a problem in itself, but no responses, without further verification, can be seen as representing the truth of what has happened. All accounts are affected by participants' memory and by how they chose (consciously or otherwise) to present themselves. What the data does give us however, is an indication of deaf people's reported experiences in accessing health care information and services.

5.2 Deafness

In order for a provider to be culturally competent to the deaf population they have to be aware of the differences between being deaf and being a member of the Deaf community (Chong-Hee Lieu et al., 2007). Although none of our deaf participants raised this issue, our key informants touched on aspects around disability and linguistic minority in line with recent literature. As indicated in the literature, our key informants considered deaf people not to have a disability, which can be cured in medical terms, but rather considered deafness as a natural characteristic of a linguistic minority (Chong-Hee Lieu et al., 2007; Taegtmeier et al., 2009; Williams & Abeles, 2004; Yousafzai et al., 2005). The key informants hereby reiterated the sentiment of fractions of the Deaf community that are very critical of cochlear implants, which is a 'cure' to a disability (Williams & Abeles, 2004).

5.3 Participants' understanding of Health

Although most of our participants found it difficult to articulate their understanding of health, many touched on the differing views and definitions covered in the literature. In line with the more negative definition of health, some of the participants considered health to be the absence of disease (Levin & Browner, 2005; McMullin, 2005), while most participants considered various components of the

WHO definition of health (WHO, 1946) and the more recently coined aspects of 'healthworld' (Germond & Cochrane, 2010).

Many of the participants focused on one aspect of health, but together they covered social well-being, emotional well-being and religion. Under social well-being our participants considered a person's relationship with their family, other members of the community and acceptance of all people as an essential indicator of health. These results are similar to those found by Izquierdo (2005) and McMullin (2005) in their studies of the Matsigenka and Hawaiians who among other things considered family and social relations and happiness to be signs of healthy living.

In a religious context, participants pointed to praying and reading your bible as a means to remain healthy and overcome certain health conditions. This must also be considered within the environment of the NID. The running of the NID is based on Christian principles with a church on the premises, while residents do not themselves have to prescribe to Christian values it could be that they are influenced by others in the community, especially with regards to the tightness of the Deaf community discussed in the Chapter 2.

Participants also provided some thoughts around healthy living practices which included drinking water, healthy eating habits, exercise, acceptance of your problems, medication and seeking health care services when needed.

5.4 Barriers to accessing health care services

Factors affecting access to health care services experienced by the deaf participants in this study are similar to those factors affecting people in the general population of South Africa; long waiting times, attitudes and socio-economic factors, to name a few (Goudge, Gilson, Russell, Gumede, & Mills, 2009; Maart et al., 2007). The problem is that the factors affecting access to health care services and health information are exacerbated in the deaf population resulting from barriers experienced by deaf

people in general; communication barriers, inequalities in health care access and education, low literacy rates and high unemployment (Fusick, 2008).

5.5 Communication barriers to health care services

The results of this study, as with other studies, indicate that communication problems in different forms are the most significant factor affecting access to health care services for our deaf participants (Iezzoni et al., 2004; Law et al., 2005; Steinberg et al., 2006). Communication problems were a problem for all our participants which included deaf students from other African countries, it would therefore appear as if communication problems is a universal problem experienced by deaf people, across some African countries.

As a result of miscommunication experienced by our participants they reported feelings of being misunderstood, treated as intellectually inferior, stress, being uninformed about their health, and concerns about possible errors in diagnosis and treatment. Concerns around misdiagnosis and incorrect medication were made worse by the fact that because of communication problems and lack of confidence most deaf participants refrain from indicating that they are misunderstanding the provider or are being misunderstood.

In addition, miscommunication also created the perception among participants that health care services misuse deaf people, that providers are scared of deaf people, that providers do not listen to the concerns of their deaf patients, that providers find it easier to simply ignore deaf patients and not provide them with all the information that they need in terms of treatment and diagnosis.

Continuity, as was found by Law et al. (2005), was also considered a problem with some of our participants as they had to establish new relationships with successive providers. Mistrust was experienced by one participant as the shared knowledge base of previous provider relationships had to be built up again, this is found to be a particular problem when one has a specific way of communicating (Law et al., 2005).

The inability to make an appointment to access health care services was another area of inequality experienced by our participants. They often had to rely on other people to make their appointments after unsuccessfully attempting, email, fax or sms.

Many deaf people have voiced concern over missing long awaited appointments because they cannot hear when they are called in the waiting room, often causing great embarrassment and frustration on the part of the deaf patient (Iezzoni et al., 2004; Ubido, Huntington, & Warburton, 2002).

Valios and Vale (2004) provide us with a good illustration of a waiting room scenario at a provider's office and how not being able to hear can cause added stress to the patient:

You're sitting in your GP's surgery and your name is called out over the tannoy system.

Unaware, you continue flicking through a magazine. After waiting for some time, you approach the receptionist to ask whether the doctor is running late, only to be told that you've missed your appointment as your name was called 15 minutes earlier. The receptionist had forgotten that you were deaf and would not have heard the announcement. (pp.30)

This same scenario was found to be a problem experienced by our participants in that staff at health care facilities often seem to be unaware of the nuances of being deaf, and without deaf awareness training, communication problems are often exacerbated (Valios & Vale, 2004). This problem is not only specific to people who are profoundly deaf but hard-of-hearing people also experienced difficulties in understanding what was being said over the intercom system, especially at times when waiting areas were overcrowded and noisy.

5.5.1 Alternative forms of communication

Many providers turn to writing or lip reading as strategies to overcome communication problems with deaf people (Iezzoni et al., 2004; Steinberg et al., 2006). While it is commendable that providers are attempting different ways to overcome communication barriers, these two alternative forms of

communication are not without problems. The problems indicated in our study are consistent with other studies on this topic (Chong-Hee Lieu et al., 2007; Iezzoni et al., 2004; Steinberg et al., 2006).

One of the biggest problems found with writing, is the limited vocabulary among deaf people who use English infrequently as a second/third language. This problem is especially noticeable with relation to medical terminology used in the health care setting. In addition to reports in literature, our participants from other African countries experienced a unique problem with writing as an alternative form of communication. Most of the students could write and understand English sufficiently to communicate with providers, however they experienced that the providers themselves were not fluent in English which inhibited communication, as the deaf participants, who were schooled in English, could not understand the main language spoken in their native countries. In order for writing to be an effective form of communication providers need to improve the vocabulary and quality of handwriting (Steinberg et al., 2006).

Lip reading on the other hand is an advanced skill of which proficiency varies across the deaf population and it is further hampered by poor lighting, distance from provider, difficulty seeing providers face and limited familiarity with provider's speech patterns (Chong-Hee Lieu et al., 2007; Iezzoni et al., 2004; Steinberg et al., 2006). The provider must consider these added barriers when communicating with deaf people that can lip read and also speak normally and clearly, refraining from shouting or over enunciating, which distorts one's lips (Chong-Hee Lieu et al., 2007).

While many of our participants used these alternative forms of communication, very often with little success, a portion of our participants from Lewensruimte would be unable to use either alternative as they are considered to be intellectually disabled which influences their ability to read, write or lip-read, limiting their communication to sign language.

5.5.2 Dependent on support

In South Africa and other African countries interpretation services are expensive and not offered at health care facilities, so in order to aid communication and access to health care services, our participants indicated that they rely on other people to accompany them to the health care services. This was not found to be of particular importance in the literature, although very few of our participants would consider accessing health care services independently, for fear of miscommunication. One of the most bothersome aspects of this dependency was the fact that participants always had to fall into someone else's schedule and could not be independent in their health care activities. It was indicated that this constant need for someone to help in accessing health care services can lead to non-utilisation of services when needed or non-utilisation, of amongst others, HIV testing services for fear of breach of confidentiality.

The NID provides support to residents in the form of accompaniment to health care services. Family members and friends provide additional support.

5.6 Structural-environmental barriers

5.6.1 Socio-economic factors

Other studies conducted in South Africa have found socio-economic barriers to be a significant factor affecting access to health care services in the general population (Levin, 2006a; Pillay, 1999).

Unemployment figures are high, even in the wealthiest provinces, the statistic for the Western Cape is 25% (Cummins, 2002), and a large portion of the deaf population fall within this group.

Communication problems and below par education were considered to be the main contributors to the high unemployment rate among the deaf. None of our deaf participants are employed on the open market and though our participants from Lewensruimte were gaining skills, they are considered intellectually disabled and therefore unable to perform work on the open market. Most of these participants live off their social grants of +/- R1010 a month, which mainly covers accommodation

costs leaving approximately R253 a month for other expenses. To supplement grant income, some participants do extra small jobs.

Although treatment at primary health care facilities in South Africa is free (Cummins, 2002; Sanders & Chopra, 2006), not all services relating to a person's disability or supplementary health care services at secondary hospitals are free. Participants indicated that they still need to pay for repairing and acquiring of hearing aids, dentistry costs and optometry services.

5.6.2 Private vs. public health care services

The public-private mix in South Africa's health care system contributes to the inequalities in health care services with only 14% to 20% of the population belonging to medical schemes while 60% of funding and 70% of doctors service this group (Cummins, 2002; McIntyre et al., 2008; Sanders & Chopra, 2006). Despite the fact that our participants experienced communication barriers at both private and public health care facilities, they perceive that private health care services are better for reasons of reduced waiting times, perceived provider knowledge, cleanliness of facilities, friendliness of staff and relaxed waiting rooms. Although many of the participants struggle with employment and experience socio-economic factors as a barrier to accessing health care services, they still prefer using the little money they have on private health care services instead of using the free public health care services in the area.

5.6.3 Transport

One of the biggest barriers to health care services in the Western Cape is vast distances, with public transport being negligible outside of big cities (Cummins, 2002). In contrast, the NID provides transport to health care facilities for all its residents and therefore transport was not a significant barrier experienced by our participants. Only two participants reported experiencing transport as a barrier to health care services in the past.

5.7 Process barriers

In line with the literature, participants in their dealings with health care services experienced lack of provider knowledge, lack of understanding around issues of deafness and lack of respect (Kroll et al., 2003; Kroll et al., 2006; Scheer et al., 2003). Some training has subsequently taken place to provide providers at the Worcester facility with insight into the challenges of communication experienced by deaf people.

Timeliness was also reported as a factor in equally accessing health care services for our deaf participants. Similarly to what was found by Law et al. (2005), participants felt that extra consultation time was needed to ensure a successful health care experience. One participant was under the impression that providers actually spent less time explaining to deaf people than they do to hearing people. Waiting times at the health care facilities was also a concern for all participants as a person could wait the whole day to be helped, even when you have an appointment.

5.8 Patient satisfaction

People who are sick, are generally less satisfied with health care services, as they are in greater need of services, have more interaction with providers and more opportunities arise for mishaps (Iezzoni et al., 2002). Deaf people are not necessarily 'sickly' but their special communication needs create problems even during routine, preventive consultations. Although persons with disabilities, including deaf people, had a significantly higher adjusted odds of dissatisfaction with health care services, overall Iezzoni et al. (2002) found that 90% of persons with disabilities compared to 98% of persons without disabilities were satisfied with health care services. Similar results were found in our study where despite all the problems with communication, most participants still reported that the health care staff were respectful, friendly and helpful.

One or two participants were concerned about the time allocated to them during a consultation, while most other participants' felt providers spent sufficient time with them during consultations, were able

to provide quality health care, show empathy and understanding around disability issues, and were patient in explaining medication dosage.

5.9 Health care information and health knowledge

There have been increased attempts by researchers to understand how deficits in health knowledge regarding illnesses, prevention, treatment, risks, medicines and related matters could contribute to health inequalities (Pollard & Barnett, 2009). This is particularly salient in the deaf population where communication problems create a barrier to accessing information and incidental learning.

Consistent with other studies, our study indicates that deaf people have perceived unequal access to health care information and do not always know about illnesses and preventive measures that hearing people take for granted, for example cancer and strokes (Barnett, 2002; Yousafzai et al., 2004).

Deaf people are a group that are at risk for low health literacy as they lack access to health information conveyed over the television, radio or incidental learning such as public conversation (Barnett, 2002; Groce et al., 2007; Pollard & Barnett, 2009; Pollard et al., 2009). Our key informants reiterated these results as they indicated that the deaf population in the Worcester area are largely excluded from mass media attempts in providing health care information. Furthermore reporting that the deaf population are excluded from incidental learning from television shows, magazines, posters and overheard conversations therefore everything needs to be explained to them.

Much of the literature on health care information has focused on deaf peoples access to HIV/AIDS information and education across America, Europe and some African countries (Bat-Chava et al., 2005; Folkins et al., 2005; Groce et al., 2007). Many of our participants confirmed this tendency, admitting that they felt that HIV/AIDS was the only illness on which information was provided. Even though the focus for many was centered on HIV/AIDS, it was reported that the information provided was superficial and not in-depth. It was found that some participants did not understand what a positive/negative HIV test result indicated and how and where HIV testing could be performed.

Participants have indicated that they would like more health information/education on coughs, sore throats, colds/flu, cancer, diabetes and tuberculosis, which touches on a concern voiced by Zazove et al. (2009) who felt that cancer education should be sharpened in the deaf population.

Another issue raised in our study centers on a concern expressed by Barnett (2002) that deaf people do not have a good understanding of their own medical history. Many of our participants have no understanding about how they became deaf, either because they have not asked or because they do not understand the explanation provided. In addition, many participants also reported leaving the providers consultation rooms without an understanding of diagnosis or treatment. This situation appears to have been made worse in many cases when deaf people use family members as interpreters in the health care setting. In these cases a parent could exclude a deaf child from health decisions by communicating directly with the provider or alternatively a deaf parent could be 'spared' a cancer diagnosis by a child until the family has reconciled themselves with the news.

From all the interviews conducted, only two participants had an understanding of their own medical history, illnesses and preventive measures. Both participants were hard of hearing, which coincides with results reported by Bat-Chava et al. (2005) indicating that differences in level of hearing loss contributed to differing access to health care information.

5.9.1 Accessing health information

The Deaf community is a very tight knit community, which strengthens their position as a linguistic minority and as a result of this tightness it was found, like in other research, that the main source of health information was reported as the deaf 'grapevine' (Bat-Chava et al., 2005; Groce et al., 2007; Tamaskar et al., 2000). While it is noted that this kind of information can be inaccurate it reinforces health beliefs among the deaf population. These beliefs are very difficult to change, as was reported in our study that deaf people struggle with independent thought, which creates a situation that they

accept what the provider says without fully understanding or questioning. Feelings of shyness, lack of confidence and fear of appearing ignorant were provided as reasons for this unconditional acceptance.

Another issue that arose in our study is that the tightness of the Deaf community could actually prohibit deaf people from seeking preventive medicine and HIV testing, as they are afraid that once they have been tested the whole community will be aware of the results, this is a particular problem when friends and family are used as interpreters.

Our data supports reports by (Bat-Chava et al., 2005; Groce et al., 2007; Yousafzai et al., 2005) which indicate that most participants received health care information via school/college health care education programmes.

The internet was reported as an alternative form of accessing health care information. While unconfirmed reports indicate that deaf people, who have finished school, use computers to avoid difficulties in communication, many studies indicate that deaf people, especially those with profound hearing loss, suffer the greatest socio-economic and health care impacts from communication problems, which would make it hard to afford computers (Zazove et al., 2004). Zazove et al. (2004) found that use of computers was more prominent among the young, more educated, employed deaf people who earn a higher income and use English, which is very important if you wish to navigate the internet websites. Therefore, while one of our participants indicated the use of the internet to acquire health care information, it is unclear whether this alternative would in fact be a viable option for the majority of the deaf population in South Africa. Another issue with the use of the internet as a source of health care information is the accuracy and appropriateness of the information provided.

Peer education is a necessary provision to be made in order to transfer health information especially in light of the beliefs in the Deaf community, this has been confirmed by other studies in Africa (Groce et al., 2007; Taegtmeier et al., 2009; Tamaskar et al., 2000). Training of peer educators has been

indicated as a laborious process to be undertaken in South Africa as reported by the Cape Town Deaf Club who has taken almost 5 years to accredit and train two deaf HIV counsellors.

5.10 Recommendations to improve health care services and information

In order for people to take better care of themselves people need faster and easier access to health care information; this in turn should alleviate some of the pressures of the health care system (Thompson, Williams, Nicholas, & Huntington, 2002). A few of the participants and key informants provided some recommendations needed to improve access to health care services and health care information for deaf people.

Consistent with other studies, communication barriers was the most significant factor hampering access to health care services and suggestions such as the use of sign language by providers, health care staff or the use of interpreters was also one of the most mentioned recommendations to improve service (Folkins et al., 2005; Levin, 2006b; Steinberg et al., 2006). Furthermore, our participants indicated that providers should take cognisance of how to communicate with deaf people, that each person's needs may be different, realising that they need to use simple vocabulary when writing to a deaf person and be aware that medical terminology is beyond the understanding of many deaf people (Kroll et al., 2006; Levin, 2006a; Mayer & Villaire, 2004; Yousafzai et al., 2005). While these are good recommendations, it must be taken into account that within the deaf population there are many diverse types of hearing loss, and different levels of language proficiency between sign language, English and lip reading (Chong-Hee Lieu et al., 2007). This creates added problems for a provider that is intent on becoming culturally and linguistically competent to the deaf population.

Specific to our study, participants suggested that due to the lack of interpreters used in South African clinics, clinics should provide sign language posters in every consultation room. These posters indicate basic sign language and through pointing at the poster the provider will then be able to pick

up the essence of what the patient's complaint is. This is of course not an ideal situation but at least there will be some clarity between provider and patient.

Another suggestion relates to a technology that already exists but can be utilised to make the deaf persons health care visit much less stressful. Participants recommend that electronic boards be placed in the waiting areas of clinics, hospitals and doctors' offices and instead of calling the person over the intercom they can simply flash the next person's name/number on the board so they can see when they are being called. This suggestion is in line with suggestions made by a deaf people's charity in the United Kingdom, who are pushing to see more technology being used, including visual alert systems and loop systems to facilitate access to health care facilities (Valios & Vale, 2004).

Also specific to the South African set up, participants recommend that clinics/hospitals allow appointments to be made in certain appointment brackets and not expect the person to wait the whole day with everyone else that has an appointment for that day. The suggestion is that clinics/hospitals could have three or four timeslots during the day for appointments, so that not everyone is sitting there at 8 o'clock in the morning.

In South Africa we have a DeafTV programme which is aired on television every Sunday. One of the Zimbabwean participants actually suggested that this already active programme be used to provide health information to deaf people, even if only to provide details of providers who can sign or use interpreters. As indicated by our participants, deaf people enjoy watching television and this medium will be a great way to impart health care information around chronic illnesses to deaf people in a way that is easily understandable to them. It will need to be further researched in order to determine how many deaf people actually have the opportunity to watch television in South Africa. Another possible medium to use in South Africa is MXit (cellular phone), this has been indicated as a favourite past time by deaf people. The only challenge in providing information in this format is that the vocabulary needs to be appropriate otherwise the essence of the message will be lost.

One of our CODA informants suggested that from a South African point of view SASL should be developed to the level of American or British sign language. Currently SASL does not cater for, among others, words such as condition and diagnosis, which are paramount in discussing and understanding chronic illnesses. The suggestion was made that appropriate words that are missing in SASL be included in the school curriculum and then it would be easier to make a DVD of health information, which can be distributed and shown at clinics in different areas. Again, additional research will need to be undertaken in this area to determine the viability of this suggestion and the anticipated reaction from activists and purists in the Deaf communities of South Africa.

5.11 Institutional support

As was discussed in the limitations section of this Chapter, our sample of participants provided us with unique insights into how living at an Institution can have additional benefits. The experiences of our participants are unique compared to what can be expected by other deaf people in the Worcester area.

In terms of accessing health care services and health care information, the NID provides support to all its residents in various ways. In most cases, the support provided in accessing health care services is provided by the NID and not by the health care services of the area.

Each department at the NID which we sampled, Lewensruimte, Shalom Old Age home and the NID College, have a hostel/house mother who lives closely to the residents. She and the registered nurses on the premises will be the first port of call for residents who take ill. The hostel mothers will take participants to the doctor when needed and will supervise medication adherence. The sisters at the institution also provide support by making residents medical appointments, accompanying them to health care services when needed, arranging pick up of medication from the various health care facilities and making sure of medication adherence.

Transport is provided to all residents that need transport to access health care facilities and interpreters/carers accompany all residents that need the services in order to facilitate access and communication.

On a weekly basis, a doctor provides clinical services on the NID premises and currently, a psychiatrist is available at the Worcester Hospital once a month and deaf people from as far as Cape Town come to utilise this service. These health care providers were reported as being more accessible by our participants', as they understand deafness and a bit of sign language.

5.12 Sign language and interpreters

5.12.1 Sign language

The data emphasises the fact that sign language is not a universal language and that there are many variations, even within one country (Aarons & Akach, 2002; Morgans, 1999). The participants at the college are from different African countries and quite a few of them found it difficult at first when they came to South Africa, as they did not understand the signing. Despite the fact that there are different 'dialects' deaf people pick up the differences quickly and are able to communicate with people from other countries.

There are some residents within the different departments of the NID that fall into the category of deaf and blind. These deaf and blind people all have different communication needs; one key informant explained to us the different forms of communication used by this sub group; sign language, tactile sign language and finger spelling. These alternative forms of communication found in this group of participants complicate communication within a health care setting.

5.12.2 Interpreters

As discussed earlier, deaf people are reliant on interpreters not only when accessing health care services but for many other services as well, so it is not surprising that another important issue

discussed in our interviews was around interpreters and their use. The use of interpreters is complicated by the fact that sign language is not universal. You cannot simply accept that a deaf person will understand any interpreter provided; this would also complicate matters in a health care setting, where medical interpreters would need to sign in the preferred language of the area, aggravating the problem around the number of interpreters that are available, training of interpreters etc.

It is acknowledged in the literature that interpreters used in health care setting should be trained, accredited interpreters (Heap & Morgans, 2006; Williams & Abeles, 2004), the situation in African countries does not compare. Interpreters who are not accredited and belong to a professional organisation do not have any need to adhere to ethical codes around confidentiality. Trained interpreters are highly important in a health care setting where assumptions made on the part of the interpreter could lead to incorrect diagnosis and treatment, the interpreter should only be a conduit of information. One of our African participants highlights the issue around training of interpreters and explains how there is no formal training of sign language in their country. The sign language proficiency of hearing people who are trained in sign language is often below par so that deaf people do not like working with them. As indicated in Chapter 3, this issue of preferred interpreters was evident throughout our data collection process at the NID College.

As reported in the literature, as recently as 2006, there were only four professionally trained and accredited interpreters in South Africa (Heap & Morgans, 2006). One of our key informants pointed to the fact that certainly, in the Worcester area, the availability of trained interpreters is limited as most of them have other permanent jobs as well. Training of interpreters was also reported to be a challenge due to limited resources and the fact that government does not provide money to extend training and numbers.

In other countries and certainly also within other areas of South Africa, interpretation services are too expensive, especially for people that are struggling with other socio-economic factors, this then further hampers access to health care services and also does not alleviate any of the communication barriers which it is meant to do. In 2006 Marion and Heap reported that DeafSA stipulated a minimum fee of R500 for interpretation services, which is almost half of the monthly disability grant, or almost double the monthly amount of disposable income available after deduction of housing expenses as reported by one participant.

5.13 Conclusion

Although this study is based on a selection of deaf participants who are supported by the NID, it highlights inequalities faced by deaf people in accessing health care services and health care information. The main barrier experienced by the participants, was communication: this is a problem that is not specific to the health care environment but is also experienced within society at large. What was evident from the data, was that even though Worcester, as a community, has been sensitised to disability over the years, there are still members of the community that do not understand the limitations in hearing and communication experienced by the deaf population in its surrounds.

Prior to data collection it was expected that communication would be a significant barrier in the health care services however the ramifications of this barrier have provided insightful information. Not only are there external barriers to health care services and information but there are also prior experiences and interpersonal factors that play an integral part in how the participants access health care services. The latter is an area that needs further investigation as I found there was a definite feeling of helplessness expressed by participants as they are dependant on others to assist them when entering into the health care environment. There is an indication that many of the deaf participants anxiety stems directly from the lack of control they experience in their own health care management, as they have to rely on secondary information about their health care status and health care information. Some

participants expressed feelings of anger and resentment towards the knowledge and understanding of some health care providers. An interplay of communication issues, personality traits and interpersonal factors contributed to many participants not utilising health care services in a timely manner as they present with feelings of insecurity, isolation, fear, shyness and lack of confidence.

Confidentiality is one of the rights due to a person entering into the health care environment, however, for this select population, this right is very often not afforded to them. There are practically no professional interpreters available at clinics and if interpreters are used an exorbitant fee is charged. Most often, friends/family are used as interpreters, in addition to a breach in confidentiality, this practice could potentially lead to further miscommunication as the language of the interpreter and the doctor are most probably not the same either, so there is another aspect of communication difficulties.

It is not purely the health care system that is to blame as it appears that the education system also has a role to play in fostering lack of independent questioning. Through discussions with key informants and reviewing of literature, it became evident that the deaf population present with a lower literacy rate and limited vocabulary, in addition there are only a limited number of schools in the country that deaf pupils can attend, so many pupils are left uneducated, which greatly limits other forms of communication. This also impacts on knowledge of illnesses and access and understanding of health care information.

In general, whether using private or public health care services, one gets the feeling that it is a rat race where you come in, get your diagnosis and treatment and are ushered out of the door, for the deaf population this is especially anxiety provoking as they need more time to facilitate communication around symptoms and explanations on treatment etc.

Concerning health care information, it was found that participants sought health care information/education about other chronic illnesses besides HIV/AIDS, which they felt was overdone. In terms of HIV/AIDS they did require more in-depth discussions on testing and the illness itself.

The main barrier to health care information was found to be the inaccessibility that deaf people experience towards mass media. This inaccessibility relates to lower literacy rates, vocabulary and problems with hearing.

Recommendations made by participants to improve access to health care services and health care information included:

- usage of sign language, simple vocabulary and/or interpreters at health care facilities;
- sign language posters to appear in all consultation rooms;
- electronic boards to be used to call for the next patient at clinics and hospitals;
- appointments to be made available at clinics and hospitals within certain time brackets;
- use of DeafTV to provide information on providers who are more accessible to deaf people and provide certain health care information;
- use of Mxit (cellular phones) to make certain health care information available; and
- SASL to be updated to the level of American or British sign language, including more appropriate words, which can be used in a health care environment.

The current study, though small, will be included in the results for the Worcester site of the larger EquitAble project.

In addition to our findings, additional research into any possible different barriers experienced by deaf people in the Worcester community who are not associated with the NID, would possibly provide support to our findings. It would also be interesting to research whether the support provided by the NID is also experienced to a similar degree by other deaf people who live in institutions in other parts of South Africa. If any of the recommendations made by the participants were to be considered, they would need to be further researched in terms of viability as an option in all parts of South Africa.

Apart from the obvious difficulty in communication between hearing and deaf people and despite, or maybe because of, the many well known work-arounds for communicating with deaf people, many barriers to health care services and information are often overlooked or ignored.

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APPENDIX A

Interview guide for in depth interview with health care users

Participant nr
Study site nr
Investigator code
Date of interview

The relevance of the topics for each specific interview will vary from one interview to another. It is the informant's history and experience that will decide which topics are important in the various interviews.

Explain to participants the nature and purpose of the study, why they were specifically asked to participate and gain informed consent.

Guiding questions:

1. What is your understanding of health and health related issues?
 - Hygiene
 - Nutrition
 - Medication
 - Training
 - Related to the disability
2. What are your health needs?
 - Hygiene
 - Nutrition
 - Medication
 - Training
 - Related to the disability
3. Do you access health care in the same way as everyone else a) in your family b) in your community?
4. What factors/problems according to you make it more difficult for a person to access health care (vulnerability factors) and why?
5. Do you experience any of these factors? If yes ask person to explain (with examples) and also to relate how this affects his/her health care access.
6. Please describe reasons that lead to vulnerability, how you are adapting to it and what strategies you are using.
7. Please describe the different kinds of health service and/or medical care you know about or have accessed/received? This can include modern health care (professional sector), traditional

health care (healers and indigenous practices) and self care in the family. What are your feelings about each of these services and why do you have these feelings?

8. Which of these types of services do you personally use and why do you choose to use them?
9. Tell me about your general health status. How would you describe your health today- excellent, good, poor, very poor? Do you have any specific health needs and if yes what are they? How are these needs catered for?
10. Please discuss your use of health care services and experiences while accessing these in the past six months (or further back if they want, but focus on past six months)
 - Why did you need health care?
 - What services did you access and receive?
 - How did you experience the service? Was it 1) excellent 2) good 3) neither good nor bad 4) bad 5) very badWith regards to:
 - Making and getting an appointment
 - Convenience of the services hours
 - The physical surroundings
 - Accessibility
 - Crowding, availability of seats, water and other refreshments, restrooms, cleanliness
 - Registration procedures
 - Security
 - Privacy
 - Status of the equipment
 - Availability of your medical records
 - Number of staff
 - Attitude of staff
 - Support received when needed
 - Skills of staff
 - Waiting times
 - Length of consultation
 - Explanation on procedures, condition and management strategies, prognosis, prevention, medication use and your questions answered
 - Equal treatment, exceptions
 - Confidentiality
 - Autonomy and informed consent
 - Treated in an acceptable manner
 - Drug dispensing: Availability of drugs, asked about – allergies, side effects, use of other drugs, Verbal and written directions given – dosage, frequency and route, follow-up
11. Were you satisfied with the service? Why / why not
12. How did the care impact on your health status and quality of life? Did you feel better after the health care?

13. Tell me about any other obstacles you face when you are seeking health care/accessing health services
14. What mode of transport do you use to get to the health care facility (Walking, Private car – own or rented, horse cart, wheelchair, bicycle, bus, taxi, train, ambulance)?
 - Does the facility assist with transport or arranging transport?
 - Cost of transport, time it takes
 - How happy are you with the location of the facility and your travel arrangements?
 - Other issues around transport that the person would like to mention
15. Cost of health care and other costs (Care, medication, bribes, loss of income, hidden costs)
 - What are all the costs you have to bear in order to access health care?
 - In your opinion is this cost acceptable
 - How do you finance these costs/ could you afford it?
 - How does it impact on your and the families general financial status
16. What happens if the facility you usually access cannot perform the services that you need?
17. What in your opinion are the main difficulties these services experience if any?
18. Do you have any ideas on how these challenges can be addressed?

Additional questions if participant is disabled:

19. Tell me about the physical accessibility of the point of service delivery. Include toilets examination rooms, pharmacy, special investigations etc.
20. Were information / explanations on procedures, your condition, and medication given in an adequate, understandable way? Do you understand what is wrong with you and how to take your medication? Are you able to ask questions and , if yes, are you happy with the explanations and answers you get?
21. To what extent does the service meet your ongoing health needs?
22. Tell me about the rehabilitation you received?
23. Tell me about any assistive devices you might need or have received – waiting times, fit, usefulness, cost, education and training, follow up

Closing the interview: Acknowledge the informant's cooperation, time spent and information shared and ask whether any other information that they want to give that they feel was not covered adequately.

APPENDIX B

Interview guide for interviews with health service providers

Participant nr
Study site nr
Investigator code
Date of interview

1. Could you explain to me what your understanding of equitable health care access is
2. What factors according to you increase people's vulnerability to poor health care access / which patients struggle to access the services at the facility?
3. How accessible is the facility where you work for patients (physical, costs, time, type of services, equipment, number of health care workers)
4. What is your understanding of vulnerability? Name possible groups.
5. What in your opinion can be done to improve access to health services if improvement is needed?
6. Tell me about how patients are treated in general in the facility (fairness, equality, respectfully, patiently)
7. How satisfied are you with your job and the service you deliver?
8. Are there any challenges in this facility that prevents you from performing your duties as you would like to perform them?
9. How satisfied are you with the support you receive from your employers and superiors?
10. Tell me about the general morale at the facility that you work?
11. What is your relationship with the community that you work for?
12. Can you tell me about your experiences (stories & examples) of providing health services at this facility (Have there been situations/ people/ cases that have been particularly challenging/ difficult/ positive/ successful?) Can you give an example of patients that are easy to treat and others that are difficult?
13. How do you understand disability?
14. Have you any experience of treating people with disabilities? Can you tell me about that? (physical/ emotional/ intellectual/ sensory/ epilepsy/ albinism) (do you find them more challenging than other patients?).

15. Are disabled people frequently seen? Which categories of disability do people who come have?
16. How does follow-up of people with disabilities take place?
17. Knowledge about disability policy?
18. Knowledge about disability in health policy and legislation and how this is implemented at the particular health service
19. Do you want to share any additional information with me?

Acknowledge the informant's cooperation, time spent and information shared and ask whether any other information that they want to give that they feel was not covered adequately

APPENDIX C

Information leaflet and consent form (service users)

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa (EquitAble)

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Prof L Swartz

ADDRESS: Department of Psychology, Stellenbosch University

CONTACT NUMBER: 0824593559

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study is the first phase of a larger project which is looking at issues of access to health care. The research is taking place in four African countries: Malawi, Namibia, South Africa and Sudan.

For this first phase of the study we will be interviewing users and non-users of health services in your area, and we will also be talking to people who work in these facilities. We will be observing various aspects of how the facilities operate such as patient flow and waiting times.

Why have you been invited to participate?

You have been invited to participate in this study as a user of the services at this facility.

What will your responsibilities be?

You will be asked some questions on a one to one basis, in a single session of an hour. In circumstances where your home language differs from that of the interviewer an interpreter will be used; we ask that you answer these questions as honestly as you can.

The interviewer will use a questionnaire as a tool to facilitate the discussion and as a participant you can halt the interview at any point for further clarification and you also have the right not to respond to a particular question.

Will you benefit from taking part in this research?

There will be no direct benefit to you from taking part in the research however the researchers will make sure that workshops are organised to provide feedback of the research findings. During these feedback workshops any new information coming from the study will be disseminated. We hope that in the longer term the research will help us create better access to health care for all people.

Are there in risks involved in your taking part in this research?

There are no risks to you for taking part in the research. Everything you say to us will be kept confidential.

Interviews will be tape recorded and responses will also be recorded in writing but no names will be used in transcription of the data thereby ensuring confidentiality.

Support will be provided/available when needed during or after the interviews.

This research project is based at Stellenbosch University and is sponsored by the European Union. Both the University and the European Union have external and internal auditors that will be inspecting the financial information pertaining to the project.

If you do not agree to take part, what alternatives do you have?

You are under no obligation to take part in the study. This will not affect your treatment at the health facility

Who will have access to your medical records?

We will not access your medical records for this study.

Who will have access to the information we collect about you?

All information we obtain will be kept confidential and will be dealt with in a professional manner. No participants names will be on record during transcription and the information will be stored in a safe location. The research team, all of whom are bound by scientific ethics requirements, will have access to the information. If auditors or the funders of the project need to inspect our records, this will be under conditions of strict confidentiality and all names and identifying data will be deleted. In the

event that auditors need to check with participants about whether they have been interviewed for the study, this information will be provided separately from any data collected from you, so it will not be possible for them to link any information back to you personally

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

- You can contact Prof Leslie Swartz, at tel 0824593559 if you have any further queries or encounter any problems.
- You can contact the **University of Stellenbosch Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2009.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2009.

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....
Signature of interpreter

.....
Signature of witness

APPENDIX D

Information leaflet and consent form (service provider)

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa (EquitAble)

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Prof L Swartz

ADDRESS: Department of Psychology, Stellenbosch University

CONTACT NUMBER: 0824593559

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study is the first phase of a larger project which is looking at issues of access to health care. The research is taking place in four African countries: Malawi, Namibia, South Africa and Sudan.

For this first phase of the study we will be interviewing users and non-users of health services in your area, and we will also be talking to people who work in these facilities. We will be observing various aspects of how the facilities operate such as patient flow and waiting times.

Why have you been invited to participate?

You have been invited to participate in this study as somebody who works in this facility and who can tell us about its functioning.

What will your responsibilities be?

You will be asked some questions on a one to one basis, in a single session of an hour. In circumstances where your home language differs from that of the interviewer an interpreter will be used; we ask that you answer these questions as honestly as you can.

The interviewer will use a questionnaire as a tool to facilitate the discussion and as a participant you can halt the interview at any point for further clarification and you also have the right not to respond to a particular question.

Will you benefit from taking part in this research?

There will be no direct benefit to you from taking part in the research however the researchers will make sure that workshops are organised to provide feedback of the research findings. During these feedback workshops any new information coming from the study will be disseminated. We hope that in the longer term the research will help us create better access to health care for all people.

Are there in risks involved in your taking part in this research?

There are no risks to you for taking part in the research. Everything you say to us will be kept confidential.

Interviews will be tape recorded and responses will also be recorded in writing but no names will be used in transcription of the data thereby ensuring confidentiality.

Support will be provided/available when needed during or after the interviews.

This research project is based at Stellenbosch University and is sponsored by the European Union. Both the University and the European Union have external and internal auditors that will be inspecting the financial information pertaining to the project.

Who will have access to the information we collect about you?

All information we obtain will be kept confidential and will be dealt with in a professional manner. No participants names will be on record during transcription and the information will be stored in a safe location. The research team, all of whom are bound by scientific ethics requirements, will have access to the information. If auditors or the funders of the project need to inspect our records, this will be under conditions of strict confidentiality and all names and identifying data will be deleted. In the event that auditors need to check with participants about whether they have been interviewed for the study, this information will be provided separately from any data collected from you, so it will not be possible for them to link any information back to you personally.

If you do not agree to take part, what alternatives do you have?

You are under no obligation to take part in the study. This will not affect your treatment at the health facility

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

- You can contact Prof Leslie Swartz.. at tel 0824593559 if you have any further queries or encounter any problems.
- You can contact the **University of Stellenbosch Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa*).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2010.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use a interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) on (*date*) 2010.

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....
Signature of interpreter

.....
Signature of witness

APPENDIX E

Ethical approval



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

15 March 2010

Dep Of Psychology
Stellenbosch University
Main Campus
Stellenbosch

Dear Prof Swartz

"Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa."

ETHICS REFERENCE NO: N09/10/270

RE : APPROVED

At a meeting of the Health Research Ethics Committee that was held on 11 November 2009, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 15 March 2010 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit. Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Yours faithfully

MRS MERTRUDE DAVIDS

RESEARCH DEVELOPMENT AND SUPPORT

Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za

Fax: 021 931 3352

Fakulteit Gesondheidswetenskappe ·

Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health

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