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Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

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Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

A report on a study project presented to

The Department of Social Work

School of Human and Community Development

Faculty of Humanities

University of the Witwatersrand



In partial fulfillment of the requirements

for the degree Bachelor of Social Work

By

Omphile Tsame

December, 2016

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b) To participants

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ABSTRACT

Confidentiality is one of the important elements when providing services to patients and clients, this includes services relating to HIV and AIDS. The study used qualitative research to explore the perceptions and experiences of community members pertaining to the maintenance of confidentiality by clinic staff. This case study employed semi-structured interviews with fourteen (14) community members at a village in the North West Province, South Africa. The data was analyzed using thematic analysis. The findings revealed that participants perceive their HIV status as being kept confidential; however they lacked confidence in the conduct of clinic staff as having the potential to maintain confidentiality in certain circumstances. They point to factors which convince them to believe that confidentiality is maintained and factors that may lead to the breach of confidentiality. Interestingly, patients showed lack of understanding of what is meant by confidentiality and maintenance thereof. The main conclusion is that with good systems and ethically conscious staff the confidentiality of patients can always be maintained. Furthermore the service providers have a responsibility of raising awareness to the patients about the 'Patient's Rights Charter' in relation to confidentiality.

Key words: HIV and AIDS, Confidentiality

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CHAPTER ONE

INTRODUCTION

1.1. INTRODUCTION

South Africa has one of the largest numbers of HIV infected persons in the world (UNAIDS, 2016). This leads to a lot of South Africans needing care by healthcare professionals. With that being said, every patient has the right to confidentiality of the information they divulge to healthcare professionals and information can only be divulged under certain conditions (Health Professions Council of South Africa, 2008). This right is in line with the right to privacy outlined in the highest law of the land-the South African Constitution (Act No. 108 of 1996) (As cited in HPCSA, 2008). With discriminatory attitudes that accompany the HIV epidemic, patients need their dignities protected (National AIDS Trust, 2009). The HPCSA (2008, P. 3) further points out that confidentiality is important because it "is central to trust between practitioners and patients. Without assurances about confidentiality, patients may be reluctant to give practitioners the information they need in order to provide good care." This study aimed to explore the experiences and perceptions of community members regarding the maintenance of confidentiality of HIV status by clinic staff. Through this exploration, the study was able to determine the experiences and perceptions of community members concerning confidentiality at the public clinic, community members' knowledge and their understanding of confidentiality.

1.2. STATEMENT OF PROBLEM

There has been a lot of literature on HIV and AIDS and its impact and it still continues to be produced. Gilbert and Walker (2002) write that HIV and AIDS does not only affect the individuals infected with the virus but affects significant others as well. The impacts of HIV and AIDs on individuals and their family members are both social and economic. This impact often presents itself in the form of absenteeism and being sick at workplace, increasing number of orphans due to AIDS causing burdens on welfare and health and reported lack of space and infrastructure to bury those who are dying from AIDS as per municipalities.

In her work, Vaas (2003) points out that HIV affects the economically active, the African continent and women in a negative way and this will consequently affect important aspects such as education.

Included in the impact of HIV/AIDS is the discrimination displayed towards those infected and affected by HIV/AIDS, and due to this discrimination, among other things maintaining confidentiality in working with HIV/AIDS becomes important (NAT, 2009). Healthcare professionals are all to abide by legislations, guidelines of practice, and policies which incorporate confidentiality and govern services provided in relation to HIV/AIDS (Gable, Gamharter, Gostin, Hodge & Puymbroeck, 2007; HPCSA, 2008).

1.3. RATIONALE

With the number of South Africans infected with HIV/AIDS and many of their family members and friends affected, it is important that measures are put in place to fight the disease (Statistics South Africa, 2015; Gilbert & Walker, 2002; Gilbert, Selikow & Walker, 2009). Healthcare professionals are at the forefront of fighting HIV and AIDS. The role of healthcare professionals is helping patients manage HIV and AIDS, in order for the patient to live a life considered 'normal' as far as it is medically possible (Gilbert et al, 2009). Protecting the confidentiality of patients' information is one of the ways healthcare professionals can help patients manage the disease (Gilbert et al, 2009).

When patients suspect that the confidentiality of their information such as HIV status may be revealed they may withhold the information from the health care service providers (NAT, 2009). Withholding information by patients may lead to patients not getting the necessary treatment or service (NAT, 2009). Since not maintaining confidentiality of patients may affect how much they disclose and can even cause them to be discriminated against, it is important that patients' rights to confidentiality are protected (UNAIDS 2016; HCSPA, 2008).

With regards to the impact of working with patients who are infected by HIV/AIDS, Mametja, Lekhuleni & Kgole, 2013) write that nurses face a number of problems when working with patients infected with HIV/AIDS such frustrations, lack of knowledge on HIV/AIDS, not having support systems, delay in treatment and having a lot of work. However, little is written about the point of view of service-users, who as indicated above face challenges when confidentiality is not guaranteed.

This study therefore looked at confidentiality in HIV and AIDS service provision, from the perspective of the service users. The focus was on how the rights of patients regarding the

manner in which private information disclosed in confidence is being handled by healthcare professionals.

1.4. *AIMS AND OBJECTIVES*

1.4.1. Research Question

What are the experiences and perceptions of community members regarding clinic staff's maintenance of confidentiality of HIV status?

1.4.2. Primary Objectives

Aim:

To explore experiences and perceptions of community members regarding clinic staff's maintenance of confidentiality of HIV status

Objectives:

- To explore community member's experience and/or observation of breach of confidentiality of HIV status.
- To Investigate community members' perceptions of the manner in which clinic staff breach or maintain confidentiality of HIV status of patients
- To explore community members' understanding of confidentiality of HIV status.

1.5. OVERVIEW OF THE RESEARCH DESIGN AND METHODOLOGY

This study sought to examine the experiences and perceptions of community members, the purpose was to describe and understand their experiences and perceptions regarding maintenance of confidentiality of their HIV status and their understanding of confidentiality of HIV status, therefore a qualitative approach was employed in this study, as it is usually "considered appropriate when the research question that has been developed involves learning about, understanding or describing a group of people, their interaction, behavior, and experiences" (Greenstein, Roberts & Sitas, 2003, p. 51).

A case study research design was used (Creswell, 2009). Stake points out that "case studies are a strategy of inquiry in which the researcher explores in depth a program, event, activity, process, or one or more individuals. Cases are bounded by time and activity and researchers collect detailed information using a variety of data collection procedures over a sustained period of time" (As cited in Creswell, 2009, p. 46).

The interview was utilized as a method of data collection (Greenstein et al, 2003). The interview can be defined as "a conversation that puts emphasis on the art of asking questions and listening" (Greenstein et al., 2003, p. 55). The semi-structured interview schedule was one of the instruments used, it includes "a clear list of issues to be addressed and questions to be answered, but there is more flexibility around the sequence in which they are asked and the interviewer allowed the respondent to speak more broadly about the topics being discussed" (Greenstein et al, 2003, p. 56).

Individual interviews were conducted with interviewees in spaces they felt comfortable. Community members aged 20 -31of the black racial grouping were sampled using quota sampling. Quota sampling is "a non-random sample in which the researcher first identifies general categories into which cases or people will be selected, and then he or she selects cases to reach predetermined numbers of cases in each category" (Neuman, 2006, p. 221). A sample of 14 people was selected and studied. Once categories were taken care of in quota sampling, the next step was for the researcher to use haphazard sampling (Neuman, 2006). Haphazard sampling means the researcher chooses any person he/she walks into (Neuman, 2006). The researcher asked to interview the first 7 male and 7 females she encountered in the village and who fitted the criteria (Neuman, 2006).

The 'pilot' study was conducted with one community member. This helped the researcher familiarize herself with the interview schedule, and also helped her to check how long the interviews may take (Greenstein et al, 2003). It furthermore helped the researcher see whether the questions she intended to ask got her the answers she needed and enabled her to see whether the semi-structured interview schedule was effective in conducting her research. In addition to the 'pilot' study as a means of ensuring reliability and validity, the researcher was the only researcher conducting the interviews.

1.6. ANTICIPATED BENEFITS OF THE RESEARCH

The study may help the healthcare sector in terms of putting measures to ensure policy implementation of the existing guidelines and policies to ensure effective service provision with regards to confidentiality of HIV and AIDS. The study may also provide insight to community members about their rights to confidentiality in the event the results are shared with them.

1.7. KEY CONCEPTS

HIV and AIDS, Confidentiality

HIV and AIDS

"Human Immuno-Deficiency Virus (HIV) is a virus that enters blood. In HIV positive people, the virus can be found in the blood, sex fluids (such as sperm and vaginal fluids) and breast milk. HIV attacks and eventually destroys the body's immune system. The immune system normally fights germs, infections, bacteria and viruses that would make a person sick. The body cannot defend itself against germs, infections, bacteria and viruses when this 'army' gets weak. HIV causes Acquired Immuno-Deficiency Syndrome (AIDS). HIV slowly damages the immune system (the army) if it gets into a person's body. This means that the body starts to lose its ability to defend itself against germs, infections and bacteria such as TB" (Aid for AIDS, 2005, p. 2).

Confidentiality

The HPCSA (2008, p. 3) states how confidentiality is to be maintained when working with HIV/AIDS:

- "Ethics, the South African Constitution (Act 108 of 1996) and the law recognize the importance of maintaining the confidentiality of the HIV status of a patient.
- The test results of HIV positive patients should be treated with the highest possible level of confidentiality.
- Confidentiality regarding a patient's HIV status extends to other health care practitioners. Other health care professionals may not be informed of a patient's HIV status without the patient concern's consent unless the disclosure is clinically indicated. For treatment and care to be in the best interests of the patient, the need for disclosure of clinical data, (including HIV and related test results), to health care practitioners directly involved in the care of the patient, should be discussed with the patient.
- The decision to divulge information relating to the HIV status of a patient must always be done in consultation with the patient.
- The report of HIV test results by a laboratory, as is the case with all laboratory test results, should be considered confidential information. A breach of

> confidentiality is more likely to occur in the ward, hospital or health care practitioner's reception area than in the laboratory. It is, therefore, essential that health care institutions, pathologists and healthcare practitioners formulate a clear policy as to how such laboratory results will be communicated and how confidentiality of the results will be maintained."

1.8. OVERVIEW OF RESEARCH REPORT

The research report consists of five chapters, a reference list and appendices (ethics clearance certificate, consent forms, information sheet and interview schedule). The first chapter is the introduction, the second chapter is the literature review and theoretical framework, the third chapter is the methodology, chapter four will contain findings/results and the last chapter will focus on the discussion of the findings (that is the main findings, recommendations and a conclusion).

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. INTRODUCTION

In the literature review, the researcher found a useful amount of literature on the importance of maintaining confidentiality of patients, but also maintaining confidentiality specifically with regards to HIV/AIDS. The researcher also looked at the impact of HIV and AIDS and the efforts to deal with the HIV/AIDS situation.

2.2. HISTORY

Keeping all medical information private is rooted in history, dating back to the Hippocratic Oath, which states "what I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about" (King, 2010, p. 196). This keeping of patient information confidential speaks to trust in the relationship between doctors and patients, and although doctors do not take the original Hippocratic Oath anymore, keeping patient information confidential is still being pledged currently (King, 2010).

Currently, important documents outline the rules of confidentiality with regards to patient information (King, 2010). It is a requirement that all health care professionals or staff maintain confidentiality of patients when working with HIV/AIDS (HPCSA, 2008). The protection of confidentiality of patient information is in line with the human rights outlined in Chapter 2 of the Bill of Rights of the Constitution of the Republic of South Africa, 1996 and the ethical guidelines in the Health Professions Council of South Africa (HPCSA, 2008) documents. Some of the same guidelines are outlined in the National Health Act 61 of 2003 and specifically national and international ethical rules developed looking at responding to challenges brought about by HIV/AIDS. Breaching of these rules and rights may result in disciplinary action (HPCSA, 2008).

2.3. ARGUMENT

Chapter 2 of the Bill of Rights of the Constitution of the Republic of South Africa, 1996 outlines human rights which can be observed when providing services to patients. The constitution points out that every person has the right to access health care services, the right to equality and not to be unfairly discriminated against, the right to freedom and security, the right to privacy and the right to an environment that will not harm people.

Therefore maintenance of confidentiality is important because it protects the human rights of patients. Furthermore, patients themselves feel more confident to share their information with healthcare providers if they are assured that confidentiality will be kept (NAT, 2009). Protecting confidentiality of patients is therefore in the best interest of patients, but under certain conditions (HPCSA, 2008).

2.4. THEORETICAL FRAMEWORK AND LITERATURE REVIEW

The problem of HIV and AIDS in South Africa

According to the South African Department of health's strategic plan 2014/15-2018/19, in the year 2012 the country continued to house the largest number of people infected with HIV/AIDS. For the year 2015, Statistics South Africa estimated that the mid-year population of the country was at 54,96 million, and the estimate for overall HIV prevalence was roughly at 11,2% of the whole South African population. The total amount of HIV positive persons was estimated at roughly 6,19 million in the same year. Adults who are from 15 to 49 years who are HIV positive was estimated at 16,6% of the population in that same of 2015.

Not only are 6,19 million people in South Africa living with HIV/AIDS but the disease also affects many of their family members and friends. The disease therefore poses a problem for any population including South Africa because it is not only a health issue but a social and economic issue (Gilbert et al, 2009). The infected and affected find themselves having to spend money on ARVs, and also with the 15-49 year group living with the disease and are being the economically active group of country this poses a problem on individuals and the country as a whole. Socially, the family members of the affected find themselves burdened with being care takers of the

infected; the disease also claims the lives of the infected so that the affected are orphaned, etc. and this affects the broader population as well.

Efforts to deal with HIV and AIDS in South Africa

It is therefore important that measures are put in place to fight against HIV and AIDS. In South Africa in addition to keeping statistics there have been other countless efforts to fight against HIV/AIDS, such as the government's efforts (South African National AIDS Council, 2011). The government efforts include prevention of mother-to-child transmission, provision of HIV counseling and testing (HCT), and provision of antiretroviral (ARVs) (SANAC, 2011; National Strategic Plan 2012-2016; DoH Strategic Plan of 2014/15-2018/19). Included in the government's efforts is laying out the roles of healthcare professionals in fighting against HIV/AIDS (Gilbert et al, 2009; NAT, 2009). Healthcare professionals are to help patients manage HIV/AIDS, they also have a role in their relationships with patients, and also have a role in keeping what is discussed between them and patients confidential (Gilbert et al, 2009; NAT, 2009).

Service provision and confidentiality

The HPCSA (2008, p. 3) states how confidentiality is to be maintained when working with HIV/AIDS:

- "Ethics, the South African Constitution (Act 108 of 1996) and the law recognize the importance of maintaining the confidentiality of the HIV status of a patient.
- The test results of HIV positive patients should be treated with the highest possible level of confidentiality.
- Confidentiality regarding a patient's HIV status extends to other health care practitioners. Other health care professionals may not be informed of a patient's HIV status without the patient concern's consent unless the disclosure is clinically indicated. For treatment and care to be in the best interests of the patient, the need for disclosure of clinical data, (including HIV and related test results), to health care practitioners directly involved in the care of the patient, should be discussed with the patient.
- The decision to divulge information relating to the HIV status of a patient must always be done in consultation with the patient.

- The report of HIV test results by a laboratory, as is the case with all laboratory test results, should be considered confidential information. A breach of confidentiality is more likely to occur in the ward, hospital or health care practitioner's reception area than in the laboratory. It is, therefore, essential that health care institutions, pathologists and healthcare practitioners formulate a clear policy as to how such laboratory results will be communicated and how confidentiality of the results will be maintained."

Furthermore the HPCSA (2008, p. 2-3) states patient's rights to confidentiality to be:

- "Rule 13 of the Ethical Rules of the HPCSA states that a practitioner may divulge information regarding a patient only if this is done:
- In terms of a statutory provision,
- At the instruction of a court,
- In the public interest,
- With the express consent of the patient,
- With the written consent of a parent or guardian of a minor under the age of 12 years,
- In the case of a deceased patient with the written consent of the next of kin or the executor of the deceased's estate.
- Disclosures in the public interest would include but not be limited to situations where the patient or other persons would be prone to harm as a result of risk related contact."

The National Health Act 61 of 2003 states that:

- "Patients have rights and responsibilities. Section 19 of the National Health Act stipulates that patients should –
- Adhere to the rules of the health establishment when receiving treatment or using health services at the health establishment;
- Subject to section 14 on confidentiality, provide the health care provider with accurate information pertaining to his or her health status and co-operate with health care providers when using health services;
- Treat health care providers and health workers with dignity and respect; and
- Sign a discharge certificate or release of liability if he or she refuses to accept recommended treatment.

Providers have rights not to be discriminated against, and to be protected against damage to their person or property, including disease transmission (section 20). This is dealt with in more detail elsewhere in these guidelines."

Looking at universal rules:

- The WMA International Code of Medical Ethics (2006) states that a physician is to protect the confidentiality of patients (As cited in World Medical Association, 2015).
- The WMA Statement on Patient Advocacy and Confidentiality (1993) outlines that practitioners have to act in the best interest of patients all the time (As cited in WMA, 2015).

The National Patients' Rights Charter, 1999 outlines important issues such as the rights of patients with regards to hospitals and clinic and the rights people have to use public and private services in healthcare. This document is not a law, but outlines guidelines to be followed by both patients and care workers. Its importance stems from it outlining rights and duties of patients who attend public hospitals and clinics. The Charter states that health care professionals need to provide treatment that respects human dignity, shows courtesy and tolerance to patients. One of the rights outlined in this document is the right to enjoy confidentiality and privacy. But also important are the duties outlined.

2.5. CONCLUSION

In conclusion, the theoretical framework and literature review section looked at discussing what was found in literature in terms of the problem of HIV/AIDS with regards to its dominance and impact, efforts to deal with the epidemic and the laws, policies and guidelines that outline the responsibilities of healthcare professionals, but also the rights and duties of patients with most of the focus being on the context of South Africa.

With there being limited literature looking at the perspective of the patients themselves, the laws, policies and guidelines discussed serve to understand and describe experiences of community members by looking at what these documents outline about the rules of confidentiality with regards to service provision, especially pertaining to HIV/AIDS.

CHAPTER THREE

METHODOLOGY

3.1. INTRODUCTION

This chapter will discuss the methodology used in data collection. It will discuss the research design and research method. Under the heading research method the population sampled and how it was sampled, the research tool, the pilot study (pretest), the data collection method, the limitations of the research, how the trustworthiness criteria might have been met by the research, and the ethical considerations by the study will be discussed.

3.2. RESEARCH QUESTION, AIM AND OBJECTIVES

Research question:

What are the experiences and perceptions of community members regarding clinic staff's maintenance of confidentiality of HIV status?

Aim:

To explore experiences and perceptions of community members regarding clinic staff's maintenance of confidentiality of HIV status

Objectives:

- To explore community member's experience and/or observation of breach of confidentiality of HIV status.
- To Investigate community members' perceptions of the manner in which clinic staff breach or maintain confidentiality of HIV status of patients
- To explore community members' understanding of confidentiality of HIV status.

3.3. RESEARCH DESIGN

This study used a qualitative approach to research (Greenstein et al, 2003). Qualitative research is usually "considered appropriate when the research question that has been developed involves learning about, understanding or describing a group of people, their interaction, behavior, and experiences" (Greenstein et al, 2003, p. 51). This study sought to examine the experiences and

perceptions of community members through interviews with the purpose of describing and understanding these experiences and perceptions regarding maintenance of confidentiality of their HIV status and their understanding of confidentiality of HIV status.

The qualitative approach provided a rich perspective which is also contextual to this research, it helped the researcher understand the worldview of those that are being studied, and study them in a setting natural to them (Greenstein et al, 2003)**.** Within this research approach, the research design used was the case study (Creswell, 2009).

Stake writes that "case studies are a strategy of inquiry in which the researcher explores in depth a program, event, activity, process, or one or more individuals. Cases are bounded by time and activity and researchers collect detailed information using a variety of data collection procedures over a sustained period of time" (As cited in Creswell, 2009, p. 46). This form of research design was used because the 14 case studies were explored.

3.4. RESEARCH METHOD

3.4.1. Population and Sampling

The target population for this study was both males and females who are black in race and are between the ages of 20 and 31. A target population is "the concretely specified large group of many cases from which a researcher draws a sample and to which results from a sample are generalized" (Neuman, 2006, p. 224). Due to the high percentage of persons aged 15 to 49 living with HIV, it was important to study people within this group.

The non-probability/non-random sampling that was employed to select the potential participants of this study was quota sampling (Neuman, 2006). Quota sampling is "a non-random sample in which the researcher first identifies general categories into which cases or people will be selected, and then he or she selects cases to reach predetermined numbers of cases in each category" (Neuman, 2006, p. 221).

A sample of 14 people was selected and studied. Once categories were taken care of in quota sampling, the next step was for the researcher to use haphazard sampling (Neuman, 2006). Haphazard sampling means the researcher chose any person he/she walked into (Neuman, 2006). The researcher asked to interview the first 7 males and 7 females she encountered at the village who fit the criteria for the research (Neuman, 2006).

The form of sampling selected which was quota sampling was suitable because the target population had to fit into a very specific category of those who had tested for HIV or heard of someone who had tested at the local clinic and were aged between 20 to 31. The village in which the target population was found was mostly made up of people of the black racial group. Haphazard sampling was suitable because such a technique allowed the researcher to speak to community members about such a sensitive thing such as HIV testing without asking other community members to help her locate others who had tested (e.g. the snowballing technique which is about people connecting people (Neuman, 2006)).

3.4.2. Research Tool

The research utilized the interview as a method of data collection (Greenstein et al, 2003). The interview can be defined as "a conversation that puts emphasis on the art of asking questions and listening" (Greenstein et al., 2003, p. 55). The semi-structured interview schedule was one of the instruments used, it includes "a clear list of issues to be addressed and questions to be answered, but there is more flexibility around the sequence in which they are asked and the interviewer will allow the respondent to speak more broadly about the topics being discussed" (Greenstein et al, 2003, p. 56).

The interview is one of the instruments used in data collection in qualitative research and so in order to understand and describe the experiences and perceptions of community members, the researcher saw the interview to be suitable in order to attain the in-depth information she needed. The semi-structured interview was specifically used in order to provide community members with structure with what was to be discussed, but also enough flexibility for them to explain and describe what they wanted to.

3.4.3. Pre-test

According to Neuman (2006), in order to have observations, which are consistent (reliable), qualitative researchers use interviews, focus groups, document studies and other techniques. He further explains that in terms of validity, "qualitative researchers are more interested in authenticity than in the idea of a single version of truth. Authenticity means giving a fair, honest, and balanced account of social life from the viewpoint of someone who lives in it every day" (p. 196).

When considering validity and reliability in collecting data for this research, the researcher not only took into consideration the above mentioned by Neuman (2006) but further ensured validity and reliability through conducting a 'pilot' study (pre-test), using the same sampling methods discussed above. The 'pilot' study was conducted with 1 community member.

Conducting the 'pilot' study helped the researcher familiarize herself with the interview schedule, and also helped her to check how long the interviews would take (Greenstein et al, 2003). It furthermore helped the researcher see whether the questions she intended to ask got her the answers she needed and helped her see whether the semi-structured interview schedule would be effective in conducting her research. In addition to the 'pilot' study as a means of ensuring reliability and validity, the researcher was the only researcher conducting the interviews.

3.4.4. Data Collection

Individual interviews were conducted with 14 participants and 1 'pilot' study participant. In the interviews, the participants and the researcher were be seated in their homes and spaces they were comfortable with. Before every interview, members were taken through the participant information sheet and the consent forms for participation and audio-recording. Once this part was done, the interview would commence.

3.4.5. Limitations

The limitations of this research are:

- Since people are different, the individuals interviewed may likely be a lot different from everyone else in the population, also it is possible that issues that are important may have been missed entirely, and also it is difficult to aggregate the data and systemically compare the data because of the limited number of participants in qualitative research (Greenstein et al, 2003).
- Quota sampling itself may be problematic because just any 7 black male and 7 black female participants were sampled and this may not be representative of the population (Neuman, 2006).
- Participants may have given answers that were based on grudges or personal encounters with clinic staff.

- Since participants were interviewed in their homes and spaces they were comfortable in, there were distractions such as family members, friends and music.
- Language proved to a barrier with regards to using the term 'confidentiality' which is an English term.
- Participants were comfortable with friends and family members sitting in on interviews and so this may have influenced information they provided in interviews.

3.4.6. Trustworthiness

Just as with data collection, reliability and validity need to be taken into consideration in data analysis (Greenstein et al, 2003). Reliability and validity in the data analysis process of this research will be ensured through checking if the research meets the trustworthiness criteria (Greenstein et al, 2003). The trustworthiness criteria has four basic components: credibility, transferability, dependability, and conformability of research (Greenstein et al, 2003).

Credibility is about how accurate the description by the researcher is in terms of how it was told by the interviewees; transferability is about the level to which what is found by the research can be applied to other participants or contexts; dependability is about how stable the information collected and conditions are over a period of time; and confirmability is about the level to which the information collected is not just imagined by the research, it looks into the issue of neutrality (Greenstein et al, 2003).

In ensuring that the research is credible, the researcher used investigator triangulation through allowing another researcher to look at some raw data (Greenstein et al, 2003). Streubert and Carpenter point out that investigator triangulation "is a process whereby two or more investigators with diverse research training backgrounds examine the same phenomenon" (As cited in Ziyani, King & Ehlers, 2004, p. 12). Burns and Gove argue that the benefit is that it takes away the bias that may potentially exist in research conducted by one researcher (As cited by Ziyani et al, 2004).

To ensure that the research is transferable, the researcher provided enough information about the participants (i.e. specific category of participants interviewed) so that those who read the research report can establish the level to which the participants and other cases are similar in order to generalize the findings (Greenstein et al, 2003).

With regards to dependability, Shenton (2004, p. 71) writes that "in order to address the dependability issue more directly, the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results. Such in-depth coverage also allows the reader to assess the extent to which proper research practices have been followed."

In order to enable those who are to read the research report to thoroughly develop an understanding of the methods used and how effective they were, the research report will cover the following: "the research design and its implementation, describing what was planned and executed on a strategic level" (Shenton, 2004, p. 71).

In ensuring confirmability, the audit trail was used (Greenstein et al, 2003). "Detailed methodological description enables the reader to determine how far the data and constructs emerging from it may be accepted. Critical to this process is the 'audit trial', which allows any observer to trace the course of the research step-by-step via decisions made and procedures described" (Shenton, 2004, p. 72).

3.4.7. Ethical Consideration

In process of this research, there were ethical issues considered (Ogletree & Kawulich, 2012). For this particular research study, ethical issues that were considered were: doing no harm to participants, and informed consent (informing participants of what the study is about, how results will be used, and the level of their involvement), and anonymity and confidentiality (Ogletree & Kawulich, 2012).

Doing no harm to participants involved not inconveniencing participants due to time (45 minutes may be too long for some patients); feeling stress due to emotionally sensitive topics in their past or present life; apprehension; humiliation, and loss of pride and dignity (Ogletree & Kawulich, 2012). In order to minimize harm to participants, they were given the opportunity to privacy in order to preserve them from humiliation and loss of pride and dignity and the time limit of 45 minutes was adhered to within interviews. They were also they were provided with contact details of social workers they could contact in case stress or emotional distress arose from discussing sensitive issues around HIV testing and confidentiality.

In terms of informed consent, the information sheet document contained three principles: the participant withdrawing from the study at any point in time of the interview, the participant needing to volunteer to participate, the participant being made aware that the study may have emotional or physical effects on him/her (Ogletree & Kawulich, 2012). This researcher further explained what each principle means to participants.

In terms of anonymity and confidentiality, Patton (2002) defines anonymity as being about the participants' identities remaining unknown to the researcher, and confidentiality as being about the researcher knowing the identities of participants but willingly informing others (As cited in Ogletree & Kawulich, 2012). In the case of this study, the researcher kept anonymity by not asking for the names and other personal information of participants apart from their ages (which is was a category for the sample); and as for confidentiality, the researcher kept it by using pseudonyms when recording her findings (Ogletree & Kawulich, 2012).

3.5. CONCLUSION

In conclusion, the research process was discussed in detail. A research design which was the case study was used within the qualitative approach to research with non-probability sampling which is the type of sampling used in qualitative research, but specifically quota sampling. Quota sampling was used to sample the target population of 14 participants who are of the black racial group and were both males and females aged 20 to 31. These community members reside in the community of Kraalhoek located in the North West province. The 14 participants were 7 males and 7 females and were made up of those who had tested for HIV or knew of people who tested for HIV at the local public clinic. 1 'pilot' study was conducted.

The interview was used as a method of data collection, specifically the semi-structured interview structure. The limitations of this research, as well as how the trustworthiness criteria (i.e. that is the credibility, transferability, dependability and confirmability) is to be met and ethical considerations of reducing harm, informed consent, and anonymity and confidentiality by the research were also discussed.

CHAPTER FOUR

FINDINGS/RESULTS

Introduction

This chapter outlines the results from the study regarding the experiences and perceptions of community members pertaining to the maintenance of their HIV status in a public clinic. The study was conducted with a sample of 14 black participants, 7 female participants and 7 male participants aged between 20 and 31 years. Three main themes summarize the results of the research, namely: satisfaction with service, understanding of confidentiality and maintenance of confidentiality. These were found during data analysis, using thematic analysis in qualitative research.

Satisfaction with service

Service provision by clinic staff was found to be satisfactory by participants. Participants felt that staff was able to provide appropriate service in terms of information explained and their friendly service. Furthermore, participants expressed that they would not do things that much differently from how they were treated and how procedures were followed. However, gaps were identified during service provision of HIV testing by a other participants. Despite the identified gaps, which were identified to be in terms of information explained regarding HIV/AIDS and records being given to another professional without permission, participants still maintained that they were satisfied with overall service provided by clinic staff. In expressing their satisfaction of service, participants outlined aspects that they felt made the service satisfactory and among these that were brought up were common courtesy and tolerance.

"Yah, I was fine. I was satisfied that er…everything I wanted was met, you see?" Peter

"No, I don't think there is something different I could have done coz the way staff was, it was fine." Kitso

"They treated me just fine, like…I can tell you fine but there are other things that, that…eish…" Tshepo

"They treated me fine cos even after they drew my blood…and threw it in that thing, they were chatting with me like so that I do not get stressed that that side they could come back…" Lisa

Although the general sense from participants was satisfaction of service provided by staff, complete dissatisfaction of service was also expressed. This dissatisfaction arose from lack of education and information identified in clinic staff during service provision. This dissatisfaction is regarding explanation by clinic staff on information about HIV/AIDS. Furthermore the service would have been carried out differently with regards to this information provided by clinic staff. The lack of explanation on some aspects such as explanations pertaining to infection and lifestyle changes by clinic staff resulted in dissatisfaction.

"Yes, I wasn't satisfied…Now you are changing your routine. Your life starts to change and how are you going to live it, like this and this and this. This would make you live for a long time." Hank

Understanding of confidentiality

An important factor in service provision with regards to HIV testing is the maintenance of confidentiality of the test results of patients (HPCSA, 2008). It was found that the common understanding among participants with regards to confidentiality in terms of HIV testing is that confidentiality is a secret that stays just between the practitioner doing the testing and the patient being tested.

"He or she is not supposed to tell people…that…the patients that come to him or her, he or she is not supposed to say that this person, that person is like this…she works with a lot of people. She is not supposed to speak, it is the secret of the individual…unless that person feels like speaking…about his or her status." Patty

"Confidentiality? It is something that is con…like, it's not for everyone…it's for that person…like it's for…it's something that maybe is too secretive…that is respected that it is for that particular person or…something that is, I don't know how to put it…"Miranda

The establishment of community members' understanding of confidentiality proved to be important in terms of understanding their experiences and perceptions with regards to the maintenance of confidentiality at the public clinic.

Maintenance of confidentiality

It was expressed by most participants that clinic staff explained to them about confidentiality. The common explanation was that the information shared during the service provided would end just between those tested and the staff themselves. Further than this, it was found that it was explained that results may go to a laboratory for verification.

"She just told me that it will be our secret…that I feel like telling a person, it's up to me but it's a secret of mine…and hers. Yes, she has no right to go and talk about the results that would be arising from there…" Kitso

"She told me that when we were in the room we were in, she told me that this information is for me and you and it won't go outside…it is our secret, it will…it will depend on you if you tell it…who you tell. Even for you to accept, you need to find one person in the family or one person whom you trust…who you can tell about this thing." Patty

However, it was also found that not all participants may had been explained to or talked about confidentiality with during service provision of HIV testing.

"Yah, that's why I say I am not sure because that one she did not mention." Miranda

Also, participants expressed that they think that clinic staff maintained their HIV status after testing them and provided reasons for this. The reasons provided were that the news of testing or HIV status had not been heard in the village, the results of the tests being negative and confidentiality being explained by clinic staff.

"Yes, they maintained confidentiality…I [Stammers] did not hear information about…around, you see? If ever he or she did not keep it confidential, it would have already been spoken about…I would have heard different things…I checked her and it is like this, you see?" Tshepi

"I would have already heard a lot of people tell me my status, you see? That I tested and my results are as like this and that. You see? But now I have not heard anything….Yes, in the village they like to gossip, so I would have already heard the news." Beauty

"Yah. I think so…Yah…Because I don't think…it would make much damage if…because I am negative." Hank

Important South African documents such as the constitution of the Republic of South Africa, HPCSA (2008), National Health Act 61 of 2003 and the National Patients' Charter, 1999 outline the rights, ethics or guidelines regarding confidentiality and service provision with regards to patients by healthcare professionals. All these documents have in common that they stress the importance of keeping patient medical information confidential.

It was also some found that participants expressed that they could not be sure and others that they would not know if the information shared between themselves and practitioners during the HIV testing service by practitioners was kept confidential, but did provide indicators which could show them that the information was kept confidential.

"Yes. I am not sure that if they continued to keep it or talked or what." Frank

"No, I am not sure…if they kept it or not." Lerato

"There I am not sure…Because I don't know them well, you see? So I am not sure. I don't know after I left what happened, but I am not sure about that they…yah, I am not sure." Miranda

"I don't know when they kept it or what they did with it…who they told? Yes…No, I don't believe they told anyone, they treated me just okay, just like anyone who comes…who comes to the clinic they treat them just okay…Yes…Yes… Because they treated me just okay." Boity

Also found was that participants revealed that they do not think their HIV status was kept confidential by practitioners and provided reasons for this in that they were tested by people who know them and because of how practitioners are known to breach confidentiality in the village.

"Yes. I don't trust them that they could keep the secret, you see? It did not comfort me. Coz of even if whoever touches the file, they are the ones who tested me and already know what is happening, right" Paul

"…you see the person that you and him or her know each other, a lot of confidential will not be there." Ray

"Which that one I can't assure…To be honest, I can't say they kept it a secret…according to the way I see how they do sometimes, you see? Even if he or she tested when it was the two of

us…for the moment it can be confidential. You see? But then later afterwards…You understand? Then she tells one of her friends and then it will be like a long story." Thapelo

In relation to breach of confidentiality, it was found that other participants have experienced and perceive breach of confidentiality of HIV status by practitioners at the public clinic. Participants explained that they have experienced and perceived breach of other people's HIV status, particularly those who are HIV positive and not necessarily their own.

"No. Some of them look like they could speak."Lerato

"But my problem is…even if someone find out that he is positive…and they tell him…and they tell him or her to come to the clinic, neh…so that they can open a file for him…and that person doesn't go to, er…the clinic, they must not tell us, as the community. Like…that that person…You understand? That's something confidential…. that means the staff, the nurses…they better try to find out the family of that person and go straight to the family…That's what I am saying, for someone who is negative, they won't say anything…but for somebody who is positive that he or she is not at the clinic, that's where they go around talking telling us that go and tell that person to come to the clinic to take his or her medication. Whereas they, I think it is best that they go to that person's home as nurses or counselors, as well as these ones of home-based, you understand?" Thapelo

"Yes. So it means that…to test at the clinic is an easy access for most people. But many people fear…the issue of confidentiality…Yah. The last time I went to test, I told them that if a person tests and is sick, people would know. No, there is no such thing, information does not come out. I just wanted to tell that I know that…It is a secret. But they don't do…the thing is they don't do it at all, you see? And I don't know…I don't have that knowledge that actually this confidentiality really means confidential…Yes. The thing is they can make an example about someone and then when you find out about that person you find that seriously, you find out that it is said he or is sick…So it means what? They spoke that he or she is sick, then another person knows that person is sick or then he or she tells you and this information ends up being spread, you see? Then if you can confront him or her that serious this guy is sick…You see? Yes, I was just giving you an example…Yes…Exactly…Why can it be known so fast? It means they speak. They release information that they are not supposed to. So I am focused on, it means, it means people that

are…the people at the clinic who test, etc. are kids from here at home that, that got a job from at home." Hank

CHAPTER 5

DISCUSSION OF FINDINGS/RESULTS

The study was exploring the experiences and perceptions of community members with regards to the maintenance of confidentiality of HIV status by clinic staff in a public clinic. The study seeks to understand and describe these experiences and perceptions of members of the community. Three main themes emerged from data analysis: satisfaction with service, understanding of confidentiality and maintenance of confidentiality. The research findings were presented under themes in the preceding chapter. In this chapter the main findings are discussed followed by recommendations and a conclusion.

With regards to the first two objectives of the research; to explore whether or not community members have experienced and/or observed breach of confidentiality regarding HIV status and to investigate community members' perceptions of the manner in which clinic staff breach or maintain confidentiality regarding HIV status of patients at the clinic, the research was able to explore the perceptions and experiences of community members and found that community members experienced that their own HIV status was kept confidential by clinic staff and provided different reasons and indicators that confirmed what they viewed as maintenance of confidentiality. Participants expressed that due to not hearing information shared in the testing service spread in the village, their HIV test results being negative, and clinic staff explaining the rules of confidentiality they viewed that confidentiality was maintained.

However other participants' perceptions were that breach of confidentiality at the clinic occurs in cases of HIV positive patients. Participants explained that they perceive that breach occurs because clinic staff explicitly asks community members to pass messages about treatment to HIV positive patients and because these patients' HIV status is heard in the village.

Pertaining to the last objective of the research: exploring community members' understanding of confidentiality of HIV status, participants shared their understanding of confidentiality and the common view among participants was that confidentiality is about the information shared during the services of testing for HIV being kept just between the practitioner and the individuals being tested. This understanding of confidentiality proved to play an important role in the participants' experiences or perceptions of breach or maintenance of confidentiality at the clinic.

With participants having viewed that their HIV statuses were kept confidential, the National Patients' Charter, 1999 outlines that confidentiality is a right of patients. Furthermore confidentiality protects the human dignity of the patients which is a human right outlined in Chapter 2 of the Bill of Rights of the Constitution of the Republic of South Africa, 1996. Also, according to NAT (2009) when patients can be assured that their HIV statuses will be kept confidential, they will be more comfortable to disclose their private information to medical practitioners. With the amount of discrimination around HIV/AIDS, patients need to be assured their information will be kept confidential (NAT, 2009). In addition, the National Patients' Rights Charter, 1999 states that health care professionals need to provide treatment that respects human dignity, shows courtesy and tolerance to patients.

With participants having expressed that they have observed breach at the clinic, specifically of those who are HIV positive, Chapter 2 of the Bill of Rights of the Constitutions of the Republic of South Africa, 1996 emphasizes how wrong this is since it states that every person has the right to privacy. This document which is the highest law of the land is complimented by documents such as the HPCSA (2008), WMA (2015) which stress the importance of confidentiality.

Furthermore, in their study Dapaah and Senah (2016) which sought to examine the socio-psychological trauma patients go through in their wanting to get healthcare in two facilities which provide healthcare in the region of Ashanti in Ghana, the researchers found that breach of confidentiality which participants observed caused them to be uncomfortable with the quality of service provided and for them to want to access service without their being identified. This shows that patients feel uncomfortable when the information they share in confidence with staff is leaked.

Understanding of confidentiality by participants, as mentioned above, is that confidentiality is a secret that stays just between the staff member doing the testing and the patient being tested. In addition to information shared between patients and healthcare professionals staying between them, there are more conditions under which confidentiality should be maintained. The HPCSA (2008, p. 3) states how confidentiality is to be maintained with regards to HIV/AIDS:

- "Confidentiality regarding a patient's HIV status extends to other health care practitioners. Other health care professionals may not be informed of a patient's HIV

status without the patient concern's consent unless the disclosure is clinically indicated. For treatment and care to be in the best interests of the patient, the need for disclosure of clinical data, (including HIV and related test results), to health care practitioners directly involved in the care of the patient, should be discussed with the patient.

- The decision to divulge information relating to the HIV status of a patient must always be done in consultation with the patient..
- The report of HIV test results by a laboratory, as is the case with all laboratory test results, should be considered confidential information. A breach of confidentiality is more likely to occur in the ward, hospital or health care practitioner's reception area than in the laboratory. It is, therefore, essential that health care institutions, pathologists and healthcare practitioners formulate a clear policy as to how such laboratory results will be communicated and how confidentiality of the results will be maintained."

Participants were able to describe their experiences and perceptions of confidentiality based on their own understandings of confidentiality, although these understandings appeared to be limited when compared to the rules of confidentiality of HIV/AIDS outlined in the HPCSA (2008).

Therefore it is the recommendation of this research that patients be informed of all the rules that apply with regards to confidentiality in terms of HIV/AIDS by staff when working with participants but also in addition to that through perhaps other modes of communication such as pamphlets which they could access at public clinics so that when patients are able to understand which rules of confidentiality apply, they will be able to determine whether breach or maintenance of confidentiality has occurred.

Also, with regards to breach observed at the clinic by some participants, it would be important for participants to report this to the proper authorities at the clinic so that the staff conducting the breach may be dealt with accordingly. The HPCSA (2008) states that practitioners who breach confidentiality will incur the consequences.

Conclusion

The results of the research showed that most participants thought that their HIV statuses were kept confidential by clinic staff and some reasons were provided for this. The reasons provided

were that participants had not heard the news in the village, the results of their HIV tests were negative and confidentiality being explained by staff.

However, the results also show that there are participants who perceive there to be breach of confidentiality by clinic staff, especially of patients who are HIV positive, but not of the participants' own HIV statuses. Participants explained that they perceive that breach occurs because clinic staff explicitly asks community members to pass messages about treatment to HIV positive patients and because these patients' HIV status is heard in the village.

Furthermore, participants' understanding of confidentiality proved to be pivotal in establishing whether there was breach or maintenance of confidentiality. Participants explained their own understanding of confidentiality and it was interesting to find that these explanations seemed to not fully represent all the rules of confidentiality which apply with regards to HIVAIDS (HPCSA, 2008).

However it seems it will be important for patients at the clinic to be made fully aware of the rules of confidentiality that apply with regards to HIV/AIDS through full explanations by clinic staff during service provision and perhaps through other modes of communication such accessible to all patients. Also, breach already observed by participants would need to be dealt with through perhaps the reporting of the staff that is responsible for the breach to the appropriate authorities at the clinic by participants so that these staff members may be dealt with as they should be. Also, breach of confidentiality observed by participants needs to be reported and dealt with.

Basically, with good systems and ethically conscious staff the confidentiality of patients can always be maintained. Also, the service providers have a responsibility of raising awareness to the patients about the 'Patient's Rights Charter' in relation to confidentiality.

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APPENDICES

CONSENT FORM FOR PARTICIPATION

CONSENT FORM FOR AUDIO-TAPING

INFORMATION SHEET

INTERVIEW SCHEDULE

ETHICS CLEARANCE CERTIFICATE

Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

CONSENT FORM FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any particular items or withdraw from the study at any time without negative consequences. I understand that my response will be kept confidential.

Name of Participant: .....

Date: .....

Signature: .....

Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

CONSENT FORM AUDIO-TAPING OF THE INTERVIEW

I hereby consent to audio-recording of the interview. I understand that my confidentiality will be maintained at all times and that the tapes will be destroyed two years after any publication arising from the study or six years after completion of the study if there are no publications.

Name: ….....

Date: ….....

Signature: …….

Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

PARTICIPANT INFORMATION SHEET

My name is Omphile Tsame and I am a fourth (final) year student registered for the degree of Bachelor of Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research on experiences and perceptions of community members on the maintenance of confidentiality of patients' HIV status by clinic staff in a public clinic. This research will serve to provide insight into how community members perceive the clinic staff in a public clinic to be maintaining the confidentiality of their HIV status as experienced by them.

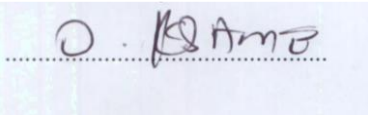
I therefore wish to invite you to participate in my study. Your participation is entirely voluntary and refusal to participate will not be held against you in any way. If you agree to take part, I shall arrange to interview you at a place that is suitable and comfortable to you. The interview will last approximately 45 minutes to an hour. You may withdraw from the study at any time and you may also refuse to answer any questions that you feel uncomfortable answering.
With your permission, the interview will be audio-recorded. No one other than my supervisor will have access to the recordings. The recordings and interview schedules will be kept for two years following any publications or for six years if no publications emanate from the study. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the research report, instead a pseudonym will be used to refer to you.

As the interview will include sensitive issues, there is the possibility that you may experience some feelings of emotional distress. Should you therefore feel the need for supportive counseling following the interview, I have arranged for this service to be provided free of charge by social workers at the Northam Clinic. I shall provide a number of one of these social workers who will link you with other social workers at this clinic - Ntsako (I071 595 1034).

Please feel free to ask any questions regarding the study; I shall answer them to the best of my ability. I may be contacted on 073 255 4014, or my supervisor Busisiwe Nkala-Dlamini on 011 717 4483. Should you wish to receive a summary of the results of the study, an abstract will be made available to you upon your request.

Thank you for taking time to consider participating in the study.

Yours sincerely



Keeping patient HIV status confidential: The experiences and perceptions of community members in a public clinic

Semi-structured interview schedule

Establishing rapport

Welcome to the interview. Your contribution to this study is highly appreciated, and also means a lot to me as the researcher.

Questions

- Do you live in this community?
- Have you used the services of this clinic before?
- How often do you use the services of the clinic?
- Have you ever tested for HIV in this clinic before?
- How did you find the service provided by the staff when you tested?
- How did you feel when you left the clinic after testing?
- What should happen when a person tests for HIV?
- What do you think you would have done differently if you were the staff at the clinic?
- What do you understand by confidentiality?
- Why do you think it is important to maintain confidentiality when working with HIV and AIDS?
- If you or someone you know were tested, do you think confidentiality was maintained when you were tested?
- How did you know when confidentiality was maintained or not maintained?

End of session

Thank you for your participation in this study, is there anything else you would like to add or contribute that you feel is important for this research?

Thank you once again for your invaluable contribution to this research.

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

DEPARTMENTAL HUMAN RESEARCH ETHICS COMMITTEE (SOCIAL WORK) CLEARANCE CERTIFICATE

PROTOCOL NUMBER: SW1/16/06/01

PROJECT TITLE: Keeping HIV status confidential: The Experiences and Perceptions of community members attending a public clinic.

RESEARCHER/S: Tsame Omphile (739928)

SCHOOL/DEPARTMENT: SHCD Social Work

DATE CONSIDERED: 10 June 2016

DECISION OF THE COMMITTEE: Approved

EXPIRY DATE: 10 June 2018

DATE: 28 June 2016

CHAIRPERSON: Francine Masson

Cc: Supervisor: Busisiwe Nkala-Dlamini

DECLARATION OF RESEARCHER(S)

To be completed in **DUPLICATE** and **ONE COPY** returned to the Administrative Assistant, Room 8, Department of Social Work, Umthombo Building Basement.

I/We fully understand the conditions under which I am/we are authorised to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the committee. **For Masters and PhD an annual progress report is required.**

O. Tsame

SIGNATURE

28/06/2016

DATE

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES