STRATEGIES UTILISED BY AN INTERPRETER AT ALEXANDRA HOSPITAL TO ENHANCE COMMUNICATION AND ELIMINATE COMMUNICATION BARRIERS

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DECLARATION

I, Nyiko Hlungwani, hereby declare that except for references to other people's works which have been duly acknowledged, the work presented here is my own, original work carried out as a student of the Department of Psychology, University of Stellenbosch, under the supervision of Professor Leslie Swartz. This work has not previously been submitted in whole or in part for any degree elsewhere.

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ABSTRACT

Language is a structured form of communication. It can be spoken or written but it is used to transmit messages from one person to the next. For a proper flow of communication to exist between two individuals linguistic understanding also has to exist. Most vital services that exist within society require the use of language to form the basis of the work. For instance, within the health care system, health care workers need to understand the language of the patient in order for them to diagnose and assist accordingly. Mental health care relies centrally on interaction for assessment, diagnosis and treatment. In multilingual countries like South Africa, the health care system faces challenges in terms of language. In many cases the health care workers speak the language of the minority within the community. There are measures that can be put in place which aim to bridge the linguistic gap that exists. In the Western Cape there is a language committee which tries to ensure that the three dominant languages spoken in the Western Cape are utilised equally. In one of the projects which was led by the Western Cape government and Stellenbosch University, community interpreters were allocated to different public hospitals within the province. One of the hospitals which benefited from the project was Alexandra Hospital which is a specialised hospital for people with intellectual disability and complex mental health needs. Many of the residents and outpatients of the hospital have verbal deficits. The interpreter at the hospital has adopted strategies which aim at improving communication as a whole with the patients.

The researcher accompanied the interpreter at the hospital for four weeks, which has led to an understanding of some of the strategies that the interpreter utilises to communicate with the patients. Semi-structured interviews were conducted with about 50 health care workers who work with the patients on a daily basis. Other interviews were conducted with other health care professionals (doctors, psychologist, occupational therapist and psychiatrist) who interact with the patients occasionally. The results showed that there is a huge difference between how the interpreter and the health professionals works together with the patients and how health care workers communicate with the patients. There were also different views that emerged between the health care workers and the health care professionals about the interpreter. The health care workers who are with the patients on a daily basis did not see communication and the usage of the interpreter as important. They believe that the patients are able to take instructions from them. On the other hand, the health care professionals see the need and the importance of working with the interpreter to eliminate language as well as communication barriers that exist. The thesis ends with some recommendations for future work.

OPSOMMING

Taal is ‘n gestruktureerde vorm van kommunikasie. Dit kan gepraat of geskryf word, maar dit word gebruik om boodskappe oor te dra van een persoon aan ‘n volgende. Vir behoorlike vloei van kommunikasie om tussen twee individue te bestaan, moet taalkundige begrip ook bestaan. Meeste noodsaaklike dienste, wat in die samelewing bestaan, vereis dat taal as basis vir die werk gebruik word. Byvoorbeeld, binne die gesondheidsorgstelsel moet gesondheidsorgwerkers die taal van die pasiënt verstaan om dienooreenkomstig te diagnoseer en bystand te verleen. Geestesgesondheidsorg steun by uitstek op interaksie vir assessering, diagnose en behandeling. In veeltalige lande, soos Suid-Afrika, staar die gesondheidsorgstelsel uitdagings in terme van taal in die gesig. Gesondheidsorgwerkers praat in baie gevalle die taal van die minderheid in die gemeenskap. Maatreëls, wat ten doel het om die taalkundige gaping wat bestaan te oorbrug, kan in plek gestel word. In die Wes-Kaap bestaan ‘n taalkomitee, wat poog om te verseker dat die drie dominante tale, wat in die Wes-Kaap gepraat word, op gelyke wyse gebruik word. In een van die projekte, wat deur die Wes-Kaapse regering en die Universiteit van Stellenbosch gelei is, is gemeenskapstolke aan verskillende openbare hospitale in die provinsie toegewys. Een van die hospitale wat uit die projek gebaat het, was Alexandra-hospitaal, ‘n gespesialiseerde hospitaal vir persone met intellektuele gestremdhede en komplekse geestesgesondheidsbehoeftes. Baie van die inwoners en buite-pasiënte van die hospitaal het verbale tekorte. Die tolk by die hospitaal het strategieë aanvaar wat ten doel het om kommunikasie in geheel met pasiënte te verbeter.

Die navorser het die tolk vir vier weke by die hospitaal vergesel, wat tot ‘n begrip van sekere van die strategieë wat die tolk gebruik om met pasiënte te kommunikeer gelei het. Semi-gestruktureerde onderhoude is met omtrent 50 gesondheidsorgwerkers, wat daagliks met die pasiënte werk, gevoer. Ander onderhoude is met ander professionele gesondheidsorgpersone (dokters, sielkundige, arbeidsterapeut en psigiater), wat soms met die pasiënte interaksie het, gevoer. Die resultate het getoon dat daar 'n groot verskil bestaan tussen hoe die tolk en die professionele gesondheidsorgpersone met pasiënte saamwerk en hoe die gesondheidsorgwerkers met pasiënte kommunikeer. Verskillende sieninge oor die tolk het ook tussen gesondheidsorgwerkers en professionele gesondheidsorgpersone geblyk. Die gesondheidsorgwerkers, wat daaglikse by die pasiënte is, het nie die kommunikasie en gebruik van die tolk as belangrik beskou nie. Hulle glo dat pasiënte instruksies van hulle kan neem. Aan die ander kant, sien die professionele gesondheidsorgpersone die nodigheid en belangrikheid daarvan om met die tolk te werk om taal- en kommunikasiehindernisse, wat bestaan, uit te skakel, in. Die tesis eindig met 'n paar aanbevelings vir toekomstige werk.

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1.1 Language in the context of health service delivery in South Africa

Language forms the core of relationships which exist in society and can be defined as follows:

> . . . a system of relatively arbitrary symbols and grammatical signals that change across time and that members of the community share and use for several purposes: to interact with each other, to communicate ideas, emotions, and intention and transmit their culture from generation to generation. (Cokely & Baker-Shenk, 1980, p. 31)

Language can be regarded as the most important medium of communication and interaction. People use language for different reasons and different purposes. For most social services, health care services and other services rendered within the society, communication is the most important component for service delivery; hence language forms the basis of the work. Swartz, Kilian, Twesigye, Attah, and Chiliza (2014) argue that within the mental health care system, language takes a central role as the entire system depends on it. For proper assessment, thorough diagnosis and accurate prescription to take place there must be a linguistic understanding that exists between the health care worker and the service user. Hence, miscommunication within the health care system in general can be deemed life-threatening (Meuter, Gallois, Segalowitz, Ryder, & Hocking, 2015). Communication has been recognised as the basis of the health professional-patient relationship and plays a major role in delivering quality health care.

If a language barrier exists, the quality of verbal communication between people also decreases, and effective communication is obstructed. According to Hadziabdic, Albin, Heikkilä, and Hjelm (2010), the level of impact of the language barrier is often disregarded by health practitioners, administrators and policy makers. The compromising existence of language barriers goes beyond access and quality service delivery (Zhao, Segalowitz, Voloshyn, Chamoux, & Ryder, 2019). If language diversity and language barriers that exist in different institutions or service rendering entities are not recognised by policy makers, this may reflect and reproduce the divisions and inequalities that exist within the country itself.

According to Ali and Johnson (2017), the greatest cause of language barriers which exist worldwide is international migration. In South Africa, however, migration is not the greatest challenge to language access. South Africa is a linguistically diverse country with 11 official languages and it is ranked as having the 18th highest level of linguistic diversity worldwide (Lewis, Simons, & Fennig, 2015). Language barriers continue to compromise a large proportion of the population's quality of life and access to health care services. The language diversity that exists in the country brings forth challenges to service rendering within the health care system. Service users are unable to receive efficient and effective services due to language barriers. Robertson (2014) argues that the services of an interpreter become necessary when language barriers exist between the health care worker and the service user. However, these services come with costs. For a formal post of a professional interpreter to exist within a health care institution, provision has to be made to cover the cost required. Such posts do not generally exist in South Africa.

In many, if not most, South African hospitals, informal interpreters are used, including cleaners, security guards and other staff members at the hospital. A study done by Kilian, Swartz, and Joska (2010), in one of the psychiatric hospitals in the Western Cape, revealed that most untrained interpreters demonstrated difficulties in translating psychiatric terminology. This clearly indicates that informal interpreters who are not trained may give inaccurate information to the health care workers which, in turn, may lead to an incorrect diagnosis. Penn and Watermeyer (2012) emphasise the importance of equipping the interpreters with interpreting skills in order to render effective services within the health care system. Hiring a qualified professional interpreter is costly, and given the current situation in South Africa there are limited resources allocated to improving service rendering within the health care system. Mbanya, Terragni, Gele, Diaz, and Kumar (2019) argue that using unqualified/untrained interpreters (such as cleaners, security guards/relatives of the patients) poses risks of recording incorrect diagnoses and administering incorrect medication, and further, this is a total disregard of confidentiality.

In the Western Cape, the Provincial Department of Health, the Extended Public Works and Stellenbosch University took an initiative to address the issues of language barriers within the health care system. The project trained 15 first language isiXhosa speakers, and these interpreters were placed in six different public hospitals in the Western Cape. Currently the Department of Health has employed nine interpreters in formal posts in different public hospitals. Alexandra Hospital is one of the hospitals which participates in the interpreter project. There is a full-time trained community interpreter who is appointed by the Department of Health stationed at Alexandra Hospital.

Alexandra Hospital is a specialist mental health care facility offering treatment and rehabilitation for adults, adolescents and children with complex mental health needs and intellectual disability. The hospital faces challenges of language barriers and the staff have adopted certain strategies which aim to eliminate these barriers, such as utilising the services of an interpreter. Some of the residents at Alexandra Hospital have verbal deficits and this poses further challenges in making services accessible. Given the complex interaction of language diversity and language deficits in the client population, the question arises as to how the institution manages language issues in practice.

People with intellectual disability face a range of difficulties, and many people in this population have verbal deficits. This poses challenges in accessing health care services since they may struggle to communicate their needs fully, even when there is no language barrier. Emerson and Baines (2010) argue that this population experiences a variety of health issues and the median death age amongst this population is cited by the authors as at around 25 years. Although there might be many reasons why people with intellectual disability have been neglected, communication between the health care workers or the care takers and people with intellectual disability cannot be ruled out (Emerson and Baines, 2010). Communication is of vital importance, especially for people with special needs, and if barriers exist the health care professionals have to make decisions without involving the patients to the fullest capacity (Primeau & Talley, 2019).

According to Ali et al. (2013), the communication barriers that occur as a result of language deficits may lead people with intellectual disability to be excluded from or discriminated against within the health care system. Health care workers may be unable to conduct proper health reviews, screening, to discuss medication plans as well as adequately assess the patients' health needs. This can have a negative impact on how people with intellectual disability receive health care services. Harris, Hewett, and Hogg (2001) argue that if effective communication does not exist, individuals may feel isolated and they may experience restrictions in making meaningful choices or having control over their lives. These feelings may lead to helplessness, frustration and even negative behaviour. Lack of ways or means to communicate their needs may result in actions that show the frustration that is encountered. Some may lead the patients to act out their feelings of frustration by showing negative behaviour.

1.2 Research problem and rationale for the study

Section 27 (1) (a) of the South African Constitution states that everyone has the right to health care services, including reproductive care services. Further, Section 27 (2) stipulates that the state should take legislative measures and allocate resources to ensure that the rights of individuals are upheld (Republic of South Africa, 1996a). However, with the language diversity that exists in South Africa, is it in practice the case that every citizen has equal access to health care? Furthermore, for individuals with verbal deficits, are there strategies or resources in place to ensure that they also have equal access to health care?

Section 9 of the Constitution is based on equality. Section 9 (3) obliges the state not to directly or indirectly discriminate against anyone based on race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth (Republic of South Africa, 1996a). This clearly indicates that systems or institutions should not directly or indirectly exclude individuals under any circumstances. Strategies to ensure that individuals are not discriminated against should be put in place. Alexandra Hospital is a government facility; thus exploring the strategies that they have employed to eliminate language barriers and enhance communication skills will indirectly explore the measures that the government has put in place to protect and promote the rights of people with disabilities.

The Batho Pele White Paper on transforming public services (Republic of South Africa, 1997) was adopted to show the government’s commitment to extend services equitably and appropriately to all citizens of South Africa. These principles are based on the Constitution and the Bill of Rights. The Batho Pele principles stipulate that the services should be accessible, transparent, accountable, efficient and free of corruption. Given the complex situation of language diversity and communication barriers that exist at Alexandra Hospital, are the services accessible? Are the strategies adopted working towards making the services more accessible?

This thesis grapples with these issues, focussing on language access questions at Alexandra Hospital. Chapter 2 introduces the reader to models of disability, and Chapter 3 focuses more narrowly on intellectual disability itself and issues of care. In Chapter 4 I explore issues of communication in the context of institutionalization and deinstitutionalization. I present my methodological approach in Chapter 5, and my data analysis in Chapter 6. In Chapter 7 I provide a discussion and some conclusions to the thesis.

Chapter 2

Understanding Disability and Disability Models

2.1 Introduction

There is no single definition of disability, with definitions varying from country to country worldwide. This has implications in the broader economic, political, social and medical spheres, as well as more specifically for those involved in advocating at a policy level, for researchers, for caregivers, and for people living with disability (Mitra, 2006). Various models have emerged from the different definitions of disability, and there is no single model which defines disability fully (Pfeiffer, 2001). However, each definition, and thus each model, brings forth a different perspective and a different understanding of disability. According to Masala and Petretto (2010), disability models can be classified into three groups: first, the model which attributes disability to individuals (medical model); second, the model which attributes disability to the environment (social model); and last, the models which acknowledge the relationship between the person and the environment (the Nagi model, the capability model and the International Classification of Functioning, Disability and Health). The following section will focus on these five different models with their differing perspectives which define disability.

2.2 Medical model

Masala and Petrotto (2010) trace the origins of the medical model to the emergence of social and health provision for diseased individuals. The medical model reflects assumptions which are based on the individual and the impairment or chronic pathology (disease). Medical intervention, institutional care and rehabilitation services, such as special education programmes and social welfare, are some of the core solutions that the model has brought forth aiming to cure disease (Palmer & Harley, 2011).

This model's entire focus is on the individual's impairment or the chronic pathology in relation to the functional consequences (Masala & Petretto, 2010). "According to this model able-bodied people have sound or normal bodies; and disabled bodied people have damaged or dysfunctional bodies" (Stubblefield; 2007, p. 166).

The main focus of this model is to cure the pathology or assist the individual in living with the limitation resulting from the pathology or impairment. The medical model ignores the impact of the environment on the individual, as well as other aspects that might affect an individual with the impairment or pathology.

According to Rapley (2004), intellectual disability has been viewed as a "clinical-medical" diagnosis throughout history. The diagnosis mainly focuses on the neurological, metabolic and physiological deficits that one might have. Barlow (1978) defined intellectual disability within the medical model as follows:

> …intellectual disability (mental retardation) is a symptom complex, the chief features of which consist of (1) intellectual subnormality associated with (2) maladaptive behaviour. The term implies onset during childhood or before… (pp. 1–2)

This model has historically advocated for the institutionalisation of people with a disability, involving specialised separate services, special schools, diagnosis and treatment. Intellectual disability is viewed as a problem existing solely at the level of the individual, for which segregated, specialised services are seen as the best practice (Johns & Adnams, 2016).

2.3 Social model

The social model moves its focus from the individual impairment to the impact that the environment has on people with impairments. Disability is viewed as being socially constructed. Palmer and Harley (2011) argue:

> Impairment itself is not important, but rather accommodations made for persons to function in society determine, and therefore are able to ameliorate disability, e.g. change in attitudes and physical accessibility… (p. 358)

The focus for this model is the environment and the barriers that exist within the environment rather than focusing on the individual's impairments. The emphasis is clearly on creating a more accessible environment rather than on trying to "cure" individuals.

Palmer and Harley (2011) argue that the social model has achieved positive results in shifting the definition of disability from a medical and individualistic perspective. However, the social model has been criticised for not recognising the impairments that individuals have; as some claim that it focuses solely on the environment. The model, according to critics, neglects the lived experiences as well as the reality of people with disability (Palmer & Harley, 2011). Regardless of the environment, an individual who has physical impairments does not always function in a similar way to an individual who does not have these impairments and is thus not physically challenged. The environment does limit the individual with impairment but the impairment itself also plays a role. By way of example, Watermeyer (2014), a strong advocate for the rights of disabled people, argues that, despite transformative efforts aimed at removing physical barriers and accommodating people with disability, there still exist significant inequalities in accessing, for example, the internet, IT skills training, and affordable literature. Watermeyer (2014) is an academic with a severe visual impairment. He notes, for example, that the fact that he cannot easily browse through books in the library is a function of his impairment rather than of social exclusion. The fact that like many other people with visual impairment he is often not granted access to written material in accessible forms, for example, in a format which screen reading software can provide, is a product of social exclusion and lack of provision of an accessible environment. The individual's impairment may have a negative impact on its own but may often be exacerbated within the context of the individual's environment.

The social model also emphasises how the environment socially constructs intellectual disability. Rapley (2004) argues that the environment, or society, creates social identities which stigmatise people with intellectual disability. The stigma, and not just the impairments, may be part of what prevents individuals with learning or verbal impairments from functioning as well as individuals without impairments, thus limiting and disabling them from participation in society. Stubblefield (2007) argues that cognitive disability is embedded in the definition of a successful life which is based on mastery of intellectual and social skills as well as competitive accomplishment. This definition leads to discrimination and stigmatisation of people with intellectual disability.

This model focuses on removing social barriers and challenging discrimination, thus making information and services accessible, reducing stigma and promoting equal rights as well as promoting inclusive education (Johns & Adnams, 2016).

2.4 Nagi model

The Nagi model differs from the social model in that it recognises the social and the physical environment as well as the socio-cultural context that has a negative impact on people with impairments. This model defines disability as follows:

> … an inability or limitation in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment… (Masala & Petretto, 2010, p, 5)

These roles and tasks emphasised within the model are regarded as normal in society. They include activities such as family roles and tasks, interpersonal relations, employment, education and self-care.

This model recognises the relationship between the individual's impairments and the limitations in functioning imposed by the environment (Masala & Petretto, 2010). The model explains how the physical and social environment impose barriers to individuals with impairments, including the reaction and expectations of society. However, the author of the model argues that the relationship that occurs is not linear, meaning that not all impairments will result in disability (Nagi, 1991).

The Nagi model places emphasis on socio-cultural expectations and the physical environment (Mitra, 2006). This means that an individual with intellectual impairments can only be disabled if he/she cannot perform the roles and tasks within a socio-cultural context. For example, if it is usual for children to not yet be able to read and write at the age of 10 within a specific socio-cultural context, then children at that age with an intellectual disability would not be disabled.

2.5 Capability model

Sen's capability approach is rooted in two concepts, namely capability and functioning (Mitra, 2006). Capability refers to the opportunity that one is given and functioning refers to the activity or task that one can perform. However, from Sen's point of view, functioning carries a broader description of the activities that one can perform as well as the state in which one performs the activity. Capability is described as "the opportunity that one is given" whereas it more specifically refers to the opportunity (freedom) that one is given to exercise choice in pursuit of what one values for a decent life (freedom to achieve functioning).

In this way, he argues that two people can have a similar capability but differ in functioning.

According to the capability approach, disability is caused by:

a) the nature of an impairment and the other personal characteristics such as age, gender, and race,

> b) the resources available to the individual, and
>
> c) the environment. (Mitra, 2006, p. 2)

This model puts more emphasis on the three aspects which it argues can cause disability. This means that according to this model intellectual disability is also caused by the nature of an impairment (intellectual impairment), the resources that are made available to the individual, as well as the environment. For example, if an institution for people with an intellectual disability does not allocate resources to make the services accessible to the residents then the institution is contributing to disabling the residents.

Further, the model places emphasis on the availability of resources, the lack of which deprive individuals with impairments of the capacity to function to their full potential. Further, the model indicates that there are two types of disability, namely potential and actual disability (Mitra, 2006):

> Potential disability is defined as the disability at a capability level and actual disability as a disability at a functional level. (p. 3)

2.6 International Classification of Functioning, disability and health (ICF)

The International Classification of Functioning, disability and health (ICF) is viewed as a product of the biopsychosocial model of disability; its focus encompasses biological, individual and social perspectives (Mitra, 2006). This model argues that disability is a manifestation of not only the health conditions which result in impairment, but also of limitations in participation within a specific context. Participation refers to the inclusion of individuals with impairments and contextual factors refer to personal and environment factors, and the services that are available within society (World Health Organization, n.d.).

The terminology embedded in the model reflects the focus on the functioning of the body and the body structure, and disability which results from activity limitations and participation restrictions (Mitra, 2006). This model gives a concrete classification of the functioning of individuals. An individual is assessed on two criteria: the capacity qualifier and the performance qualifier:

> Capacity qualifier refers to the measures an individual's ability to execute tasks or actions in a standardised environment to neutralise the impact of different environments on the abilities of the individual. A performance qualifier measures the actual lived experiences of people in the actual context in which they live. (Palmer & Harley, 2011)

This approach focuses on the individual, the social context, the psychological wellbeing and the medical needs. For people with intellectual disability, intervention will focus on treatments, health supports and adaptive devices, and on specialised interventions such as occupational therapy, reasonable accommodation and inclusion (Johns & Adnams, 2016). Further promoting equal rights as well as challenging discrimination also forms part of this model. Figure 1 below gives a summary of the ICF model.

Figure 1. International Classification of Functioning, disability and health (ICF).

"Disability is diverse and no single definition of disability will encompass this heterogeneity" (Agronnik, Campell, Ressalamp, & Lesson, 2019). These models contribute to a better understanding of disability, including intellectual disability. Acknowledging and recognising them may help policy makers to create suitable interventions which will address the needs of people living with disability. As mentioned above, not only one model/perspective can define disability fully on its own. For proper intervention for people with disability, and specifically people with intellectual disability, to occur, all the models and perspectives should be carefully considered. This study will prominently use the Social Model where it is believed that the environment contributes significantly to disability. In this study we are going to focus on how the interpreter eliminates language barriers which exist between the health care workers and the patients. The following chapter will focus on the classification of people with intellectual disability, which will lead to a better understanding of intellectual disability, as well as the prevalence and issues related to caring for people with intellectual disability.

Chapter 3

Intellectual disability classification, prevalence and issues related to care

3.1 Intellectual disability classification

The DSM-5 (2013) defines intellectual disability as follows:

> Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:
>
> A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualised, standardised intelligence testing.
>
> B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
>
> C. The onset of intellectual and adaptive deficits during the developmental period.
>
> (DSM-5, 2013, p. 33).

Further, the DSM-5 classifies this population into four categories, namely: mild, moderate, severe and profound, and these four categories are discussed below:

3.1.1 Mild

As children, these individuals learn slowly and lag behind schoolmates, though they can be expected to attain roughly sixth-grade academic skills by the time they are grown. As they mature, deficiencies in judgment and solving problems cause them to require extra help to manage everyday situations – and personal relationships may suffer. They usually need help with such tasks as paying their bills, shopping for groceries, and finding appropriate accommodations. However, many work independently, demonstrating the ability to learn and implement fairly structured, routinised tasks.

Though memory and the ability to use language can be quite good, these patients become lost when confronted with metaphor or other examples of abstract thinking. IQ typically ranges from 50 to 70. They constitute 85% of all patients with intellectual disability (DSM-5, 2013).

3.1.2 Moderate

When they are small children, these individuals' differences from non-affected peers are marked and encompassing. Though they can learn to read, to do simple math, and to handle money, language use is slow to develop and relatively simple. Far more than mildly affected individuals do, in early life, they need help in learning to provide for their own self-care and engage in household tasks. Relationships with others (even romantic ones) are possible, though they often don't recognise the cues that govern ordinary personal interaction. Although they require assistance making decisions, they may be able to work (with help from supervisors and co-workers) at relatively undemanding jobs, typically at sheltered workshops. IQ will range from the high 30s to low 50s. They represent about 10% of all patients with ID (DSM-5, 2013).

3.1.3 Severe

> Although these people may learn simple commands or instructions, communication skills are rudimentary (single words, some phrases). Under supervision, they may be able to perform simple jobs. They can maintain personal relationships with relatives, but require supervision for all activities; they even need help dressing and with personal hygiene. IQs are in the low 20s to high 30s. They make up roughly 5% of the total of all patients with ID (DSM-5, 2013).

3.1.4 Profound

> With limited speech and only rudimentary capacity for social interaction, much of what these individuals communicate may be through gestures. They rely completely on other people for their needs, including activities of daily living, though they may help with simple chores. Profound ID usually results from a serious neurological disorder, which often carries with it sensory or motor disabilities. IQ ranges from the low 20s downward. About 1%–2% of all patients with ID are so profoundly affected (DSM-5, 2013).

Given the definition and the classification of intellectual disability from the DSM-5, the social and adaptive components of people with intellectual disability has been neglected. Schalock, Luckason, Tasse, and Verdugo (2018) argue that there are four perspectives that aim to give a holistic view to intellectual disability, however, they go beyond the four perspective that classify intellectual disability into subgroups. The four perspectives that Schalock el at. (2018) mentioned are as follows:

- The biomedical perspective emphasises the genetic and physiological factors that result in intellectual disability.

- The psychoeducational perspective emphasises the intellectual, psychological/behavioural, and learning limitations associated with intellectual disability.
- The sociocultural perspective emphasises the interaction between people and their environment through which social meaning of intellectual disability develops from society's common beliefs, behaviour, language and events regarding people with intellectual disability and responses of individuals to the interaction.
- The justice perspective emphasises that all individuals, including those with a diagnosis of intellectual disability, have the same human and legal rights.

All four perspectives recognise and acknowledge the social and adaptive components of people with intellectual disability. Mostly the sociocultural perspective focuses more on how people with intellectual disability adapt and develop within the society.

In the past the focus on classifying disability was mainly from the perspective of the medical model which emphasised the etiology and the assignment of the diagnosis (Vale, daSilva, Pimentel, Marques, Rodrigues, Cunha, Machado, Saches-Ferreira, & Semionson, 2016). In recent years there has been a paradigm shift where the focus was moved from the medical model, where the DSM and ICD were the primary determinants of the level of intellectual disability and functioning. There is now focus on multidimensional, comprehensive models which are based on health and functioning (Vale et al., 2016).

3.2. Prevalence

According to Harris (2006), the prevalence of intellectual disability varies from 1% to 3% in the population worldwide. And amongst this population, there are people with mild, moderate, profound and severe mental impairments. As mentioned above, different categories have different needs and different deficits. In the 1970s, intellectual disability was defined differently, with the use of the IQ Score to measure intelligence and showing a prevalence of approximately 3% (Mckenzie, Milton, Smith, & Quellette- Kruntz, 2016). Obviously, using the IQ Score only did not give an accurate measure to intellectual disability since it solely focuses on the measurement and neglects the other components of intellectual disability. Factors which may lead to intellectual disability include genetic abnormalities, prenatal exposure to alcohol and diseases, trauma during birth, early childhood infections, exposure to heavy metals and severe malnutrition. (Mckenzie et al., 2016). Shifting from only using the score to focusing on incidences increases the chances of getting an accurate prevalence of intellectual disabilities.

According to McKenzie, McConkey, and Adnams (2014), the overall prevalence of intellectual disability in South Africa remains unclear, due to the lack of specific epidemiological data and the fact that overall studies of disability use different methods and definitions. This gives rise to different definitions of intellectual disability, and disability as a whole, within the country. In the Western Cape province, intellectual disability is estimated at 3.05%, of which 2.5% is considered to be mild, 0.4% moderate, and 0.15% severe (Kleintjes et al., 2006). A small number of the estimated population are living in care facilities. A study done by McKenzie et al. (2014) revealed that residential facilities in the Western Cape house around 2000 individuals with intellectual disability, which is far less than the estimated population of people with intellectual disability.

3.3 Vulnerability and care

Copper, Allan, Greenlaw, McSkimming, Jasilek, Henderson, McCowan, Kinnear, & Melville (2020) argue that it is widely recognised that the population with intellectual disability have a higher rate of health problems compared to the general population. These health problems include mental disorders, physical disorders and disabilities which in many cases go untreated (Jansen et al., 2004). Research has shown that this population also have a low life expectancy as compared to the general population. Research done by Copper et al. (2020) revealed that people with intellectual disability die at a younger age than people without ID.

Although there may be other factors that contribute to the excess mortality rate, lack of access to health care is one of the major contributing factors. However, Patja et al. (2001) found that the life expectancy for people with disability has increased resulting in an ageing population of people with intellectual disability. This clearly indicates that there is a change in terms of the health status of people with intellectual disability. Copper et al. (2020) argue that there are actions that can be taken to reduce mortality for people with intellectual disability; for example, training to avoid aspiration, choking, pain identification to address problems before they are advanced and reasonable adjustments to improve health care quality.

Some of the studies done have revealed that in some countries the death rate of people with intellectual disabilities is slightly higher for people living in a community setting as compared to people living in institutions (Patja et al., 2001). This may be due to the fact that, within institutions, people with intellectual disability are not exposed to the same risk factors as the general population and this includes limited health care resources. In institutions, although there might be limited services, all the resources are allocated to specifically assist and treat patients with intellectual disabilities.

Many people with intellectual disability have verbal deficits, a factor which hinders service delivery within the health care system. According to Ali et al. (2013), the communication barriers that occur as a result of the language deficits may lead people with intellectual disability to be excluded or discriminated against within the health care system. According to Lennox, Ware, Gomez, and Copper (2010), communication barriers are one of the reasons why there are difficulties in gaining access, short consultation time which leads to patients with intellectual disability having unrecognised diseases. Regardless of the skills that the health care professional has, without effective communication between the individual with intellectual disability and the health care provider, health care service provision will be ineffective. Lennox et al. (2010) argue that if effective communication does not exist, individuals may feel isolated and they may experience restrictions for making meaningful choices or having control over their lives. These feelings may lead to helplessness, frustration and even negative behaviour. As the use of collateral, clinical acumen in systematic use of treatment options, and in the case of this research, use of interpreters as noted.

3.4 Institutions, intellectual disability and language

Dalton and Sweeney (2011) argue that some institutions adopt communication techniques and some innovative methods to enhance communication for people with intellectual disability. They aim to uphold the rights of their residents and make their services accessible and beneficial to the residents. Some of these institutions adopt a rights-based approach and the social model, intending to eliminate some of the barriers. Dalton and Sweeney (2011) also emphasise that if institutions can recognise the methods that individuals with intellectual disability utilise to communicate, the services that they render can facilitate and support these individuals regardless of the level of their disability. This may require a certain level of attuning and empathy from the service providers. The health care workers will have to position themselves on the level of the patients in order to communicate with them effectively.

Different techniques which have been used by different institutions have brought forth positive outcomes in eliminating the communication barriers that exist. The study done by Meuris, Maes, and Zink (2014) has shown that the usage of key word signing has enhanced communication between the clients with intellectual disability and their service providers.

This is one of the strategies that aims to eliminate communication barriers that exist within these institutions. Another aspect that is important in improving the quality of life of any individual is interpersonal relationships. Schalock, Brown, Brown, Cummins, and Felce (2002) argue that in residences or institutions where individuals with intellectual disability reside, the interpersonal relationships that exist between the staff members and the residents are a core aspect that enhances the quality of life of the patients. If good interpersonal relationships exist between the staff members and the patients, needs, preferences and wishes can be communicated more easily. There is a reciprocal relationship here: better relationship leads to better communication and vice-versa. Policies and practices of the institutions should directly reflect the purpose and the aim of the institution; it should direct the culture which focuses on improving the quality of life for the patients (Bigby & Beadle- Brown, 2018).

The following chapter will focus on the institutions for people with intellectual disability and on the strategies that can be utilised to bridge the communication barriers within the institutions and enhance communication. At the end of the chapter deinstitutionalisation and its effects is also discussed briefly in order to highlight the positives of institutionalisation.

Chapter 4

Institutionalisation and deinstitutionalisation of individuals with intellectual disabilities: Communication strategies that can be utilised

4.1 Introduction

The history of the establishment of institutions for people with intellectual disability is long and very complex. According to Malacrida (2015), initially institutions were established to achieve three goals, namely the education, training, and reintegration of people with intellectual disability into the community so that they would be sufficiently skilled to contribute to the economy. However, this intention was not fulfilled as short-term residencies became long-term institutionalisation.

In the early twentieth century, institutionalisation was one of the eugenic strategies of separating individuals who were deemed mentally defective from their parents and the community as a whole. These people were taken into institutions where they were prevented from living a normal, productive life, specifically with regard to childbirth. The eugenics movement was established by Galton in 1865, where he argued that "hereditary talents and character that human mental qualities have can be manipulated or cultivated the same way as breeders control the quality of domestic animals" (Jacobson & Curtis, 2000). Involuntary sterilisation was one method implemented within the institution to limit reproduction (Malacrida, 2015). The impact of this movement was felt more broadly than within institutions, however, with the immigration of people regarded as having undesirable traits being restricted in the United States in the 1800s. Thus, desirable human traits, which were associated with the development and prosperity of civilisation, were prevented from degenerating through contact with undesirable traits (Malacrida, 2015).

People with an intellectual disability were committed to institutions and they were led to believe that they were not normal human beings; they were treated in ways which were dehumanising. Malacrida (2015) conducted a study in an institution for individuals with mental deficits in Canada, revealing a number of dehumanising factors, namely, the layout of the institution, the usage of space and time, the segregation in the ward and the hierarchical structures that are available within the institution. The institutions were designed to strip individuals with an intellectual disability of their rights to be human (Malacrida, 2015). The residents within the institution were deprived of the essential freedom that is necessary for a normal human being to function normally. Malacrida (2015) found that the institution's layout was not suitable for stimulating the development of children, despite there being children in the institution.

Malacrida (2015) also mentioned that the institution was characterised by violence which was viewed as part of the disciplinary process. Residents were accustomed to violence that existed between residents and between the residents and the staff members. According to Davids (2001), people with intellectual disability's perception of violence differs depending on the severity of the individual's intellectual impairment. People who have a severe intellectual disability would not be able to discriminate actions as assault or to communicate to others about the incidents. On the other hand, people with less severe intellectual disability might be able to perceive that they are being assaulted but may not know how to communicate verbally due to verbal deficits.

4.2 Institutionalisation and the medical model

As mentioned above, the medical model historically supported the institutionalisation of people with disability and argued for the provision of specialised separate services, special schools, diagnosis and treatment. However, in reality, the institutionalisation of people with intellectual disability has led to stigmatisation and segregation of this population, depriving them of their freedom (Glaser & Glaser, 1999). This is reflected in the challenges that the institutions face, which hinder effective service provision.

4.3 Challenges in communication and support offered within the institutions

Communication and intellectual disability is a very sparsely researched topic, hence there is limited literature which aims to guide practice within institutions for people with intellectual disability. Institutions for people with an intellectual disability, at their best, provide specialised services which aim to improve the quality of life of individuals with intellectual disability. With the nature of the patients in these institutions, there are challenges that are faced while rendering these services.

Many people with intellectual disabilities have difficulties in expressing themselves explicitly, verbally, and according to Grove, Bunning, Porter, and Oisson (1999), the following characteristics can be found in this population:

- Highly dependent on the interpretations of others to make themselves understandable.
- The level of awareness and intentions cannot be easily understood or determined.
- Difficulty in determining the level of comprehension, which is in most cases very low.
- Limited independent ability to use a formal linguistic expression of any form such as speech, signs or graphic symbols.
- Inconsistency in ways of communication which may lead to vagueness of meaning.
- A tendency to comply with the suggestions of others and an inability to challenge an interpretation, saying, for example: “No, that’s not what I meant”.

Studies done by Ali et al. (2013) highlight some of the barriers which pose challenges for people with intellectual disability in accessing adequate health care; these include communication barriers, as discussed above. Harris et al. (2001) argue that without effective communication, individuals may feel isolated and have little or no control over their lives. Effective communication enhances the lives of individuals since one can make meaningful choices by communicating ones' needs and concerns.

Ware (2004) argues that in institutions where communication barriers occur between the health care worker and the patient, other alternatives should be utilised to breach the gap. For effective and efficient services to be rendered to the patients within the institution, the communication barriers that exist should be eliminated. Support strategies should be put in place for patients who cannot express themselves verbally.

Most government documents, internationally, place emphasis on the person-centred approach where services within any government institution should be compelled to focus centrally on the patients or service users (Murphy, 2008). For this aim to be achieved, different techniques and strategies should be employed to eliminate barriers that may hinder the person-centred approach. Institutions for people with intellectual disability worldwide have used different strategies to improve communication and enhance the lives of people with intellectual disabilities. Ali et al. (2013) argue that a lack of techniques which improve the communication environment for people with an intellectual disability leads to exclusion of this population. Exclusion from access to the health care system can lead to the escalation of health problems as well as lowering the life expectancy further. In many cases, due to communication barriers, people with intellectual disabilities are misdiagnosed, for example, their physical or mental health care problems are misattributed to the individual's intellectual disability.

Murphy (2008) argues that people with intellectual disabilities should be included in decision-making processes regarding their wellbeing and they should also have freedom to choose and control their lives, and this requires effective communication. Dalton and Sweeney (2011) found that some institutions adopted communication techniques and some innovative methods to enhance communication for people with intellectual disability. These institutions aimed to uphold the rights of their residents and make their services accessible and beneficial to the residents. Literature has revealed a link between communication difficulties and challenging behaviours. Jacobs, Drew, Ogletree, and Pierce (2009) argue that many people with an intellectual disability tend to utilise gestures, vocalisation and other behaviours to communicate their needs. In many cases, they tend to act out their frustrations and feelings which they cannot communicate verbally (Hagan, 2013; Lund & Light, 2006). This has implications for communicating with, and caring for people with intellectual disability.

4.4 Utilising Argumentative and Alternative communication

Argumentative and Alternative communication (AAC) has been utilised worldwide with the aim of substituting verbal or written language by using different symbols, pictures and devices (Beukelman & Mirenda, 2005). These techniques and strategies have been used to assist people with verbal deficits. Ogietree and Pierce (2009) show that where AAC was used for individuals with a severe intellectual disability, the results revealed that AAC proved to be appropriate for individuals with a severe intellectual disability as well as for any individual who displays verbal deficits. Using symbols and other kinds of techniques has proven to be useful in enhancing communication skills for people with intellectual disabilities. Different techniques which have been used by different institutions have brought forth positive outcomes in eliminating the communication barriers that exist. Below, different forms of

AAC will be discussed as well as other communication techniques which aim to enhance the lives of individuals with intellectual disability.

4.4.1 Speech generating device as a form of AAC

AAC includes the utilisation of speech generating devices (SGDs) which help individuals with speech impairments to express themselves, maintain a topic, take conventional turns and reduce communication breakdown. A study done by Hagan (2013) revealed that there was an improvement in communication skills when the individuals with intellectual disabilities used SGDs. However, as much as these devices are helpful, they are costly. Low-income countries might not be able to provide SGDs to individuals with intellectual disability.

4.4.2 Graphic symbols as a form of AAC

The use of graphic symbols is another form of AAC where non-electric symbols, lines or pictures are utilised to communicate with people with verbal deficits. Studies were done where children, adolescents and adults used aided communications such as pictures, lines and symbols. The results showed that many people have demonstrated improvement in learning functional communication (Mirenda, 2003; Schlosser & Blischak, 2001). This form of AAC requires materials such as pictures and symbols. Mirenda (2003) argues that this form of AAC requires multiple stimuli or discriminants, as compared to Key Word Signing, which will be discussed below.

4.4.3 Key Word Signing as a form of AAC

Key word signing (KWS) usage is another form of AAC. KWS includes key words in spoken sentences which are supported by manual signs (Meuris et al., 2014). According to Clibben (2001), KWS has a number of different rationales. Some of these rationales are discussed below:

- Signs are a possible and achievable alternative if oral-motor is challenging.

- Signs are easier to teach as they can be produced more slowly than speech and hands are used to produce these signs.
- Signing does not require any additional equipment except the body.
- Signing is multi-modal which can improve the understanding of speech.
- Signing does not obstruct the usage of speech, but rather enhances it.
- Signs are derived from the natural language and can thus be extended grammatically.

Meuris et al. (2014) conducted a study which aimed to account for the usage of KWS in residences and day care programmes for adults with intellectual disability. The study focused on both the clients (individuals with an intellectual disability) as well as the staff. The results showed that half of the residents were using KWS, and a quarter of the clients were familiar with KWS and knew 10–50 sign words (Meuris et al., 2014). It was evident that the usage of KWS was enhancing communication between the clients and the staff within the residence. KWS is more common and more accessible to the public than the other forms of AAC.

4.5 Other factors that can contribute to enhancing communication for people with intellectual disability within institutions

Dalton and Sweeney (2011) emphasise that if institutions can recognise the methods that individuals with intellectual disability utilise to communicate, the services that they render can facilitate and support these individuals regardless of the level of their disability. Health care workers will have to position themselves on the level of the patients in order to communicate with them effectively and render a meaningful service. This can be achieved if the staff members are also equipped with appropriate skills which will allow them to communicate effectively with service users who cannot use verbal expressions (Healy & Noonman Walsh, 2007).

4.5.1 Health care professionals' interpersonal skills

Health care workers have to be actively involved in improving communication skills and making services more accessible and more beneficial for individuals with intellectual disabilities. A study conducted by Griffiths and Fedoroff (2014) revealed that people with severe and profound intellectual and multiple disabilities have a functional ability to engage in communication, and that they do this when they are attuned with their communication partner. This means that for effective conversation to occur health care workers have to be able to understand patients. This requires both skill in effective communication with people with intellectual disability as well as empathy from health care workers.

4.5.2 The interpersonal relationships that exist between the health care professionals and patients

Another aspect that is important in improving the quality of life of any individual is their interpersonal relationships. Schalock et al. (2002) argue that in residences or institutions where individuals with intellectual disability reside, interpersonal relationships existing between the staff members and the residents are a core aspect that enhances the quality of life of the patients. If good interpersonal relationships exist between the staff members and the patients, needs, preferences and wishes can be communicated more easily. There is a reciprocal relationship here: better relationship leads to better communication and vice-versa. This means that health care professionals should focus on building positive relationships with patients, especially within institutions. If a supporting environment is created within institutions, then there exists the will to succeed in bringing about better results, which includes improving the wellbeing of people with intellectual disabilities.

4.6 Facilitative communication for people with intellectual disability

Ziviani, Lennox, Allison, Lyons, and Del Mar (2004) conducted a study in Australia focusing on how communication can be improved within health care consultation. Results showed that involving a third person in consultation improved communication and brought forth positive results. However, from the people with intellectual disability's perspective, there were three issues they encountered. First, although they found a consultation with the third person beneficial they were frustrated at not being able to have the consultation alone with the doctor. Second, they were concerned about the doctor and the third person making decisions on their behalf, and in most cases addressing the patients in a manner that was age-inappropriate. Last, the patients were annoyed by the doctors not talking directly to them and not having eye contact with them, but rather with the third person.

4.7 The Intellectual Disability (ID)- Communicate model

ID- Communicate is an innovative, modular educational model that can be used in a variety of ways to educate health care professionals on how to communicate with patients with intellectual disability. The ID- Communicate model was designed to guide the content and formation of an education programme for health care providers (Primeau & Talley, 2019). The ID- Communicate model is divided into 10 distinct components or modules. Below the 10 modules will be discussed briefly.

4.7.1 Visit time/Reimbursement

The first module focus on rhythm and pacing. While dealing with patients with intellectual disability there should be extra time scheduled (at least double time). This will allow the health care worker to work appropriately with the patients as well as for billing purposes. The set of skills needed for this module is: Patience, cultural competence, innovative mind-set, listening skills, respect for differences, challenges of everyday life, and use of people's/patients' first language (Primeau & Talley, 2019).

4.7.2 Disability knowledge

This module aims to orientate the health care workers to use the strength perspective while dealing with the patients. There is a core belief which puts emphasis on the patients' possessing strengths that can be utilised to improve the quality of life of the patients. It encourages the health care workers to facilitate clients' self-discovery and usage of their inner strength. Using strength perspective is proven to be the most effective care based on the recognition and the use of individual strength and resiliency. It focuses on strength instead of the things that the clients cannot do. Further it focuses on common consultation issues and client communication. The Health Care workers do not have to treat patients with intellectual disability differently. They have to be treated and spoken to like their peers. They have need to be addressed based on their chronological age. The health care workers should ask them about their hobbies, interests and concerns. They should establish rapport with the patients and ask them about inclusion and isolation. The most important skill that is needed for this module is communication skills and listening skills. The health care workers should be able to communicate in some other ways with the clients who are unable to speak, this may include using signs, pictures, etc. The health care workers should also spend more time with the patients in order to understand their needs better (Primeau & Talley, 2019).

4.7.3 Clinician attitude

The third module focuses on the common issues of the patients as well as the common client complaints. Most health care workers are uncomfortable in working with people with intellectual disability. Thus they require training in order for them to change their negative attitude. Negative attitudes from health care workers to patients have a detrimental effect. Direct relationship with greater interaction leads to a more positive attitude. Interaction skills are deemed very important and people with intellectual disability have the same physiological, emotional, social and sexual needs as their peers. Health care workers should not assume that they understand the client's needs/desires. They should rather ask the patients about their needs and listen to them. They should speak directly to patients, not the caregiver or the family member. They should use demonstration as much as possible during the interaction, and repetition is crucial. The health care workers should avoid speaking too loudly or too slowly with exaggerated expression. And lastly, the health care workers should view care holistically and take a team approach while working with the patients (Primeau & Talley, 2019).

4.7.4 Environment

This module focuses on the facility and the importance of the facility layout. The facility has to be accessible to all patients since some of the patients might have physical issues. Consultation rooms should have enough space for family or caregiver/interpreter. The clinical atmosphere should be open and supportive from all staff. Signs and symbols within the facility should be utilised accordingly. Rooms should be clearly marked and there should be less distractions in the rooms (Primeau & Talley, 2019).

4.7.5 Provision of information

This module mainly focused on health literacy, age appropriateness, situational relevance, task teaching, confirmation of learning and clear communication techniques. Health care workers should assess the client's ability to understand, this includes patient-provider communication, drug labelling, medical instruction for compliance, informed consent and other relevant issues. The resources needed are also included in the module. The health care workers should focus on age appropriateness and situational relevance while providing information. Information can be provided through task teaching and confirmation of learning, which can involve breaking tasks into small steps as well as repetitions while dealing with the client. Skills needed are clear communication techniques which focus on the patient's specific needs, simplifying language (staying true to basic concepts), and plain language – using a logical organisation of the information and positive rather than negative words (Primeau & Talley, 2019).

4.7.6 Language

This module focuses on teaching the health care workers about plain language techniques, word meaning as well as people first language. The health care workers should use personal pronouns, active voice, action verbs and present tense. They should be direct, use short sentences and simple words. They should avoid unnecessary exceptions: keep the jargon, acronym and medical terms to the minimum. Carefully explain and repeat necessary technical terms: word meanings and keep words simple but do not change the concept. Patients are often very literal, choosing unambiguous words and vivid examples. The use of people first language involves putting clients first while speaking – put person first before disability when speaking or writing. Taking into account that disability is what they have, not what they are (Primeau & Talley, 2019).

4.7.7 Listening skills

This module focuses on client attitudes and confirmation of learning. The patients' attitudes may commonly include the following:

- They want people to like them and they will often say what they think you want to hear.
- They are experienced in not being understood and being ignored.
- They may shut-down if they believe providers not listening/interested.
- They may say they understand even if they do not understand because they want to be liked. (Primeau & Talley, 2019)

4.7.7.1 Verbal and non-verbal communication

Watch for signs from the patients that may indicate frustration or agitation; the more you interact with the patients, the easier it is to understand their speech; use the client's words and body language as a starting point of the conversation.

4.7.7.2 Confirmation of learning

It is important to review and take account of information from family and caregivers too. This is aimed at ensuring that the family and the caregivers understand the information given them. A quick role play may be effective way to elicit retain demonstration and to make sure they refer to the practical example given. (Primeau & Talley, 2019).

4.7.8 Verbal communication

The module focuses on speaking skills, active voice, age appropriateness, clarification and repetition. Health care workers should pay attention to all behaviours since these have potential for communicating all skills learned by the patients with intellectual disability. Patients often watch carefully to observe other persons' indication of emotions (anger, amusement, etc). Patients may mimic others' expressions if they do not understand what is being said, e.g., they might laugh when others laugh (Primeau & Talley, 2019).

4.7.8.1 Ways to communicate nonverbally

- Written
- Visuals
- Picture exchange
- Makaton programmes
- Sign language
- Facial expression
- Touch

- Gestures
- Postures
- Interpersonal spacing

Clinician expressions should avoid overt negative expressions, distaste habits and other involuntary actions. They should be animated as when speaking – clients pick up cues from facial expressions; use appropriate facial expressions.

4.7.9 Teaching/communication aids

This module focuses on health literacy, age appropriateness, situational relevance, task teaching, confirmation of learning and clear communication techniques, as well as the resources needed.

This programme is designed to help the health care professional improve their communication skills as well as learn new skills to be able to work with people with intellectual disability effectively.

4.7.9.1 General teaching strategies

- Find variety of ways to present information.
- Consider sensory needs, vision, hearing, smell and touch.
- Minimise distractions (visual, auditory, odours).
- Utilise common TV/cartoon characters, you-tube, videos, and songs.
- Focus on reactions to different media: repeat the use of favourite formats.
- Stress real life applicants.
- Activities should correspond with client’s skills.
- Provide small rewards appropriate to the client.
- Sequence tasks to offer progression of skills.
- Use Power Points – audio visual materials.

- Print and AV techniques.
- Layout should be clear.
- Readability and plain language.
- Communication aids.

4.7.9.2 Session length

- Teaching should be no longer than 5–10 minutes.
- Focus on 1–2 main points.
- Spend time on repetition and presenting materials in different ways.

While doing evaluation, do some short spot checks, quick questions; keep it informal and non-threatening (Primeau & Talley, 2019).

4.8 Deinstitutionalisation and its effects

Deinstitutionalisation of people with intellectual disabilities began decades ago worldwide. A primary reason for the deinstitutionalisation of people with intellectual disabilities was a changing political climate. Institutionalisation was seen as contributing to the perpetuation of further mental health problems for the residents (Nøttestad & Linaker, 1999). Studies carried out by TØssebro and Lundeby (2006) in Norway, to assess the mental health of people with intellectual disability, focussed on the use of psychiatric services before and after deinstitutionalisation. The results showed that deinstitutionalisation had not solved any problems related to the mental health care of people with intellectual disabilities. In some cases, the mental health problems were worse than before deinstitutionalisation and this might be due to the challenges of a limited access to health care that is experienced by the general population. Although the social models of disability tend to view specialist and segregated services within institutions as exclusion, it has become apparent that the physical presence of people with intellectual disabilities within the community does not guarantee greater social inclusion.

South Africa has also implemented the deinstitutionalisation process in different provinces across the country and this was mainly due to budget cuts in different departments. Janse van Rensburg, Khan, Fourie, & Bracke, (2019). One of the cases which caught the public attention was the deinstitutionalisation that took place in Gauteng and this has impacted many psychiatric patients. Van Rensburg, (2017). More than 1300 patients were transferred from Life Esidimeni care facilities and they were transferred to their families, NGOs and other hospitals. This resulted in a critical situation with multiple fatalities. Capri, Watermeyer, Mckenzie & Coetzee, (2018)

Many people with an intellectual disability not residing in institutions have caregivers assisting them on a daily basis. In most cases, these carers are responsible for assisting them in accessing health care services. Ali et al. (2008) conducted a study which focussed on carers of people with intellectual disability and how they experience accessing health care services. The results indicated that in spite of worldwide initiatives to improve access to health care for people with an intellectual disability, there are still barriers which hinder that access

There are a number of strategies and techniques that aim to enhance communication between health care workers and patients. However, there has to be commitment from the management and other health care professionals in ensuring that these skills are instilled to all health care workers working with people with intellectual disability (Bigby & Beadle-Brown, 2018). Communication can be challenging when language barriers exist, and this happens especially in countries where there is high language diversity. Services of a trained interpreter are always recommended whenever language barriers exist. However, if language barriers exist in an intellectual disability institution setting where communication barriers are already existent, the situation becomes complex. The following section will focus on the language barriers which exist within the health care system in South Africa.

4.9 Language diversity within the health care system in South Africa

As discussed in the previous section, communication is of primary importance within the health care system and within institutions providing care for people with intellectual disability. Hagan et al. (2013) argue that communication is the most important aspect of psychiatric treatment, or any other treatment within the health care system. Ulrey and Amason (2001) argue that effective communication is very beneficial within a range of industries including the health care industry. Effective communication is very important for the physical and mental wellbeing of patients. Communication involves the usage of language, gestures and symbols. If communication barriers exist, health care workers may be unable to conduct proper health reviews and screening, or discuss medication plans as well as adequately assess patients' health needs.

For effective communication to occur, verbal and non-verbal behaviour must be understood (Ulrey & Amason, 2001). However, for one to be able to understand non-verbal, and even verbal communication, one has to be well informed about the cultural context in which that communication occurs. According to Ulrey and Amason (2001), communication and language are inextricably linked. Their study revealed that health workers who knew more about the culture of the patients were able to communicate effectively with them and experienced less work-related stress (Ulrey & Amason, 2001), thus demonstrating the inseparable relationship between language, communication and culture. This relationship becomes complicated in a country where language and culture are diverse. Wherever cultural diversity and language diversity exist there is less progress within the consultation rooms. A study conducted by Mbanya, Terragni, Gele, Diaz, and Kumar (2019) in Norway showed that the Sub-Saharan African patients showed less interest in consultation with health care workers who have different cultural background. The reason might be that there are certain sicknesses or illnesses that are culturally related and could be understood better by a health care professional within the same culture.

According to Elkington and Talbot (2015), in South Africa, indigenous languages have been historically divided across the country. With 11 official languages existing in the country, and South Africa ranked as having the 18th highest level of linguistic diversity worldwide (Lewis et al., 2015), linguistic diversity impacts on how services are rendered.

The language diversity that exists in South Africa brings forth challenges to service-rendering within the health care system. Service users are unable to receive efficient services due to the language barriers that exist. The South African constitution obligates the government to make their services more accessible in terms of language. The National Patients' Rights charter states that every individual has the right to access to health care services and that such services should be offered in the language best understood by the patient (Health Professions Council of South Africa [HPCSA], 2008). This obligates public health care services to formulate and implement strategies that aim to eliminate language barriers that exist between health care workers and service users; however, in practice, this does not always happen (Swartz et al., 2014).

Levin's (2006) study, carried out in one of the hospitals in the Western Cape, revealed that despite the patients' choice to use their home language, only 6% of medical interviews were conducted in a language which the patient partly or fully understood. This is due to the fact that the health care system in South Africa is largely monolingual in a country which has high language diversity (Benjamin, Swartz, Hering, & Chiliza, 2016).

There are strategies that can be put in place to bridge the gap of language diversity. As mentioned previously, Robertson (2014) proposes that the services of interpreters be utilised when language barriers exist between the health care worker and the service user. However, formal posts for a professional interpreter to exist within a health care institution requires provision to cover the cost required, and, as such, these posts do not generally exist in South Africa (Hagan, Hunt, Kilian, Chiliza, & Swartz, 2020).

In many South African hospitals, informal interpreters are used, including cleaners, security guards and other staff members at the hospital. A study carried out by Kilian et al. (2010), in one of the psychiatric hospitals in the Western Cape, revealed that most untrained interpreters demonstrated difficulties in translating psychiatric words. Thus, informal interpreters who are not trained may give inaccurate information to the health care workers which, in turn, might lead to incorrect diagnoses (Penn & Watermeyer, 2012). Kilian, Swartz, and Chiliza (2015) emphasise the importance of equipping interpreters with interpreting skills to render effective services within the health care services, a view which is borne out by other studies (Kilian, Hunt, Swartz, Benjamin, & Chiliza, in press).

4.9.1 The challenges that exist in a triadic relationship

4.9.1.1 Conduit and utilitarian models of interpreting

In many health care settings interpreters are seen as instruments which are there to translate the messages without influencing the content and dynamics of the provider-patient communication (Hseih & Kramer, 2012). The interpreters thus become conduits, following the conduit ideology as set out in the conduit model. In the conduit model interpreters are expected to be neutral, faithful, and passive while serving. The process of interpretation is seen as a simple one-to-one machine-like process. Tension can arise between health care provider and the interpreter if the provider suspects that the interpreter is not following the ethical standards set. The conduit model also reflects the utilitarian model in the way in which the interpreter is viewed in the process. The utilitarian model views the interpreter's role and function in the following way: (a) Existing within a hierarchical structure with unidirectional communication; (b) The interpreter is seen as an information gatekeeper; (c) The interpreter is seen as a proxy; and (d) The interpreter's emotional support is perceived as a tool. The conduit model limits interpreter's power by objectifying interpreters as language-transferring machines, a restricted role that silences the interpreter's voice.

Within the South African context, where language, cultural and communication barriers exist in the health care system, the use of an interpreter is often necessary to ensure the successful outcome of service provider-service user consultations. Kilian et al. (2010) propose that the competency levels of interpreters must be sufficient to ensure that optimal mental health care services are delivered, thus emphasising that the training of interpreters is of vital importance. Interpreters are required to be competent in strategies which eliminate both language and communication barriers. The health care system uses specific terminologies, and interpreters must be familiar with these terms.

The literature reviewed above suggests that utilising trained interpreters within the health care system can facilitate positive outcomes in service provider-service user interactions. The literature review has also revealed that there are strategies or methods that can be utilised by both the interpreter and the health care professional to ensure this positive outcome. Steps must be taken to ensure that the health care workers are trained and well equipped with skills and knowledge on how to work with people with, for example, intellectual disability. The trained interpreters should also be well aware of the privacy and confidentiality of the patient's information.

Given the importance of communication and language issues within the health care system, it is also necessary that evaluations are carried out continuously to ensure that these strategies implemented to eliminate language barriers and to enhance communication are effective. The current study therefore sought to explore the strategies that are being utilised to eliminate barriers and enhance communication at the Alexandra Hospital. In order to achieve this, institutional observation took place and semi-structured interviews were conducted with the health care workers and health care professionals. These were built around an institutional ethnographic framework, together with an interpretative thematic method of analysis, which is the subject of the next chapter.

Chapter 5

Methods and data collection

5.1 Research design

This study is qualitative in nature. The qualitative research method starts with the research question which needs to be answered, then progresses to collecting verbal or observed data from a small number of participants. Qualitative research methods allow a researcher to investigate attitude and feelings and to gain insight on a particular topic or phenomenon.

Case study research is a particular form of qualitative research and it aims to bring about a thick description of a contemporary phenomenon or detailed observational evidence (Yin, 2014). This study employs a case study research method and this will facilitate an in-depth inquiry into the strategies which are utilised at Alexandra Hospital to eliminate language barriers and enhance communication. This method will allow a deep exploration of the views and perceptions of health care workers at the hospital, the challenges they experience and observed barriers that exist. Yin (2014) describes the core of the case study as follows:

> The essence of a case study, the central tendency among all types of case studies, is that it tries to illuminate decisions or a set of decisions that were taken, why they were taken, how they were implemented, and with what results. (Yin, 2014, p. 15).

Further, a case study aims to carry out an in-depth investigation into the existing phenomenon in its real-world context. This is necessary since the phenomenon cannot be separated from the context. This case study will take the form of an institutional ethnography aiming to bring an in-depth understanding of the functioning of the institution.

5.1.1. Institutional ethnography

According to Smith (2003), in an institutional ethnography, the investigator takes part in the work that is done in a particular setting and aims to take note of the recognised and non-recognised activities that take place in an institution. The analysis of institutional ethnography also focuses on how the people in the context do the activities that they do, and why they are drawn to doing the activities that they do. Institutional ethnography does not focus on the activities that are done by individuals in isolation. It focuses on the activities and behaviour of individuals within the institutions as well as how they carry out everyday professional practices (Smith, 2005). Observation forms the core of institutional ethnography; it allows for the broader social organisations and relations to be explored (Rankin & Campbell, 2009). This will ultimately give a clear picture of how people's activities are connected within the institution. This study focuses on observing different activities that are done by different individuals within the institution, aiming to eliminating language barriers. The activities that take place within the institution will be explored, and in a second stage, individuals who are involved in these activities will be interviewed using a semi-structured interview.

Further, the institutional ethnography focuses on textual and discursive dimensions of social life, and the study of "texts-in-use" as a means of understanding social connections (Eastwood & DeVault, 2001). The text can, for example, be medical charts, enrollment reports or strategic plans (Smith, 2005). The focus of analysing texts and documents helps to examine the institution as a whole and their form of practice. This study will also focus on studying the policy documents that are available at the hospital which aim to eliminate language barriers and enhance communication within the institution. Policy analysis will also track whether the policies which are formulated are being implemented or not.

5.2. The research settings

As mentioned above, Alexandra Hospital is a specialist mental health care facility offering treatment and rehabilitation for adults, adolescents and children with complex mental health needs and intellectual disability. Alexandra Hospital has a trained community interpreter from the interpreter project, as mentioned earlier. Due to the complexity of the nature of the patient system at Alexandra Hospital the interpreter has adopted certain strategies which aim to enhance communication at the hospital.

In preparation for this study, I visited Alexandra Hospital several times and a conducted an interview with the interpreter. The interpreter at Alexandra Hospital is multilingual; he is able to interpret English, Afrikaans and Xhosa. He is involved in the interpreting duties on a daily basis with the health care workers and the patients. He facilitates activities at the hospital to enhance communication with the patients. For example, he teaches the residents simple basic signs which help them to communicate effectively. On Thursdays, he works with the outpatients who come to receive medication from the hospital. During that day he engages with both the patients and their carers ensuring that they have a clear understanding of their prescription. On a daily basis, the interpreter is involved in a day-care programme for an hour, where he interacts with outpatients who come in every weekday from 8am until 4pm. During these hours the interpreter communicates with the patients and he teaches them signs or symbols which enhance their communication skills. On some occasions, the interpreter does home visits with the Social Worker and he interprets where there is a need.

During the study, I accompanied the interpreter for a month with the aim of observing his daily activities at the hospital. Further, I conducted semi-structured interviews with other health care workers who are working together with the interpreter to implement strategies to eliminate language barriers and enhance communication.

5.3. Data collection

5.3.1 Procedures

This study took place in three phases. Phase 1 – Study of archival data: Policy analysis; Phase 2 – Observation of practices; Phase 3 – Semi-structured interviews: Reflections of participants on practice.

5.3.1.1 Phase 1 – Study of archival data: Policy analysis

A qualitative analysis of the relevant policy documents was carried out. Policies were analysed following the recommendations that were given by Walt et al. (2008), who argue that policy analysis should be done in a systematic way This included documents which were strategically formulated with the aim of eliminating language barriers that exist at the hospital, specifically documents that give a broad overview of the language issues and communication barriers within the hospital. These documents were systematically analysed which has helped to identify the gaps and the need for language and communication policies to be formulated.

5.3.1.2 Phase 2 – Observation of practices

Firstly, observation of the daily activities that the interpreter is involved in on a daily basis took place. During the observation, more in-depth information was gathered from the interpreter's point of view. The researcher engaged with the interpreter and asked questions related to the activities that he does at the hospital. Observation has revealed the strategies that are utilised to eliminate language barriers at the hospital, and it has also helped the researcher to identify the staff members who are involved in implementing these strategies. A research journal was kept during this phase and supervision from Prof Swartz was received on a weekly basis; during this time the journal was discussed.

5.3.1.3 Phase 3 – Semi-structured interviews: Reflections for participants on practice

Participants who were interviewed were staff members from the hospital who were implementing the strategies which aim to eliminate language barriers and enhance communication. These participants included the hospital Chief Executive Officer, the head of clinical services, the head of the psychology department, the head of occupational therapy, the head of physiotherapy, the head of nursing and two nursing staff.

5.3.2 Measures/instruments

5.3.2.1 Semi-structured interviews

According to Bless, Higson-Smith, and Sithole (2013), semi-structured interviews aim to bring clarity to the concepts and problems in question. They allow a list of possible answers or solutions. During the semi-structured interviews, the researcher was in direct contact with the participants and facilitated answers from the participants' point of view. The same starter questions were used during the study to ensure reliability across interviews (see Appendix B).

5.4. Data analysis

5.4.1 Phase 1 – Archival data: Policy analysis

Policy analysis followed the recommendations that were given by Walt et al. (2008), who argue that policy analysis should be done in a systematic way. The policies around language issues in Alexandra Hospital were systematically analysed using a network framework. Network analysis reflects a phenomenon of shared decision making as well as shared resources. Utilising the network framework allowed for the identification of individuals or groups required to take action and make the policy a success. The policy analysis provided a background to explore actual practices

5.4.2 Phase 2 – Observation of practice

Sequential or interim analysis was utilised to analyse data collected through observation. According to Pope, Ziebland, and Mays (2000), sequential or interim analysis has an advantage of allowing the researcher to go back and refine the research question and follow other emerging aspects of the study which lead to a more in-depth analysis. The data collected during observation was analysed and provision was made for further avenues of the study to be explored.

5.4.3 Phase 3 – Semi-structured interviews

All the data collected during the semi-structured interviews were transcribed, the data were coded into ATLAS.ti (v.7). ATLAS.ti is a qualitative data analysis software which helps to organise and examine the participants' responses. The software assists with systematic coding of data. The coded data were then analysed using thematic analysis.

5.4.3.1 Thematic analysis

Themes that emerged during the interviews were analysed. According to Braun, Clarke, and Terry (2015), thematic analysis is a method which aims to identify, analyse and interpret meanings of themes that emerge from qualitative data. After identifying the themes that emerge from the data collected, the content of the themes was analysed and defined. This has further helped to refine and focus the data collected.

5.5. Ethical considerations

For the observation phase (Phase 2), not all participants were able to give consent or assent to participate in the study (See Appendix A). Regarding this issue, an expert in the field of intellectual disability was consulted and I have followed the recommendation of Capri and Coetzee (2012) regarding the rights of patients with intellectual disability to participate in research. Ethical approval from Stellenbosch University, the Provincial Department of Health

(Western Cape) and Alexandra Hospital management granted consent by proxy to the researcher to observe patients and staff at the hospital. Please see Appendix C for a copy of the ethics approval letter.

For the semi-structured interview, the interviewer followed the interviewing procedure regarding ethical issues. Firstly, she introduced herself to the participants and then explained the aim of the study. Each participant gave consent for their participation, and the interviewer assured the participants about confidentiality before the interview. The interviewer also informed the participants of their right to withdraw from the study if they felt uncomfortable about the questions during the interview. The interviewer explained to the participants about anonymity and she ensured participants that no names would be mentioned on the report, but that their roles or positions at the institution would be mentioned. The interviewer also assured the participants that no harm would be done to them. After consent was obtained a semi-structured interview was conducted with the participants.

Lastly, consent is an on-going process and the researcher ensured that the study was conducted in a reflective way where questions from the participants were welcomed and transparency was kept. After an internal review by the Departmental Ethics Screening Committee (DESC) of the Psychology department, a research proposal was submitted to the Stellenbosch University Research Ethics Committee (REC) for full ethical review. Permission to commence with data collection was granted on the 04 September 2016: Number –SU-HSD- 002888

Chapter 6

Data analysis

6.1 Introduction

6.1.1 Phase 1: Policy analysis

Alexandra Hospital does not have institution-specific policies on language and communication which guide their service delivery. They use the standard policies and laws that the national government has adopted to guide and improve service delivery in South Africa. These policies and laws are aimed at improving access to health care services as well as to protect, respect, promote and fulfil the rights of citizens. The laws and polices below with be discussed:

- The Constitution of the Republic of South Africa
- The Batho Pele Principles
- The Patients' Rights Charter
- The National Health Act

Primarily Section 9 of the Constitution guides how services are rendered. The White Paper on transforming public services (Batho Pele Principles) and the National Health Charter are the other key documents that guide service delivery at Alexandra hospital. Below, I will firstly discuss relevant sections of the Constitution that addresses language issues and communication. Secondly, I will discuss the White Paper for transforming public services (Batho Pele) principles. And lastly, I will discuss the Patients' Right Charter as well as the National Health Act.

6.1.1.1 The Constitution of the Republic of South Africa

The Constitution of 1996 stipulates that public service “must be governed by the democratic values and principles enshrined in the Constitution”, including the following principles:

> a. A high standard of professional ethics must be promoted and maintained.
>
> b. Efficient, economic and effective use of resources must be promoted.
>
> c. Public administration must be development-oriented.
>
> d. Services must be provided impartially, fairly, equitably and without bias.
>
> e. People’s needs must be responded to, and the public must be encouraged to participate in policy-making.
>
> f. Public administration must be accountable.
>
> g. Transparency must be fostered by providing the public with timely, accessible and accurate information.
>
> h. Good human resource management and career development practices, to maximise human potential, must be cultivated.
>
> i. Public administration must be broadly representative of the South African people, with employment and personnel management practices based on ability, objectivity, fairness, and the need to redress the imbalances of the past to achieve broad representation.
>
> (Republic of South Africa, 1996a)

6.1.1.1.1 The Bill of Rights

The Bill of Rights, states that: "Everyone has the right to have access to a. health care services" (Republic of South Africa, 1996b, Section 27). This means that everyone has a right to access equal and fair services within the country. According to the Constitution (Act 108 of 1996) (Republic of South Africa, 1996a), South Africa has 11 official languages, with each language having an equal standing in the eyes of the law. This means that everyone has a right to be get medical attention or medical help in their own language. Furthermore, the Constitution states that: "recognising the historically diminished use and status of the indigenous languages of our people, the state must take practical and positive measures to elevate the status and advance the use of these languages" (Republic of South Africa, 1996c, Section 6.2). The Bill of Rights, which is outlined in Chapter Two of the Constitution, describes two related set of rights, namely civil and political rights. Political rights refer to rights of freedom, economic and social rights. To put it simply, civil and political rights refer to equality and human dignity, while economic and social rights refer to human needs in our daily existence such as education, health, housing, justice and social security. Section 9 of the Constitution expressly prohibits the state and private parties from discriminating unfairly, directly or indirectly, on a number of grounds including race, language, culture and ethnic or social origin. This means that all government/public entities have to ensure that they uphold the rights of the citizen by providing services in an equitable manner, thus language barriers must be eliminated.

6.1.1.2 Batho Pele Principles

The Batho Pele White Paper on transforming public services (Republic of South Africa, 1997) was adopted by the government to commit to extending services to citizens of South Africa. The main aim of these principles is to ensure that public services are more citizen-orientated and to help encourage the culture of efficient, effective and friendly public services. These principles are directed to all public workers who render services to the public. All government departments and all government entities are governed by these principles. They have to work from what is termed the "people first" perspective ensuring that they put a smile onto the customer's face. The present state of public management aims to shift away from passive and top-down public services to a strong, responsible public service that prioritises accepting responsibility for the success and prosperity of the people that they render services to. The Batho Pele White Paper aims to transform all the public entities to lead from the front and to be more orientated towards citizens' needs.

There are eight Batho Pele principles which guide service delivery within the public sector, namely: consultation, service standard, access, courtesy, information, openness and transparency, redress and value for money.

6.1.1.2.1 Consultation

"Citizens should be consulted about the level and quality of the public services they receive and, wherever possible, should be given a choice about the services that are offered" (Republic of South Africa, 1997, p. 7).

6.1.1.2.2 Service standard

"Citizens should be told what level and quality of public services they will receive so that they are aware of what to expect" (Republic of South Africa, 1997, p. 7).

6.1.1.2.3 Access

"All citizens should have equal access to the services to which they are entitled" (Republic of South Africa, 1997, p. 7).

6.1.1.2.4 Courtesy

"Citizens should be treated with courtesy and consideration. This means that the citizen has to be treated in a polite manner and with a good attitude" (Republic of South Africa, 1997, p. 7).

6.1.1.2.5 Information

"Citizens should be given full, accurate information about the public services they are entitled to receive" (Republic of South Africa, 1997, p. 8).

6.1.1.2.6 Openness and transparency

"Citizens should be told how national and provincial departments are run, how much they cost, and who is in charge" (Republic of South Africa, 1997, p. 8).

6.1.1.2.7 Redress

"If the promised standard of service is not delivered, citizens should be offered an apology, a full explanation and a speedy and effective remedy; and when the complaints are made, citizens should receive a sympathetic, positive response" (Republic of South Africa, 1997, p. 8)

6.1.1.2.8 Value for money

"Public services should be provided economically and efficiently in order to give citizens the best possible value for money" (Republic of South Africa, 1997, p. 8).

6.1.1.3 The Patient's Rights Charter

The main purpose of this document is to ensure that right of access to health care services is guaranteed to all citizens and it guides good practice to all professionals. This document also covers the rights as well as responsibilities of patients. Below I will focus on the rights of the patients.

6.1.1.3.1 Patients' rights

6.1.1.3.1.1 Health and safe environment

"Everyone has a right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal, as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection" (National Department of Health, 1996, para. 3).

6.1.1.3.1.2 Participation in decision making

"Every citizen has the right to participate in the development of health policies, and everyone has the right to participate in decision-making on matters affecting one's own health" (National Department of Health, 1996, para. 4).

6.1.1.3.1.3 Access to health care

"Everyone has the right to access to health care services that include:

i. receiving timely emergency care at any health care facility that is open, regardless of one's ability to pay;

ii treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;

iii provision for special needs in the case of new born infants, children, pregnant women, the aged, disabled persons, patients in pain, persons living with HIV or AIDS patients;

iv. counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS;

v. palliative care that is affordable and effective in cases of incurable or terminal illness;

vi. positive disposition displayed by health care providers that demonstrates courtesy, human dignity, patience, empathy and tolerance;

vii. health information that includes information on the availability of health services and how best to use such services, and such information shall be in the language understood by the patient" (National Department of Health, 1996, para. 5).

6.1.1.3.1.4 Knowledge of one's health insurance/medical aid

"A member of a health insurance or medical aid scheme is entitled to information about that health insurance or medical aid scheme and to challenge, where necessary, the decision of such health insurance or medical aid scheme relating to the member" (National Department of Health, 1996, para. 6).

6.1.1.3.1.5 Choice of health services

"Everyone has a right to choose a particular health care provider for services or a particular health facility for treatment, provided that such choice shall not be contrary to the ethical standards applicable to such health care provider or facility" (National Department of Health, 1996, para. 7).

6.1.1.3.1.6 Be treated by a named health care provider

"Everyone has a right to know the person that is providing health care and, therefore, must be attended to by only clearly identified health care providers" (National Department of Health, 1996, para. 8).

6.1.1.3.1.7 Confidentiality and privacy

"Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or any order of court" (National Department of Health, 1996, para. 9).

6.1.1.3.1.8 Informed consent

"Everyone has a right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and risks associated therewith and the costs involved" (National Department of Health, 1996, para. 10).

6.1.1.3.1.9 Refusal of treatment

"A person may refuse treatment and such refusal shall be verbal or in writing, provided that such refusal does not endanger the health of others" (National Department of Health, 1996, para. 11).

6.1.1.3.1.10 A second opinion

"Everyone has the right on request to be referred for a second opinion to a health provider of one's choice" (National Department of Health, 1996, para. 12).

6.1.1.3.1.11 Continuity of care

"No one shall be abandoned by a health care professional who or a health facility which initially took responsibility for one's health without appropriate referral or hand-over" (National Department of Health, 1996, para. 13).

6.1.1.3.1.12 Complaints about health service

"Everyone has the right to complain about health care services, to have such complaints investigated and to receive a full response on such investigation" (National Department of Health, 1996, para. 14).

6.1.1.4 The National Health Care Act

The National Health Care Act is regarded as the most important source of the health services rights apart from the Constitution itself. It is the only document/law that can be enforced directly. The National Health Care Act emphasises a change of mind-set regarding viewing the people utilising the health care system as passive recipients who do not have a choice nor a voice. The Act refers to people utilising the health care system as health care users rather than patients and they are viewed as people who are entitled to a certain standard of care and respect.

The National Health Care Act 61 of 2003 (Republic of South Africa, 2004) states that a user has the right to be informed by a health care provider, in a language and a manner that they understand, of the following:

- Their health status;
- The range of diagnostic procedures and treatment options generally available to them;
- The benefits, risks, costs and consequences of each option; and
- The right to refuse health care services and implications of refusing.

The National Health Care Act also places emphasis of privacy and confidentiality of the user within the health care system. According to the National Health Care Act 61 of 2003 (Republic of South Africa, 2004), the health care professional who has access to the health records of a user may only disclose this personal information to another person without the user’s consent if the disclosure is:

- For legitimate purposes;
- In the ordinary course and scope of the health care worker’s duties; and
- In the user’s interests.

The National Health Care Act covers all rights of citizens with regards to access to health care and it directly enforces the Constitution. It is a national Act, hence all public and private facilities are guided by this Act.

6.1.1.5 Western Cape Government

In the Western Cape there are three main languages that dominate in the province, namely English, Afrikaans and isiXhosa – these are the three official languages in the province. The Western Cape Government is committed to ensure that these three languages are equally promoted within the province and there is a language committee which is responsible for formulating language policies within the province. “The Western Cape Language Policy is a first of its kind in South Africa. The aim of the policy is to ensure the equal status and use of the three official provincial languages, Afrikaans, English and isiXhosa. It also supports and promotes South African Sign Language, marginalised languages and the other official South African languages. The policy is available in English, Afrikaans and isiXhosa” (Western Cape Government, 2020, para. 1). The Western Cape is the first province to formulate a language policy which aims to equally promote languages which are dominant in the province. The policies are in line with the constitution, Western Cape Language Act of 1998, the Pan African Language Board Act, the National Language Policy Framework and the Batho Pele principles.

The purpose and the goals of the language policy are to encourage and advance the use of all three languages which are dominant in the Western Cape, as well as to promote the spirit of caring within the province in becoming a multilingual province. This also promotes the Batho Pele principles which lead to services being more accessible to citizens. This fosters social cohesion within the province and shows acceptance of language diversity in the province. This policy also recognises the need for interpreters as well as the use of sign language. The aim is to promote accessibility of services by eliminating communication and language barriers. Hence, all documents, whether electronic or written, should be in all three languages. Translators are being utilised to ensure that all documents are in these three languages. The policy also indicates that citizens can use any of the three languages in any local or provincial institution within the province and interpreters should be utilised if needs be.

6.1.1.6 The hospital

Alexandra Hospital is in the Western Cape and the majority of the patients in the wards speak the main three languages which are dominant in the Western Cape (English, Afrikaans and IsiXhosa). Hence, it is important that the services rendered should be accessible in these three languages. Alexandra Hospital does not have specified language policies but management is committed to language access through three main strategies:

6.1.1.6.1 Language courses

Since the early 2000s, the hospital has utilised different strategies to assist staff members in communicating more effectively with patients. Firstly, there is a language course that is available for the health care workers who are unable to speak the three languages which are dominant amongst the patients. Most of the health care workers are bilingual, either speaking English and Afrikaans fluently or speaking English and Xhosa fluently. For the English/Afrikaans speaking health care workers there are Xhosa language classes which are made available to them. And for the English/Xhosa there are Afrikaans language classes available for them as well. This is aimed at eliminating the language barriers that might exist between the health care workers and the patients.

6.1.1.6.2 Language interpreter

The hospital makes extensive use of the interpreter provided to them by the project mentioned in Chapter One. The interpreter is based at the hospital and assists with interpreting when there is a need. Sipho (who has indicated to me that he wishes to be known by his name and not by a pseudonym in this thesis) is the interpreter at the Alexandra

Hospital, and the services that he renders are made available to all the health care workers at the hospital.

6.1.1.6.3 Application of the Batho Pele principles

The Batho Pele principles, which aim to transform service delivery within the public sector, place emphasis on language and communication. The way in which these principles are engaged with at Alexandra Hospital is discussed below.

Consultation requires two-way communication, which is impeded by language barriers. At Alexandra Hospital, the appointment of an interpreter, Sipho[1], has gone some way in the attempt to overcome these barriers, ensuring that consultation between the health care workers and the patients is effective. Sipho is a trained[2] community interpreter who is also trained to use simple sign language, which assists the patients who have verbal deficits. Where patients are not intellectually equipped to engage in communication with health care workers, their caretakers are consulted and decisions are made on their behalf. Sipho plays a vital role in this communication between health care workers and the caretakers. Linguistic barriers within the health care system might lead to misdiagnosis and the administration of incorrect medication, placing the patient at risk. With the clarity of communication facilitated by a trained interpreter, this potential risk is addressed.

The second Batho Pele principle focuses on the standard of service delivery. The patient is entitled to communicate dissatisfaction with health care services received, and health care workers are required to address these issues. In the context of linguistic barriers, this process is impeded. At Alexandra Hospital the interpreter manages the Client Satisfaction Survey which gives patients an opportunity to voice their complaints and discuss issues of concern

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[1] Sipho has chosen that I use his real first name for this study.

2 Sipho was trained through the collaboration with Stellenbosch University, discussed earlier in this thesis. The training was short, and would not count as a full professional training by Global North standards.

regarding the services they receive at the hospital. The interpreter is multilingual which allows for the patients voicing their complaints in their own language.

One of the principles involves the dissemination of information, such as where to report unfair treatment and what services are available. For this to happen communication between public workers and citizens must be effective. This information should be available in a language which is understood by the citizen and requires that public workers are fully aware of the languages understood by the citizen. In South African all 11 official languages are regarded as being of equal importance, and thus should be communicated accordingly. At Alexandra Hospital, the language courses that are offered ensure that the health care workers are able to provide information to patients in their own language. In addition, the interpreter plays a vital role in ensuring that patients understand the information given to them.

Courtesy, as one of the principles, addresses the care, respect and consideration of patients by health care workers. Addressing patients in a language that they understand is an important aspect of this principle. Alexandra Hospital's interpreter fulfils the requirements of this principle by offering the care, respect and consideration which comes with being addressed in a language that one understands. That the interpreter communicates in sign language further fulfils this principle.

Patients and their caregivers should be kept informed regarding the level of health care they are going to receive and when referrals are necessary. At Alexandra hospital, most of the patients are not able to understand or conceptualise the information given to them. However, this does not mean that the caregivers or family members should not be informed about the level of care the patient will receive. These caregivers should also be addressed in the language that they will understand, hence where language barriers exist an interpreter at the hospital should be utilised. In the Western Cape there are three languages which are dominant and the Western Cape government is committed to promote all three languages equally. At Alexandra Hospital the majority of the patients speak Afrikaans, English and Xhosa. The health care workers at the hospital also speak the three languages and there are language courses offered at the hospital to ensure that the health care workers are well equipped to make the services accessible to the patient. The interpreter is also available at the hospital to ensure language barriers are eliminated if they exist.

6.1.2 Phase 2: Observational data analysis

For 30 days, I accompanied Sipho (the interpreter) to observe his daily duties and activities at the hospital. I observed all the interactions that he made with different individuals on a daily basis. From the observations I discovered that there were a lot of activities that he was involved in at the hospital. I was also part of some activities during the observation. Due to limited space not all the data collected during observation will be presented. I have chosen to present much of the data as a narrative in order to give a sense of the story of the everyday work of the interpreter in context.

6.1.2.1 The relationship that the interpreter has with the patients

6.1.2.1.1 Inpatients

As I accompanied Sipho during ward visits daily, I was able to observe interactions that Sipho had with the patients. The patients seemed to have built a very good relationship with Sipho and they engaged with him in a very good manner. Most of the patients we met outside different wards greeted Sipho with a smile and some of them even shook hands with him. They all seemed pleased to see him. Some of the patients communicated confidential issues with Sipho. For example, as we were walking past one of the wards, one of the male patients approached Sipho and he told him that he was looking forward to going home during Christmas holidays. He further explained to him what the doctors told him regarding his condition. From the way the patients looked up to Sipho it was clear that the patients trusted him. In return, Sipho communicated with the patients very well. Even the patients who are unable to communicate verbally were able to use gesture and rudimentary sign language with Sipho and they had what seemed to be productive conversations.

In general, patients seemed very happy when they saw Sipho walking around different wards. The patients who had verbal difficulties were also able to express themselves in a way that showed they were excited to see him. Some of the patients showed their excitement by smiling and clapping their hands. Sipho was also able to engage with the patients with verbal deficits. One afternoon, as we were walking past one of the wards, one elderly woman who has verbal deficits came to Sipho and she communicated with him using signs. Sipho responded to the woman and they had what seemed to be an effective conversation, with back and forth communication. Later Sipho explained to me that the woman collects magazines and she loves reading. He told me that he used to collect magazines to give to her on a weekly basis, but he could not do it anymore because of high demand from the patients.

The fact that Sipho is multilingual has helped him to build strong and meaningful relationships with different patients. All the patients that we met were communicating with him in their home language. Sipho can speak the three different languages (English, Afrikaans and isiXhosa) that are dominant amongst patients at the hospital. The patients communicated with Sipho with a great deal of confidence. Their trust in him seemed evident from their discussing what could be viewed as personal and confidential issues with him. For example, one of the male patients, as we were walking from ward 7, came to him and he started venting out to him in Afrikaans. He looked so disturbed and from the look you could tell that he was not happy about the issue that he was discussing with Sipho.

Sipho seemed to be seen as the person to whom the patients expressed frustrations about the institution, and they raised their personal concerns with him. For example, one patient approached Sipho as we were walking, and he told him that he is tired of being at the hospital. He told Sipho that he misses home, and he wants to go home. Though Sipho was not able to solve most of the issues, he listened attentively. He was clear with the patients with regards to the limits and boundaries of his role. The fact that he would get back to patients after having taken their concerns to hospital staff seemed to be much appreciated by patients. Sipho's effective communication skills played a huge role in helping him build a strong relationship with the different patients in different wards.

Some of the patients were inquiring with regards to the activities that are supposed to take place at the hospital. Sipho is actively involved in organising the activities as well as the outings that take place. For example, one of the female patients came to Sipho and asked him about the trip to the beach which takes place each and every year during summer. Sipho was able to talk to the patient and explain to her that they are still in the process of arranging transport as well as finalising the dates. Further he told the patient about the sports day/culture day which was going to take place in few days. The patient looked excited about the event and she asked questions about the food and goodies. It was clear that the patients relied on Sipho for such information. They looked free and relaxed while they were interacting with him; they also looked relieved after he gave them answers to their questions.

6.1.2.1.2 The relationship that the interpreter has with his colleagues

On a daily basis, Sipho has administrative work that he has to do. He is part of the quality assurance team and he is responsible for keeping a record of the incidents that happen at the hospital. He routinely collects the incident forms from different wards and he makes sure that he keeps clear records of them on the computer. He is also involved in the investigation of any untoward incidents which may take place at the hospital, forwarding any complaints as he sees appropriate to relevant professionals such as doctors, social workers, psychologists and occupational therapists. Sipho is the first person that get to see different incidents reports that take place at the hospital and he is also responsible for analysing the incidents and requests for more information from relevant parties if there is a need. He has to capture incidents accurately and ensure that he does not omit or add information to the incident.

For example, one morning he received a report of an incident that took place on one of the wards. The report was not clear as to what exactly happened on the evening. The health care worker only wrote that a fight took place between two patients and one patient was slightly injured. There was not enough information for him to capture the incident and the information on the report did not give him enough details to analyse and refer the incident to a relevant professional. Sipho had to call the ward manager and ask for more information on the incident. The ward manager was unable to help since she was off duty when the incident occurred. Sipho had to wait for the health care workers who were on duty during the time when the incident took place. He managed to contact the health care worker who was on duty and she further elaborated on what had happened on that day.

Sipho explained to me that he is usually frustrated by his duty of capturing incidents since in most cases he only gets one side of the story. Most especially if the incident involves a health care worker and the patients. He explained that the health care workers always write their own version of the incident on the report and in most cases the patient’s version of the incident is not considered or recorded. Most of the patients who are involved in the incidents are deemed as cognitively unable to express their views or version of the incident. Sipho also mentioned that most of the incidents are not being reported, especially the ones that involve patients who are unable to communicate verbally. He said the health care workers only report when they see that the outcome of the incident will be noticed by the next person or the ward manager. He told me that in most cases he can see that some of the patients are hurt while doing his daily ward visits and if he asks about it they will say the patient hurt himself/herself.

Interestingly enough, most of Sipho's colleagues do not see him as an interpreter, and they all see his work as far broader that what would generally be understood to be the work of an interpreter. It was notable that his colleagues often asked Sipho, rather than anyone else, about events and changes occurring within the hospital. Sipho works from the administration building and many colleagues will ask him about issues concerning management and administration. He is also a very active member of different committees that exist within the hospital. He is a source of information for many of his colleagues and they rely on him to get updates on new developments as well as updates on current issues. Sipho is also well informed about the events and issues that takes place at the hospital. He is very involved with the current affairs and events that take place at the hospital. In most cases Sipho usually refers his colleagues to relevant parties who will assist them with whatever they need.

For example, on a number of occasions, the nurses in different wards asked Sipho about the outcome of a recent administration meeting which they did not attend; they also learned from Sipho what the actions were that needed to be taken after the meeting. Informally, and probably partly as a result of his communication skills, his commitment, and his personality, Sipho seems to have developed a depth of involvement with many forms of communication at the hospital – and not just the question of how staff communicate with patients. It seemed to be Sipho rather than other staff, for example, who was seen as the source of up to date information about upcoming events and other issues affecting the hospital. Within quite a short time, it appears that this broader communication role seems to have been entrenched in his life and he has now developed interest in the current affairs that affect the hospital.

Sipho is also trusted by new staff members for information regarding their documents or contracts. They rely on him for information and the old staff members also refer new staff members to Sipho for assistance. For example, one morning two of the new staff members were sent to him by the older staff to ask about the documents that they need to submit in order for their medical aid to be activated. Sipho was able to give them information as well as to refer them to the right person who was going to assist them further.

6.1.2.1.3 The Quality Assurance Survey process

During the time that I was accompanying Sipho, the Quality Assurance Manager tasked Sipho with assisting with the Client Satisfaction Survey. This survey was a quality assurance requirement for the hospital and the requirement to complete such surveys is an instruction from the provincial health department to all hospitals in the province. Sipho was entrusted with this administrative task that will require a lot of hours to complete. This showed that the manager knew that Sipho is very good with the patients and he is multilingual too. The Quality Assurance Manager instructed Sipho to conduct the survey in all the wards and then later compile a report. I accompanied Sipho and as part of my participant observation, I assisted Sipho in conducting the survey interviews with Sipho in all the wards. Four wards out of the 13 at Alexandra are wards with frail patients and these were viewed as not appropriate for the survey. Before conducting the survey, we visited all the remaining nine wards and we requested lists of potential participants – patients who could give us feedback on how they experienced the hospital services. In most of the wards, the nurses seemed sceptical about the survey and nominating potential participants. They told us that we would not be able to get information from most of the patients, in other words they were telling us that the patients do not have cognitive abilities to participate in the survey. They described most of the patients as uncontrollable and destructive. Regardless of how they were describing the patients, Sipho requested a list from the health care workers for participants.

In Table 6.1, below, the total number of patients in each ward and language breakdown is presented. I have omitted the ward numbers for reasons of confidentiality.

Table 6.1

Breakdown of Patient's Languages in Different Wards

Ward Number	Total number of patients	Xhosa speaking patients	Afrikaans speaking patients	English speaking patients
(anonymised)	12	1	9	2
(anonymised)	12	0	8	4
(anonymised)	17	4	12	2
(anonymised)	23	1	20	2
(anonymised)	19	0	13	6
(anonymised)	25	1	21	3
(anonymised)	21	2	15	4
(anonymised)	23	1	18	4
(anonymised)	23	3	16	4

Table 6.2

Breakdown of Patients who have Verbal Deficits and Patients that can Communicate Verbally

Ward Number	Total number of patients	Verbally communicate	Verbal deficits
(anonymised)	21	0	21
(anonymised)	14	0	14
(anonymised)	12	6	6
(anonymised)	12	4	8
(anonymised)	17	6	11
(anonymised)	23	7	16
(anonymised)	19	3	16
(anonymised)	25	9	16
(anonymised)	19	0	19
(anonymised)	22	0	22
(anonymised)	21	0	21
(anonymised)	23	8	15
(anonymised)	23	3	20

After the health care workers compiled a list of potential participants, Sipho and I compiled a list together and then we created different time slots for the interviews. Before we conducted the interviews, the nurses told us that most of the patients were uncontrollable and we would not get any useful information from them. But as we conducted the survey, Sipho was able to communicate well with the patients and we managed to get the information from the patients. Notably, a number of patients that the nurses described as aggressive and destructive, were calm, and were able to answer all the questions. They were able to cooperate during the session and give valuable information. Sipho was able to ask them questions from the standardised questionnaire and he was able to use the language that the patients understood. He made sure that the questions he asked the patients were as simple as possible and he also used signs to help the patients understand better. The patients who participated looked very comfortable around Sipho and they were free to answer all the questions that he was asking. The interviews were interactive; it was more than just answering a set of questions. The patients had an opportunity to voice all their concerns and complaints to Sipho. Some of them requested Sipho to speak to some of the health care workers on their behalf. Even though some of the patients had verbal deficits they were able to engage well with Sipho. They used signs where necessary to voice their concerns and they were very interactive. The patients that the health care workers labelled as “trouble makers” were the patients who had a lot to say during the interview. They trusted Sipho so much and they believed that he will do something with the information that they were giving him. They cooperated and they gave clear views with regards to the services that they were receiving in the different wards. Most of the patients we interviewed were speaking in Afrikaans and Xhosa. Only few patients spoke English. Sipho was able to communicate accordingly with all the patients in the language of their choice. The sessions were productive and we were able to gather as much information as possible for Sipho to be able to compile a report. The sessions took longer than expected due to participants having more information and concerns to raise with Sipho.

6.1.2.1.4 Patient feedback

Most of the patients were unhappy to be at the hospital. They sounded frustrated and said they wanted to go home. Some of the patients mentioned that they are tired of cleaning the wards and they do not like cleaning the toilets. They told us no one listens to them in the wards. The only thing they get if they try to communicate with the staff is punishment. They told us that the security guards are the ones responsible for initiating punishment by dragging the patients to the "single" room whenever they have done something wrong. They explained that the security guard would drag the patients and even pull them by their hair to the single room. They all wanted to go home and stay with their families. The primary problem was that staff members were not communicating with the patients effectively and purposefully. The patients only received instructions from the staff members and they were supposed to act accordingly. The patients also emphasised that the health care workers were not interested in listening to their concerns and problems. They did not show interest in building a relationship with the patients. Most of the patients also indicated that they do not understand why some of them were punished and why they were dragged into the single room. One of the patients said that he always acts out or shows aggressive behaviour if the staff member does not listen to him. However, this does not help him because if he shows aggressive behaviour then he gets punished for it.

6.1.2.1.5 Outpatient department

Sipho generally works at the outpatient department (OPD) once a week, but goes there only by appointment. Most of the health care professionals at the outpatient department request for his services and they make appointments with him in advance.

6.1.2.1.5.1 A doctor's consultation session

One Thursday Sipho was called by one of the nurses at OPD. The nurses explained to Sipho that they needed help with the patient that has behavioural problems. I accompanied Sipho to the OPD. The patient was locked in a room with the security guard. The patient was pacing up and down the room when we entered. He did not show any destructive behaviour, but he was restless. We went inside the room and asked the security guard if we could see the patient. After seeing the patient, we left him with the security guard to speak to the patient's mother. The mother was very open with Sipho and it seems that they had a good relationship.

The patient’s mother started explaining to Sipho the challenges that she was facing with the patient. It was evident that the mother trusted Sipho and believed that he was going to do something to help the patient. Sipho told the patient’s mother that she should explain everything to the doctor in the upcoming consultation. When it was our turn to go into the doctor’s room, Sipho went inside first and explained to the doctor that I would be observing the consultation session. We then went inside with the mother of the patient. The security guard also came in with the patient. The doctor started talking to the mother and asking her about the symptoms and the behaviour of the patient. Sipho had to interpret for the mother since she did not understand nor speak English. The doctor was focused more on Sipho than on the patient’s mother. It seemed to me that she was more concerned about understanding what the mother was saying than on focusing on the patient. The patient was pacing up and down the room. He seemed restless, but he was not destructive. As the mother was talking to Sipho and the doctor, the security guard was also adding some of the information the mother was giving the doctor. He even attempted to explain to me the patient’s problem, but I did not give him attention since I did not want to disrupt the session. The security guard did not seem to get the message I was trying silently to convey to him; he continued adding information and creating a side conversation during the session. The security guard did not seem to view this as a consultation conducted primarily by a medical doctor in the context of the doctor’s understanding of the interests of a patient. When the doctor was prescribing medication to the patient, the security guard informed the doctor that the patient used to get double the dosage of the one of the suggested medication dosages prescribed by the doctor. He told the doctor that during the time that the patient was hospitalised he used to get two not one tablet as she had indicated. He also took it upon himself to explain to the doctor how the patient had behaved since being hospitalised and how the dosage has helped the patient. The security guard provided his views without being asked and it appeared as if he knew the patient very well. It seemed like from his point of view, he was trying to help the patient as much as he could. The doctor then prescribed medication to the patient and provided dates for follow-up appointments. It was not clear if the doctor gave the patient medication based on what the security guard had said because she was listening to him during the session. After the session Sipho was not happy at all with how the session had proceeded. We had a conversation about the session and I asked about his thoughts on the session. He told me the sessions differ and different doctors have different ways of conducting a consultation session with the interpreter included. Sipho said that most of the doctors who have been working with him for a while know how to handle a session where there is an interpreter involved. Further he explained how some of the sessions become chaotic because the doctor does not know how to work with an interpreter. He told me that the security guards in the wards as well the cleaners know the patients very well and they are more involved with them during their stay at the hospital. In most cases the health care workers, if they are "struggling" with the patients, call the security guard to come and assist with the patients. He explained that the security guards help the patients during bath time and during lunch breaks. When the patients are sitting together during the day the security guard is usually present to watch their moves.

6.1.2.1.5.2 A psychology consultation session

One Thursday Sipho was called by one of the psychology interns and he was asked to come and interpret for her. Sipho went in with me to the consultation room and he introduced me to the intern before the patient arrived. The patient arrived, and she entered the room with her sister. The intern conducted an assessment with the patient and she asked the sister to leave the room. The intern was very focused on the patient. She asked questions directly to the patient, and Sipho interpreted in both directions. The intern used a standardised assessment tool to ask all the questions of the patient, and the format of the document made it difficult for Sipho to interpret the set questions. He struggled to interpret some of the words on the standard form from English to Xhosa without losing meaning. The session took much longer than expected due to the difficulty of the assessment tool. He tried his level best to make the patient understand the questions that she was asked by the intern. He used similar words or words with the same meaning to explain some of the questions to the patient. The intern could also pick up that Sipho was getting frustrated with the form that she was using. Sipho was not aware that a standard assessment tool was going to be used during the session as the intern did not inform him about it. Even though Sipho was struggling to interpret, the intern did not shift her focus away from the patient. She continued focusing on the patient and the answers she was giving. She engaged with the patient regardless of the challenges which she was facing with Sipho. This also made the patient respond to the questions that she was asked as well as to engage with the intern effectively. After the assessment form was completed the intern called in the sister of the patient. The sister understood and spoke English with the intern. There was no need for Sipho to interpret. After the session the patient left the room and the intern thanked Sipho for his help. He told her that next time if she is going to utilise a tool that needs to be translated she should provide him with the document beforehand. He explained to her that this would give him time to translate the words from English to Xhosa, making sure that they do not lose meaning in the process. The intern also told him that she had learned from the session and going forward she would ensure that she gave Sipho the document to work on beforehand.

6.1.2.2 Summary

During this phase a lot of activities took place and different occasions were observed, however, I have chosen to focus on the activities which were related to the topic in question due to limited space and time. Sipho engaged with different people on different levels at the hospital on a daily basis. He is clearly an asset to the hospital and he is carrying different functions as well. The patients regard him as someone they can confide in while staff members rely on him for information. He is a friendly and outspoken person who always shows respect for the patients as well as to everyone whom he communicates with on a daily basis. He takes his interpreting position very seriously and he is committed to it. He ensures on a daily basis that he does not miss a session by double checking his diary. He is also committed to learning new skills which will make him effective and efficient in his role. This includes learning more signs which will help him communicate much better with the patients. He also showed that he enjoys interacting with the patients during the quality assurance survey that we conducted. His managers also showed that they trust him by delegating to him difficult tasks which might have an impact on the hospital operations. They provided him with tools to get the information from the patients and he modified the tools to ensure that they were suitable to the nature of patients which are residents at Alexandra Hospital. Sipho always had a way of ensuring that service delivery or any activity that involves communication at the hospital is achieved effectively. He goes beyond his scope of duty to ensure that everyone at the hospital get the assistance that they need. He is a friendly person who loves working with different people on a daily basis. He always shows respect to both patients and his colleagues. The main aim is to improve the patient’s experiences at the hospital and he is working well together with the management team to ensure that this aim is well achieved.

6.1.3 Phase 3: Semi-structured interview analysis

This section will focus on the analysis of semi-structured interviews which followed after observations. The section will be divided into two parts. The first part will focus on the analysis of interview results from the health care workers who work with the patients daily in different wards. The second part will focus on the analysis of the results from the health care professionals who work with outpatients and occasionally with inpatients.

6.1.3.1 Part 1: Interviews with nurses, cleaners and security guards

From different wards I was able to interview 35 staff members who work full-time at the hospital. Of the 35 staff members, 27 were professional nurses, four were cleaners and four were security guards. The themes which emerged will be defined and analysed below. Many health care workers had similar views regarding communication as well as language usage at the hospital.

6.1.3.1.1 Language as instruction

Health care workers in different wards expressed different views regarding language and language usage at the hospital. All the views expressed emphasised that language barriers existed but that language was generally not regarded as a problem or a challenge which could hinder service delivery. Most of the participants mentioned that there is language diversity among the patients but the challenges they experience, according to them, do not relate much to the language. It was clear that they did not see the need for linguistic understanding to take place between them and the patients:

> The patients listen to everything that we tell them, when we tell them to go and take a bath they do so and if they do not listen to us then we call the security to help. (Female nurse)

It seems that the health care workers were more focused on patients getting the messages or instructions that they were giving to them, than the staff and patients being in conversation. In the passage above, the health care worker mentioned that if the patients do not act according to the message given then they seek assistant from the security guard. This means that the security guard will have to force the patient to act according to the message given by the health care workers. It does not seem that the health care workers are especially concerned whether the patients understand the language or not. They only want to see reaction after the message is relayed to the patients. Different health care workers use different techniques to ensure that the patients react to the messages that they give out:

> They always listen to me. I think they are scared of me because I do not smile with them. I do not want them to get used to me because they won't listen to my instructions. (Male nurse)

It is clear that the health care workers tend to frame issues of communication as solely issues of instructions from nurses to patients. They do not view communication as a two-way process that needs to exist between them and the patients. This is the main reason why the health care workers do not consider language barriers to be an issue within the wards. Most of them further explained that the patients know the meaning of every instruction that they get. They always know when it is time to bath, time for medication, time for meals and when it is time for afternoon nap, etc. They explained that they do not have much to say to the patient except saying words like "bathtime", "breakfast time", "lunch time", "supper time", or "naptime/slaaptyd". The patients understand those words and they respond accordingly. If they experience problems with the patients not responding accordingly they then call the security guard in the ward to intervene.

Most of the health care workers have expressed their views in a manner which may suggest that they see the patients as people who are less valued than others. Most of them did not show any concern about interacting with the patients. Their focus seemed to be on their own safety. It often seemed that they were frightened of the patients, and fear may well be a barrier to relationship-building:

> When I start here the other nurses told me that I must be careful with the patients, they mentioned that the patients can be violent sometimes. They told me that I should not

> talk to them too much because they must get too comfortable with me and not listen to my instructions.

The health care workers did not seem to regard good communication between the patients and themselves as central to good practice. They avoided communicating with the patients with the aim of protecting themselves from any harm that the patients could cause them. They viewed patients as dangerous and they ensured that they made minimal contact with them. In this way language barriers and language difficulties were not experienced because communication was not deemed as important in different wards. Instructions are given to the patients and they have to act accordingly, otherwise consequences will follow.

6.1.3.1.2 Language courses

Alexandra hospital offers language courses which aim to help nurses and other health care professionals to learn Afrikaans and/or Xhosa. Afrikaans speaking health care workers should focus on learning Xhosa so that they can help Xhosa speaking patients effectively, while Xhosa speaking health care professionals should focus on learning Afrikaans. The language courses which were offered at the hospital for employees are not compulsory. Different health care workers had different views regarding the languages courses which are offered at the hospital. Some of the health care workers mentioned that they did not know about the courses and some mentioned that they heard about them from their colleagues. The language courses which were offered at the hospital did not carry much weight of importance for the health care workers. Many health care workers saw the language course as something fun that they could do in their spare time. Most of them did not see it as tool that could help them communicate effectively with their patients:

> I attended the courses it was much fun and helpful for me, I was able to learn few Afrikaans words. It helped me a bit. (Female nurse)

> I learned few Xhosa words like “molweni”, “unjani” this has helped a bit. I can greet my colleagues in their language. (Male nurse)

Both the nurses above did not mention how the language course helped them to interact better with the patients. They also did not highlight the importance of the classes and how often they attended the classes. From the way they answered the questions and expressed themselves regarding the language course it was clear that they did not see it as important.

Some of the health care workers indicated that they heard about the course but they did not see the importance of attending the course. They believed it was made available for the people who want to learn a new language:

> I heard about the language courses, but I never attended the course, I think you only attend if you want to learn a language. I am ok with languages. (Female Nurse)

Some of the health care workers were not aware of the courses. But they also did not show concern about the courses and they did not mention how learning a new language would help them communicate effectively with the patients. It was clear that there was little publicity regarding the language courses that are taking place at the hospital. Some health care workers expressed their interest but only for personal gain and not related to helping the patients:

> I never heard about the course, it is the first time hearing about it from you. I will ask my colleagues about it because it will help me to learn Afrikaans. (Female nurse)

Once again, though, the issue of language as instruction emerged. Some of the health care professionals explained that the language course was a good initiative, but it was not necessary in their setting. One of the nurses said the following statement in one of the wards:

> The patients listen to all the instructions that we give them whether in English or Afrikaans, they understand the language and the words that we use here in this ward.

> If they don’t do as we tell them to do, then they are being difficult and in those instances, we call the security guard to assist us. (Male nurse)

The statement above clearly shows how the health care workers perceive the patients in different wards. The health care worker above did not see the need to learn a new language since he was able to give instructions to the patients and he was listened to. According to him, there was no need for the patients to reply to his instructions, they were only supposed to act accordingly. There was no need for a two-way communication based on linguistic understanding to take place between him and the patient.

Other staff could not see the value of language courses since they were dealing with patients who have verbal deficits. They believed that they were there at the hospital to look after the patients who were not able to look after themselves. They believed that learning other ways of communicating would be more beneficial that learning a language.

However, it was clear that there were other health care workers who wanted to communicate effectively with the patients:

> Most of our patients here cannot communicate verbally thus learning languages is a waste of time for me. If I can learn sign language, then it will be better because then I will communicate with them much better and they will understand me much better. (Female nurse)

This health care worker showed more concern about the patients and she expressed how frustrated she becomes when she does not know how to communicate with the patients. She was one of the few health care workers who viewed the patients at the hospital as human beings who need to voice concerns and need to be heard. She has been working for more than 10 years and she has built relationships with different patients. Most of the patients know her and they usually come to her when they need help. She is able to understand the few words that the patients speak and she able to respond accordingly.

6.1.3.1.3 Communication and challenging behaviour

Patients are allocated to different wards according to the severity of their psychiatric illnesses and challenging behaviour. Two wards (Ward 6 and Ward 7) at the hospital mainly have people with severely challenging behaviours. If patients in other wards show aggressive behaviour they transfer them to these two wards. During the interviews most of the nurses from different wards indicated that there is no link between communication barriers and challenging behaviour. They explained that the patients have to listen to instructions to avoid punishment. If they do not listen to instructions, then the security guard will be called, and the patients will be forced to listen to instructions or punished. Security guards are viewed as protective staff members who are in different wards to help with destructive behaviours. And from the way the nurses explained how the security guards were called when the patients were being “difficult” it is clear that the patients were scared of the security guard. One of the punishments for challenging behaviours is being closed in a separate room which is available in all the wards. The security guards are the ones responsible for moving the patients in and out of the Separate room.

The security guards that were interviewed also confirmed what the nurses said above:

> They always call us when the patients are difficult, we always help the nurses to bath the patients and to call them to order. Sometimes we take them to a separate room until they are calm then we take them out again. (Male security guard)

It was clear that the nurses and the security guards work together to manage the patients. They emphasised that there are no communication difficulties and they can manage challenging behaviour. Most of the nurses made it clear that they are not concerned about building a relationship with the patient nor improving communication. They were more focused on being heard and obeyed:

> I do not have a problem with the patients as long as they listen to what I tell them and take their medication when it’s time for medication. (Female nurse)

The patients were viewed as recipients of medication and they did not have a say in what happens in their surroundings. Some of the nurses viewed the patients as dangerous and destructive. They believe that they need physical strength to work at the ward and that they must be hard or strong for the patients to follow their instructions:

> I have no problems with the patient, they are scared of me and I think is because I am big and strong, they cannot take chances with me. These patients can be very aggressive sometimes and some of the staff members are scared to be attacked by the patient. (Male nurse)

It seemed that the nurses were always prepared to defend themselves when the patients attacked them. They also trusted that the security guards would defend them when needed. The nurses did not see the importance of communicating better with the patients. They did not associate aggressive behaviour with frustration or the inability of the patients to communicate their frustrations. The nurses clearly did not view the patients as human beings who have feelings and who want to express their views. The nurses were only focus on themselves and how they wanted the patients to listen to them while communicating with them.

6.1.3.1.4 Patients as children

Some of the nurses viewed the patients as children who cannot have an opinion about anything. They believe that the patients cannot make their own decisions thus they do not need to listen to their opinion or to what they have to say. They believe they are only there in the wards to look after patients who cannot look after themselves. They did not see the patients as individuals who are old enough to make a decision and old enough to have a choice:

> My patients listen to me, I don’t have a problem with my babies, they are always good to me. (Female nurse)

Some of the nurses were happy to work with individuals whom they believed did not have a voice to raise concerns and complaints. They treated them like children who need attention and proper care. They believed that if the patients start showing challenging behaviour it is because they are hungry and they need food. These nurses did not view the patients as dangerous or violent and they made did it clear that they get along with them:

> I do not have a problem with these patients. I look after them well as I am told and they listen to me. They are harmless and lovable kids. (Female nurse)

Other nurses were very positive about the patients even though they viewed them as children. They were very proud of the work that they do during occupational therapy sessions. They showed me some of the patients’ painting and drawing. I could see and tell that the nurses are proud of the patients:

> My kids in this wards are very talented, they make beautiful things during OT and we sell these things for them here in the wards. They even make us beautiful things and we buy from them. They are so lovable and kind. (Female nurse)

These nurses above, though they did not see the patients as harmful and dangerous, were seeing them as children who need repeated praise for good behaviour. They related to their patients in that manner hence they did not experience any challenges with the patients. Patients were also nice to the nurses and they were always happy to see them when they come to work. One of the nurses explained that the patients know her shifts and they even know her off days:

> My kids in the ward knows my shifts and they know when I am off. They always asking me and they do not forget my shifts. If I am off for seven days or longer they ask the other nurses the dates when I will be back. When I get back to work I will find them waiting for me outside the ward and they will show me how excited they are to see me. I always make sure that I am in good mood when I go to work because I do not want to disappoint them.

It seemed that some nurses have a very good relationship with the patients though they regard the patients as children. The nurses showed much care towards the patients and they viewed the patients as their responsibility. The patients also behave in a manner which showed trust and loyalty towards the nurses. There were less problems experienced in these wards and both patients and nurses sounded happy. The nurses looked like they were satisfied with what they were doing at the hospital.

6.1.3.1.5 The need for an interpreter

The majority of the nurses interviewed indicated that there was no need for an interpreter in the wards. Most of them knew Sipho as one of the employees who works at the admin building. They did not know his official role at the hospital. They indicated that they interact with Sipho on a daily basis regarding issues at the hospital but not issues regarding language barriers and the patients. They mentioned that they never heard that Sipho was an interpreter for the hospital. Some mentioned that he is a very friendly person who enjoys working with people:

> I know Sipho, he works by the admin building and I think he does admin work with the managers. (Male nurse)

> I know Sipho, he is a very friendly guy and he is involved in all the events that takes place at the hospital. I think he is a PA or something. (Female student)

Some of the nurses knew Sipho's role at the hospital and they have talked to him about his role. They mentioned that they do understand his role at the hospital but they do not use his services due to several reasons. Most said that Sipho worked very far from the wards and they need to call him to come to the wards when they need his services. They also mentioned that his working hours make it impossible for them to utilise his services:

> In most cases things happens so fast here at the ward and Sipho is very far from us, so I just call the security to come interpret for me. It is easier and quicker that way because I do not have to pick up the phone and call him to come. (Female nurse)

They explained that it was too much effort to call and wait. They further explained that they would rather call the security guard or the cleaners to do the interpreting. Some of the nurses mentioned that Sipho only works weekdays and office hours. This means that he is not always available when needed. They explained that it is useless to rely on the services that are available at certain times:

> We work here in the ward every day, 24/7 but Sipho is only here during the week. What about Saturday and Sunday? What about after hours, at night? I rather use the security guard because they are always here. If I rely on Sipho's services, then I am shooting myself on the foot. (Female nurse)

Some explained that they do not need an interpreter because they are coping very well with the patients. They emphasised that the patients listen to the instructions that are given, and they act the way they want them to act. Some indicated that most of the patients have verbal deficits thus an interpreter would not help with anything. They explained that if they could get an interpreter who can use sign language it would be better, but it might not be useful since most of the patients with verbal deficits have very low cognitive functioning:

> Most of our clients cannot communicate verbally, they only use signs. Sipho won’t be useful in this regard. We understand them when they need something, and they use signs. They know how to communicate with us and we know how to communicate with them. (Female nurse)
>
> If could get a sign language interpreter who will understands the signs that these patients use. It will be much better. (Male nurse)

Some of the nurses mentioned that if the patients do not understand the language that the nurse speaks she also calls the security guards and the cleaner to assist with interpreting. They mentioned that the security guard and cleaners work at the wards on a daily basis. They have built a relationship with the patients and the patients are familiar with them. The security guards and the cleaners also confirmed that they work together with the nurses to help the patients. During the interviews the security guards and cleaners showed that they knew the patients very well. It was clear that they were more involved with the patients and they knew more about the patients:

> Sometimes they call me to come help them with the patients, especially when they do not want to take their medication. Most of them know me and they are comfortable with me. (Female cleaner)
>
> I know this patient and I work here every day. They know me as well. If they misbehave they call me to come give them medication. I always help them bath, help them eat and sometimes they call me to come and give them medications. (Male security guard)

It is clear from the statement above that the security guard was going above his duties to ensure that the patients are well taken care of at the wards. It seems that they are very involved in all the activities that the patients do on a daily basis. The security guards are even involved in giving the patients medication when they are being difficult. One of the cleaners also mentioned confidently that the patients preferred her to give her medication than the nurses. Another cleaner mentioned that the nurses rely on her to assist with the patients:

> The nurse calls me every day to come and help her with the patients. They know that she likes me and she understands me. And by now I know that the pills that she takes on a daily basis. She likes me and I also like working with her. She can't speak very well but I understand what she wants at a given time. (Female cleaner)

It seems that all the nurses, cleaners and the security guards work together to ensure that the patients go through their daily routine. But the security guards were utilised to help out with bathing the patients and feeding them when necessary. The cleaners were also trusted to give patients medication. They also mentioned that the patients also trust and rely on the nurses and security guards to assist them with the patients. Both the security guards and cleaners were confident that they are able to assist patients just like nurses. They were also proud that the nurses rely on them for help:

> When I am off I am always worried that the nurses won't have anyone to help them with patients when they are being difficult. (Male security guard)

> I was on leave the other week and I missed the patients especially the one that only take medication from me. I felt so sad that the nurses will struggle with the patients. (Female cleaner)

It was clear that the security guards and the cleaner were attached to the patients. It seems that they have built a meaningful relationship with the patients. The way they spoke it was clear that they were passionate about their work and the impact they make on patients on a daily basis. The nurses entrusted them with the wellbeing of the patients in the wards and in doing that the nurses did not build a relationship with the patients. It seems that the nurses were not worried about building relationships with the patients as much as the security guards and the cleaners. And as mentioned above, most of the patients were more responsive to security guards and cleaners than to the nurses. The security guards and cleaners were more comfortable and dedicated to working with the patients. They viewed them as human beings who need to communicate comfortably in their own language and they need to be listened to when they speak:

> Before I can take the patients to the separate room as instructed by the nurses I always ensure that I listen to the patients and try to understand why they are being difficult to the nurses. (Male security guard)
>
> Sometimes the patient is not feeling well maybe that is why they do not want to eat. If I saw a nurse struggling with a patient who does not want to eat I always go closer and talk to the patient especially the Xhosa patients because I am a Xhosa. (Female cleaner)

It seemed that the security guards and the cleaners have some level of care towards the patients. They showed that they know the patients individually and they are willing to understand the causes of their behaviour in the wards. On the other hand, the nurses in the ward did not show much interest in building relationships and understanding the behaviour of the patients. They were more concerned when the patients were not taking their instructions as given.

6.1.3.2 Part 2: Health care workers dealing with patients on an outpatient basis (doctors, psychologists)

Five health care workers (one doctor, one psychologist, one psychology intern, one social worker and one intern doctor) from the outpatient department were interviewed, as well as Sipho and the hospital manager. Themes which emerged from these interviews will be defined and analysed below.

6.1.3.2.1 Language difficulties

Most of the health care professionals who work at the outpatient's department indicated that they experience language barriers. They explained that it is difficult to having productive sessions with the patients without the help of the interpreter. Most of these professionals are bilingual (English and Afrikaans), but some only speak one language, which is English. They indicated that they need the help of Sipho if they have patients who speak a language that they do not understand:

> Language barriers is an issue here at the hospital because our patients are not multi-lingual. Most of our patients have limited vocabulary to express themselves. We always utilise the interpreter to assist us, we rely on Sipho's services. (Female psychology intern)

Further, they elaborated and mentioned that linguistic understanding does not exist there will be improper assessment which will lead to the incorrect prescription of medication. It was clear that they need and value the services that Sipho was giving at the hospital. Language formed the basis of their daily consultation and if language barriers existed then they could not do their jobs properly. They further explained that they make appointments with Sipho well in advance in order for him to avail himself and to be prepared:

> For us do a proper assessment and prescribe medication accordingly we need to understand what the patients/the caregiver says, we have to make sense of the situation before making a prescription. (Male doctor)

> I always ensure that I make an appointment well in advance so that he can be available and so that he can prepare himself as well. (Male doctor)

> We only need him on Thursday with the outpatients and it is very important that we book him well in advance because it gets so busy here at our department on Thursdays. He is always available for us and he is very helpful. (Female social worker)

The health care workers who were in the position of prescribing medication mentioned that they needed Sipho’s services more often than others. They mentioned that mostly for outpatients that visit the hospital on a weekly basis they rely mainly on the caregiver’s explanation of symptoms and behaviour. And most of the caregivers do not understand nor speak the language of the health care professional. This clearly indicated that Sipho was on high demand at the department on Thursdays:

> For the patients that visits the hospital weekly we only rely on the information that we get from mainly the caregivers and the patients themselves. For inpatients we rely on the staff members which are on duty 24/7. Some of the health care workers can speak and understand Xhosa, English and Afrikaans which are the languages that are predominant at the hospital. (Male doctor)

> For the outpatients I mainly rely on Sipho to interpret for me. I am an English speaker and I understand a bit of Afrikaans. My patients are mainly Afrikaans speakers and Xhosa speakers. So Sipho has to be present in most of my consultation sessions on a

> weekly basis. If he is not available, I struggle and the session takes longer due to language difficulties. (Female intern doctor)

Sipho always makes himself available for the outpatient department on a Thursday. It is clear that he is needed at the department for different sessions and consultations. Some of the patients come on a monthly basis and Sipho has built a relationship with them. This makes his duty easier because he is used to the patients:

> For the patients that come here at the hospital regularly, it is easier for me to interpret because I know their history or medical history. I have also built a relationship with them so communicating with them is also easy. (Sipho)

> Sometimes once-off consultations take longer and go slower. I have to understand the nature of the patient's sickness before I could interpret. Interpreting is much easier when you understand what is going on with the patients, it's not about translating words you know. (Sipho)

From the statement above one could tell that Sipho also experiences challenges in his job. Interpreting is not just translating words, especially in a health care setting. It is even more challenging in a hospital like Alexandra Hospital due to the nature of the patients at the hospital. Most of the patients have verbal deficits and they are unable to communicate. Sipho has to rely on interpreting narratives of symptoms from their caregivers and he has to be able to relay messages from the caregivers to the doctor to make a diagnosis in order to prescribe the correct medication. The health care professionals are dependent on Sipho to get correct information from the caregivers and then interpret accurately for them to do their job accurately as well.

6.1.3.2.2 Communication and challenging behaviour

Most of the health care workers mentioned that, in their understanding, there is a link between communication and challenging behaviours. They believed that most of the patients that showcase challenging behaviours are frustrated and as they are unable to verbalise their frustration this results in their acting out negatively. They also mentioned that some of the behaviours might also be because the patients feel that they are being treated like children and no one is listening to their concerns and problems:

> Most of our patients have verbal deficits, they cannot express themselves verbally and hence they resolve the issues by fighting with other patients or staff members. (Male psychologist)

> Some of the patients feel like they are being treated like children both in the wards and here, hence they resort to showing bad behaviour. Some of them fight with the nurses, they don't listen to the nurses and they fight with the fellow patients as well. In the wards the nurses ask security guards for help if need be and we also call security guards to help us if we are experiencing difficulties with a patient. (Female social worker)

Some of the staff members mentioned that they usually call Sipho to come and assist with challenging behaviour since he is trained to calm the patients down. They explained that they were in most cases unable to calm the patients down but Sipho was able to do it. Sipho is also able to use basic signs hence, in most cases, he is able to communicate well with the patients. Most of the training that he has attended has taught him how to make patients respond and to start behaving in a positive manner:

> Somehow, the patients respond positively to Sipho when he intervenes, we always call him to come and he is very helpful. Sipho is also able to use basic signs to

> communicate with the patients and he is good. He is a very calm guy and he hardly panics; even if the patient is very distractive and aggressive they usually respond to Sipho in a positive way. (Female social worker)

Sipho is partially trained to do work with patients with intellectual disability. His duties are not restricted to interpreting only at the hospital. He is dedicated to go beyond his duty to ensure that the stuff members get all the help they need with the patients. The hospital manager mentioned that Sipho is responsible for a lot of activities at the hospital which aim to improve service delivery and the patients' experiences:

Sipho is a jack of all trades. He is very helpful here at the hospital and he is involved in many activities that focus on improving service delivery here at Alexandra. He is not just an interpreter; he goes beyond his job description to ensure that he offers support to the staff members and patients (Senior Management Team Member).

Most of the health care workers found Sipho to be very useful. They usually work with him regularly. They knew his role at the hospital and they utilised his service accordingly. They also mentioned that Sipho helps them to build a better relationship with both the patients and their caregivers. They also emphasised that a good relationship with the patients helps in terms of delivering effective services. The health care workers who work at the hospital only on weekdays during office hours found Sipho more accessible and more helpful. Most of them always makes appointments with him in advance.

In the following chapter I will discussed and analyse the policies that governs language at Alexandra hospital as well as the policies which the government has put in place to govern language in Public institutions. A thorough analysis of the semi structured interview will also be presented as well as issues that came out throughout. Ethical issues such as confidential issues and custodial vs authoritarian approach will also be discussed.

Chapter 7

Discussion and Conclusion

Firstly, I will focus on discussing policies that guide the practices at Alexandra Hospital as well as the language policies designed by the government to guide South African public institutions. Secondly, issues that were raised during institutional observation will be discussed and analysed this will include ethical issues such as confidential issues and the approach which is most likely guiding practice at Alexandra Hospital. Lastly, the themes that were dominant during semi-structured interviews will be discussed and be integrated with theory to give a full analysis.

7.1 Policies

On a National and Provincial level there is an enabling policy framework put in place regarding language usage in public institutions such as Alexandra Hospital. The Constitution (Bill of Rights), Batho Pele principles, and Patients' Rights Charter clearly recognise and provide guidance on how language and communication issues should be addressed in public entities. As mentioned in the previous chapter, the Western Cape government language policy aims to equally promote the three languages which are most dominant in the Western Cape. Afrikaans, English and Xhosa are the most dominant in the province and the government is committed to ensure that all these languages are equally accessible within the government institutions. Interpreters are made available in most of the government institutions especially within the health care system. Lennox et al. (2020) argue that interpreters are needed where communication barrier exists. Alexandra hospital has an interpreter as well even though his role is more complex than originally intended. The interpreter still upholds the basic principles of his role where he always ensures the elimination of language and communication barriers that exist between the health care workers and the patients.

Access is one of the Batho Pele principles, which guides all governments' institutions in South Africa. This principle emphasises that all citizens should have equal access to all services, including the use of indigenous languages and sign languages. None of the participants in the study mentioned the policies that govern practices, and I did not ask the participants about the policies. I am aware that this might be a limitation to this study. There is an empowering policy framework put in place, however, the implementation and the interpretation of these policies is questionable. The Batho Pele principles aim to empower public workers/servants nationally to render a client-centred service and provide guidance to achieve this end. These principles are supposed to be a reference point for all the activities that the health care workers do at the hospital. The health care workers are supposed to be well aware of the principles and practice accordingly. Alexandra Hospital experiences a very challenging situation due to the nature of the patients within the institution. This may be one of the reasons why there is a huge gap between the intention behind the policies and the implementation of the policies. Formulating policies that are directly addressing the specific needs of the institution might be a solution which could lead to bridging the gaps that exist.

7.2. Observation

As mentioned above, there exists an enabling policy framework, however, what I saw during observation did not reflect the implementation of these policies. It seemed that there was a huge gap between the policies and the actual practices at the hospital.

The Provincial Department of Health, the Extended Public Works and Stellenbosch University project placed the interpreter at Alexandra Hospital, his main aim being to bridge the linguistic gap that exists between the health care workers and patients. According to Verrept (2019), the role of an interpreter in a health care setting is to act as a mediator and facilitate linguistic exchange, which includes linguistic interpretation and transmitting messages in one-on-one consultation between the health care worker and the patient.

However, it seemed that his role had expanded extensively at the hospital and he was doing far more than interpreting across languages in a clinical setting. He had become the in-between person that worked with both the patients and the health care workers. He had become a person that both the patients and the health care workers relied on.

Sipho's personality put him in a place where his colleagues and the patients seemed to view him as trustworthy or genuine (Hadziabdic et al., 2010). A professional relationship has to exist between the interpreter, heath care worker and the patients. I observed that at times patients enquired from the interpreter, and not from hospital staff, about the events that happened at the hospital and it seemed that they may rely on him for such information more than they do on the health care workers. As discussed, he was trained to deal with challenging behaviour and he has skills to calm the patients who are destructive. This put him in a position where the health care workers also relied on the interpreter to calm and instil the disciple the institution views as proper in the patients who seemed challenging or destructive. This demonstrates that people with intellectual disability value relationships and they open up to people that seem to listen to them.

Interpersonal relationships established with the patients are crucial in institutions. A study done by Ziviani et al. (2004) reveals that the patients preferred health care workers who were caring and showed interest in them. At Alexandra Hospital, it was the interpreter who was often preferred as he was able to communicate using sign language and he was more patient with them than other staff members I observed. He listened carefully to the patients and he made sure that he went an extra mile with them. It becomes difficult to build a good relationship if there is a language or communication barrier. Hence other health care workers utilised Sipho to bridge the language and communication barrier. However, a triadic relationship has proven to be challenging as well. During the observation I was able to see how one of the doctors minimised contact with the patients and focused more on Sipho, the interpreter and the caregiver than on his own relationship with the patients. However, according to Hadziabdic et al. (2010), it is very important to have a trained interpreter who has a professional attitude and who understands the medical language as well as the settings. Hadziabdic et al. (2010) argued that untrained interpreters can relate or transmit different messages to the patients and this may hamper the whole consultation process. If the message is not communicated correctly, then the use of an interpreter can potentially be damaging to, rather than improving, the quality of the consultations. Some of the untrained interpreters do not understand the boundaries that exist between the health care workers, the patients and themselves as the “interpreter”. In this case, the interpreter is going far beyond what is generally understood as the interpreter role, but what the interpreter does seems important and helpful for the patients and the institution.

7.3. Language and communication barriers

Literature has revealed methods that can be utilised to enhance communication in institutions such as Alexandra Hospital. The study has also revealed some of the methods that the health care workers have adopted to enhance communication at the institution.

7.3.1 Strategies that are utilised at Alexandra Hospital to eliminate language barriers and enhance communication

All the participants on the study indicated that they knew the interpreter and they had met him on several occasion at the hospital. Most of the participants did not know the interpreter’s role at the hospital. For those who knew his role, only some were utilising his services. Tribe et al. (2008) argue that working with an interpreter can be beneficial to the health care workers in terms of broadening clinical knowledge and perspective. However, there might be lack of training and very little knowledge on their part in terms of how to work with an interpreter (Cerci & Neale, 2018). The participants who knew what the interpreter’s role was at the hospital gave some insights into why they were not working with him. Some did not know how to work with him. Some of them did not see the need to utilise his services due to his working hours and some preferred using other staff members at the wards such as security guards and cleaners. A study done by White et al. (2019) in a hospital setting in Australia has also revealed that one of the reasons why health care workers are not using the services of the interpreters is a perceived lack of services and increased workload. However, utilising security guards and cleaners who are untrained can cause problems since they do have less knowledge of interpreting practice and understanding of clinical terms. This might lead to misdiagnosis and administration of incorrect medication which may lead to worsening the patients' health status.

All the participants who use other staff members as interpreters were concerned about the accessibility of the "official interpreter" at the hospital. They mentioned that the cleaners and the security guards were always available at the wards to assist them when needed. The health care setting is highly demanding and it is difficult for staff to wait. The issue of confidentiality between the health care worker and the patient is, however, crucial. The untrained interpreters, such as the security guard or cleaners, did not seem to be aware of the confidentiality issue and they were not registered with any health care services board. Hence if they were accused of a breach in confidentiality, they could not be held professionally liable for their actions. Dale and Melling (2000) argue that confidentiality should be discussed with the interpreter prior to each consultation. In these cases, where untrained or lay interpreters were utilised, it is very clear that the issue of confidentiality was not focussed on. Trained interpreters are aware of the confidentiality clause within the health care setting and they are aware that they need to conduct themselves accordingly.

Some of the participants mentioned that they work together with the interpreter and these were mainly those working in the outpatient's department. These were the health care professionals who were indirectly working with the patients. They usually played a consultative role with the patients and they only met with the patients by appointment. Most of them mentioned that they make an appointment with the interpreter well in advance to ensure that he is prepared for the session. Cerci and Neale (2018) argue that consultation should take place between the health care worker and interpreter before the session, focussing on the confidentiality clause, the purpose of the session and cultural issue relevance. As part of my observations I accompanied the interpreter to a few sessions. In one session with the intern psychologist, the session took a long time, and there seemed to be some awkwardness between the intern and the interpreter. I thought that part of the reason for this was that the interpreter had not been consulted beforehand. On the positive side, the psychologist was able to continue focusing on the patient rather than on the interpreter. Cerci and Naele (2018) note that it is crucial for clinicians to focus on the patients rather than on their relationship with the interpreter for a successful session to occur.

According to Robertson (2014), a number of alternatives can be utilised to bridge the communication barriers that exist between the patients and the health care worker. This includes using an interpreter, using sign language, and other digital materials. Sipho is the only interpreter at the hospital who is trained to use sign language with the patients. The other health care workers have mentioned that they are struggling with the patients and this may result in patients getting frustrated. Most of the health care workers mentioned that the patients display challenging behaviours and in many cases they do not feel safe when they are with them.

The hospital has invested in training the interpreter and equipping him with skills which will allow him to be useful in many areas. He is able to calm the patients down when they are presenting challenging behaviours and he is able to communicate with them using basic sign language. Ziviani et al. (2004) argue that if patients get involved in a conversation regarding their lives they feel recognised and are likely to co-operate more. This seems to be true at

Alexandra Hospital because the patients seemed to respond more positively to the interpreter than to untrained security guards and cleaners. Sipho seemed to have a very good relationship with the patients and they seemed to have a great deal of trust in him.

The interpreter has to be multi-skilled to be able to assist the health care worker to be more productive. This is not supposed to be one-sided; both the interpreter and the health care workers have to have certain skills to be able to manage patients with intellectual disability. According to Chung and Harding (2009), health care workers working in institutions with patients with intellectual disability need to have specialised training on how to deal with patients of that nature. The patient with challenging behaviour might have a negative effect on health care workers who are not equipped with skills to deal with the situation. Many of the health care workers revealed that they were frightened of patients, and they relied on the security guards to deal with patients with challenging behaviour. Other health care professionals revealed that they always call Sipho to calm the patients down.

The findings also revealed how different health care workers have different views of the patients. The way the health care workers view the patients is very important because it determines in part how they will treat the patients. Some of the participants referred to the patients as babies and this also affects the way they communicate with them. Some patients in the study done by Ziviani et al. (2004) mentioned that they get annoyed when the doctors address them as children rather than treating them as adults. This may lead to patients being frustrated which may result in patients expressing challenging behaviour.

7.4 Ethical issues

7.4.1 Confidentiality

Confidentiality is one of the most important issues within the health care system. All the health care workers which work within the health care system are sworn into by the code of ethics ensuring that they should manage all patients' cases with confidentiality. At Alexandra Hospital this is questionable, since security guards and cleaners are very closely involved in the patients' lives as well as their day to day activities. The nurses in different wards use the security guards and cleaners as interpreters. The issue of confidentiality does not seem to be deemed important and this might be because some staff view the patients as less human being compared to other patients without intellectual disability. According to the Health Professions Council of South Africa (HPCSA, 2006), the health care practitioner shall only divulge verbally or in writing information regarding a patient under the following circumstances: In terms of a statutory provision, at the instruction of the court of law, or where justified in the public interest. The health care workers were probably well aware of this, but, if the security guards and the cleaners were also exposed to information regarding the patient's health, how are they safeguarding the patient's information? Within the National Health Care Act (Republic of South Africa, 2004), confidentiality and privacy is also one of the patient's rights. This demonstrates that the policies are in place to ensure that a patient's information is protected by health care professionals, however, in this case it seems that there is a gap in implementing these policies. A key reason given for this is shortage of resources. There is only one interpreter at the hospital and he is only there during the day and only on weekdays. For the effective use of a trained interpreter in an institutional setting training has to be provided and there has to be a multidisciplinary effort for these services to be used effectively (White et al., 2019). This also means that policies that streamline communication and care should be created to guide practice.

7.4.2 A custodial or authoritarian approach

The practice of care at the hospital tends to be authoritarian in nature where the health care providers are regarded as having control over the patients. In an institution such as Alexandra Hospital, as in other institutions, routine is deemed very important and the nurses in a ward expect the patients to take instructions and behave accordingly. The National Health Care Act (Republic of South Africa, 2004) put great emphasis on how the service users should be treated with care and respect. It views the patients as service users with the right to voice their concerns and issues. However, it seems that the health care professionals view the patient population as vulnerable, lacking agency, and in need of directed and managed care (Primeau & Talley, 2019). Patients are not seen as active participants in their own care. Primeau and Talley (2019) argue that utilising a strengths based perspective, where the health care professional acknowledges the patient's strength and resiliency, is ideal. The primary belief in this approach is that the patients have strengths that can be utilised as motivation as well as improving their quality of life.

In terms of what I observed and heard, however, communication is not seen as important as the maintenance of order, and the patient's voice is often ignored within the institution. If the patients raise concerns, it may be that no one is available to listen. This may lead to patients acting out their frustration, which leads to punishment. The security guards are involved in ensuring that the patient who displays destructive behaviour is isolated from the other patients in order to have time to think about the acceptable behaviour in question. Sashidharan and Saraceno (2017) argue that wherever there is a paternalistic attitude and practice, the focus always shifts away from the patients' needs to increased security. The big ethical question is, are the security guards trained to act as agents to change behaviour? Do they explain to the patients the reasons for being placed in isolation? What does the exercise mean to them? Do they understand why they are isolating the patient?

The main role of the security personnel/guard is to safeguard the building, patients, visitors and staff. The role of the cleaners working in clinical and non-clinical areas is important: they need to make sure that all areas are clean and safe places where staff can care for patients. This includes dusting, using spray cleaners, cleaning hard floors with mops or electric floor cleaners, using vacuum cleaners or carpet cleaners, cleaning toilet and bathroom areas. Both the security guards and the cleaners play a big role at the hospital and they go beyond their job scope to ensure that the patients receive the help that they need from the health care workers.

Limited resources and the number of patients within the institution may be one of the many reasons why the health care workers use an authoritarian or paternalistic approach while rendering services. Another may relate to staff lack of skills: health care workers seem to struggle to interpret and implement the policies which are in place to make services more accessible to the patients. Health care workers may not be sufficiently well trained to work with people with intellectual disabilities and mental health care issues. However, it was clear from the study that the health care workers (nurses) that are in regular contact within the wards seem to behave in a more authoritarian way than do the other health care workers who work with patients by appointment (the doctors, psychologists, social workers and occupational therapist). These health care professionals tend to believe in the kind of transformation outlined in the policies and laws outlined in the previous chapter. They use a more dialogical approach and they tend to utilise Sipho's services a great deal. This concurs with a study conducted by Aasland, Husum, Forde, and Pedersen (2018). They observed the relationship between the health care professionals and patients within mental health care and addiction centres. Nurses working within the wards were seen as more authoritarian while working with the patients. The other health care professionals, such as the psychologist and the psychiatrist, took a more dialogical approach with the patients. Similarly, at Alexandra Hospital, the management and other professional are more focused on bringing about transformation within the institution where the rights of the patients are being upheld. As argued by Hsieh and Nicodemus (2015), interpreters are unique health care professionals who aim to bridge linguistic gaps that exist between the health care professionals and patients, however, if there are no clear guidelines and no clear guidance exists, the interpreter might be over-extended across a range of duties. At Alexandra Hospital this was clearly evident, and not optimal, despite the positive contribution this made to the patients and to his colleagues.

In summary, there are different strategies within the hospital which are focused on bridging the language barriers that exist, however, there is a huge gap in the implementation of these strategies. The management of the hospital is committed to make changes within the hospital to ensure that the quality of life of patients is improved, however, they are faced with challenges due to lack of resources. Their budget on a yearly basis has to be cut due to lack of funds provided by the state. Limited resources block the implementation of strategies which are aimed at increasing services delivery and making services more efficient and effective.

In recent years in South Africa there have been substantial budget cuts across government departments. The National Health Department has been affected, hence Alexandra Hospital has been affected as well. An example, as discussed in Chapter 4, was the Life Esidimeni tragedy. This clearly indicates that the government has made substantial budget cuts in South Africa as a whole and this has affected all the institutions in the country. Thus Alexandra Hospital management has been challenged to implement strategies which will improve the quality of patient care within the institution.

In conclusion, in order for the gaps to be filled it will take multidisciplinary efforts, where hospital management and health care professional have to ensure that the health care workers who works with people with intellectual disability in the wards on a daily basis are well trained. Policies have to be put in place which aim at directing the activities at the hospital as well as promoting effective communication within the hospital. A study conducted by Haines and Brown (2018) in the UK revealed a similar result as that found at Alexandra Hospital, where health care workers who worked with the patients on a daily basis had different beliefs and attitudes towards working with patients compared to health care professionals who worked with patients only on appointment. Further, the authors suggested a way forward which could help in bridging the gap and improving the quality of life for the patients. They suggested that management, together with the health care professionals, should collaborate with the health care workers working in a ward on a daily basis, providing effective leadership and building relationships with them. In building relationships, they would gain an understanding of their underlying values, the culture within the workplace, their attitudes and motivations, as well as their shared goals and responsibilities. It is clear from my study that though there has been important progress on the issue of language access, notably with the employment of the interpreter, the institution has some way to go to creating an environment in which the communication needs of clients are better served.

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APPENDICES

Appendix A: Consent Form

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Participant information form

Title of the research: The strategies utilised at Alexandra Hospital to eliminate language barriers and enhance communication.

You are invited to participate in the following study. The principal investigator of this study is Ms. Nyiko Hlungwani, a student from the department of Psychology at Stellenbosch University. You have been selected to participate because you have shown that you have somehow involved in implementing the strategies that aim to eliminate language barriers and enhance communication at Alexandra hospital. The purpose of the study is to explore the strategies which are implemented as well as the reasons why these strategies are implemented.

We would greatly appreciate it if you can give honest opinions regarding the subject. All the information that will be discussed will be confidential, and anonymity (no names will be mentioned) will be kept at all times. However, the position that one holds may be mentioned and this could make the participants identifiable. Your participation will involve semi-structured interviews which will be recorded using a digital recorder. The audio records of the interviews will be transcribed within two months after the interviews. The information will be kept in a safe and secured place on a password-protected computer.

The study does not anticipate causing any harm to you during the process. The interview will last approximately 30 to 45 minutes. There are no rewards of any form that will be offered for your participation; however, your comments and contribution may help at improving the functioning of the hospital. You have a choice if you want to take part in the study or not, and if you decide to take part be aware that you can withdraw at any time should you feel uncomfortable. Should you choose to withdraw during the study there will be no negative consequences and all the information you provided previously will not be used. Additionally, you can choose not to answer certain questions which make you feel uncomfortable.

This study will take place within a few months and the last phase of the study will focus on giving feedback on the findings, and this will give you an opportunity to participate again. Please feel free to ask the interviewer any questions before and after the interview. You may call the principal investigator, Ms Nyiko Hlungwani on 0738550904/ Prof Leslie Swartz on 0824593559 if you have any questions. If you agree to take part in the study, please sign below to show consent. You may keep the information sheet and submit the copy with the signature.

Thank you.

Participant consent

I have read and understood the information provided to me in the above sheet, or it has been read and explained to me. I also had an opportunity to ask questions about it and they were answered accordingly. I therefore consent voluntarily to participate in this study and understand that I have the right withdraw from the study at any time without any consequences.

Signature of participant: ____________________________ Date: _________________________

Signature of interviewer: ___________________________ Date: __________________________

Permission to be voice recorded

I hereby give permission to be voice recorded during the interview and for the information to be transcribed and reported accordingly.

Signature of participants: _________________________ Date: ____________________________

Signature of the interviewer: ______________________ Date: ____________________________

Permission to quote from my interview

I hereby give permission for relevant portions of my interview to be quoted in reports and publications if necessary, understanding that the information will be unidentifiable in the quote.

Signature of participant: _______________________________ Date: ___________________

Signature of the interviewer: __________________________ Date: _____________________

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Interview Schedule

As explained earlier when you were recruited for this study. I will be asking you questions related to the strategies which are utilised at the hospital to eliminate language barriers as well as to enhance communication. Please feel free to answer any questions I ask in any way that you feel. Remember that you are free to choose to answer the questions that you are comfortable with only. Also feel free to indicate if you want to stop altogether. You can also ask me any questions that you have in mind.

Do you have any questions? Should we start?

A. Can you tell me about your background?

1.Gender:

2. Level of education:

3. Position at the hospital:

4. Number of years at the hospital:

B. Tell me about your work?

1. How does language work here?

2. How communication with your clients/ residents an issue for you?

3. Can you give me an example?

4. What works well, can you give me an example of where this has worked well?

5. Do you know Sipho, the interpreter?

6. Do you work with him?

7. What is it like working with him?

8. How often do you work with him?

9. What have you learned working with him?

10. Does working with him work?

11. Give me an example? What has worked? What has not worked?

12. What advice do you give to people who are working at a similar setting as you? In terms of utilising strategies that can improve communication with residents/ the Clients?

Appendix C: Ethical Clearance letter

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Approval Notice

New Application

13-Sep-2016
Hlungwani, Nyiko NC

Proposal #: SU-HSD-002888

Title: The strategies utilised at Alexandra Hospital to eliminate language barriers and to enhance communication

Dear Miss Nyiko Hlungwani,

Your **New Application** received on **10-Aug-2016**, was reviewed
Please note the following information about your approved research proposal:

Proposal Approval Period: **05-Sep-2016 -04-Sep-2019**

Please take note of the general Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

Please remember to use your **proposal number** (**SU-HSD-002888**) on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Also note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary).

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 218089183.

Included Documents:

SUPPORT FOR PROPOSED RESEARCH AT

ALEXANDRA HOSPITAL.doc DESC Report

REC: Humanities New Application

Sincerely,

Clarissa Graham
REC Coordinator
Research Ethics Committee: Human Research (Humanities)

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch Universtiy Research Ethics Committee Standard

Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.