

Deaf Futures: Challenges in Accessing Health Care Services

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Declaration of Originality

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

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Date: 28 September 2018

For every Deaf person who's been told: "I'll tell you later."

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A final word of thanks must be made to the hearing community: for every boundary placed in our way for their convenience, the Deaf community will overcome it and be stronger for it. We will continue to fight for our utopia.

Deaf Futures Imagined...

(Fareeha)

“Reality: I get out of my car. I walk into the practice, fidgeting with the papers in my hands. The pre-written papers to give to the doctor to read. I walk to the reception, and say I am Deaf by pointing my ears and mouthing ‘DEAF’. I show them the paper of the time and which doctor I have the appointment with. The receptionist scrambles, being all awkward, trying to point at the waiting room. I sigh, I walk over to the waiting room. I sit. I wait. I anxiously wait as I watch closely at every doctor coming out to mouth the patient’s name. Sometimes there’s something blocking my sight to the corridor where the doctors come out, so I have to move my head many times... The doctor calls out my name few times. Fareeha... Fareeha... Fareeha... I watch closely, hoping I was right that it is my name. I stand up. The doctor nodded. We walk to the doctor room, awkwardly. Not saying a word. Not even thumbs up. We sit down. I give her the pre-written papers. She writes back. I write back. She points at the bed. I go to the bed. I follow her instructions. We go back to the table. She writes down the diagnosis. I nod. She gives me prescription pad. She said bye. I wave ‘Bye’. I leave.

Utopia: I get out of my car. I walk to the practice with nothing in my hands. I go to the reception and let them know I am Deaf. They sign: “What is your name?” I respond in sign language, and they ask me to sit in the waiting room. I go in the waiting room with ease. Maybe there’s a TV with notifications on it when it’s our turn to go in. Or the doctor can fingerspell my name. Or the doctor comes and taps me on the shoulder. We go to the doctor’s room together, exchanging a few words, like: “How are you today? The weather is nice!” We get in her room. We sign. I write a little to be more detailed. She signs, and writes whenever she feels the need to. She asks me to go to the bed. I go to the bed. I follow her instructions, and she’s telling me what she’s doing in detail, for example, why the blood pressure is important to check, why she is checking my ear, my throat, etc... She is telling me how sick I am. We go back to the bed. She signs the diagnosis if it’s a simple one, then writing it down to be 100 percent sure. She asks if I have questions. I ask questions. She answers. Until I am 100% satisfied, we say our goodbyes with smiles on our faces.”

Abstract

The purpose of this research is to explore the structural forces that limit the access to health care services for Deaf people. Literature has acknowledged the disconnection between the Deaf and hearing worlds, particularly in health care. Much of the existing literature exploring these fields have failed to include input from the Deaf community members. As such, hearing perspectives dominate the research and hence also in the lives of Deaf individuals. The narrative presented indicates that hearing people need to be made more aware of Deaf people's own perspectives and respect the policy of self-representation so that laws and regulations do not negatively affects Deaf people's lives. Using ethnographic methods, including narratives, participant observation, informal and semi-structured interviews, and photo-elicitation interviews, this study highlights the structural violence experienced in accessing health care by six Deaf people in Cape Town, South Africa. The findings confirm previous studies' assertions that the dominant biomedical view towards deafness negatively affects Deaf people overall, particularly because of lack of communication access to health care.

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Chapter One:

Deaf Futures in Health Care Services

“School did not educate me in depth on health care, they only educated me the basics of HIV/AIDS, and sex education. So, when the doctor told me I have cancer, I couldn’t ask any questions because I didn’t really know what cancer was. I had to go home and open Google to research what cancer was, which cancer I have etc. then I had the questions.” - Paul

Introduction

I was born Deaf and have grown up with a proud Deaf identity. As such, I have learnt a lot about the way of life and the culture of my community. Over the years, I have invested much time and effort into building relationships with other Deaf individuals and united our community. The relationships that I have developed span across gender, economic status, place of residence and age. From young children to older persons, I have gotten to know many people from various walks of life. One aspect about the culture and lifestyle that I have observed and participated in over the years and which sparked my interest, is the Deaf experience of health care. You see it in the never-ending number of children that are constantly in and out of doctor appointments and hospital visits, the multiple horror stories we hear about their experiences with health care services and in so many other places. Because of my observations, I started to inquire about health care services with my closest friends and the more I asked, the more I discovered the complexity of accessing health care services within the Deaf community.

One of the biggest experiences that has sparked my interest in health care happened four years ago. My mother, who is also Deaf, did not see the step in front of her. She fell and was in so much pain. She decided it was probably nothing and went home to sleep it off. The next morning, her pain had gotten worse. She asked my hearing sister (age 18 at the time), who is a good signer, to phone the ambulance. When they arrived, my sister informed the paramedics that my mother did not have medical aid so they took her to a state hospital in Johannesburg. My mom was loaded into the ambulance and my sister and a friend followed in a car. There was no communication with

my mom during the trip to the hospital. Upon arriving, she had to wait for hours to get an X-Ray done. There was no explanation for the wait or any attempt to manage the excruciating pain she was in. Finally, a nurse took her to get the X-Ray done and the doctor came out with the results. The doctor spoke to my mom while my sister (who was also very stressed by the situation) tried to interpret. He explained that she had broken her ankle, with three fractures and would require surgery to put in a metal plate with a few screws. However, the doctor warned her that having the surgery at that hospital was not recommended as the air-conditioning in operating room was not working and surgery in such conditions would lead to infection and probably land up in amputation. My sister interpreted 'amputation' first and then added the reason why after but all my mom saw was AMPUTATION. Naturally, she screamed and went in a panic mode. She imagined the worst-case scenario - being Deaf and disabled. She messaged me, as I was in Cape Town at the time and I also freaked out. My sister then asked the doctor to clarify what he said to my mother. The doctor repeated that my mother should go to another hospital, preferably a private hospital, to get the surgery because they would not be able to operate her without the air-conditioning and would likely have to amputate her foot as a result of infection if done at the state hospital. One simple miscommunication and my mom freaked out for hours unnecessarily.

In the end, she decided to go to a private hospital after experiencing such a distressing and traumatic event at the state hospital. She made the decision to save her foot but my family got into so much debt as a result. My sister was in middle of final matric exams so I had to leave my studies for two weeks and flew to Johannesburg to help them out. As soon as I entered the private hospital, my mother was about to go in the operating room with a nurse who claimed he could sign. I remember she was not being herself, she was so stressed and expecting the worst. When she came out of the operating room, an hour and half later, my sister heard her wailing for fifteen minutes. Finally, the nurse yanked the door open and begged my sister to come in and help her. He said my mother would not respond to his sign language. I went in instead, and my mother was frantically moving her leg and crying. The nurse attempted to sign again, but I could not understand him. He was not signing, he was gesturing instead. My mother could not understand him and told me everything hurt and wanted something to soothe her pain. The nurse said they had to wake her up to ask if she is feeling any pain but could not understand her. I had to call my sister to interpret for my mother. She stayed in the hospital for two days and I have never seen her so stressed and

depressed. This traumatic experience inspired me to choose to research Deaf people's experiences at health care services.

After this personal, traumatic event, I initiated conversations about health care services with several Deaf individuals I met and they became my family. Despite our shared culture and experience, many of these individuals would argue that services were not too bad - weary of my or others' opinions. I knew they were not telling me the truth, but as someone they respected, they felt they could not be completely honest, since the subject is apparently a 'taboo' in the Deaf community. Conversations with men and women were equally fascinating. Some of my male friends spoke of the communication barrier while some of my female friends focused on the fact that they deserve better health care. Eventually, after hours and hours of conversations, they all opened up the deepest truth of their experiences and became very willing to participate in my research in order to make others feel they are not alone in this. Everyone had a story. I started to connect all the information that I had accumulated and found a huge discrepancy between the Deaf and hearing experiences of accessing health care services in Cape Town and South Africa.

For my research, I wanted to look deeper into all the aforementioned observations as I got to know the people and share a common language and culture with them. Health care is a basic human right, and I aspired to learn more about how deeply it was rooted in their lives as a Deaf individual. Additionally, I wanted to investigate its link to the hardships of the Deaf community, to aspire and thrive in the "Other" world, the hearing world, as it stands as an obstacle in the relationship to their health care (Foucault, 1999). I sought to discuss barriers to health care services, structural violence, immediate community care and cultural barriers standing in the way of effective health care services in Cape Town. I wanted to do this in order to both gain a better understanding of how they make sense of the continuous barriers to health care services within our community and to open up the conversation to find a culturally appropriate and sustainable strategy for change. This study has broad implications for the community, especially because of the intersection of many significant socio-cultural issues such as women's health, poverty and gender roles. Through a discussion with my participants and other Deaf individuals, the significance of these repercussions for the community is exposed, opening their eyes to the importance of health care as an important tool to reduce our daily suffering.

Human suffering is experienced by everyone to a certain extent (Das, 1999), however, it is substantially exacerbated among (socially, economically and politically) disadvantaged groups who are further at risk of violence, injury, and disease. In this dissertation, I argue that huge disparity occurs in the Deaf community in Cape Town – a community which I am a part of. As a result of structures, such as lack of access to health information and lack of access to communication at health care service centres, the Deaf community experiences the structural violence of accessing health care. Farmer (1997) describes structural violence as a form of human suffering caused by “structures that allow such indirect yet noteworthy forms of human suffering.” Drawing on the ethnography, I explore what it means for Deaf individuals who use South African Sign Language (SASL) as they navigate through spaces of health care and try to access related information. I am attentive to how Deaf socialites¹ and goals are made in Deaf space as they share their experiences and encounters, examining what it means to be Deaf in health care systems and envision what Deaf futures may look like in health care services if there were to be full access and no structural violence.

It is known anecdotally that Deaf people struggle to access health care services - even those aspects (e.g. making appointments, receiving advice, advising the health care worker of concerns) that are considered straight forward for the broader population. The hypothesis of this study is based on this information and holds that full access to health services in Cape Town is not possible for Deaf people of the city. This in turn is likely to result in compounded disadvantage for this population group. However, such a situation is contrary to the rights of all South Africans to receive full access to health care without discrimination on the basis of their preferred language for communication. The Constitution of the Republic of South Africa, 2006, in the Bill of Rights (Chapter 2, Section 9 (3)) states:

“The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth” (The Government of South Africa, 1996).

¹ Deaf forms of sociality captures better the fluid, creative, dynamic character of Deaf persons and their social interactions rather than the term society which seems more fixed and static. South Africa Deaf community has forms of sociality and social interaction that involve modes of negotiation, adaption and improvisation that were highly situational and dependent on the context of health.

Further, in Section 27 (1):

“Everyone has the right to have access to a) health care services, including reproductive health; b) sufficient food and water; and c) social security, including, if they are unable to support themselves and their dependents, appropriate social assistance.”

Despite this constitutional right, many South African citizens are still unable to access health services as a result of the language they use. Among those denied access to health care services are SASL-users and as such, being Deaf prevents patients from accessing their right to equal health care. However, being Deaf does not only affect the experience of being isolated from proper care. Intersectional theory is part of the experience where class, race and gender further impact on the experience of health care service provision. This theory is further investigated in this study.

As highlighted above, this research contributes to anthropological literature on Deaf individuals' experiences of structural violence in health care services. Structural violence is however not the only type of violence which may be experienced by people. Johan Galtung (1969 and 1990) argues that there are three types of violence in society: 'direct violence', 'structural violence' and 'cultural violence'. He believes that violence exists when people are affected in such a way that they cannot attain their full potential. Direct violence can be explained as a violence that physically and mentally hurts people directly. For example, in war, when you are injured and you face the possibility of dying, that is direct violence. Conversely, within structural violence, there is no direct actor and as such the violence is more indirect. In this case, violence is built into the structure and can be detected through unequal conditions in society, which contributes to different circumstances in life (see also Farmer, 1997). This can be seen, for example, by uneven distribution of the country's resources and the power to decide on the allocation of the resources. Structural violence can also be explained as social injustice (Kleinman et al., 1997; Das, 2007). The problem with structural violence is that since it usually does not create immediately visible damage as direct violence does, it becomes even more difficult to detect when living in the midst of it. However, it can do as much harm as the direct violence.

The final type of violence proposed is cultural violence. This violence normalises direct and structural violence within a particular group. As a result of this, forms of direct and structural violence are accepted and not seen as wrong within the relevant cultural context (Jenkins, 1998).

It arises when one aspect of culture such as religion, ideology or language justifies the violence although it does not imply that the whole culture itself is necessarily violent. Jenkins (1996: 33) discusses direct violence as “seen as an event, structural violence as a process and cultural violence as something lasting.” This dissertation will be focusing on the Deaf community’s experiences of structural violence as embedded in health care provisioning within South Africa.

Structural violence is built into relations between two or more parties. It is built-in and inverse in society, and thus difficult to see and change. It is only when someone highlights the oppression that the violence becomes apparent and clear. Structural violence thus deprives people of fundamental values and rights necessary for a dignified life, which in some ways, the Deaf community experiences with regards to access to health care services. Therefore, the individual (Deaf person) and the collective (Deaf community) “construct themselves as actors” (Das, 1995:2). De Certeau (2009) centres on the idea that ordinary people are not passive and submissive consumers but active and can manipulate the environments around them through everyday actions. He divides society into two groups - the producers of culture (or the ruling class) and the users (ordinary people). He sees the production of culture as a means of exercising power and a mechanism of discipline. Studies of representation are in themselves a creative process because each person reads a text or an image differently based on his or her needs and experience and draws a different meaning from it. One way that the users can exercise their power is through ‘resistance’ (De Certeau, 2009). The Deaf community exercises this resistance by revealing their experiences and appropriating space to their own interests within the framework laid out by the majority.

De Certeau (2009) goes on to discuss the power struggle by differentiating between “strategies” and “tactics”. A strategy is the overarching framework of the ruling institutions and their objectives, whereas tactics are the individual actions included in everyday activities. Unlike strategies, tactics do not seek profits and are not results of planning, but depend on the situations and opportunities. They are the limited freedoms allowed by the framework of strategies. For this reason, De Certeau sees everyday practices as a form of political resistance: “the tactics of consumption” are “the ingenious ways in which the weak make use of the strong” (2009: 17). The resistance by people and groups and their awareness of it varies. Some may actively seek to resist

the dominant ideology, while others are content with their position in society, yet subvert it unknowingly. Therefore, in this research I argue that most Deaf people actively seek to resist the health care system in South Africa by, using De Certeau's (2009) theory as a foundation.

The structural violence discourse sometimes neglects to engage with persons as moral agents who are not passive in the face of such forces but are often active agents. The key area where people recast and reformulate the forces that they are subject to is through narrative and storytelling, through actively engaging and reshaping their lived experiences. The Deaf community has the collective identity of accessing language, culture, and national belonging. This collective identity enables Deaf persons to reclaim power with respect to their own lives. Being part of a community makes it possible to collectively resist attempts to control them, thereby giving individuals agency. Examples of claimed power are events such as Deaf Awareness Month, which aims to improve access to rights for Deaf people. The belonging and agency of the Deaf community allows persons to actively negotiate the structures of power, barriers and inequality rather than being passive recipients. As such, the community is re-affirmed as individual members take up their agency and share common experiences.

To explore the narratives of Deaf individuals and accessibility to health care services, this dissertation also “contributes to anthropological literature on the experiences of Deaf individuals and the rise on Deaf subjectivity in connection to the changing nature of the state” (Kohrman, 2005:5). Thoughts of Deaf universalism have driven some researchers and activists to view “Deaf” as an identity and utilise it as a point of analysis (Corker, M. 1998; Eckert, R.C. & Rowley, A.J. 2013; Harmer, L. 1999; King, J.F. 2005). However, it has been argued that using identity as a classification does not offer much in terms of analysis (Branson and Miller, 2002) especially since the Deaf community is considered so diverse and politically charged, with multiple positionalities. Expanding on previous work on subjectivity, I consider being “Deaf” to be a subjective experience, rather than a reified identity, to maintain a strategic distance from the broad classification of identity. Subjectivities are “embodied experiences within a hierarchy of power” (Pine, 2009: 12). I argue that “Deaf” should be viewed as embodied subjectivity – one of the many subjectivities – built and authenticated through intersubjective experiences within societal barriers and signed languages. Exploring Deaf subjectivities as embodied experiences within hierarchies of power

takes into consideration a more adaptable comprehension of differing Deaf experiences situated within frequently overlapping social categories such as disability, culture, class, education, geography, history, ethnicity, linguistic competency, race, gender and religion.

Drawing from my fieldwork experience, I have gathered the narratives of the participants' experiences and forms of structural violence that they have been subjected to. Notwithstanding, from the narratives and my personal experiences with Deaf individuals in Cape Town, the political standing of belonging and acceptance in Cape Town and the Immediate Community Care² (ICC) surfaced. It became clear how participants feel with regards to belonging and acceptance, how they are separated from ICC and with regards to the ways they are treated unequally. This was particularly true for matters related to accessibility to health care information, educational knowledge and communication. These barriers emerged as the most serious amongst Deaf individuals in Cape Town.

My primary research method for this study involved working closely with six Deaf people over a period of three months from 31 July 2017 to 25 October 2017. During this time, I accessed my participants' narratives of their experiences with regard to health care services in Cape Town. To avoid ethical constraints, I avoided going to health care centres with my participants and instead accessed their narratives by developing a timeline of their lives to turn into life stories and experiences. My participants are SASL-using Deaf individuals between the ages of 25 and 56. I selected a variety of Deaf participants for the study. Although all the participants use SASL at their primary language, some also read lips, and/or speak, some wear hearing aids (depending on availability of finances, level of hearing loss and parental insistence) and others refuse to use spoken language or hearing aids. Three of my participants are women, the rest are men. One of them is Indian, one is Black, two are Coloured, and two are White. In addition, the participants report being representative of various religious persuasions. Some of my participants did not complete school while others completed higher education. What united my participants was the fact that their preferred language of communication is SASL and their wish for better accessibility in health care services.

² Immediate Community Care is a focus on the circles or networks of care in everyday familiar situations and are not directly linked to hospital care.

The intersectional theory approach was used during this study. Intersectionality refers to the experience of multiple oppressions within one context, one person's experiences and how that impacts that individual (Crenshaw, 1991; Collins & Bilge, 2016). In this thesis, intersectional theory was used to examine how Deaf identity stems from a mutual interplay between race, class, and gender. Intersectionality in Deaf Studies increases efforts to incorporate stories of other Deaf intersectional identities and recognising that narratives may not include the perspectives of all Deaf people. Using this approach allows the narratives to evolve to address multiple and diverse experiences and acknowledges when the narratives need to be decentralised.

The forms of data used in this study were stories, interviews, and photo-elicitation interviews. These narrative stories are not direct, clear arrangements of occasions but rather an impression of various realities Deaf individuals face. Stories open up the likelihood of speaking to multifaceted experiences, vulnerability and inconsistencies. Life narrative interviewing is a technique for data gathering where individuals are asked to document their life over a particular time frame. It is an individual's record of their life in their own particular words and utilising their very own course of events. Frank (1995) provides insights into how illness stories are therapeutic for others, in this case, Deaf individuals. Thus, the possibility exists that other Deaf people may read the stories which will enable them to realise that they are not the only one; other individuals can understand their experience and even have comparative encounters. I see in Frank's (1995) discourse the possibility to create remedial narrating where people share their stories as a major aspect of their experiences with health care. By recounting their stories, Deaf people will be in a position to speak about their lives. It is through recordings individual lives that we may comprehend more inclusive society by placing the narratives of an individual lives within a broader context for in-depth analysis.

As is consistent with the requirements of such research where the stories of individuals are central to the study, all the necessary ethical considerations were adhered to. These included aspects such as ensuring participant protection from harm, informed consent and the right to anonymity which were upheld during and after data collection.

This study aims to better illuminate how Deaf people perceive the hearing-dominated health care system and how this affects their overall health and well-being. In South Africa, the provision of health care services varies greatly depending on the socio-economic group. The consequence is that health care services are offered on “an ability-to-pay approach” (McIntyre et al. 2008: 44). McIntyre et al. (2008: 44) also stress that:

“political change in South Africa, since the end of apartheid, has empowered the health care services to make progress towards WHO’s definition of health care services by endeavouring to amend the disparities of the past.”

This was accomplished by building 1300 new clinics and remove charges for persons with disabilities. However, in spite of concerted efforts from the state, large inequities and vastly different experiences in terms of access to health care for those who use public as opposed to private health services, are still found which illustrates my mother’s experience. Hence, the perceptions of Deaf people in Cape Town, in their own words, as documented through the interviews and participant observations enhances respectful collaboration between health care providers and Deaf individuals, as well as enhances an anthropological approach to health care. In a time, such as now, when various marginalised groups of people, including Deaf people, are worried about what the future might hold for them due to the political climate and the increasing advocacy of the biomedical approach, anthropological approaches to improving health have never been more relevant.

Conclusion

This chapter considered the experiences and factors that motivated my study. My positionality within the Deaf community sets the context of the research and provides the reader with insight into my relationship with the Deaf world. A guideline of the theoretical framework was presented and methods used to gather data and ethical considerations were introduced. The chapter which follows provides a detailed view of the Deaf world and further highlights the difficulties experienced by the Deaf community in accessing their rights.

Outline of the Chapters

Chapter One: Deaf Futures in Health Care Services

The first chapter introduces the positionality of the researcher in the study, examines notions of barriers to health care services and establishes the research aim, rationale and the context of the study. The methodology and ethics considerations are also briefly described.

Chapter Two: Social Context and Historical Background

The second chapter explores the social context of the Deaf community including some historical background of influential figures and Deaf Education in South Africa.

Chapter Three: Positionality and Methodology

The third chapter explores the methodology used in both fieldwork and writing. It establishes the format this dissertation uses and discusses population sampling and the way forward for data collection and analysis.

Chapter Four: Literature Review and Theoretical Framework

The fourth chapter explores literature on Deaf Studies, accessibility and communication obstacles and key approaches. Theoretical frameworks are also described and considered for an approach for this dissertation.

Chapter Five: “BARRIERS MANY WHY?” Results

The fifth chapter explores the results of the study. The themes explored are: ‘White Paper on the Rights of Persons with Disabilities’; ‘Health Care as a Concern’; ‘Differing Perspectives on Communication’ and ‘Relationship with Health Care Practitioners’.

Chapter Six: Imagining Deaf Futures

This chapter concludes the research and highlights the study’s findings as well as presents recommendations for further research in this particular area.

Chapter Two: Social Context and Historical Background

“So, let’s imagine there’s a beautiful and delicious cake. Sometimes people make the mistake of cutting a small slice while the other person gets the bigger slice. The person who go the smaller slice would feel unfair. It’s similar to the Deaf community, how we feel being the smaller slice. Imagine if it was the other way around, our Deaf community is the majority and the hearing community is the minority. They would feel excluded in the world of sign language.” - Paul

Introduction

The Deaf community is a diverse community of different persons with different backgrounds and experiences, yet we share the same culture and language. The South African Deaf community, like other Deaf communities, is viewed as a group. According to Barth (1969), cultural distinctiveness which is recognised as such, both socially and ideologically, is the hallmark of an ethnic group. Further, Eriksen (2001: 263) highlights that social practices, such as language, are an essential characteristic of cultural distinctiveness. With respect to the South African Deaf community as a distinct group, the identifying cultural feature is the use of sign language - in this case, South African Sign Language (SASL). In addition, the existence of Deaf identity and various assumed status reinforces the position that the Deaf community is indeed a distinct group. In this chapter, the various perspectives, discourses, membership, historical backgrounds and sign language will be explored to illustrate the factors that unite the Deaf community.

D/deaf and Hearing People

The terms ‘deaf’, ‘Deaf’, and ‘hearing’ are used throughout this dissertation. These terms are commonly used in research with d/Deaf, and hearing communities. Generally speaking, ‘deaf’ refers to deaf individuals not involved in Deaf culture and who do not use sign language while ‘Deaf’ refers to Deaf individuals who embrace Deaf culture and who use sign language as their first language. Those who are Deaf are generally intimately involved with the Deaf community which is defined as “the social and cultural formation of Deaf people who use their Deaf identity

and sign language to communicate” (Padden and Humphries, 1988: 24). The term ‘hearing’ refers to individuals who can hear. It is a concept used in the Deaf community to identify the other (Foucault, 1999), or “those who are not part of the group” (Haualand, 2007:12). This will be explored further later in this chapter.

Varying perspectives of deafness and Deaf culture

There are three prevalent, but vastly different, broad perspectives of deafness: the biomedical view, the social justice view, and the cultural-linguistic view. These perspectives will be referred to throughout the dissertation. Underpinning the biomedical view is the notion that deafness is a deficit and that it is the pathological absence of hearing. As such, Deaf people are commonly regarded as impaired and disabled. It is referred to as the biomedical discourse because medical interventions, such as cochlear implantation to remedy the perceived fault, are often recommended by medical professionals (DeVault, 2014; Fjord, 1996; Senghas, 2002). In contrast, the cultural-linguistic view of deafness has gained momentum in recent years. This perspective focuses on recognising Deaf people as a minority cultural group with their own language. In this view, deafness is regarded as just another human variation that becomes part of an individual’s identity and self-identity is in no way linked to the disability discourse. Similar to other minority cultures, the Deaf community has its own histories, traditions, values and social norms that are passed down through generations (DeVault, 2014; Fjord, 1996; Senghas, 2002). Fjord (1996) asked several Deaf people, “What if there was a cure for your deafness?” and then noted that he had “yet to see a Deaf person wish to be ‘cured.’ Instead, they have responded that their deafness is an integral part of their wholeness, a sentiment common among people who fall into other ‘disabled’ categories” (1996:66). This exemplifies the cultural-linguistic perspective toward deafness, not the biomedical or social justice perspectives. Finally, the social justice view focuses on individuals with disabilities gaining access into general society. This view consists of elements of both the biomedical and the cultural-linguistic view. While this perspective provides advantages for Deaf people on certain levels, it does not address the central issues related to Deaf culture and sign language. The ultimate goal of mainstreaming individuals with disabilities into society unwittingly isolates the Deaf person from their own people and language (DeVault, 2014; Fjord, 1996; Senghas, 2002).

The biomedical discourse argues that deafness is an impairment of the body itself and is therefore a disability and a medical problem. Deafness is seen as a deviation from the image of a standard, “healthy” body (Fjord, 1996). In contrast, the cultural-linguistic view argues that existing social structures and ideologies of society disable the individual because they do not accommodate or accept disabilities or differences (Mauldin, 2012). In more recent years, the South African Deaf community has explored strategies to reduce the lack of awareness by increasing SASL’s prestige, foregrounding the community’s legitimate power in the eyes of the dominant community and creating a strong presence in lobbying for SASL to become South Africa’s 12th official language. These varying perspectives highlight the need for more education about the Deaf community and their culture. I argue that, overall the dominant biomedical perspective toward deafness negatively affects the Deaf community. While the views of Deaf people cannot be generalised across the whole community, Deaf people could have a more positive health care experience overall if medical professionals had a better understanding of and more respect for the Deaf community. The dominant biomedical discourse is a perspective creates the lack of access, trust and respect that Deaf people often feel toward the health care system.

Deaf people in South Africa still struggle to gain recognition as a cultural group, especially in the political and educational arenas. The Deaf community’s own perspectives are frequently overlooked and hearing legislators often make decisions regarding the lives of Deaf people without any real input from Deaf people themselves. This can affect them in every aspect of their lives, including health care. One way their lives are affected is by the manner in which medical professionals disregard the lived experiences of Deaf patients. Foucault (1994) said that classificatory medicine “detaches individuals from experiences of physical suffering, conceiving of subjective experiences as secondary to the manifestation of diseases or ailments” (Foucault, 1994, as cited in MacDougall, 2015: 156). Biomedical approaches to deafness parallel these perspectives by classifying deafness as an ailment requiring medical treatment while overlooking the important role that deafness and sign languages play in collective experiences of identity within the Deaf community (MacDougall, 2015).

On the one hand, the Deaf community’s fight is about being recognised and respected as a minority cultural group, with their own language while on the other hand, the dominant hearing society

disregards the perspectives of the Deaf people and continues to view deafness negatively. These perspectives often affect a Deaf individual from a young age. Roughly 90% of Deaf children are born to hearing families (Fjord, 1996; Senghas, 2002). Given that parents likely first learn of their child's deafness in a medical setting, deafness is often presented from a biomedical perspective. This is rooted in a disability and impairment discourse as a perspective in which the intent is to fix or cure the child's deafness, with the overarching goal of functioning in the dominant hearing environment using spoken language and lip-reading (Higgins, 2016).

As members of a minority culture, Deaf people in South Africa are surrounded by a majority culture: hearing culture. Since deafness is classified as both a low incidence and invisible disability, the vast majority of hearing people have never encountered a Deaf person or learnt about our culture. As a result, Deaf people have both positive and negative daily experiences with hearing people and their actions affect Deaf people in various ways (Lentz, 2014). Overall, there is an extensive lack of knowledge about and disregard toward the Deaf community and their culture and language (Munoz-Baell, 2000) which creates communication obstacles that makes it difficult for Deaf people to access essential utilities in their daily lives. This lack of knowledge has unfavourably influenced medical, legal, and educational policies regarding Deaf people.

Membership in the Deaf Community

Members of the Deaf community will identify themselves as Deaf, with a capital D, because they see themselves as belonging to a distinct cultural group. With the definition of Deaf in mind, what then constitutes the Deaf community? Depending on who is describing it, the Deaf community is not compiled solely of people who lack the sensory ability to hear. Rather, the Deaf community is comprised of those who are Deaf, Deaf-Blind, Hard-of-Hearing, Children of Deaf Adults (CODAs,) Siblings of Deaf Adults (SODAs,) and even hearing people who advocate for the community (Lees, 2015).

Individuals who are Deaf have different "levels of hearing and often identify themselves somewhere along the spectrum of hard-of-hearing to profoundly deaf" (Richardson, 2014:3). Some may call themselves Hard-of-Hearing (HoH) if they could hear a little and have mastered spoken language alongside sign language, while some may call themselves Deaf if they could not hear at

all and have a strong Deaf identity. It is important to note that Deaf people are not a homogeneous group with the same degrees of hearing who all live their lives the way other Deaf individuals may live. It is also “important to note that the terms ‘hearing-impaired’ and disabled are considered extremely derogatory in Deaf culture due to their focus on inability instead of cultural empowerment” (Barclay, Rider and Dombo, 2012: 67). The Deaf community strongly believe their deafness is a small part of their whole Deaf identity. Their identity consists of language, culture, tradition, and beliefs (Lane, 2005). This allows Deaf people to go on with their lives without being labelled as disabled or as hearing-impaired, but rather thrive, being labelled as Deaf and as a member of a culturally empowered community.

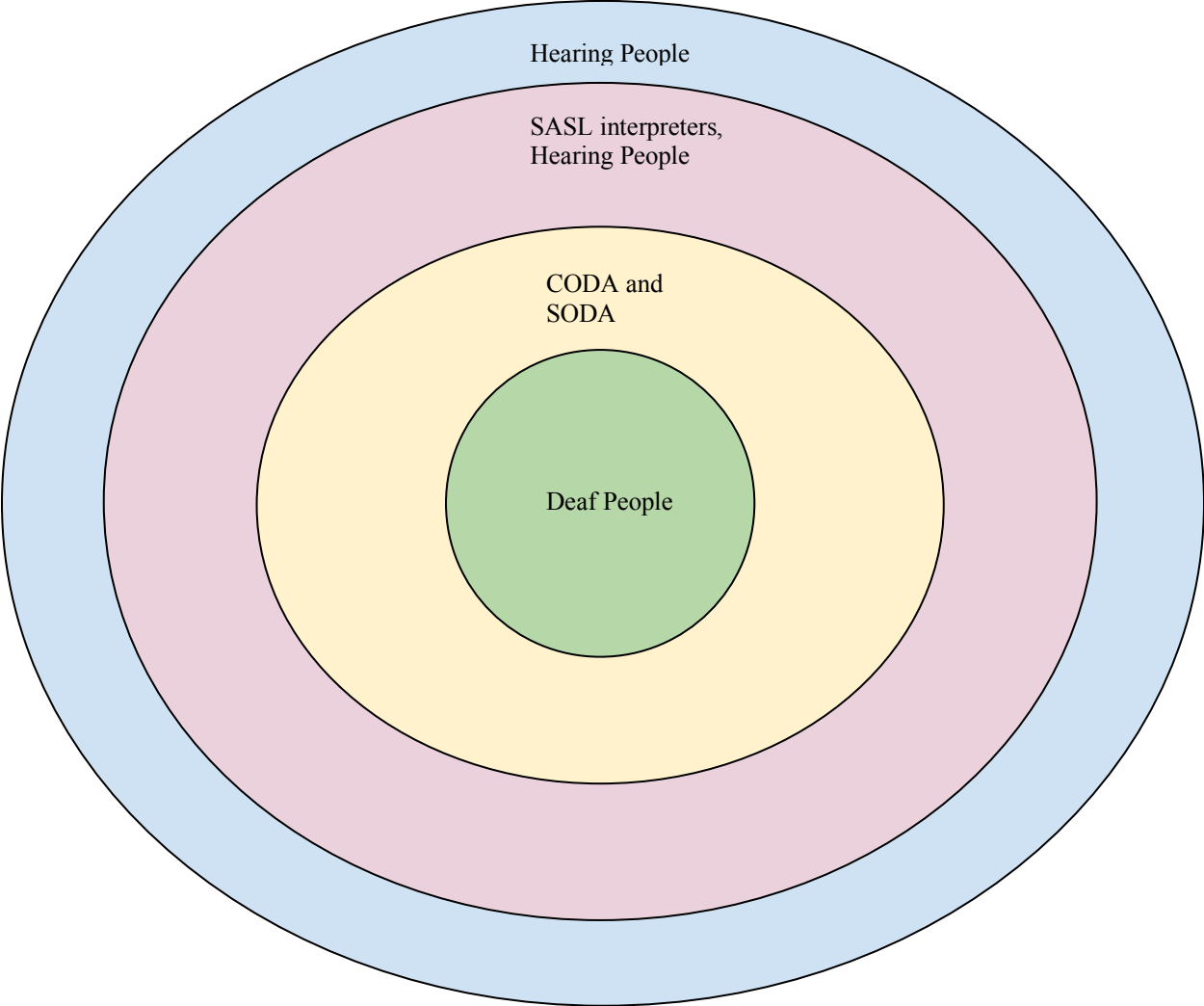


Figure 1: Circles of Deaf Community (Barclay, Rider and Dombo, 2012)

The graphic representation of the Deaf community is shown in Figure 1 (Barclay, Rider and Dombo, 2012) and consists of four circles. The innermost circle consists of the Deaf individuals, the second circle consists of Children of Deaf adults (CODA) and Siblings of Deaf adults (SODA), the third circle from the centre consists of hearing people who can sign and who are involved in the Deaf community (including some South African Sign Language interpreters). The outermost circle consists of hearing people in general. Be that as it may, there are no precise statistics on the number of deaf people who are involved in the Deaf community in South Africa. Census report on Profile of Persons with Disabilities in South Africa (2011) estimated a total of 3% of persons aged 5 years and older had mild difficulty in hearing, while those who experienced severe difficulty in hearing constituted less than 1% of the total population of the country (Census, 2011).

South African Sign Language (SASL)

There is no universal form of sign language. Instead “each country develops their own sign language through the needs of the specific community, which develops over time” (Morgans, 1999: 2). South African Sign Language (SASL) has its own grammar and structure and is not derived from or related to any other spoken languages. Within the history of Deaf education in South Africa, SASL was influenced by three other languages: British Sign Language, American Sign Language and Irish Sign Language (Morgans, 1999). Like any other language, SASL has many dialects and although there is a common grammar, there are nevertheless dialects and variations used across the country.

Deaf History: Influential Figures and Deaf Education

The Deaf community has had a long and turbulent history to get to where it is today. Unfortunately, there is scant research on Deaf history in South Africa. In this sub-chapter, I explore the international influential figures in Deaf education, with reference to the known history of Deaf Education in South Africa. Early Deaf Education history in the USA is dominated by two men - Thomas Gallaudet and Alexander Graham Bell. These two men epitomise the social and biomedical views of deafness and their actions had far reaching consequences on perceptions of the Deaf. In the early 1800s, Gallaudet was exposed to teaching the deaf daughter of a prominent medical doctor. Impressed by the success he had the community enabled him to travel to Europe where he learnt about the “French method” of teaching the Deaf - using sign language. He returned

to America with a Deaf teacher from France, Laurent Clerc, and introduced the method at a new school for the Deaf, established in 1817 (Cokely, 1980; Lane, 2005). At the time of their deaths, these men helped establish a growing number of schools which used sign language for instruction.

In contrast, in the 1870s and 1880s, before inventing the telephone, Alexander Graham Bell was dedicated to teaching deaf people speech and lip-reading. Even though Bell was able to sign because his mother and sister were deaf, he believed that deaf people should accommodate the hearing majority by learning how to speak and lip-read (Lane, 2005). Bell believed that the very future of the nation depended on eradicating minority languages and is quoted as saying, “it is important for the preservation of our national existence that the people of this earth should speak one tongue” (Lane, 2010:8). He also feared that using sign language would result in deaf people marrying one another and ultimately to the continuation of a “deaf variety of the human race” (Fjord, 1996: 62). Bell was a respected individual and as such his view toward deafness and sign language influenced by society’s view of deafness as a disability. His actions advanced the biomedical perspective of deafness and he banned the use of sign language in his schools.

Due to the influence of prominent societal figures like Alexander Graham Bell, in 1880 the Second International Congress on Education of the Deaf almost unanimously declared a ban on the use of sign language in Deaf Education. The congress was attended by only one Deaf person and the vast majority of attendees were in favour of oral-only teaching methods (Lane, Hoffmeister and Bahan, 1996). These methods remained strictly in place until the 1960s when research emerged that proved oralism as ineffective and the Deaf community made progress establishing itself as recognised cultural and linguistic group (Lentz, 2014).

Having a background of the tension which existed internationally, it is also important to understand the history of Deaf Education in South Africa in order to grasp the background of the barriers currently experienced by Deaf people in the country. Storbeck and Martin (2010) explored a historical overview of Deaf education in South Africa. The history began in 1860 with a missionary opening a school for the Deaf. Further schools were established in response to the Milan Congress of 1880 but focused only on provision of education for white Deaf children. In 1933, the school in Worcester, Nuwe Hoop School for the Deaf, was established for coloured Deaf children by the

Dutch Reformed Church and later more schools opened for black and Indian Deaf children. As was typical of apartheid education planning, resources were very unevenly distributed which resulted in schools for black, coloured and Indian learners having few, if any, resources. The same policy was applied to schools for the Deaf and this further affected the education status of Deaf South Africans. While South Africa is now a democratic country, Magongwa (2010) argues that Deaf South African learners are still negatively affected in the Deaf education system through the process of employing Hearing teachers who cannot sign and the unofficial status of South African Sign Language in South Africa.

Historical events such as the Milan conference, described above, have contributed to establishment of a binary relationship between Deaf and hearing people. In the modern Deaf community, the Milan Congress is a part of Deaf folklore, remembered as a terrible event that devastated the core of Deaf education and the Deaf community. This single event is so significant to the international Deaf community that it constitutes a “collective memory” (Novick, 1999) - a single, unwavering perspective on a tragic event that impacted on the community. The shared memory of the Milan congress expresses the tragedy of the destruction of a vibrant, healthy and respected Deaf community by the hearing majority - a traumatic event that ironically united the community. The various events and their impacts on the Deaf community described above have resulted in many Deaf South Africans having limited opportunity to learn about health care and their associated rights. It is because of this that Deaf South Africans continue to face many barriers.

Conclusion

This chapter provided the social context of deafness and historical background of Deaf education in order to provide insight into the Deaf community. The narrative presented indicate that hearing people need to be made more aware of Deaf people’s own perspectives and respect the policy of self-representation so that laws and regulations do not negatively impact Deaf people’s lives. Seeing deafness as a relational mismatch between the abilities of an individual and the design of the social and material surroundings, as opposed to a medical condition allows for the recognition that the problem is not always within the individual, but rather, is a result of the lack of existing knowledge about it as a cultural condition and not just a sensory one (Haualand, 2014). With this

understanding, the next chapter describes in detail the manner in which the study was undertaken and introduces the reader to the Deaf participants in the research.

experimental and qualitative in approach. Using hybrid methods, data collection instruments used were semi-structured interviews, photo-elicitation interviews, participant observation and drawing upon on my own experiences as a member of the Deaf community. Data within these methods were collected with video recordings with participants' permission. The research was done in South African Sign Language which was translated to English for the writing purposes.

Targeted Population/Sampling

The targeted population of interest in this study is Deaf South African men and women (ages 25+ years). The sample was taken from various locations in Cape Town. Initially, I had difficulty finding participants as openly discussing medical matters is a taboo subject in the Deaf community. After weeks of searching for participants not known to me, my friends showed interest and wanted to participate in the study. Eventually, I decided to let them become my participants as the nature of my study demands a considerable number of stories from my participants and therefore a lot of time spent with them. I was careful to ensure that the participants and I would observe a strictly participant-researcher relationship before initiating the research with them. It may be suggested that turning friends into participants may challenge the notion of 'other,' which requires the researcher to keep some sort of distance from participants to keep the results unbiased. However, "it opens up new possibilities within the storytelling with someone they trust" (Yuan, 2014: 101). The detailed process of sampling of each participant will be discussed below. A few of the participants wanted the interviews to take place at their homes, while some wanted them to take place at their workplaces or in a public place such as a corner café. In all locations, I closely observed the participants while they were telling me their experiences and it allowed me to step into their own world.

Participants

The design of this research reflects my own beliefs about engaging in community. It was important to me to work alongside people, to assist them in identifying their own needs and to formulate a vision for social change. Because of this, I chose people I met over the years in Cape Town as participants. A total of 3 women and 3 men participated in the study. The participants' demographic profiles are presented below.

The first participant I approached is a friend of many years. She always tells me stories about her experiences in health care services. She is a 26-year-old, straight, Indian female. Her name in this research will be 'Fareeha'. Fareeha was born and raised in Kwa-Zulu Natal. South African Sign Language became her home and first language from the age of two. She chose hearing aids as her hearing devices. Her immediate family is all hearing; however, she has a Deaf uncle and deaf distant cousin. Her mother learned SASL when she was two years old in order to communicate with her. She attended a Deaf signing school near her home in KwaZulu-Natal and matriculated in 2009. She enrolled at a university to study two different Bachelor degrees but did not finish either in the 4 years she was registered due to the lack of understanding of her needs as a Deaf student. She then registered at another university and recently completed her Bachelor of Arts degree in Linguistics and Gender Studies. She is currently working at an NGO. She battles with her mental health, included but not limited to general anxiety disorder and *dermatillomania* (chronic skin picking). She was incorrectly diagnosed with depression *in lieu of* unresolved grief by her general practitioner at the university's wellness centre shortly after her father passed away in 2016. It was only a year later, after her maternal aunt passed away, that she was properly diagnosed with general anxiety disorder and *dermatillomania* by her psychologist whom she saw biweekly with a voluntary SASL interpreter.

Paul became the second participant when we became friends on social media. He expressed interest in becoming my participant. He is a 38-year-old, straight, white male. He was born in Windhoek, Namibia and was raised in Cape Town, Western Cape. He grew up orally and attended an oral school in Cape Town. He learned to sign when he was in his teens years after observing a group of signing Deaf people. His parents have never learned sign language and communicate with Paul orally. He enrolled in a college to obtain his diploma in I.T. However, he had to have a bridge year before starting in order for the institution to observe his abilities. After he graduated, he began working for a private company. He is currently working as a software developer at a university in the Western Cape. His mother encouraged him to get a cochlear implant in 2016, which he was unsure about, but decided to go for the screening test to see if he is eligible for the hearing device. The test did not reveal if he could get cochlear implant but it revealed that he had stage 2 nasopharyngeal carcinomas. The cancer went away in 2017 but he went through many stressful experiences in his encounters at the health care centers.

My third participant is a friend of mine. When I moved to Cape Town to study B Soc Sc at UCT, he made sure I was comfortable and settling in well. We share common traits and habits, so we became very close. He has experienced numerous barriers, including in accessing health care services so he was willing to participate in my research. His name in the research will be 'Ahmed'. He is a 36-year-old, straight, Coloured male. He was born and raised in Cape Town, Western Cape. His family is all hearing and he communicates with them orally. His mother passed away when he was seven years old and his father passed away when he was eighteen years old. He was enrolled in an oral school at the age of three and fitted with hearing aids and forced to learn to speak. When he turned seven years old, his parents enrolled him in a Deaf school where he learned SASL. SASL became his second language while English is his home language. Eventually, he adopted SASL as his true home language. After matriculating, he enrolled in a college to obtain a diploma in financial management then enrolled in a university to obtain a B Com degree in Public Management. He is currently a high-level manager in the NGO sector. Ahmed has a generalised stress disorder and sinusitis-related health problems. He visits his GP approximately six times a year and he has visited hospitals a few times. Recently, he had his tonsils removed. Ahmed's mother took him to the family doctor until she passed away and his domestic worker took over until he was 18. Ten years later, he realised the doctor was not suited for his communication and medical preference as the doctor did not believe in antibiotics, Western medicine, so he found another doctor.

My fourth participant works at the same NGO as Ahmed. I was interviewing Ahmed when she approached us and asked if we would like some tea or coffee. Ahmed brought up that she recently had a life-threatening heart attack and a few other medical problems. He turned to her and explained her what I was doing and she said she was very interested in participating because she has so many stories to tell. Her name in the research is 'Renee'. She was born and raised in townships in Cape Town, Western Cape. Her family is all hearing and she communicates with them through her daughters who can sign. When her parents found out she was Deaf at 5 years old, they put her in a Deaf boarding school. She was never around her family much until she was pulled out of school in Grade 5 at 17 years of age, to start earning money as a domestic worker to

support the family. She gave birth to her son and daughters at 16, 18, and 33 years old. She is battling with heart disease and multiple illnesses: diabetes, cholesterol, asthma and depression. She recently had a life-threatening heart attack. Before her heart attack, she was in a car accident and her daughters had to aggressively put her in an ambulance because she did not want to face the communication barrier with the health care practitioners.

My fifth participant is a very close, childhood friend of mine. We have known each other for 21 years and we are always there for each other whenever there are emergencies. Whenever she goes in for an operation, I video-call her and she shares things with me and I comfort her before they wheel her off. I carefully decided to ask her to become one of my participants because I believe her stories will add great value to my research. She graciously accepted. Her name in the research is 'Elize'. She is 25 years old, straight, white female. She was born and raised in Durban, Kwa-Zulu Natal. Her immediate family is all hearing and she communicates with them through SASL and Home-Signs³. When her parents found out she was Deaf, they took her to a hospital in Cape Town to discuss their options. Eventually, they decided to enrol her in a Deaf school near their home. She matriculated in 2011. Thereafter, she enrolled to study Certificate in Photography in Durban for a year, then a college in Cape Town to study diploma in beauty therapy for three years. She then worked for various beauty spas until releasing this field was not for her. She is currently working as a foundation phase teaching assistant at a Deaf school. She experienced numerous health problems growing up, however, she had the most surgeries and consultations done during her time in Cape Town. She has a social anxiety disorder as well as nervous tic disorder. Whenever she is nervous, shy, embarrassed, etc. her neck and head shake uncontrollably. She has had numerous surgeries including removal of moles, a breast reduction and 5 knee surgeries.

The sixth participant only became one of the participants in the middle of the fieldwork. He expressed interest when he observed my discussion about my research with someone else at a workshop. He approached me and told me he does not care about the health care system and that we can create our own health care system to accommodate Deaf people better. I was intrigued with

³ Home-Signs is a system when hearing families with a Deaf child develops their own gestures and signs to communicate that is different to SASL. For example: "EAT" with a thumbs-up on the mouth; "SLEEP" with a flat hand over ear; "SHOP" with a gesture that looks like a trolley.

his opinions so I asked him to become my sixth participant. He accepted with excitement. His name in this research is 'Jonathan'. He is a 29-year-old, straight, Coloured male. He was raised in Cape Town. He is the only Deaf person in his family but he communicates with them through SASL and Home-Signs. He left school when he was sixteen years old to work. He is currently unemployed. Since leaving his family at sixteen years old, Jonathan has experienced a hard road to his health care all by himself until he was 28. He was involved in a few accidents, went for an MRI for his migraines and recently had a heart attack. He finally gave up at 28 years old and asked his family for help.

The participants are various ages and from a mixture of both rural and urban locations with no majority number. The education of participants ranged from primary school certificates to national senior certificates and undergraduate degrees. The participants varied in employment from cleaner to director.

Data Collection

On 31 July 2017, I obtained clearance from the UCT's Ethics in Anthropological Research Committee to start collecting data. My interview participants are all Deaf individuals with different backgrounds and experiences, therefore, I adjusted the interviews slightly to account for this. The main set of questions focused on structural violence, access to health care services, experiences with health, decision-making processes as well as personal questions about their lives, culture, and identity. Their narratives allowed the interviews to flow with new ideas and questions popping up. The notes I took during interviews were used to formulate thoughts and arguments. Over thirty photographs, supplied by the participants, were selected, stored and appear in Chapter 5. The data that were collected and analysed focused on the elements of structural violence linked to my participants' experiences and narratives. Through this, I was able to uncover three themes surrounding structural violence and access to health care services. Three methods of data collection (interviews, photo elicitation and participant observation) were employed during the course of my fieldwork.

Participant Observation

Since the premise of my study revolves around my experiences as a Deaf person, participatory observation was used within my research. Observations allow the researcher to provide a “written photograph” through the description of the situation observed using the four senses. Participant observation as explained by Schensul et al. (1999: 92) is “the process of learning through exposure to or involvement in the day-to-day or routine activities in the research setting”. I have been Deaf my whole life, I have gotten to know the people within our community, and I have been able to study their day-to-day life and get an understanding of why they do things the way they do. Throughout my time in Cape Town, I have spent time sharing meals with my participants, visiting their homes, attending funerals and weddings, and celebrating holidays with them. When I began my research study, I formalised participant observation by keeping a field notebook. I also became strategic in my observations and began to initiate conversations specific to health care services.

Semi-structured and informal interviews

Based on Jacobson’s work (1991), this study is ethnographic in that it centres on argument engagement and observation interpretation. He further suggests that in ethnographic fieldwork we look at ‘thinking’ and ‘actions’. During the participant observations, these aspects were obtained through observing behaviour and verbal interaction. Thoughts were captured through interviews (semi-structured and informal). Semi-structured interviews were arranged to take place at a time and place that suited the participant, and the interview was structured in relation to open-ended questions. However, the interview had no fixed structure or outcome and lasted as long as the participant was willing to continue. The interviews were conducted *ad hoc* during the participation monitoring process with people I interacted with, with organised questions related to the health care experience and wider discussion in the decision-making process in the areas of care that could be involved in medical decisions. I captured these exchanges through video recording due to the visual nature of SASL. It has been noted that visual methods provide many opportunities for exploring deaf ways to be in the world (O’Brien and Kusters, 2017). Deaf people have a strong visual orientation, and I have adopted the use of the term ‘visucentrism’, coined by Eckert and Rowley (2013) which is opposed to ‘audiocentrism’ which refers to the broader community focused on hearing and speaking.

Photo-Elicitation Interview

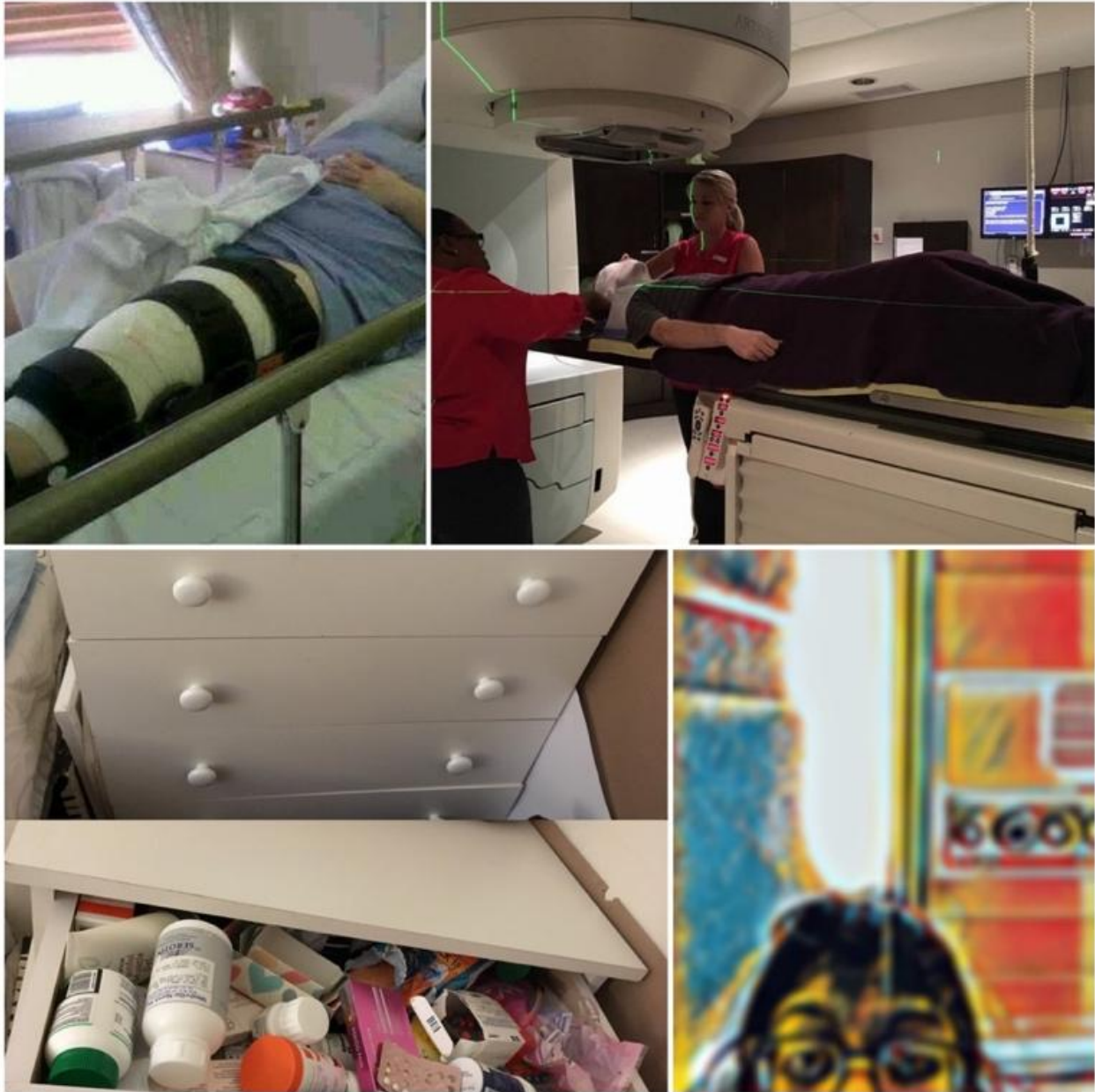


Figure 3: Sample of participants' photos

In preparation for the auto-driven photo-elicitation interviews, participants were asked to depict their health and how they cope with it on an average day (see Figure 3). This method was used in order to explore the environments in which the participants live and also to examine how the visucentrism of Deaf people is used to formulate their health narratives. This method also made it possible to use the image to begin and sustain conversation around the depicted items in the photograph as well as the motivation behind or intention of the picture, including reasons for the

image being captured in the specific way it was chosen. Along with the information from the interviews, I analysed the narratives with a deeper insight into the participants' intentions and the meanings behind their stories and photographs. My purpose for choosing photo elicitation interviews is supported by Collier and Collier (1989: 99) who suggest that conducting interviews around images can build 'communication bridges' between the interviewer and participant. This is done by shifting the focus of the interview from the participant, to the image, which results in easier communication. This is also useful for this study as there are many SASL dialects and the potential exists for my participants and I to use different dialects, which may cause some tension. With the photos as the centre of the interview we are more likely to communicate smoothly. Finally, the photographs provided an insider's perspective on the lives of the participants.

Data Analysis

The next chapter will provide a detailed analysis of data gathered for my ethnographic study. Creswell (2009) demonstrates ethnographic study as a method of addressing theories and questions in order to analyse a holistic image of "the research participants that focuses on the experiences of participants to reveal how people express and construct their worlds" (2009: 11). The underlying focus of the research is on structural violence and access to health care which fall within the field of medical anthropology. Farmer (2004) argues that ethnographic study is the best tool to explore structural violence in marginalised groupings, as it allows the researcher to explore the stories and experiences the participants reveal with deeper meaning in order to understand the larger context of structural violence. Farmer (2009: 48) added insight to the question: "How do social factors such as poverty and discrimination become embodied in individual experiences?" In order to explore the question, he shares stories he found in his fieldwork which explore social factors through the daily suffering of marginalised groupings.

To analyse my data, I first transcribed a total of 24 filmed interviews done with 6 participants and re-read my journals. After all of the data from videos and field notes were included, the transcripts were completed. I then began the analysis process. The analysis was underpinned by grounded theory, which is used to "identify categories and concepts within text that are then linked into formal theoretical discourses" (Corbin & Strauss, 2008: 2). It can also be described as a set of methods that include reading the transcribed data, then identifying possible themes, followed by

comparing and contrasting themes and identifying structure among them, and finally, building theory and checking it against the data. Grounded theory research aims to understand social context through people's experiences. In my research, my aim was to start a conversation about barriers to health care with Deaf people in Cape Town. In doing so, to understand the social context of the barriers standing in the way of effective health care in South Africa, as well as expose them to the complexity of health care in their society in order to strategise for a way forward.

Study limitations

While conducting the research, I was mindful of some limitations to the study that are now described. All of my interactions with participants during fieldwork was conducted using SASL. Nyamnjoh (2007: 38) stressed: "it is important to pay attention to the language usage during research." I was thus aware that some of my participants may use a different dialect of SASL and could therefore experience some difficulty in understanding my signing. To mitigate this concern, I learnt their dialects as fast as I could and adapted my signing to make communication more smoothly.

Another challenge was experienced during transcription process where I found it extremely difficult to translate and transcribe from South African Sign Language to English because these two languages are distinctly different in terms of grammatical structure. One of my participants used facial expressions to describe her feelings instead of signing them, which made it difficult for me to transcribe facial expressions into English words that would appropriately distinguish them. As a result of the complexity of the languages used in the study, the transcription of data took incredibly long to complete. Edwards (1998: 2) discusses the process of translation as a lengthy process in order to achieve a "correct version of a text". In order to translate for transcription, researchers have to be careful to translate into correct versions of a text in order to express the message best described by the participants for example, the message of "register, ethics, matching social characteristics, and neutral stances" (1998: 4). South African Sign Language is a visual language with no written form so when translating video-recorded SASL data into English, one would need to "freeze" a text that is otherwise in constant movement, thus making it amenable to "context analyses that depends on the segmentation and rearrangement of a fixed written text" (Hutchinson, 2012: 113).

Role of the researcher

My previous research in the field of Deaf Studies inspired me to conduct a study within my community and this informed my research approach. My personal experiences as a Deaf woman especially prepared me for conducting research with Deaf individuals. Although I am deeply rooted in the Deaf community, my positionality as a white, female, heterosexual and privileged researcher could have an impact on the community as a whole. The term ‘positionality’ is derived from feminist and critical theory (Crenshaw, 1991; Butler, 2004). Positionality both describes an individual’s world-view and the position they have chosen to adopt in relation to specific research (Foote and Bartell, 2011). The individual’s worldview or where “the researcher is coming from concerns ontological assumptions (the nature of social reality), epistemological assumptions (the nature of knowledge), and assumptions about human nature and agency” (Sikes, 2004:38). Butler (2004) argues that we “cannot be who we are without drawing upon the sociality of norms that precede and exceed us” (2004: 32).

“How we see the world is influenced by how we exist in the world”

- Ahmed

This quote is derived from Ahmed in one of the interviews. I found this saying poignant while conducting research within a Deaf community because the community is so diverse and politically charged, with multiple positionalities, leading us to rely on one another in order to keep the community viable. bell hooks (1994) focused on how positionalities can reflect the researcher’s focus on various themes such as social factors, race, gender, class, education, and background. bell hooks (1994) also acknowledges that “people can be fearful of their own positionalities and intersectional ties while discussing these topics” (1994: 33) and therefore encourages researchers to carefully identify the fears from their participants and talk through the topics. Throughout my research and dissertation writing, I was cautious to avoid tokenism as I cannot let the reader assume that I, as a Deaf, white woman, represent the entire Deaf community. There are various identities and intersectional ties i.e. women, disability, persons of colour, amongst the Deaf community. My identity may be different to others, as I identify as Deaf, I use SASL as my first and home language, and I was born to a well-known Deaf mother who has always been an activist in the Deaf community with a strong Deaf identity. I was brought up with careful attention to my evolving

Deaf identity while using SASL naturally and learnt about Deaf culture. Many Deaf children in South Africa are born to hearing parents and thus only acquire their Deaf identity once they attend a school of the Deaf. As such, my identity from birth makes me privileged in the Deaf community.

Conclusion

This chapter has highlighted the manner in which the study was conducted. The participants' backgrounds as well as my own positionality as the researcher were described and the specific data collection tools that were used in the study were highlighted. The ethnographic data analysis and grounded theory approach were explained and the identified limitations of the study discussed. Finally, the ethical considerations that were taken into account during the study were clarified. In the chapter that follows, the major themes that emerged in the study are explored - beginning with the role of communication as a barrier to accessing health care for Deaf people.

Chapter Four: Literature Review and Theoretical Framework

“I was walking home with my two daughters when a car hit me. I had a head wound so my daughters phoned the ambulance just in case the wound was too deep but I did not want to go. I sat on the floor, next to the car, and would not move. My daughters had to pick me up, push me into the ambulance, quite aggressively. I did not want to go because I fear they would not understand me and I them. I really did not want to go.” - Renee

Introduction

The literature on access to health care and structural violence complements findings which talk to the economic, social and political barriers within the health care systems and how these impact access to health care resources for Deaf individuals. The literature review and theoretical framework presented in this chapter highlights previous studies, which assist to understand this dissertation in its entirety. The chapter begins by exploring various interconnected concepts focusing on access to health care, health disparities, structural violence and deafness. The health care services for Deaf individuals were found to be inadequate due to difficulty in communication with the providers and the resultant gaps in health knowledge. Even though the South African literature on health care services and deafness are limited, I draw on both South African and international contexts while addressing intersectional theory, structural violence and health disparities. Additionally, within the literature reviewed, this chapter positions the study within a theoretical framework by exploring deafness within the medical anthropology theory of structural violence.

Deaf Challenges in Health Care Services

As clarified in depth above (p.21), Deaf people are a proud community and do not see their deafness as an impairment or deviation from society. In the biomedical discourse, deafness is defined as an impairment, where one cannot hear and is seen as an abnormal medical case. The biomedical discourse therefore imposes impairment and disability upon the Deaf community and Deaf patients. As a result, the majority of health care professionals are unable to establish trusting

relationships with Deaf patients, due to the fact that they cannot communicate with them in the ways the Deaf patients want them to. This causes tension, stress, and misinformation and therefore a trusting relationship is not developed. This section explores the challenges found in health care services and experiences of Deaf patients worldwide.

Their vastly different perspectives and communication preferences fuel doubt and distrust between Deaf people and medical professionals. Medical and health care professionals who do not understand deafness, Deaf culture and Sign Language fall in the outermost circle of Deaf relationship as mentioned earlier (p.25). Iezzoni et al. (2004) found five themes around the communication barrier:

1. Conflicting perspectives on being Deaf;
2. Differing perspectives on effective communication strategies;
3. Risks postured by miscommunication;
4. Communication issues during consultations and treatment;
5. Telephone correspondence.

There are many myths hearing people (including medical professionals) assume about Deaf people. The most common of these is probably that all Deaf people can lipread. This is simply not true. Some Deaf people cannot lip-read, some Deaf people can lip-read with hearing aids on, but cannot without them; and some Deaf people can lip-read without any use of hearing devices. The presence of audism⁴, unfortunately, pressures Deaf people to show beyond doubt that they understand what they are being told by the hearing population. This leads to many Deaf people nodding through interactions without understanding what is being discussed (Richardson, 2014).

Steinberg et al. (2006) explored different possible ways for Deaf patients to communicate with health care practitioners if no sign language interpreter is present. In the end, it was found that these are only two possible communication methods - lip-reading and writing. However, these are

⁴ “Audism is the notion that one is superior based on one’s ability to hear and the belief that life without hearing is futile and miserable, which results in a negative stigma toward anyone who does not hear and their use of sign language” (MacDougall, 2015: 157).

only suitable for very few Deaf individuals. Lip-reading was found to be commonly used but the efficacy thereof is highly questionable. Lip-reading is inadequate in circumstances where a Deaf person cannot lip-read, the professional has thick facial hair or does not move his/her mouth when talking. In addition, even the most skilled lip-reader can only understand 30 to 40 percent of the message with someone they are not familiar with (Luckstein, 2012). Similarly, although widely used, written communication was also found to be ineffective because of the low literacy levels of many Deaf people.

Steinberg et al. (2006) concluded that the most effective way to ensure barrier free communication in a health care setting is through the use of professional sign language interpreters. In their study, it was found that Deaf patients felt the interaction and communication was much smoother and they understood more with a certified medical sign language interpreter present. Deaf people may adopt different methods of communication including spoken language, lip-reading or sign language. Sign language may take various forms such as: South African Sign Language, Signing Exact English (SEE) or Pidgin Sign English (PSE) which is now known as ‘contact sign language (Engelman et al. 2013: 3). The benefit of SASL is that each sign is defined by five parameters, which consists of: handshape, location, palm orientation, movement, and non-manual feature (facial expression). These parameters allow Deaf people to communicate a dominant piece of information past the capacities of a straightforward English word (Hoffmeister and Caldwell-Harris, 2014). Figuring out how to compose or communicate in English is, largely, expected by hearing parents and is frequently vital to communicate (Richardson, 2014). It is important to consider that English and SASL have different sentence structure, grammar rules and dialects. SASL is not derived from English or any other spoken language. For most Deaf people in South Africa, English is their second or third language and has been found to be a difficult language to learn for Deaf people (Hoffmeister and Caldwell-Harris, 2014). Literacy levels do depend on the Deaf individual and their situation. In addition, in South Africa, many Deaf people have low literacy levels. This leads to potential misunderstandings. Handwritten messages are also often time-consuming and illegible for them (Hoffmeister and Caldwell-Harris, 2014).

Communication is a vital requirement for human beings and communication barriers prevent meaningful interaction between two parties. This is the case with the Deaf community in accessing

health care services, i.e. Deaf patient and hearing doctor (Wilkins & Heir, 2008). Communication challenges have led to many Deaf people refusing to seek health care services, such as mental health (Fusick, 2008). McAleer (2006) argues that if Deaf patients prefer to not have a sign language interpreter present during consultations, the communication between them and the health care providers becomes very difficult. Thus, even though sign language interpreters are thought to be the most effective way to ensure adequate communication, some prefer not to have that third-party present and it is therefore not the most ideal method.

In research conducted by Middleton et al. (2010) in the United Kingdom, it was found that half of all respondents (sign language users) preferred to use sign language interpreters for access, while 43% preferred direct communication with a health professional who can sign. The remaining 7% prefer lip-reading or speaking where the health professional is aware of the limitations of this form of communication with a Deaf patient (Middleton et al., 2010). The research concluded that being Deaf does affect the communication access with health care services and that intervention and cultural competency training for the health care services is needed in order to accommodate the Deaf patients properly. It is essential to acknowledge that Deaf individuals have different communication preferences and cultural competency training would best benefit the Deaf community and health care service providers.

Sign Language Interpretation

The infamous case of the “fake interpreter” at Nelson Mandela’s funeral service is both disappointing and indicative of serious disrespect to the Deaf community and the interpreting world. It is worrying to consider what might have happened if this “interpreting” emerged in a healthcare setting where an individual’s life could potentially depend on the information received by and from the interpreter. Deaf individuals recognise the extreme shortage of qualified sign language interpreters in South Africa (Deaf Federation of South Africa, 2015). The result of this chronic shortage is that health care access via an interpreter is highly unlikely. To secure a professional sign language interpreter with training in medical settings is very complex and challenging for Deaf patients, even in countries that are well-resourced with legal rights to provide Deaf individuals with full accessibility (Henning et al., 2011).

After reviewing a variety of sources on this issue, it is clear that many Deaf patients prefer to use sign language directly with health care service providers as the communication method (Napier, J. & Kidd, M.R., 2013; Reeves, D. & Kokoruwe, B. 2005; Henning, M.A. et al. 2011; Fusick, L. 2008). However, since this is not possible in most countries, most of them prefer to have a sign language interpreter with training in medical settings to be a mediator between them and the providers in order to gain effective communication access. Research conducted by Henning et al. (2011) in New Zealand found that 39% of the Deaf individuals interviewed felt alienated from the health care services they attended. In addition, they felt that they were unable to access the interpreting services as the interpreters were not adequately trained to work in medical settings. The responses concluded that having adequate sign language interpreters with training in medical settings would reduce the communication barrier for Deaf patients. Henning et al. (2011) ended the study with a recommendation to New Zealand's interpreting associations to provide medical setting training to their trainee interpreters in order to achieve the optimal health status of the Deaf community.

It must be remembered though that while using a sign language interpreter makes the appointment much smoother, there is a simultaneous loss of privacy (Phelan & Parkman, 1995). At the appointments, everything is communicated between the practitioner and Deaf patient through the sign language interpreter, and it is considered to be confidential. The interpreters are also not supposed to provide medical advice or opinions (RNID, 2005). The literature argues that health care services should provide a sign language interpreter if requested, and ensure there is two-way communication between the doctor and the patient. While it is expected that interpreters keep the consultation and session information confidential, many Deaf patients do not trust interpreters to adhere to this ethical principle (Steinberg et al. 2002). This in itself presents a barrier to adequate communication.

Intersectional Theory

Intersectional theory refers to Crenshaw's original concept that people have intersectional ties that shapes their identities (1989). Cultural ties such as race, gender, disability, and socioeconomic status interact in different ways that ultimately inform the person's experiences and shape their identities. Intersectional theory asserts that a certain group, for example, Deaf people, differ based

on additional factors. Thus, experiences of a White Deaf woman differ from a Person of Colour Deaf woman. When discussing an intersectional analysis of Deaf persons, there are one body of literature I am going to apply. I feel that for Deaf Studies, the meaning of intersectionality as set by Cho, Crenshaw and McCall (2013: 795):

“what makes an analysis intersectional (...) is its adoption of an intersectional way of thinking about the problem of sameness and difference and its relation to power. This framing – conceiving of categories not as distinct but as always permeated by other categories, fluid and changing, always in the process of creating and being created by dynamics of power – emphasizes what intersectionality does rather than what intersectionality is.”

This definition incorporates both the customary spotlight on power and disparity and regard for how crossing intersections produce openings as well as strengthening. An intersectional theory looks at how individuals change each other’s opinions. For instance, deaf and blind or deaf and research cannot be seen as commonly constitutive, but instead as commonly formed through each identity is changed by drawing in with others (Walby et al. 2012). Deaf individuals with various intersections may be privileged in certain circumstances and disadvantaged in other.

Deaf persons in South Africa has more than one intersectionality ties tied to their identity. It could be Deaf and Person of Colour. It could be Deaf and Disabled. It could be Deaf and Woman. In order to emphasize on their identity, I needed to consider their intersectional ties to understand their struggles in health care services.

Theoretical Approaches and Key Concepts in Medical Anthropology

By discussing the experiences of accessing health care services in Cape Town, I address the following theoretical approaches in the research: grounded theory and social suffering approach including structural violence. The experiences of the Deaf participants are therefore analysed holistically, considering all the aspects of their lives. The experiences within healthcare services are linked with the societal factors, which affects individual perspectives throughout this dissertation.

The conceptual approach of social suffering, underpinned by the notion of the self and embodiment in the context of suffering, facilitates macro-analysis. This allows me to explore the existing societal factors and the ways in which oppressive societal constructions affect individuals’

subjectivities and bodies. It looks in particular at individuals' experiences of emotional distress. Barriers to accessing health care services may result in both personal and social displacement. As such, the cultural construction of the concept of 'self' can be described by referring to the process of such displacement. The approaches above stem from most commonly used theoretical frameworks in medical anthropology. Through medical anthropology, I am able to unpack and discuss the structural violence of health care systems experienced by the Deaf community. Thus, from considering inequality, poverty, and other social processes as factors, we notice the direct or indirect repression that they have on the health status of individuals.

The Social Suffering Approach

Medical anthropology focuses in-depth on matters related to health disparities and health care. Further, this research situates the subject of health care access in the anthropological literature of structural violence within health systems. Theories, including health disparities and structural violence, look at the impact of "social inequalities on health outcomes" (Baer et al. 1997: 22). The structural violence theory allows me to explore "the relationship between health and structural force" (Rylko-Bauer, 2012: 24). The literature reviewed on these theories include socioeconomic and socio-political processes of Deaf individuals' vulnerability in health care services. Tallman (2016) explores the factors of structural violence in health care services and how it falls upon vulnerable, minority communities. He argues that vulnerability is an important factor to consider when looking into structural violence of health care services, since vulnerability is the vital point between the social, political and economic factors.

The literature reviewed explores the barriers minority and marginalised groups face in health care services. The factors of structural violence, including health disparities, health care information and opportunities in health care affect the Deaf community and other marginalised groups. It has been suggested that "health disparities cause significant inequalities in health for marginalised populations" (Becker, 2004: 22). Hence, this framework is important in this dissertation in order to focus on Deaf individuals' experiences in accessing health care services in Cape Town. The immense impact and struggles found in their stories reveal the significant barriers to accessing health care services experienced by this community through the factors of inequality, political economy and structural violence. Using this theoretical framework allows the researcher to explore

the experiences, focusing on the factors that affect their access. However, the current literature on access to health care services for Deaf individuals in South Africa is very scarce and it is not tied to the aforementioned factors. Therefore, applying the above theoretical framework will allow the researcher to shape and address the current gap in South African literature on Deaf people's access to health care services.

Health disparities or health inequalities result in enduring variations between populations in health standing and well-being. Health inequalities are delineated by social factors, such as race, class, gender, disability and socio-economic status, and can be described as variations in health outcomes between socially disadvantaged and privileged groups. There are multiple definitions of health disparities worldwide. Centers for Disease Control and Prevention (2011: 1) presents a concise definition: "Health disparities are differences in health outcomes between groups that reflect social inequalities." The United States Department of Health and Human Services (2008: 28) adds that:

"A health disparity is a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health, based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion."

Such disparities frequently result in suffering, especially in smaller, marginalised populations. Researchers have aimed to unpack the ways in which processes of distress are found in social situations and habituated by cultural situation. Social worlds are engraved upon the embodied experience of suffering and pain. Through this, the individual with experience of suffering and pain should be considered as an expression of social structural oppression with collective experience of cultural trauma (Kleinman et al. 1997). It is also argued by Kleinman et al. (1997) that the quality of a person's physical and mental health represents the circumstances around their social experience. In order to experience or witness marginality, one has to draw the attention on social suffering of people living in developing societies as well as engaging the global social understanding. The advocacy of human rights is one of the great tools of putting the attention on marginalised societies who suffer from societal discrimination as well as social deprivation (Das, 1995; Schepher-Huges, 1992).

Kleinman et al. discusses social suffering as any situation in which experiences of pain, trauma and disorder take place as result of “what political, economic and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems” (1997: 6). Kleinman et al. also took a shift of focus on what ‘really matters’ for the societies who experience social suffering through the moral challenges faced by individuals and what they experience. Social suffering exists in individuals’ experiences however the attention are always drawn to the force of prevailing social structures and established cultural practices on people’s moral sensibilities. Here, Kleinman and Fitz-Henry (2007) shifts the focus on a new ‘anthropology of subjectivity’ that aims to focus on the struggles of individuals while trying to make sense of their lives with the task of maintaining relationship with others.

Minority groups face multiple barriers “with structural and social factors that limit their access to movement through the social sphere” (Benson, 2008; Bauer and Kantayya, 2010: 8). As a result of these barriers, such as the impact of low education status, low English proficiency, inadequate work benefits and sub-poverty wages, these groups “are prevented from accessing adequate healthcare services” (Bauer and Kantayya, 2010: 9). These vulnerable populations are therefore affected by social inequalities arising from unjust social, political and economic systems. Women and/or Persons of Colour (PoC) Deaf populations in South Africa are particularly vulnerable as a doubly marginalised population and experience unjustified lack of accessibility to health care services. In general, Deaf populations are also vulnerable due to communication barriers and lack of health knowledge in health care services. However, there are times when the structural forces that tend to marginalise, are negotiated by Deaf people in ways that enable them to take steps towards creating a less hostile engagement with the health care system. These are some of the experiences that impact the health of Deaf populations and adds to the state of their physical and mental health. Many Deaf people lack a family doctor, medical aid, identity documentation, reliable transport and safety, and are therefore at higher risk of becoming victims of structural violence. This combination of “social, political and economic issues perpetuates inequality and may affect the way these populations view their health and health practices” (Bauer and Kantayya, 2010: 11).

Kleinman and Fitz-Henry (2007) also calls upon researchers to focus on

“the particularity of experience ... [to] affirm that our subjectivities and the moral processes within them are forever in flux – not static, abstract, biologically fixed, or divorced from political, social and economic processes, but fluid, contingent and open to transformation” (2007:55).

The priority of the dissertation is to document Deaf persons’ experiences in social context with importance placed on the efforts of varieties of social practice that create the community.

Conclusion

Researching the barriers to health care services through an anthropological perspective fills the gaps in the understanding of health inequalities and their impact on the behaviours of marginalised populations. Using the theoretical framework of social suffering with a particular focus on structural violence the researcher was able to explore the experiences of Deaf individuals as a minority group, as they interact with the health care system. This chapter highlights earlier findings that structural violence is closely linked to poor health outcomes and thereby indicates the importance of this research to diminish the barriers experienced by Deaf people in health care services. In the chapter that follows, I will discuss the themes that emerged during the study, starting with a focus on communication as a major barrier to accessing health care for Deaf South Africans.

Chapter Five:
“BARRIERS MANY WHY?”
Results of the Study

“I had the operation on my knee when I injured it from jumping on the trampoline. They put a brace in it and stuff. But six weeks later, it did not feel any better. I was still so sore. I went back to the doctor, he said it's fine. Nothing to worry about. But it didn't feel fine. I couldn't explain how I feel because he did not understand me. Then a week later, there was infection. The scar expanded, and yellow liquid came out, it was horrible. It was very swollen. So, I decided to go back to the hospital and requested another doctor. The doctor was so shocked and immediately requested blood tests. I did not understand why. He was frantically talking, pacing around the room and that frightened me. I was sore, I wasn't feeling well, I wasn't myself for few weeks but I thought it was just the operation that made me feel like that. Turns out the infection has spread all over in my bloodstreams, and I was septic. I underwent an emergency operation to reduce the dramatization of the infection.” - Elize

Introduction

This chapter highlights the experiences of the participants in accessing health care and makes extensive use of direct quotes to foreground their voices. The chapter begins with an examination of South African White Paper on the Rights of Persons with Disabilities (WPRPWD) and how it came to be. This is a significant policy for South Africans with disabilities and although Deaf persons in my research strongly state they are not disabled, they live within the context of the rights of persons with disabilities and receive social assistance grants as a result of their deafness being classified a disability. The notion of stigma is also raised and how these raises concerns among the Deaf community with regard to accessing health care. An analysis of the results of the study is then presented under various themes. These include how and why communication is an obstacle to adequate health care, how health care workers' lack of awareness negatively impacts

access, inadequate access to health care information and the effects of low literacy levels. It was found that all these factors create obstacles to health care for the Deaf.

Historically, disabled people were treated as ‘other’, ‘different’, and ‘not one of us’. Many people with disabilities were institutionalised because it was perceived to be easier to deal with them by not dealing with them. Beginning in the 1960s, disability advocates saw the opportunity to join forces alongside other minority groups fighting in movements to demand equal treatment, access and opportunity (Welch, 1995). During apartheid, disabled people were viewed using the biomedical discourse. The apartheid government addressed persons with disabilities as “a social welfare and medical concern” (White Paper on the Rights of Persons with Disabilities, 1996: 2). The medical discourse is a discourse where factors are determined to ‘fix’ the problem, ‘fix’ the disability, in order for that person to return to the ‘norm’. This discourse, driven by the apartheid government, has altered the lives of persons with disabilities by providing little to no opportunities for career choice and career advancement. Further, it does not take account

“the role that a barrier-free environment access can make to the independence and human dignity of persons with disabilities; the human, social, political and economic rights of persons with disabilities; the rights of persons with disabilities to full inclusion and integration into mainstream society, and the abilities of persons with disabilities” (ibid, 2015: 18).

The white population of persons with disabilities received more services and accessibility than their black, Indian and coloured counterparts, thus providing them with greater opportunities. Ultimately, the lived experiences of persons with disabilities under the apartheid regime has disadvantaged them greatly, and as a result this group is now one of the most marginalised groups of our society.

Under democracy from 1994, according to the WPRPWD (2015), there have been notable changes for persons with disabilities. The government has developed an agenda for all vulnerable groups in society, in order to transform their lives. This included persons with disabilities. The Development Programme (DPO) lobbied for the rights of persons with disabilities and after an intense, lengthy period of lobbying, the Office on the Status of Disabled Persons (OSPD) was established (ibid, 2015). The vision of Integrated National Disability Strategy (INDS) is “A society for all, one in which persons with disabilities are actively involved in the process of transformation.” The vision and mission of the organisations above are rooted in the social

discourse of disability. This positioning allows for transformation and improvement. South Africa also ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, which ensures the commitment of the country to respect and uphold the rights of persons with disabilities.

The UNCRPD advocates for upholding various rights and fulfilling several obligations, including “strengthening the implementation of its mainstreamed legislative and policy framework and accelerating implementation of policies and programmes that aim to provide equal access to persons with disabilities.” These have been slowly implemented in South Africa since 2007. The social discourse acknowledges persons with disabilities as part of the norm, part of the society and advocates for full inclusive space in our society without looking down on them because of their disabilities. It fosters respect for the persons with disabilities and recognises them as equal citizens with full political, social, economic and human rights. According to the results of the census in 2011 (Census, 2011), the rate of persons with disabilities in South Africa is 7.5%, but this excludes “children between 0-4 years, persons with disabilities in residential care and school boarding facilities and persons with psychosocial, neurological and/or emotional disabilities” (ibid, 2015: 23).

Ways in which the rights titles are lacking for Deaf people

The White Paper on the Rights of Persons with Disabilities attempts to improve the rate of employment of persons with disabilities. This is done by ensuring that persons with disabilities can access the same employment opportunities and benefits that are available to their non-disabled counterparts. The goal is that persons with disabilities are given ‘reasonable accommodation’ to obtain and retain employment. Such reasonable accommodation in the “work environment implies making changes to the way things are normally done to enable an individual with a disability to have an equal employment opportunity” (White Paper on the Rights of Persons with Disabilities, 1996:35). In many Deaf social events, or workshops, many Deaf persons are unemployed because there is no ‘reasonable accommodation’ provided to them when interviewing for jobs, or working under hearing superiors. The small percentage of Deaf adults who are employed often earn less and are overlooked for promotion, raises and recognition.

Approximately three quarters of all Deaf adults rely on the social grants from the government (fieldnotes 28/9/17; *ibid*, 2015: 38). While Deaf organisations are fighting for the rights of Deaf people to receive equal experiences at employment, Ahmed, a provincial director at one of the Deaf organisations, mentioned that the organisation has an extremely long waiting list for Deaf people looking for jobs. They are advocating for preferential employment for Deaf people in jobs that require SASL and cultural competency. Ultimately, all my participants agreed that they only want the same employment opportunities as their hearing counterparts because they deserve the same opportunities to buy houses, support their families and pursue their dreams (fieldnotes, various interviews, 2017). A woman at the event felt that her employer was ignoring her ability and focusing on her inability as a Deaf person:

“I was employed at (a company) for five years when there was this new person who was employed for three months. We have the exactly same jobs. The person got promoted, and a year later, promoted again. Today she owns a Range Rover. I own nothing. I asked my employer about a raise, or a promotion and they responded, “You are Deaf. You can’t.” I am Deaf, yes, but I am far better at my job than that person! The position she is in, there is no need for communication except few meetings... It can be arranged with SASL interpreters, or note takers, or skype, or whatever. It can be done! She is there a lot less than me and she is constantly asking me for help. Still today!” (Fieldnotes, Event One, 9/9/17).

Several of the participants reported being unable to go through the interview processes because there are insufficient SASL interpreters and others have low English literacy thus making their employment opportunities difficult.

Section 6.1.1.4 of WPRPWD declares that Deaf persons require “access to SASL training, SASL interpreters, as well as note-takers, captioning and sub-texting to facilitate access to information and communication” (*ibid*, 2015:52). Examples of places where one may want to access information include hospitals, clinics, private practices, restaurants, day-care centers, and movie theatres. Sadly though, much of the reasonable accessibility required by the policy is constantly ignored. These public reasonable accommodations are required to remove any existing barriers i.e.

wheelchair access to buildings where it would be costly and require renovations. The request for information and communication access for Deaf persons is also costly however no different to other requests by other disabled groups. As previously explained, health services can be differentially allocated based on race, class and gender, and these interact to affect health and health care services (Minkler et al., 1994). Critical medical anthropology highlights the structural aspects of poor health or limited access to health services in relation to economic considerations. In the case of Deaf individuals, they are discriminated against and face obstacles in receiving adequate health care because general social customs do not accommodate their bodies (Lane, 2005) nor do they wish to cover the costs of providing reasonable accommodation measure.

In terms of health care access, Deaf people's experiences can thus be understood through the lens of theories of the political economy of health and critical medical anthropology. These theories highlight the structural causes of poor health or constrained access to health services as they relate to capitalism and neoliberal economics, and to health systems (Kleinman et al. 1997). Through this theoretical framework, researchers can emphasise the structure of social relationships, rather than purely biomedical factors in analysing health and accounting for its determinants (Baer, 1986).

While few of my participants explicitly mentioned the WPRPWD as an obstacle to health care or other day-to-day needs, many of the frustrations they did mention resonate with how the policy does not extend its services to Deaf people where it is most necessary. The policy dictates that health care settings will provide reasonable modifications, but attendees of Deaf social events and the participants have reported that such modifications do not exist. The fact that one of the focal points of the workshop was language access demonstrated this was a major concern for the Deaf community. The three biggest priorities of the communication access platform were to “enforce equal access to government and public services, increase numbers of qualified SASL interpreters and enforce effective communication for equal access to health care” (Fieldnotes, Event One, 9/9/17). As one Deaf man explained:

“Government and public services are still not accessible - there are no interpreters, unqualified interpreters, unwillingness from offices to pay for

communication access, there's no technology from the state, and people are unaware of the policy."

The policy is supposed to ensure provision of reasonable accommodation to ensure accessible communication that allows for equal opportunities. From what Deaf participants in Cape Town told me and expressed at community events, this is not happening. It is interesting that there was a need to explicitly state what does and does not qualify as disability under the policy. Where this can become controversial is the fact that most Deaf people do not see their deafness as a disability, and yet they are specifically covered under the policy. They rely on the policy and they want it improved upon to ensure more equal opportunities, but it is a conundrum since they fight to not be seen as disabled.

As explained at length in the Chapters 1 and 2, many members of the Deaf community do not regard their deafness as disability. Instead, it is an element of their identity, of which many are proud, due to the common language, cultural experiences and shared history with fellow Deaf people (Lane, 2010; Padden, 2006). As such, Deaf people do not want people to focus on a *cure* for deafness, but instead want to be accepted as a minority cultural group and respected for who they are (Tucker, 1997). In other words, "Let the Deaf be Deaf" (Munoz-Baell, 2000:40). When a reporter asked I. King Jordan, the first Deaf president of Gallaudet University in 1988, if he would rather be hearing, he replied, "That is almost like asking a Black person if he would rather be white... I do not think of myself as missing something or as incomplete... It is a common fallacy if you do not know Deaf people or Deaf issues. You think it is a limitation" (Lane, 2005: 298).

It can be difficult for hearing people to understand how the inability to hear is not necessarily a disabling condition. To hearing people, it is a fundamental sense they take for granted and struggle to imagine what life would be like without it. However, Deaf people, especially those born Deaf, are equally used to being Deaf. They want to be seen as more than their deafness and prove that they are capable of doing most everything that hearing people can. This is related to the anthropological concepts of cultural relativism and ethnocentrism. Ethnocentrism is the evaluation of another culture based on the preconceptions originating from the standards of one's own culture (Jost, 2000). The opposite of this is cultural relativism – regarding another culture's values and

practices based on the perspectives of that culture itself (Donnelly, 1984). Being culturally relative would mean understanding and respecting the perspectives of the Deaf community and recognising them as a cultural group; not seeing deafness as a medical anomaly in need of a cure (Kleinman et al. 1997).

While Deaf people fight to be seen as a non-disabled group, there are certain accommodations that Deaf people do require in the dominant hearing world, such as flashing smoke alarms and medical interpreters. Deaf people and advocates insist that the larger and more dominant hearing society should compensate by aiding people who cannot hear, specifically through the policy.

Stigma

If one deviates from the so-called 'norm', they are at risk of being stigmatised. Deaf people face stigma in various ways. Becker (1981) determined that Deaf identity and a social support system are two key elements of coping with stigma. The Deaf community might not face the same level of stigma that other groups do, but there is still an element of stigma associated with being Deaf. Such stigma can be especially difficult for people to deal with in the larger hearing society. The widespread lack of understanding about the Deaf community and possible real and feared repercussions for them, within the health care realm, causes rift between the Deaf and hearing worlds: a rift exacerbated in health care settings. Throughout my fieldwork and data collection, participants expressed their frustration towards hearing people who are not aware about their abilities, culture and linguistic rights.

I attended the annual event at one of the Deaf organisations where hearing and Deaf people participate to raise the funds for the Deaf community. I attended to support my friends who were working for the organisation and took the opportunity to observe the interaction between Deaf and hearing people. I noticed that Deaf persons' sign more quickly and boldly when they are conversing with other Deaf persons, however their signing changed immediately when they are attempting to converse with hearing persons. The grammatical structure of their signing changed to reflect English grammar so that the hearing persons would understand them. However, when the event ended, I noticed there was a conflict between a hearing young man in his twenties and a Deaf woman in her thirties. The woman was furious because the young man-made fun of her voice

which she used while signing to try accommodate him (Fieldnotes, The Silent Walk, 3/10/17). I had never witnessed a hearing person intentionally back away from a conversation with a Deaf person at the event, however I noticed how frustrated Deaf people can be when conversing with hearing people because of the lack of immediate understanding. This demonstrates how normalised hearing-dominance is and how Deafness is stigmatised without intent, reinforcing the hearing's world assumption that deafness is a disability. This is another example of an experience at an event:

“A journalist was at the event to record everything in order to raise awareness around the desire to see SASL recognised as an official language. He walked in front of the audience sitting and proceeded filming the person signing on stage. The person on the stage became incredibly uncomfortable and kept moving away from the journalist and his camera because the audience could not see her signing. He then turned his camera to the SASL interpreter interpreting what the person on the stage was signing and tried to talk to her (see Figure 4). She could not respond because she was busy interpreting and had to stay in her position. He became furious and walked away. When he returned, he approached a group of Deaf women and asked them a few questions without the interpreter present. The group looked at each other, with their eyebrows raised, and told the journalist that they are Deaf. The journalist then rolled his eyes and walked away to approach a hearing person who could sign. That person happens to be my friend and she told me the journalist shouted, “Why can't they speak? Aren't they supposed to speak? How do they get by in the world? That's ridiculous, how can I communicate with them? Why would they call me here when I can't even communicate with them?” My friend then explained that there are a number of sign language interpreters available at the event and he walked away rolling his eyes.” (Fieldnotes, Event One, 9/9/17).

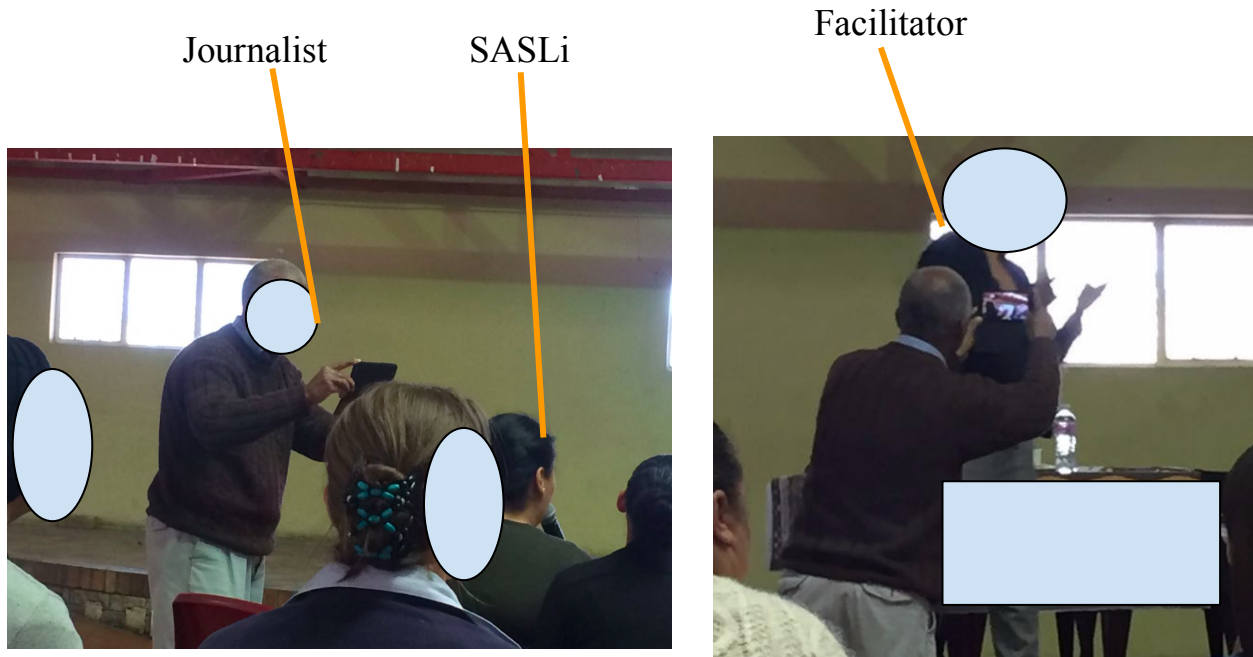


Figure 4: Journalist recording the SASLi and Facilitator at the workshop. Pictures used with permission.

In both of these situations I witnessed examples of the widespread lack of understanding about the Deaf community. This lack of understanding is what leads to real and feared repercussion for Deaf people, including within the health care realm. Most hearing doctors think that a person’s deafness is a medical issue and as such is his or her own responsibility to overcome in order to access care. However, culturally Deaf people see deafness as part of their identity that those around them should accept it. This clash of perspectives results in Deaf people struggling in order to be heard by hearing people in the health care system. This frame of analysis calls upon how social forces condition the experience of suffering and set limits on the ways this is acknowledged and responded (Wilkinson, 2005). We can also see from these examples that disability is socially constructed. As Susan Wendall, a critical disability theorist, argues:

“Disability is a socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to the subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies” (1996: 58).

As such, disability cannot be defined solely in biomedical terms because the biological and the social interact in creating disabilities. One of the examples that shows disability as a social construction comes from Groce's *Everyone Here Spoke Sign Language* (1980). She wrote an ethno-historical account about the Deaf community and society in the famous Martha's Vineyard. From the early 18th century to 1952, almost everyone in Martha's Vineyard could sign. Sign language was widely accepted there, and it was described by Deaf people living there as "a Deaf utopia." Frequently, in many modern Western societies, people who are labelled as disabled have been expected to adapt to the ways of the dominant, non-disabled society. Groce's ethno-historical account of Martha's Vineyard is an example of where this did not happen. She wrote:

"The fact that a society could adjust to disabled individuals, rather than requiring them to do all the adjusting, as in the case in American society as a whole, raises important questions about the rights of the disabled and the responsibilities of those who are not. The Martha's Vineyard experience suggests strongly that the concept of a (disabled) is an arbitrary social category. The most important lesson to be learned from Martha's Vineyard is that "disabled" people can be full and useful members of a community if the community makes the effort to include them. The society must be willing to change slightly to adapt to all" (1985: 108).

Health Care as a Concern

During fieldwork, it became obvious that receiving adequate health care was the prominent issue Deaf individuals face. This was first noticed in the interactions at Deaf social events where Deaf individuals shared their experiences about accessing health care services. They highlighted how there are not enough programs offered by Deaf organisations about health care as well as no specialist training for sign language interpreters working in health care. The concern over health care services was evident through the number of stories circulating in the Deaf community in Cape Town.

I met with a friend, John, seven years ago when I was new in Cape Town and we went to a Valentine's Day Ball event at a Deaf organisation so he could introduce me to other Deaf residents in Cape Town. After the long interaction of introductions, I approached a group who were discussing something that seemed intense. They all turned to me before I could say hello and asked me if I knew anything about vaccines. I told them as much I knew about vaccines and one of them

turned to others and said, “See, I told you. She is educated. Why aren’t we?” They proceeded by asking me many questions related to health i.e. pap smear, HIV/AIDS testing, and TB. During the discussion, Deaf people slowly joined and they were fascinated by how much I knew about health. It was this moment when I became intrigued by how little they knew about health care and how this is a huge concern for their well-being. In many other Deaf social events, more and more topics about health care in Cape Town were brought up. They varied from things regarding communication and health care information to medical aid and stories of experiences with health care practitioners.

I also noticed that there is very little information being sent out by Deaf organisations in Cape Town about health care. When there is, it is usually only brochures, posters and small workshops focusing on one health care issue e.g. pregnancy and HIV/AIDS. As a result, most Deaf people rely on other sources of information about health care such as flyers handed out in the streets and in public transport, TV advertisements and TV shows.

Attending Deaf community events further proved to me that access to adequate health care is a priority concern among Deaf people in Cape Town (and South Africa). One powerful event I attended was a workshop lobbying the rights of South African Sign Language. The workshop was an eight-hour event run in collaboration with the Deaf community in Cape Town. I sat toward the back of the room leaving front seats available for other Deaf people in attendance to give me a better view of whomever was signing and easier access for them to the front if they wanted to get up and share something. I was there to observe and participate. The first hour the organiser gave a presentation of what the workshop was about and the following hours were spent with group discussions of the implementation of SASL in different institutions, including health care. The last hour was spent with representatives of each group sharing what was discussed. The organisers asked attendees to discuss thematic points and share their experiences. Almost everyone contributed to the sharing in the remaining hour and some people got up more than once - a clear indication that the Deaf community want to be heard and want to share their opinions and experiences. In the end, the official recognised the gap in the data on the health of Deaf people. One official said:

“We understand that these are your real experiences and frustrations. I actually cried learning about some of your experience and I will try my best to work on improving health care provision for Deaf people, however it is difficult because of the insufficient data we have on Deaf people” (Fieldnotes, Event One, 9/9/17).

The woman in charge of the workshop was respectful and understanding of the frustrations of attendees about the process of SASL becoming South Africa’s 12th official language. I got the sense that they had some knowledge about the historical grievances and did not want to repeat any program that failed or made things worse. They were patient and took notes of everything everyone shared and encouraged people to email them with their information. They proved their commitment to improving services for Deaf people in general with careful concern that it would take a long time because of the gap in data. One lengthy discussion at the workshop was around cultural misunderstandings and how it can be difficult for Deaf patients to find a doctor who understands how to work with them (Fieldnotes, 9/9/17). Many Deaf people I interacted with protested that there is still a long way to go because there are not enough Deaf academics and pioneers to fight for the access to adequate health care. However, some of them felt that there are simple measures that providers can take to make the experience better for both the Deaf patient and the hearing provider. These measures have to do with educating providers more about the Deaf community as well as improved communication methods. Jonathan, who I met at the workshop and eventually became my sixth participant, told me:

“Some people’s views have not changed. But I think it depends on where one is, which hospital they are at, and who the doctor is, and how well educated they are about our culture. The people in my generation (age 20 to 30) has better knowledge about the need for better communication with Deaf people. It is better than past generations. But it also depends on how well educated my generation is.... For example, this one school in Cape Town is so bad, Deaf people are coming out really uneducated, but this other school is really good, Deaf people are coming out well educated.”

Jonathan and other people at the workshop recognised that receiving adequate health care could depend on the provider. Just as all patients are different, every provider is different as well. As a result, some providers could have knowledge about Deaf community and culture and be understanding from the start; others might know nothing. Most of the Deaf people in the workshop spoke about how providers should be more understanding, patient with them and allow enough time in appointments with Deaf patients to allow for more adequate communication (Fieldnotes, 9/9/17). Jonathan also recognised that the political economy of an individual changes the system depending on their background. In some cases, an educated Deaf person from a good Deaf school would likely overcome the obstacle of communication while an uneducated Deaf person from an average/bad school of the Deaf would find it difficult to overcome due to numerous factors such as low English literacy, low health care information and little support from the Deaf organisations.

Generally, most adult Deaf people become their own advocates (De Certeau, 2009). Advocating and actively negotiating of structures of power and inequality has allowed them to recognise the different ways that people can engage with the operations of power. Conversely, most Deaf children often rely on their parents or guardians to communicate with their doctors for them. Most Deaf adults have had enough experience to know what works best for them in medical settings but still face obstacles to adequate communication with their providers which exacerbates the negative experiences. Fareeha (who was also at the workshop) and I discussed various communication issues she faced:

‘Whenever I have an appointment of any kind, I make sure I could get an interpreter. If I can’t, I write everything down to make it accessible for the provider to understand me and I request them to do the same. If they won’t, I find another provider.’

This excerpt demonstrates Fareeha’s self-advocacy. Similarly, Ahmed and I discussed barriers to communication extensively. He told me:

“Getting a good health care service depends on the provider. One provider did this: they would be like “Oh. Oh... Oh...Okay. Ummmm.... Just sit down for a

bit.” Then I would go and sit and watch them rambling around things, trying to figure out what to do when they could have asked me instead of ignoring my suggestions. The other provider asked me for a guideline how to approach a Deaf patient to be better prepared next time and I gave her the guideline that works for me i.e. emailing me all the content and medication information after the appointment and it was accessible for me.”

Also, as a self-advocate, Ahmed was adamant about having doctors email him because it is the communication method that works the best for him. He makes it the provider’s responsibility to figure out some way to continue the appointment with the guideline he provided. Deaf people often have certain perspectives of how the appointments should go and how the providers should behave when having a Deaf patient. A lack of understanding about Deaf culture on the part of the providers exacerbates these different perspectives, which often results in negative experiences at appointments. These experiences in turn lead to health care concerns in the Deaf community.

Perspectives on using SASLi for Communication

When I asked about interpreters as a means to break the communication barrier in health care services, my participants mentioned that it is not the best tool in Cape Town. A sign language interpreter is an individual who facilitates communication between two or more parties who use different languages (i.e. SASL and English; SASL and IsiZulu) (see figure 5). In the case of a sign language interpreter (in South Africa, the acronym used is SASLi), their job is twofold in that they are not interpreting across different languages, but also across different modes of communication (i.e. spoken into signed and vice versa) (DeafSA, 2012). If an interpreter is not fully prepared or qualified to interpret for a health care situation, the following problems can occur to the Deaf client’s detriment (Metzger, 1999):

1. Leaving out chunks of message to catch up;
2. Guessing sign meanings;
3. Producing sign-for-word or word-for-sign translations;
4. Giving into the stress of the situation;
5. Poor control of time lag;

6. Poor grasp of SASL structures (e.g. placement, numbers, fingerspelling, role shift).

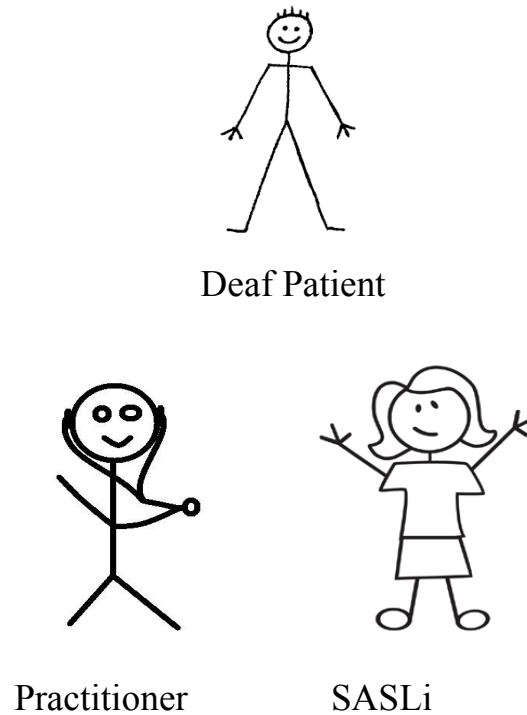


Figure 5: discourse of SASLi with Practitioner and Deaf Patient

To date, using a SASLi is probably the most effective way of ensuring communication between two parties. However, there are very few SASLis available in Cape Town (and South Africa) which further obstructs communication access for many Deaf people. For her monthly appointments at the state service, Renee is forced to use her daughter as an ‘interpreter’:

“My daughter can sign, but she can’t really interpret well. She would miss out a lot and summarises for me. Sometimes I can’t understand her because she doesn’t understand them, or because I don’t understand health care.”

Ideally, SASLis go through years of training to become accredited interpreters. However, it is not uncommon in South Africa for unqualified interpreters to interpret for Deaf patients without checking for accreditation. SASLis can also slip through the cracks and end up at an important event. For example, at Nelson Mandela’s memorial service on 10 December 2013, “sign language

interpreter” Jantjie (see Figure 6 below) caused an international outcry when it became clear he was not qualified to interpret and could not be understood. He was accused of being a “fake” who acted as a sign language interpreter but was a “fraud, who simply made “childish hand gestures” for hours as he stood on stage” (Laing and Ensor, 2013). He was identified as a fake interpreter because he produced very few handshapes and used no non-manual features (facial expression).



Figure 6: The Fake Interpreter next to Barack Obama at Nelson Mandela’s Funeral

Unqualified interpreters, like the fake interpreter, create further barriers to communication access for Deaf individuals. The experience of the fake interpreter is exacerbated in a health care setting where an individual’s life could potentially depend on the information received. One also cannot expect a family member, friend or acquaintance to interpret well for the Deaf person because they are not trained and cannot remain neutral in the situation. It is a common misconception that anyone who can use SASL can interpret. This is not so as the interpreting process requires much more than just being able to use two languages proficiently. In the same way as knowing the law does not necessarily give you the right to practice as a lawyer, so knowing SASL should not grant one the privilege to interpret.

Despite South African having enabling legislation (South African Language Practitioners Council Act, 2014) which seeks to prevent “fake interpreters” and other dubious language practitioners from creating barriers in communication, the law has not been implemented. The Act stated the

council is responsible to “grant, refuse, ratify, and withdraw accreditation” (2014: 10) however since the council has not been established, there is no authority to ensure service standards and to whom interpreters are accountable. Within this vacuum of responsibility, there are few SASLis who have studied or experienced medical settings i.e. studied psychology as an elective in their university degree, attends psychologist appointments or experienced trauma settings, are better candidates to interpret in the medical settings than those who do not have the same experience. There is no known medical training provided for SASLis in South Africa. The result is a lack of knowledge of vocabulary and the tendency to fingerspell too much. This is a proven obstacle to Deaf patients with little or no knowledge of health care and low literacy level, as Renee explained:

“Sometimes I ask for an interpreter to come with me if the appointment is important but sometimes I don’t ask them. Their signing is so different to mine, their dialect is so different to mine, so I don’t understand them so I just nod, nod, and nod, because I am embarrassed to tell them I don’t understand them. They also don’t know how to sign the medical words, how to describe them, how to express them, and I don’t really understand English, so it’s hard to understand what’s going on. I can’t use pad and pen as a communication method and I can’t really use SASLi because I still don’t understand them. I feel like there is no way for people like me. The uneducated Deaf people.”

Despite the Language Practitioners Council not being in place, SASLis are required to follow the Code of Ethics. One of the central principles of the CoE is confidentiality. Many Deaf individuals, including myself, feel that we cannot trust interpreters. In the SASLi code of ethics, it states: “... keep all assignment-related information strictly confidential and adhere to professional standards of confidentiality” (DeafSA, 2012). While this is an important clause in the code of ethics, some interpreters do not adhere to it.

However, using a SASLi proved to be an effective way to overcome the communication obstacle for Fareeha. She used a SASLi of her own choice at her psychologist appointments. She was fortunate enough to meet a few academic-level SASLis during her study at university. As a result, she was able to secure a SASLi she trusted and knew for many years. However, this experience is

not shared by all of my participants and other Deaf individuals. She gained this opportunity through her position as a privileged university Deaf student whereas those who are uneducated cannot access similar opportunities. Uneducated Deaf individuals are exposed to fewer events where they get to meet SASLIs when compared to those who are educated:

Fareeha: "I bring my interpreter to my appointments with psychologist. She interpreted for me for years, and when it was time for me to see a psychologist, I asked her if she's willing to interpret for me. She was very willing although she did not get any training in mental health. I feel comfortable with her around, so the communication with my psychologist is really good."

Jonathan: "I don't really know any interpreters personally. If I need one, I'll have to go through the process of contacting a Deaf organisation to provide me one. Most of the time the communication would not be smooth because their dialect is really different to mine, and the interaction would be really awkward. I don't have the privilege to choose who I want. I don't have that kind of network."

To further complicate the situation, Deaf people recognise that there is a severe shortage of qualified interpreters everywhere, but especially in medical settings. As a result, there can be scheduling conflicts between doctors and interpreters or just not enough interpreters in a particular area in general. Consequently, there can be a long process in booking an interpreter and it is not viable for short-notice appointments.

Relationship with Health Care Practitioners

As described in Chapter Two, Deaf people are a proud community and do not see their deafness as deviation from society. Notwithstanding, the whole notion of western medicine is to treat that which deviates from the norm. The medical discourse of deafness imposes impairment on the Deaf community and disregards cultural affiliation. The majority of health care professionals are unable to establish trusting relationship with Deaf patients, as they cannot communicate with them in ways the Deaf patients want them to. This causes tension, stress and misinformation, which

prevents the formation of a trusting relationship. Furthermore, a precise history and definite report of diagnoses cannot be obtained and medical assessments cannot be performed (Atkinson and Wolla, 2012).

The three most significant challenges encountered between the participants and practitioners are: 1) conflicting perspectives on being Deaf; 2) differing perspectives on effective communication strategy; and 3) risks presented by miscommunication. The conflicting perspectives on being Deaf include the feeling of isolation, at a loss and vulnerable when being questioned about their choice to be Deaf. The questions brought up by health care practitioners present a conflicting perspective on being Deaf. These are questions such as “Why can’t you speak? Why don’t you learn so you can communicate with us?” and “I think you need a cochlear implant to help you. I’m 100% sure you agree?” These questions become threats for the Deaf patients, causing them to feel more isolated and having no sense of belonging in the health care spaces, which are deemed hostile. This poses as a factor of the vulnerability and is a structural factor that isolates Deaf patients.

The differing perspectives on effective communication strategy also made the space difficult to navigate freely. Deaf patients have different preferences in communication. One may prefer writing everything down, another would prefer lip-reading, and yet another would prefer using email to clarify everything. However, practitioners are not always accommodating to use these unconventional methods and they may prefer other methods. These conflicting views on communication methods can cause discomfort for both parties. This happens more often when practitioners are not trained or aware about Deaf culture.

The third theme, risks presented by miscommunication, came up more than once during the interviews with my participants. Participants made many mistakes in managing their health needs as a result of miscommunication with their practitioners. All of the above themes require focused attention on the societal and structural factors that shape the hostile and unstable relationship between a medical practitioner and Deaf patient. Each theme will now be explored in more detail.

Conflicting perspectives on being Deaf

The debate on deafness has been widely discussed in Deaf studies. The different discourses (biomedical, social and cultural-linguistic) were outlined in Chapter 1 (p. 21). In respect of their perspective on deafness, my participants all had overlapping responses and I have thus decided not to split them for discussion. All the responses added significantly to understanding the experiences of Deaf people in medical settings as well as the barriers encountered in such an environment. The participants all feel strongly that they are not disabled. They are Deaf, part of a linguistic minority with a long history of Deaf culture and traditions. They also all feel strongly that it is their Deaf identity that is causing the barriers to health care. From this standpoint, I asked them how they felt about the word “minority”:

Jonathan: *“I eventually learned that the Deaf community is not part of the disability community, we are a language minority because we are deprived of our rights to our language. We are denied access because of our language. In regards of health care, I feel that my language and identity are making my access difficult, not my deafness.”*

Renee: *“I think we have really bad experiences with access because of our language. And there’s not much of us, maybe around 300 000. So yes, we are a minority, and I am not ashamed of it. The world should be ashamed they are not giving us the access we deserve.”*

Effective Communication Strategy

The close-knit Deaf community is very empowering and positive as a linguistic minority; however, it acts as a barrier to health care services:

Fareeha: *“Even though I am so proud of being Deaf, I feel that I am battling the most with English and SASL in health care settings. I want my doctors to either learn SASL or write English instead of talking, expecting me to lip-read them. I am not a good lip reader.”*

Fareeha went on to explain that she sees two doctors - one (a male) who insists on her lip-reading and another (a female) who is happy to read and write back and forth and who is willing to write out the diagnosis and explain how it is treated in full. She expressed her appreciation of the female doctor who respected her preferred communication choice.

The participants are a part of the strong and positive Deaf community with strong feelings about what should happen. However, I noticed during the narrative interviews that they lack self-confidence to raise their issues and ask questions to the health care service providers. Generally, health care practitioners are not sufficiently prepared to care for Deaf patients; academic curricula do not include the necessary abilities to meet the needs of this population group. Undoubtedly, effective communication with Deaf patients is important in health care; inadequate communication may lead to wrong diagnoses and misguided therapy. Responses during interviews indicated that they would simply accept what happened, without questioning it or suggesting new methods of communication. This disempowered response also contributes to the communication barriers experienced. It became clear that language creates a significant barrier as lack of a common language results in lack of understanding and terminology of health care. Despite being aware of the difficulties experienced, the participants have not approached their practitioners about them, thereby making the access more difficult.

However, all participants did not experience the difficulty with communication in the same way, as this quote shows:

Fareeha: "Around four years ago, my friend asked me to come with her to the doctor appointment because we had plans thereafter. It would be easier if I came with her. She was a Deaf white woman who comes from upper-middle class however we go to the same medical practice. As it turns out, we also see the same doctor because she is a bit educated about deafness. When we went in, the reception immediately made arrangements for her, writing bunch of things down i.e. where to sit, how long to wait, the doctor will be with you soon. Then we sat down and the doctor came and tapped her on the shoulder, then she went. She

returned with bunch of notes in her hands, which seems to be the conversation between her and the doctor. I didn't experience that until I changed medical practice, and demanded them to communicate with me this way. Is it because I am an Indian woman and she's a white woman? I never brought it up with her because I was too embarrassed to talk about it."

This participant struggled to understand why the medical practice she and her friend both attended accommodated her friend better than herself. They are both Deaf, but their races are different - an example of how intersectional ties can further disadvantage people. Her experience was that the medical practice better accommodates white people, even if they are disabled or Deaf. However, most health care services seem to react inappropriately when they are first approached by a Deaf patient:

Jonathan: "All health care services I've been to treat me like I'm an idiot. They would try to force me to do things I am not comfortable with, for example, sitting in that exact chair, holding my arm to the appointment room, and talking very closely to my face and ear hoping I could hear them a little."

Elize: "I have a nervous tic; my head and neck shake uncontrollably whenever I am anxious or nervous. This happens a lot when approaching hearing people because I feel like they never understand me. At health care centres, I would get really bad nervous tic and they would stare at me for a long moment then instruct me to do things, like go sit on that chair, go through that door, all whilst looking at me like I'm damaged goods."

The cultural stigma, occurring over time by hiding their true identity at services, creates a certain paradox in the hearing world of health care services. One of the participants explained it in the following way:

Fareeha: "In school, college, or workshops, we would be constantly reminded to be wary of the hearing world. They would tell us that it's very dangerous out there

for Deaf people. So, we were brought up thinking we would never fit in. Then all of sudden, we have to fit in if we want certain services, like health, and be put in front of people who can hear, and expected to speak freely with no anxiety.”

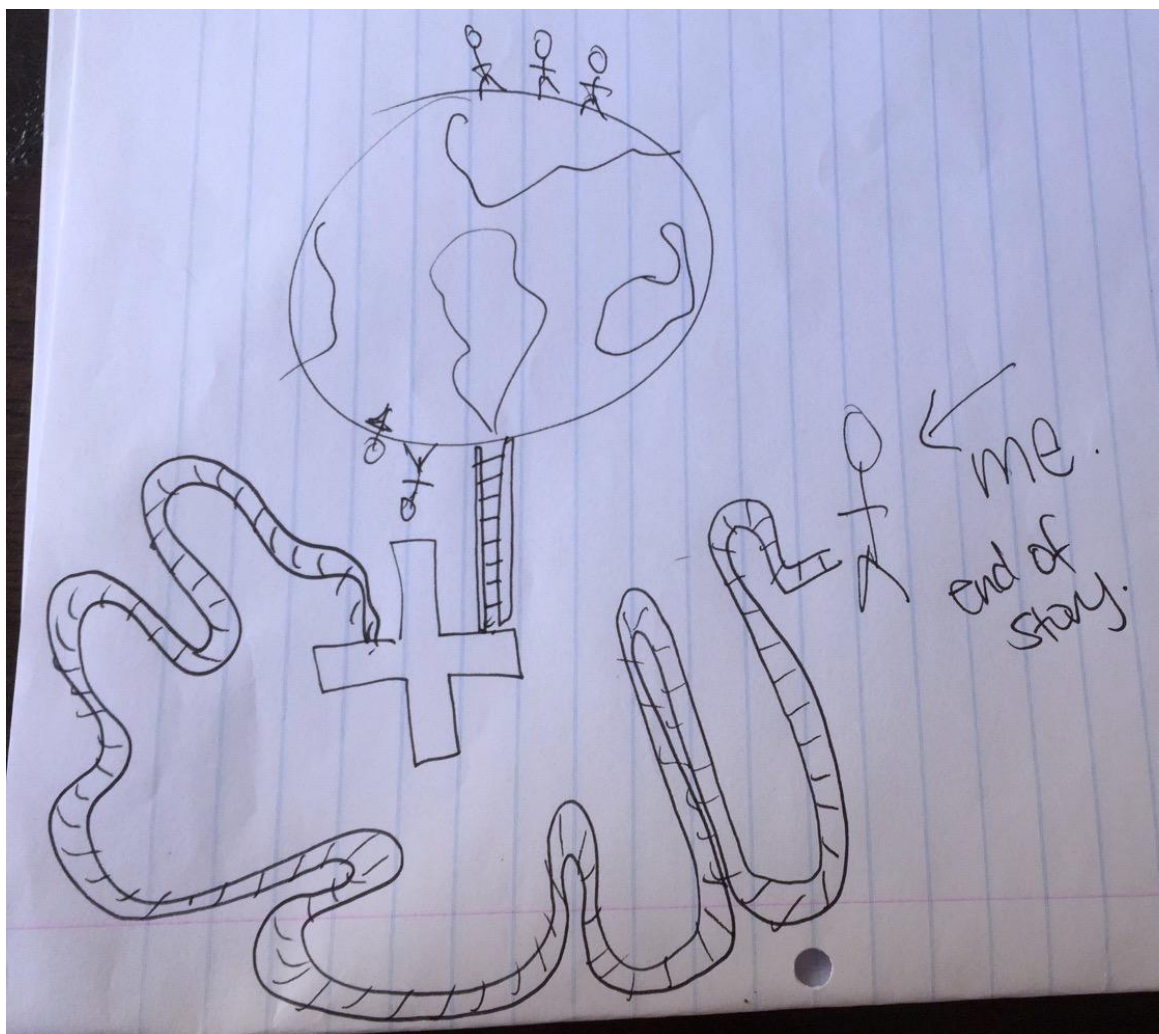


Figure 7: “Me, end of story”

The drawing (Figure 7) above shows the illustration of earth with a cross below, symbolising health care and two different kinds of ladders. The first ladder is short and is connected between the earth and the cross; whereas the second ladder is long and in curves and connected between the earth and the person. Jonathan discussed his drawing:

“Instead of photographing my life in the way people would expect, I decided to photograph this drawing. I drew this immediately after you asked me to take a few photos. I think this drawing will be with me all of my life. The earth is the hearing world, the people around the earth are hearing people. The cross is hospital, or health care centre, and the ladder from the earth to cross is the easiest access. The hearing people have it easier than us, they have the communication access to health care services. Then there’s me, not on the earth, out in the isolated space, with a super long ladder to climb in order to access the health care services. This is how I feel. I have to climb above and beyond to be included.”

He expressed in great detail that he feels isolated and left out. He feels that he needs to put in excessive effort in life in order to fit in with others:

“I feel like I am forced to learn to speak if I want to fit in. My doctors try to convince me to go to speech therapists or get cochlear implants because they can’t communicate with me. Why can’t I fit in with my wonderful language, SASL? Why do I have to speak? I don’t want to learn, so I have to go through this really hard life with million steps of that ladder in order to reach the services I really want. I am probably only three or four steps in because they do not give me what I deserve.”

What is seen here is the health care practitioners behave in a certain way when they are approached by a Deaf patient because they have never had a Deaf patient before. After they adapted with the fact their patient is Deaf, they start behaving in different way with respect to their intersectional axes. Jonathan is a coloured Deaf man who grew up culturally Deaf however his doctors have tried to convince him to abandon his Deaf identity and go in the path the predominantly Hearing world expects many Deaf people to take. Apart from the behaviours Deaf people experience at health care centres, providing cultural awareness or sensitisation training seems to be lacking among service providers. It was felt that if they had such training, none of the Deaf patients would have such experiences. The tendency to be perceived as “not normal” because they cannot hear is problematic for Deaf patients. Some of the patients feel fortunate to be able to speak to avoid these

awkward encounters but others feel they should learn to speak just because of certain situations occurring at health care services even though they have no desire to learn to speak in other situations.

Risks presented by lack understanding of health

During the narrative interviews, the participants expressed in detail that they do not understand much about ‘health’: the meaning, how to attain or retain it, or what ‘unhealthy’ means. Even though they really battled to explain what the terms meant they did mention some important aspects of health. There was a tendency to describe health negatively as the absence of illness. One important factor of good health that was mentioned was the importance of social well-being including having good relationships with family and community members. Of concern is that the general lack of health knowledge is likely to remain undetected by uninformed health care providers especially if the Deaf patient does not indicate a lack of understanding or advocate for their preferred communication method. This gap in knowledge is a factor that contributed to the communication barrier, in that the provider could unknowingly use more difficult terminology which is not understood by a Deaf person with limited vocabulary:

Renee: *“The doctor I was seeing for my asthma started writing all information down for me to get medication because my daughter was only a teenager. He was also writing the instructions, however, I did not understand any of it because of the words he chose. I asked my daughter to translate the text for me when I was home, and many questions popped in my head. It was too late. I wish he used easier words.”*

Robyn: *“Did you try to reach out and explain your situation? To explain which communication method you would have preferred?”*

Renee: *“No, how could I? I can’t write English well and my daughter dismiss me because she doesn’t know how to interpret properly. She feels that I am her burden so she dismisses me, so I try to go on my own. I asked him the questions when I*

returned for my next appointment but I don't think my daughter interpreted them properly because I did not get any response."

Some of the participants did acknowledge that in spite of the frustration experienced when trying to independently access health care services, it is nonetheless important to seek out such services when required to ensure that health is maintained.

Conclusion

The current volatile political climate, hostile to many vulnerable communities, including people with disabilities, also has many Deaf people worried about certain protections of the WPRPWD being regulated by hearing people who have no knowledge of Deaf community and culture. The perspective stems from historical oppression, which, in turn, has led to poor understanding of Deaf culture in the medical fraternity and a resultant lack of adequate services and protections. In this chapter, I have shown that since hearing people have labelled Deaf people as disabled, Deaf people are forced to embody this label in order to receive the necessary accommodations. Such stigma and the presence of structural obstacles prevent Deaf people from easily receiving adequate health care. A significant obstacle is that of communication and the chapter highlighted the various options available for Deaf patients and indicated that the experiences of the participants with respect to communication greatly affect their health outcomes and perceptions of the health care system. The chapter which follows imagines building Deaf futures that take into account the experiences of the participants in this study. Recommendations and key approaches are provided to make it possible for the stories told in the Deaf community to change.

Chapter Six: Imagining Deaf Futures

“I would say that health care, all in total, ... um... I know some Deaf people are used to the barriers, but other Deaf people who sign, they have difficulty in communicating. They do want things to be better. I think it depends on the character and language choice of the Deaf person. Some sign, some lip read, some speak, and some can't. I would say that not all Deaf people are the same, so thinking of a utopia would be difficult. As long as there are different platforms and choices, there could be a utopia, otherwise the relationship between the health care system and the Deaf community would be shaky and difficult. The biggest problem is their side, the medical side, they do not really bother to go this far for us. This makes Deaf people feel alienated. Sometimes they would not believe that I am Deaf because I don't look Deaf. I would like the health care services to have TV screens for us in the waiting rooms and doctors' rooms for the speech-to-text, text-to-speech technology as well as relay services (if South Africa is ever going to let this happen) ... or interpreters to receive proper medical training. This would make us feel include. It's our basic human right, after all, to access the full information.” - Paul

Introduction

The research set out to explore six Deaf people's narratives of accessing health care services in unequal social environments, exacerbated by the hearing medical professionals. This dissertation identifies the effects of structural violence within the marginalised group that marks Deaf people's daily experience. The research also revealed nuanced observations made by my six participants and how these observations offer insights into the broader meanings that are created and reinforced socially. The participants in this study are diverse and the study therefore offers insight into a range of experiences and positionalities. The research question sought to answer: What can we infer about the experiences of Deaf people in health care services by looking at their narratives of health in terms of how they navigate their lives through unequal structures?

A subsequent goal of this research has been to stress the need for activism on the part of Deaf people. As seen in the participants' responses, activism is necessary in order to improve the lives of Deaf people. Different views of deafness, unequal power relationships and the lack of understanding about the Deaf community, have led the dominant hearing society to believe that they know what is best for Deaf people. As such, many Deaf people have become strong advocates for themselves and others in order to provide people with a better understanding of their community.

Summary of the Narratives

Explaining the Deaf community to a hearing person requires a long time. One cannot assume what the community consists of after meeting a Deaf person for an hour. Therefore, I dedicated Chapter Two to the social context and historical background of Deaf community. The chapter unpacked and explored the differing perspectives of deafness and Deaf culture, membership in the Deaf community, South African Sign Language, as well as the historical background of Deaf experiences worldwide and South Africa. This chapter allowed the reader to be familiarised with the Deaf community and the main theme of my dissertation. Deaf people have faced oppression throughout history. The different influences of two prominent figures largely affected the Deaf community worldwide today and the effects of this, both positive and negative, were explained. Current advocates of the Deaf community more closely follow the example of the first prominent figure, Thomas Gallaudet, while many hearing people and medical professionals more closely follow the example of the second, AG Bell.

Due to the oppression Deaf people have faced throughout history, they fight back against the disability label, and for better accommodations. However, they recognise that there are some things they do need access to, such as interpreters, in order to have equal opportunities and thus need to rely on the White Paper on the Rights of Persons with Disabilities policy to a certain extent. The varying perspectives of deafness show that disability is socially constructed, which garners an element of control over the 'disabled' body. Deaf people do not want to be seen as disabled, but they cannot receive the necessary accommodations in order to survive in the larger hearing society without outwardly labelling themselves as disabled. Therefore, applying theoretical concepts from

critical medical anthropology, I have argued that many Deaf people engage in self-advocacy, picking and choosing which services they accept and reject, and what they fight for within and outside of existing systems.

Chapter Three introduced the methodological approaches in the research. The three main methods used were participant observations, semi-structured and informal interviews, and photo-elicitation interviews. The methods allowed me to explore deeper into their everyday life experiences as well as elicit more comprehensive narratives. Data analysis was also discussed in considering the results within the grounded theory and structural violence frameworks. The chapter has also identified limitations of the study including difficulties in translating and transcribing interviews from South African Sign Language to English. The ethical considerations that were taken into account during the research were also briefly discussed.

In order to have a sense of the ethnographic orientation of my dissertation, I moved the literature review and theoretical framework into Chapter four. The literature review unpacked previous international studies and highlighted the significance of structural violence associated with economic, social and political barriers inside the health care systems and the ways in which these impact access to health care resources for Deaf individuals.

In Chapter 5 the results of the study are described. Current events such as budget cuts throughout the country have negatively affected the lives of Deaf people. Even more troublesome for many Deaf community members is the fear of what the future might hold for them. The participants recognise that not all health care is perfect – there can be improvements made for all patients, even those who are not Deaf. However, Jonathan also recognises that there are added obstacles for Deaf patients because of communication barriers. Communication barriers can be especially problematic in a health care setting because of potentially life-threatening situations. As such, medical professionals need to allocate enough time in appointments with Deaf patients to make sure they understand exactly what is going on. Jonathan went on to say,

“Every patient is different. That means doctors should have open minds. They need to find a way to communicate depending of the patient’s preference. Whether it be through an interpreter, typing or writing, spoken language and lip-reading.”

Since this study specifically highlights the detailed perspectives of only six Deaf people involved in the Deaf community, their views cannot be generalised. While there are similarities among other members of the Deaf community, there are differences as well. While this study would be ethnographically stronger with more interview participants, the experiences of my six participants cannot be discredited, as they are underscored by the perspectives of many others with whom I interacted during many months of participant observation at community events. Their experiences are real and their frustrations are legitimate. Their voices deserve to be heard; their signs deserve to be seen. Ultimately, this study can serve as a stepping-stone for further research. Any research regarding the health of Deaf people, or any other aspect of their lives, must be fully inclusive of Deaf people. Decisions cannot be made regarding their lives without their input, and their lives certainly cannot be improved without listening to their qualms and concerns and by seeing what they have to sign.

What is apparent from my research is the urgent need for Deaf people to tell their stories of everyday experiences with health care services. The final methodological module - photo-elicitation interviews - was the most enjoyable part of my research with them. Throughout the interviews, my participants expressed rich feelings and stories coming from their own photos. This allowed me, as the researcher, to step inside their own world. The production of all the photos the participants provided showed various factors that have emerged strongly in the study. Each photo produced a different story, in their own words and feelings. Their stories have inspired me and need to be heard in the world.

Key Approaches and Recommendations

There are a few key approaches suited to Deaf persons accessing health care services from the literature, and there are additional key approaches brought up by my participants which would strengthen the Deaf community’s access. I am going to list some of the key approaches to put forward as recommendations for further study in this area. According to my participants and Deaf

individuals I met over the period of my fieldwork, there are not enough workshops about health held at Deaf schools and Deaf organisations. From the analysis, I suggest the organisations and the public health sector include the Deaf community in their workshops and promote learning about health in order to improve their access to health information.

A key factor in improving health information is the media. The media (including the internet) should provide better communication access for Deaf individuals, i.e. adding closed captions, providing more qualified and trained interpreters on news broadcasts, providing translations to any videos being broadcast about health. With this improved access, Deaf children and adults will be given the opportunity to learn about health. The responses of my participants indicate that there are still not enough qualified or experienced SASLis to interpret well for a patient in a health care setting. Most of the SASLi training does not include medical training, including mental health and emergencies. The implementation of medical training in SASLi training should be considered by the organisations in order to improve the access to health care information and full communication for Deaf patients. Some of the participants felt the communication barrier could be resolved if their health care practitioners learned basic sign language. However, others are concerned that it would be difficult for sign language courses to be held for medical professionals as there is currently very limited medical vocabulary in SASL. A key approach is to develop the medical vocabulary before implementing sign language classes nationally to all medical professionals. The participants and other people at Deaf community events recognised that receiving adequate health care could depend on the provider and on the country's ability to provide their needs. Just as all patients are different, every provider is different as well.

Further, my participants and other people have not experienced any access to technology provided in South Africa. Access technologies include (but are not limited to) Video Remote Interpreting (VRI) and Speech-to-Text. The VRI services allow the provider to call up a remote interpreter, who appears by video on a portable monitor in the exam room or by the bedside (DeVault, 2014). Video interpreting services have existed worldwide since 1995. They are defined mostly as a telecommunication tool which allows communication over a distance. Assistive technology is also defined as a device that is used to increase, maintain, or improve the functional capabilities of someone with a disability. In many cases, Deaf people in South Africa report that it is still not

possible to access communication through technology because of numerous factors including costs of technology and health care services' refusal to meet their requests.

Whilst participant observation and deep immersion tend to involve long periods spent at field sites with certain individuals, the limitations of time placed upon this research as a minor dissertation has meant it was not possible to spend nearly as long in the field as I would have wanted. However, the data I collected in my project provides a starting point for further research. The dissertation could contribute to further study around the topic of health care services for Deaf community in South Africa that could therefore help the future Deaf patients. Nonetheless, the stories told and experiences shared during the course of this study can guide all stakeholders in the provision of health care services to work together to ensure better futures for Deaf people in South Africa.

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Bibliography

1. Alder, N.E. and Newman, K. 2002. Socioeconomic Disparities in Health: Pathways and Policies. *Health Affairs* 21 (2)
2. Baer, H.A., Singer, M., and Susser, I. 1997. *Medical Anthropology and the World System*. Westport, CT Bergin & Garvey
3. Barnett, S. and Franks, P. 2002. Health care utilization deaf adults who are deaf: Relationship with age at onset of deafness. *American annals of the Deaf* 144 (1)
4. Bauer, S. and Kantayya, V. 2010. Improving access to primary care and health outcomes in migrant farm worker populations: Challenges and opportunities. *Disease-a-month* 56 (12)
5. Barclay, D., Rider, M., and Dombo, E. 2012. Spirituality, religion, and mental health among deaf and hard of hearing people:A review of the literature. *Journal of the American Deafness and Rehabilitation Association*. 46 (1)
6. Becker, G. 1981. Coping with stigma: Lifelong adaptation of deaf people. *Social Science and Medicine Part B Medical Anthropology* 15 (1)
7. Becker, G. 2004. Deadly Inequality in the Health Care “Safety Net”: Uninsured Ethnic Minorities’ Struggle to Live with Life-Threatening Illnesses. *Medical Anthropology Quarterly*. 18 (2)
8. bell hooks. 1994. Teaching to transgress: education as the practice of freedom. New York: Routledge

9. Benson, P. 2008. El Campo: Faciality and Structural Violence in Farm Labor Camps. *Cultural Anthropology* 23 (4)
10. Bills of Rights. 1996. Constitution of the Republic of South Africa. Accessible at [\[https://www.gov.za/documents/constitution/chapter-2-bill-rights\]](https://www.gov.za/documents/constitution/chapter-2-bill-rights)
11. Branson, J. and Miller, D. 2002. Damned for their difference: The cultural construction of Deaf people as disabled. Washington, D.C.: Gallaudet University Press
12. Butler, J. 2004. *Undoing Gender*. New York: Routledge
13. Collier, J. and Collier, M. 1989. *Visual Anthropology: Photography as a Research Method*. New Mexico: University of New Mexico Press
14. Constitution of the Republic of South Africa. 1996. Constitution of the Republic of South Africa No. 108 of 1996. Accessible at [\[https://www.ru.ac.za/media/rhodesuniversity/content/humanresources/documents/employmentequity/Constitution%20of%20the%20Republic%20of%20South%20Africa%201.pdf\]](https://www.ru.ac.za/media/rhodesuniversity/content/humanresources/documents/employmentequity/Constitution%20of%20the%20Republic%20of%20South%20Africa%201.pdf)
15. Corbin, J. and Strauss, A. 2008. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, C.A.: Sage
16. Corker, M. 1998. Deafness/Disability – Problematizing Notions of Identity, Culture and Structure. In Ridell, S. and Watson, N. (eds) *Disability, Culture and Identity*. London: Pearson
17. Crenshaw, K.W. 1991. Mapping the Margins of Intersectionality, Identity Politics, and Violence against Women of Colour. *Stanford Law Review* 43(6)

18. Creswell, J.W. 2009. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, C.A.: Sage
19. Das, V. 2007. *Life and Words: Violence and the Descent into the Ordinary*. Berkeley: University of California Press
20. Eckert, R.C. and Rowley, A.J. 2013. Audism: A Theory and Practice of Audiocentric Privilege. *Humanity and Society* 37 (2)
21. Edwards, R. 1998. A Critical Examination of the Use of Interpreters in the Qualitative Research Process. *Journal of Ethnic and Migration Studies* 24
22. Engelman, A., Ivey, S.L., Tseng, W., Dahrouge, D., Brune, J. and Neuhauser, L. 2013. Responding to the deaf in disasters: establishing the need for systematic training for state-level emergency management agencies and community organizations. *BMC Health Services Research* 13
23. Farmer, P. 1997. On Suffering and Structural Violence: A View from Below” in Kleinman, A., Das, V., and Lock, M. (eds) *Social Suffering*. Berkeley: University of California Press
24. Farmer, P. 2004. An Anthropology of Structural Violence. *Current Anthropology* 45 (3)
25. Fileccia, J. 2011. Sensitive Care for the Deaf: A Cultural Challenge. *Creative Nursing* 17 (4)
26. Fjord, L.L. 1996. Images of Difference: Deaf and hearing in the United States. *Anthropology and Humanism* 21 (1)

27. Foucault, M. 1999. *Abnormal: Lectures at the College de France: 1974 – 1975*. New York: Picador
28. Frank, A.W. 1995. *The Wounded Storyteller*. Chicago: University of Chicago Press
29. Fusick, L. 2008. Serving clients with hearing loss: Best practices in mental health counselling. *Journal of Counselling and Development* 86 (1)
30. Galtung, J. 1969. Violence, peace, and peace research. *Journal of Peace Research* 6
31. Galtung, J. 1990. Cultural Violence. *Journal of Peace Research* 27 (3)
32. Groce, N. 1980. Everyone Here Spoke Sign Language. *Natural History* 3
33. Groce, N., Yousafzai, A., Dlamini, P., Zalud, S., and Wirz, S. 2006. HIV/AIDS and disability: a pilot survey of HIV/AIDS knowledge among a Deaf population in Swaziland. *International Journal of Rehabilitation Research* 29 (16)
34. Guillford, M., Figuerora-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., and Hudson, M. 2002. What does 'access to health care' mean? *Journal of Health Services Research and Policy* 7
35. Harmer, L. 1999. Health care delivery and Deaf people: Practice, problems, and recommendations for change. *Journal of Deaf studies and Deaf education* 4
36. Hualand, H. 2007. The Two-Week Village: The Significance of Sacred Occasions for the Deaf Community. In Ingstad, B. and Reynolds Whyte, S. (eds) *Disability in Local and Global Worlds*. Berkeley and Los Angeles: University of California Press.
37. Henning, M.A., Krageloh, C.U., Sameshima, S., Shepherd, D., Shepherd, G., and Billington, R. 2011. Access to New Zealand Sign Language interpreters and quality of

life for the Deaf: A pilot study. *Disability and Rehabilitation* 33

38. Hoffmesiter, R.J. and Caldwell-Harris, C.L. 2014. Acquiring English as a second language via print: The task for Deaf children. *Cognition* 132 (2)
39. Horton, S., McCloskey, J., Todd, C., and Henriksen, M. 2001. Transforming the Safety net: Responses to Medicaid Managed Care in Rural and Urban New Mexico. *American Anthropologist* 103 (3)
40. Hutchinson, J. 2012. Analysis of Notation Systems for Machine Translation of Sign Languages. [Unpublished Honours Dissertation] Grahamstown: Rhodes University.
41. Iezzoni, L.L., O'Day, B.L., Killeen, M., and Harker, H. 2004. Communicating about health care: observations from persons who are deaf or hard of hearing. *Annals of internal medicine* 140
42. Jacobson, D. 1991. *Reading Ethnography*. New York: SUNY Press
43. Jenkins, J.H. 1996. Women's Experience of Trauma and Political Violence. In Sargent, C. and Brettel, C. (eds) *Gender and Health: An International Perspective*. Upper Saddle River, NJ: Prentice Hall
44. King, J.F. 2005. Practical considerations for accommodating the Deaf patient. *Patient Care* 39
45. Kleinman, A., Das, V., and Lock, M. 1997. *Social Suffering*. Berkeley: University of California Press
46. Kohrman, M. 2005. *Bodies of Difference*. Berkeley: University of California Press

47. Kuenburg, A., Fellingner, P., and Fellingner, J. 2015. Health care access among Deaf people: Table One. *Journal of Deaf studies and Deaf education* 21 (1)
48. Laing, A. and Ensor, J. 2013. Nelson Mandela Memorial Interpreter ‘was a fake’ in *The Telegraph United Kingdom* accessible at [\[https://www.telegraph.co.uk/news/worldnews/africaandindianocean/southafrica/10510455/Nelson-Mandela-memorial-interpreter-was-a-fake.html\]](https://www.telegraph.co.uk/news/worldnews/africaandindianocean/southafrica/10510455/Nelson-Mandela-memorial-interpreter-was-a-fake.html)
49. Lane, H. 2005. Ethnicity, ethics and the deaf-world. *Journal of Deaf Studies and Deaf Education* 10
50. Lane, H., Hoffmeister, R., and Bahan, B. 1996. *A Journey into the Deaf World*. California: DawnSignPress
51. Lees, K. 2016. Internalized Oppression: Especially in the Deaf community where we believe in UNITY. Retrieved from *Partners Interpreting* at <https://www.partnersinterpreting.com/internalized-oppression-especially-in-the-deaf-community-where-we-believe-in-unity/>
52. Lieu, C.C., Sadler, G.R., Fullerton, J.T., and Stohlmann, P.D. 2007. Communicating Strategies for Nurses interacting with Deaf patients. *Patient Care* 39
53. Luckstein, K. 2012. *Mayo expert offers communication tips for medical staff, hearing-impaired patients*. Retrieved from <http://newsnetwork.mayoclinic.org/discussion/mayo-expert-offers-communication-tips-for-medical-staff-hearing-impaired-patients/>
54. Magongwa, L. 2010. Deaf education in South Africa. *American Annals of the Deaf* 115 (4)
55. Mathews, J., Parkhill, A., Schlehofer, D., Starr, M., and Barnett, S. 2011. Role-reversal exercise with deaf strong hospital to teach communication competency and cultural

- awareness. *American Journal of Pharmaceutical Education* 75 (3)
56. Mayer, G. and Villaire, M. 2004. Enhancing written communications to address health literacy. *Online Journal of Issues in Nursing* 14
57. McAleer, M. 2006. Communicating effectively with deaf patients. *Nursing Standard* 20 (19)
58. McIntyre, D., Cleary, S., Boule, A., and Castillo-Riquelme, M. 2008. The Burden of HIV/AIDS in the public healthcare system. *South African Journal of Economics* 76
59. McKee, M., Schlehofer, D., and Thew, D. 2013. Ethical issues in conducting research with Deaf populations. *American Journal of Public Health* 103 (12)
60. Metzger, M. 1999. *Sign Language Interpreting: Deconstructing the Myth of Neutrality*. Washington D.C.: Gallaudet University Press.
61. Middleton, A., Niruban, A., Girling, G., and Myint, P.K. 2010. Communicating in a health care setting with people who have hearing loss. *BMJ* 341
62. Minkler, M., Wallace, S.P., and McDonald, M. 1994. The Political Economy of Health: A Useful Theoretical tool for Health Education Practice. *International Quarterly of Community Health Education* 15 (20)
63. Morgans, H. 1999. Where Did South African Sign Language Originate? *Language Matters* 30 (1)
64. Munoz, K.F., Bradham, T.S., and Nelson, L. 2011. A systematic analysis of audiological services in EDHI. *The Volta Review* 111

65. Napier, J. and Kidd, M.R. 2013. English literacy as a barrier to health care information for deaf people who use Auslan. *Australian Family Physician* 42
66. Nyamnjoh, F.B. 2007. Stories from Abakwa. *Citizenship Studies* 11 (1)
67. O'Brien, D. and Kusters, A. 2017. Visual methods in Deaf studies: Using photography and filmmaking in research with Deaf people. In Kusters, A., De Meulder, M., and O'Brien, D. (eds) *Innovation in Deaf Studies*. Oxford: Oxford University Press.
68. O'Daniel, A.A. 2008. Pushing Poverty to the Periphery: HIV-Positive African American Women's Health Needs, the Ryan White CARE Act, and a Political Economy of Service Provision. *Transforming Anthropology*. 16 (2)
69. Padden, C. and Humphries, T. 1998. *Inside Deaf Culture*. Cambridge: Harvard University Press
70. Phelan, M. and Parkman, S. 1995. How to work with an interpreter. *BMC* 331
71. Pillay, K. 1999. Access to health care services: Language as a barrier. (Socioeconomic rights newsletter). Community Law Centre: University of the Western Cape
72. Pollard, R.Q. and Barnett, S. 2009. Health-related vocabulary knowledge among deaf adults. *Rehabilitation and Psychology* 54
73. Reeves, D. and Kokoruwe, B. 2005. Communication and Communication Support in Primary Care: A Survey of Deaf Patients. *Audiological Medicine* 3 (2)
74. Richardson, J.T.E. 2014. Academic attainment of students with disabilities in distance education. *Journal of Postsecondary Education and Disability* 27

75. Royal National Institute for Deaf People. 2005. *Working with a ESL/English Interpreter. Fact Sheet*. RNID: London
76. Scheper-Hughes, N. and Lock, M. 1987. The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly* 1 (1)
77. Schensul, S.L., Schensul, J., and LeCompte, M.D. 1999. *Essential Ethnographic Methods: Observations, interviews, and questionnaires*. Walnut Creek, CA: AltaMira Press
78. Schneider, J.A. 1999. And how are we supposed to pay for health care? Views of the poor and the near poor on welfare reform. *American Anthropologist* 101 (4)
79. Shuler, G.K., Mistler, L.A., Torrey, K., Depukat, R. 2013. Bridging communication gaps with the Deaf. *Nursing* 43 (11)
80. Smeijers, A.S., and Pfau, R. 2009. Towards a treatment for treatment: On communication between general practitioners and their Deaf patients. *The Sign Language Translator and Interpreter* 3
81. Department of Arts and Culture. 2004. *South African Language Practitioners Council Act No. 8*. Accessible:
<http://www.dac.gov.za/sites/default/files/Legislations%20Files/South%20African%20Language%20Practitioners%27%20Council%20Act%208%20of%202014.pdf>
82. Steinberg, A.G., Barnett, S., Meador, H.E., and Zazove, P. 2006. Health care system accessibility: Experiences and perceptions of Deaf people. *Journal of General Internal Medicine* 21 (3)

83. Storbeck, C. and Martin, D. 2010. South Africa: An Overview. *American Annals of the Deaf* 155 (4)
84. Ubido, J., Huntington, J., and Warburton, D. 2002. Inequalities in access to health care faced by women who are deaf. *Health and social care in the community* 10
85. Van Cleve, J.V. 1984. Nebraska's Oral Law of 1911 and the Deaf Community. *Nebraska History* 65
86. Watson, L.M. 1999. Literacy and Deafness: The Challenge Continues in *Deafness and Educational International* 1 (2)
87. Wilkens, C.P. and Heir, T.P. 2008. Deaf Education and Bridging Social Capital: A Theoretical Approach. *American Annals of the Deaf* 153 (3)
88. White Paper on the Rights of Persons with Disabilities. 2015. The Constitution of the Republic of South Africa. Accessible at [\[https://www.ru.ac.za/media/rhodesuniversity/content/equityinstitutionalculture/documents/White%20Paper%20on%20the%20Rights%20of%20Persons%20with%20Disabilities.pdf\]](https://www.ru.ac.za/media/rhodesuniversity/content/equityinstitutionalculture/documents/White%20Paper%20on%20the%20Rights%20of%20Persons%20with%20Disabilities.pdf)
89. WHO (World Health Organization). 1946. Constitution of the World Health Organization. Accessible at [\[http://www.who.int/governance/eb/who_constitution_en.pdf\]](http://www.who.int/governance/eb/who_constitution_en.pdf)
90. Yuan, Y. 2014. Turning Friends into Research Participants: Rationale, Possibilities and Concerns in *Cambridge Open-Review Educational Research eJournal* 1 (1)

