Perspectives of community health care workers (CHCW'S) on destigmatisation of HIV and AIDS.

by

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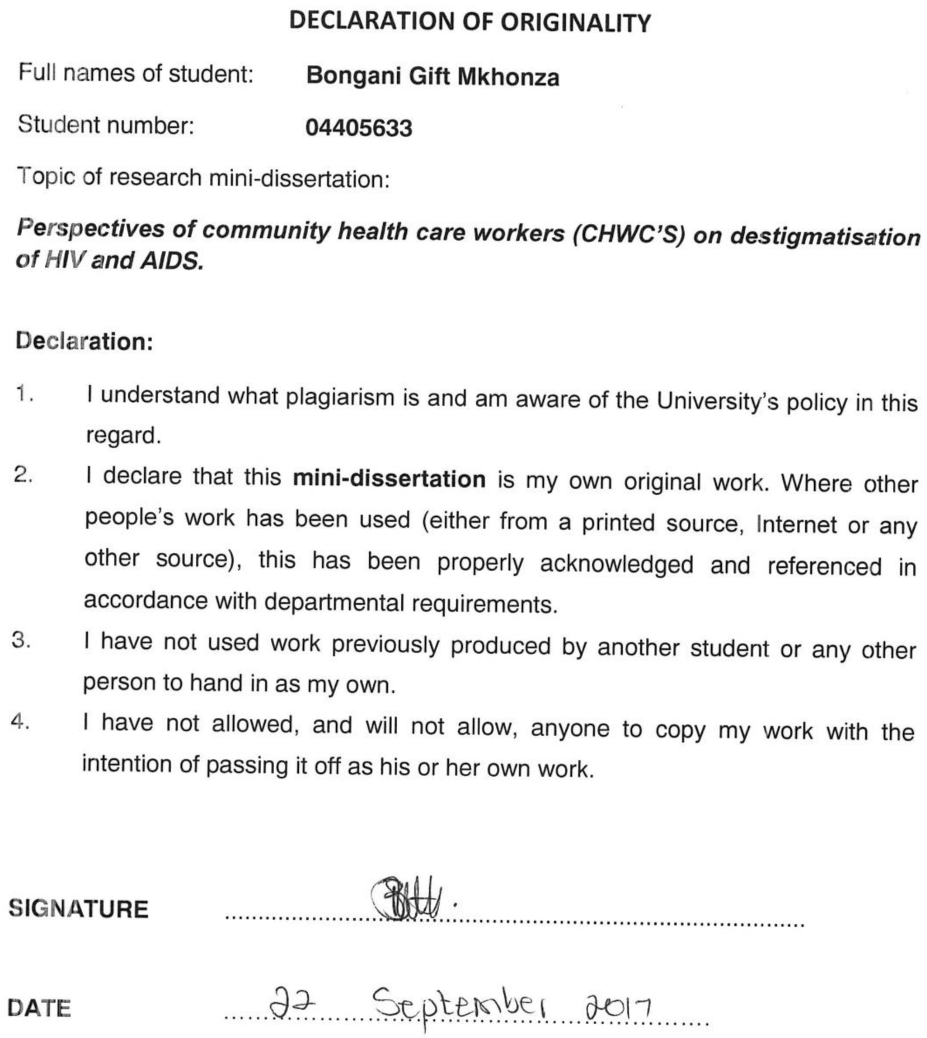
DECLARATION OF ORIGINALITY



DECLARATION OF ORIGINALITY

Full names of student: **Bongani Gift Mkhonza**

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Topic of research mini-dissertation:

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DEDICATION

This study is dedicated to:

- All the people who are affected and/or infected by HIV and AIDS in and around the community of Hammanskraal, as well as;
- Those who have endured any form of prejudice by means of stigma and discrimination related to HIV and AIDS, and to;
- The unsung heroes in the community who have dedicated their lives in helping people who are living with HIV and AIDS.

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ABSTRACT

Candidate: Bongani Gift Mkhonza
Title: Perspectives of community health care workers (CHCW'S) on destigmatisation of HIV and AIDS
Degree: MSW (Health Care)
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It has been over 3 decades since the emergence of the epidemic of HIV and AIDS, yet there is still the issue of stigma and discrimination that is faced by people affected and infected by HIV and AIDS across the spectrum. This has acted as a barrier for voluntary HIV counselling and testing for many people in the society. HIV and AIDS related stigma impacts on many levels in society from the individual, family and community. There are various contexts in which stigma related to HIV and AIDS occurs, such as the health care setting, the family, the educational sector, the work place and the society at large. Stigma and discrimination has been observed to be prevalent from a geographical, societal and historical level in society. Two major types of stigma have been written about immensely and they are namely; anticipated and enacted stigma. The former, referring to the perceived stigma by mostly individuals towards the self and the latter being acts of discrimination enforced by those who have prejudices towards PLHIV. This calls for intervention strategies to be devised from a co-operative level in order to alleviate stigma and discrimination related to HIV and AIDS. As much as many studies have focused on accounts of PLHIV in order to understand the phenomenon of HIV and AIDS related stigma, rarely could one find an inquiry that seeks the standpoints of those who are involved in rendering services to people affected by HIV and AIDS especially at community level. Thus, the rationale for this study was to give a voice to community health care workers in order to tackle HIV and AIDS stigma and discrimination and the goal was to explore and describe the perspectives of community health care workers on destigmatisation of HIV and AIDS.

A qualitative inquiry was employed in order to explore and understand the perspectives of community health care workers on destigmatisation of HIV and

AIDS. An attempt to conduct an applied research was done by means of engaging in a collective case study research design in order to gain multiple viewpoints of the participants involved in the study rather than to rely in a single case. A total of 13 community health care workers from 2 non-governmental/non-profit organisations in Hammanskraal were interviewed, in the form of 2 focus group interviews that were conducted separately. The data that was collected from these focus group interviews was later transcribed verbatim and analysed by the researcher. The researcher also relied on field notes collected during the interviews to identify themes and sub-themes as they emerged.

The following themes and sub-themes emerged from the study: Fear: fear of HIV and AIDS, fear of stigma and discrimination by health care professionals, fear of disclosure and fear of exercising one’s rights; Social support: family as a support system and support groups; Lack of some knowledge and information about HIV and AIDS: education about HIV and AIDS; Health care professional’s attitudes and behaviour towards PLHIV: discrimination through patient’s clinical information, separation of patients in the clinic, lack of trust between patients and health care professionals, stigma and discrimination by other clinic staff and strategy to address the attitudes and behaviour of health care professionals towards PLHIV; Disclosure: disclosure to the public, disclosing to family, non-disclosure and importance of disclosure.

The findings of the study showed that there is an underlying thread of fear that is experienced by people affected and infected by HIV and AIDS in relation to the illness itself, stigma and discrimination by health care workers, a fear of disclosure and fear to exercise one’s rights. It also revealed that there appears to be a lack of knowledge and information concerning the epidemic in the community and that education can best address this concern. Furthermore, the study findings also showed that attitudes of health care professionals are problematic and perpetuate stigma and discrimination especially through treatments of PLHIV in the health care settings such as clinics and hospitals, even more so by other staff members. Community health care workers provided a strategy they thought would best address the abovementioned issue. Social support in the form of family support and support groups were thought to be vital in alleviating stigma and discrimination related to HIV and AIDS. The issue of disclosure was also regarded as key in ensuring that stigma is mitigated, especially when done in public. This will empower other community members, but not totally disregarding the family and, that the opposite of disclosure can also be detrimental.

The recommendations of the study included emphasis on informal education and the use of mass media in order to educate the community on HIV and AIDS. The reinforcement of ethical conduct and the understanding of patient’s rights by health care professionals were also recommended. Support systems such as the family and support groups were also recommended as important in fighting the issue of HIV and AIDS related stigma.

Key words: AIDS, community health care workers (CHCW’S), destigmatisation, discrimination, HIV, PLHIV, stigma, social work.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CHCW'S	Community Health Care Workers
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
MSM	Men who have sex with other men
NGO	Non-governmental organisations
PHC	Primary Health Care
PLHIV	People Living With HIV
PMTCT	Prevention of mother to child transmission
SANAC	South African National Aids Council
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

1. CHAPTER ONE: GENERAL INTRODUCTION AND STUDY BACKGROUND

1.1 INTRODUCTION

Sidibe (2011) as quoted in UNAIDS Guidance Note (2012:2), mentions that it has been three decades since the epidemic of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) arose, yet we are still faced with major challenges of stigma and discrimination related to HIV and AIDS, including legislation that drives people away from HIV services such as Voluntary Counselling and Testing (VCT) (Kalichman & Simbayi, 2003:442). Such situations undermine the response to HIV universally. However, this can be altered by efforts to invest in programmes which will reduce this phenomenon, in permitting access to justice for people who are affected by HIV (UNAIDS Guidance Note, 2012:2).

The impact of HIV and AIDS has detrimental effects on all levels of human functioning, from the individual who is infected, to those who are merely affected by this disease. According to Lekganyane (2010:1), these levels of impact can be seen on the societal, community and familial and/or individual level. On the societal level, it has budgetary constraints by the state in order to manage this epidemic, as currently it is a known fact that HIV and AIDS has no cure although it is a chronic manageable disease (Castro & Farmer, 2005:57). On the community level, the burden lies on certain institutions that lose essential human resource due to the ultimate consequences of this illness such as death or chronic illness (Peltzer, 2008:103). When it comes to the familial and individual level, the issue of stigma and discrimination plays a major role. People living positively with HIV (PLHIV) carry a double-edge burden of living with such a detrimental illness and the stigma attached to it, as they often experience a violation of their human rights (Lekganyane, 2010:1). This creates negative consequences when it comes to efforts of prevention, care, treatment and support programmes. Research has shown that the stigma associated with HIV is a barrier to prevention and treatment efforts and although there has been some significant attention given to reducing stigma associated with HIV and AIDS since its breakthrough almost three decades ago, stigma has not been completely wiped out and continues to manifest itself extensively (Earnshaw and Chaudoir, 2009:1160).

Larger involvement of communities in health care services contributes to more effective, sustainable programmes, with a view that health services may otherwise be lacking. The benefits of this involvement can be found beyond a better understanding of clients' needs, resources and limitations. There is greater researchable evidence that reveals the involvement of community members in the development, implementation and monitoring of activities that are more acceptable to communities and yield more effective outcomes. Hence, the opposite can be true, with the lack of involving communities, which can be seen to yield adverse results (Rutenberg, Field-Nguer & Nyblade, 2003:3).

The researcher thus intends to explore and describe the perspectives of community health care workers in addressing the phenomenon of stigma and discrimination related to HIV and AIDS. Community health care workers (CHCW'S) play a major role in the primary health care system. Their function at community level is to assist the community with health services as well as informing them about health priorities. They serve as a point of first contact since they operate in the communities they are based in (Languza, Lushaba, Magingxa, Masuku & Ngubo, 2011:3). The perspective of CHCW'S will be looked at through the lens of the labelling theory and attribution theory as a theoretical framework that will provide a basis for understanding the phenomenon under study. In the subsequent sections, a detailed discussion of the research proposal for the above-mentioned topic will be outlined.

1.2 DEFINITIONS OF THE KEY CONCEPTS

HIV: The human immunodeficiency virus targets the immune system and weakens the body's defence systems against infections and some types of cancer. People infected by HIV, have impaired immune cells. This immunodeficiency results in susceptibility to a wide range of infections and diseases (World Health Organisation, 2014:1).

AIDS: AIDS is the advanced stage of HIV and its development is gradual and can take 2 to 15 years to manifest (World Health Organisation, 2014:1). AIDS is an epidemiological definition based on clinical signs and symptoms. It is caused by HIV which destroys the ability to fight off opportunistic infections and disease, which can ultimately lead to death (UNAIDS: Terminology guidelines, 2011:6).

Community health care workers: “A community health worker may be defined as any health worker delivering health care services and who is trained in the context of the intervention but has no formal professional tertiary education” (Languza et al., 2011:3).

Destigmatisation: Warren (1980:60) provides a definition that says, the “aims of destigmatisation are either the reformation of the individual or the reformation of society‘s attitude toward the deviant collectivity.” Another definition by Mortensen (2000:84) refers to destigmatisation as the process of restoration of dignity, respect and human rights.

Stigma: Sociologist Ervin Goffman (1963) defines stigma as “an attribute that extensively discredits an individual, reducing him or her from a whole and usual person to a tainted, discounted one” (Major & O’Brien, 2005:394). Many authors concur with this definition, however, some like Link and Phelan (1995), Herek (1999) and Lekas Seigel and Leider (2011) as cited by Mbatha (2013:518), provides a definition of AIDS-related stigma as prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or HIV as well as individuals, groups and communities with which they are associated.

1.3 THEORETICAL FRAMEWORK

HIV and AIDS related stigma is a psychosocial problem that can be understood from different theoretical perspectives. In context of the previously mentioned, the researcher discusses a theoretical framework that may help in understanding the issue of HIV and AIDS related stigma. The theoretical framework for this study is based on two theories, one being the labelling theory as described by Howard S. Becker, who is seen as the most prominent founder of the theory as he conducted a study and described how a person accepts the deviant role. He later published a book called *Outsiders*, which serves as the basis of this theory (Plummer, 2000:191-192).

According to Becker (1973) as cited in Cockerham (1995:165) deviance and the deviant role is created by a social group who make rules or norms that constitute deviant behaviour when contravened. Thus, deviance is not the act a person commits, but it is a consequence of the definition applied to the act by others. In other words, deviance can be understood through the social interaction with others as they determine what is or is not deviant behaviour. Therefore, the labelling theory is based on the premise that deviant behaviour regarded by an individual or a social group may not necessarily be regarded as such by another. Thus, when applying the labelling theory, one needs to bear in mind that illness behaviour stems from a biological state of which human perception creates as a social state (Cockerham, 1995:165). In order to bring the issue of HIV and AIDS related stigma into context of this theory, it is important to look into the idea brought upon by Herek (2005:123). The argument is that HIV and AIDS-related stigma is attached to people who are perceived to have engaged in risky sexual or other form of abnormal behaviour. This then means that such people have deviated from what the society has come to know as normal behaviour, like using condoms, having one faithful partner, not sharing razor blades or syringes. Such people are susceptible to labels of stigmatisation in the sense that they have brought the illness upon themselves by their “deviant behaviour”. However, those people who acquire HIV through such behaviour may not have necessarily regarded their behaviour as deviant, such as sex workers or drug addicts who share syringes.

Similarly to the labelling theory, the attribution theory in relation to stigma as discussed by Lekganyane (2010:11) attests to this idea. This theory state that since people are regarded as living in a just world, they are exposed to different choices available to everyone and can choose the consequences of their choices. Thus, regarding HIV, this theory basically infers that people living with HIV have ignored the protective measures of preventing infection of the virus and must suffer the consequences of rejection and avoidance, which consequently leads to stigmatization (Malle, 2011:72 and Vishwanath, 2014:517-519). In other words, they are placed at fault for acquiring the disease. However, those whose circumstances of acquiring HIV are different from the above-mentioned ones, such as victims of sexual assault or rape, are regarded as deserving of pity and sympathy (Lekganyane, 2010:12).

The applicability of this theoretical framework in this study; is that the labelling theory can be seen as a lens to view how individuals’ self-identity and behaviour may be exposed by the terms used to describe or classify them. The attribution theory on the other hand seeks to explain stigma by making an inference with regards to who is responsible for a behaviour or disease. This is how stigma is used as a powerfully negative label that influences a person’s self-concept and social identity.

1.4 RATIONALE AND PROBLEM FORMULATION

Stigma and discrimination have a role in the prevention of the provision of quality treatment, inhibiting people who are HIV positive from seeking care and support and people being misled and prevented from utilising protective measures in intimate settings (Parker & Birdsall, 2005:4). The effects of stigma and discrimination can be deemed as problematic, as they can be felt on many levels such as individual, family, community, programmatic and societal. Furthermore, the rights of people affected by HIV and AIDS may be infringed because of stigma and discrimination in many instances (Morrison, 2006:3-5). Zuberi (2005:13) states that people living with HIV and AIDS are suffering from a violation of their basic human rights, due to knowledge or presumption of their HIV status. Thus, they tend to carry a double burden, namely the burden of the disease as well as the burden of stigma and/or discrimination. This situation transforms to the fact that stigma is deep seated within society and is not only felt on an individual level. Its effects not only have an impact on those who are involved in the immediate situation, but it can also have an impact on bureaucratic and medical efforts (Mbatha, 2013:518).

It is the researcher’s opinion that in order to address the issue of HIV and AIDS related stigma it remains important to keep in mind that there exists a need for a collaborative effort that seeks to address the challenges. This means that not only those who are directly involved need to participate, but also those who take interest in HIV and AIDS. The success of such a holistic approach has been confirmed in studies such as the one conducted by Bharat (2011:146-147) in India.

More often than not, the voice of understanding the impact of stigma is usually given to the people who are living with HIV and AIDS or their families and/or significant others. Rarely does one find an inquiry that invites the community health workers who are community based and are thought to have first-hand experience in issues of stigma related to HIV and AIDS. According to Cruse(1997:v):

> "It is essential that community health workers (CHCW'S) are not seen as providers of cheap or inferior quality health care. Their value is that because they are community-based, they can more successfully provide an affordable first level contact within a primary health care system than other health providers".

Thus the main aim of this study is to give a voice to these community health care workers who are operating in non-governmental organisations that render services to people living and affected by HIV and AIDS to share their perspectives of how stigma and discrimination can be mitigated. Their views may be an addition to policies and could ultimately inform strategies that can be used to destigmatise HIV and AIDS in the community. With that said, the research question for the study consequently becomes:

What are the perspectives of community health care workers on destigmatisation of HIV and AIDS?

1.5 GOAL AND OBJECTIVES

The goal of this study is to explore and describe the perspectives of community health care workers regarding the destigmatisation of HIV and AIDS. Thus, the researcher has formulated certain steps or objectives, which will be followed in order to achieve this purpose (Fouché & De Vos, 2011:94). These are stipulated as follows:

- To describe people infected and affected by HIV and AIDS, with specific reference to stigmatisation within the context of the labelling and attribution theories.
- To explore and describe the perspectives of community health care workers on the destigmatisation of HIV and AIDS.
- To recommend strategies for intervention on the reduction of HIV and AIDS related stigma.

1.6 RESEARCH METHODOLOGY

A detailed account of the research methodology is provided in the third chapter under research methodology. In this section the researcher only highlighted a brief overview of the research design and methodology that was undertaken to complete this study.

A qualitative research approach was used to undertake this study. The reason for choosing this approach was that the researcher aimed to explore and understand the perspectives of the community health care workers on destigmatisation of HIV and AIDS (Fouche & Delport, 2011: 64).

The type of research that was selected in this study was applied research in that the researcher wanted to understand the standpoints of the community health care workers on destigmatisation of HIV and AIDS. The purpose of this was to use the findings contribute into policy and community development as well as to address the issue of stigma in general as Neuman (2011:27) states that applied research is done with the purpose of addressing a specific concern and/or to offer a solution to a problem.

The collective case study design was chosen for this study as the researcher wanted to gain multiple perspectives of the community health care workers on the phenomenon under study. This form of research design enabled the researcher to link the perspective of the community health care workers to the larger understanding of the issue of stigma and discrimination related to HIV and AIDS in the general society and how their views could influence a better understanding of this phenomenon (Neuman, 2011:42).

The population for this study were all the community health care workers employed at various non-governmental and non-profit organisations in Hammanskraal, Gauteng province (Neuman, 2011:241). Thus, the researcher used non-probability purposive sampling method with specific selection criteria to identify the non-governmental and non-profit organisations in which the sample of community health care workers were obtained. Then volunteer sampling (Strydom & Delport, 2011:394) was used to obtain participants from the centre managers or directors of the above-mentioned organisations. Lastly stratified random sampling (Babbie, 2010:21 and Strydom, 2011:230) was then used to select the participants with the same known characteristic to obtain representativeness.

The researcher used focus group interviewing with an interview schedule, in order to collect data from the thirteen community health care workers on the destigmatisation of HIV and AIDS. This form of interviewing allowed the researcher to gain multiple viewpoints of the participants simultaneously (Creswell, 2014:314).

1.7 LIMITATIONS OF THE STUDY

The limitations of the study can be indicated as follows:

1.7.1 Language interpretation

During the data analysis process with specific reference to the transcribing of data in verbatim, the researcher relied on his own understanding of the Setswana language and did not use a professional interpreter. This could limit the accuracy of the information as the researcher’s mother tongue is not Setswana, however he could understand the language.

1.7.2 Sample

The number of participants that were utilized in this study do not represent every community health care worker’s viewpoint in the whole of South Africa regarding the phenomenon under study. However, in both qualitative and quantitative research, sampling gives the researcher an idea of what can be expected in the total population (Strydom & Delport, 2011:390). Also, Paton (2002) in Strydom and Delport (2011:391) states that in qualitative research there are no rules for the sample size, as what is of utmost importance is what the researcher wishes to know and what can be done with the available resources and time. Thus, the use of these few participants in this study is important in understanding what their perspectives on destigmatising HIV and AIDS are.

1.8 CHAPTER OUTLINE

There are four chapters that are contained in this research report and they are outlined as follows:

Chapter one

This chapter provides a discussion of the theoretical framework, rationale and problem formulation, research question, aim, objectives and a brief overview of the research methodology and the limitations of the study.

Chapter two

This chapter includes a thorough discussion of HIV and AIDS, stigma and discrimination, as well as measures to mitigate stigmatisation. This also includes a discussion of the community health care workers in the South African context.

Chapter three

This chapter gives a description of the research methodology and a presentation of the findings of the empirical research.

Chapter four

This final chapter provides a discussion of the key findings, conclusions and recommendations.

In the following chapter an in-depth literature review on HIV and AIDS related stigma and discrimination is discussed.

2. CHAPTER TWO: LITERATURE REVIEW: HIV AND AIDS RELATED STIGMA

2.1 INTRODUCTION

Stigma associated with HIV and AIDS can be very problematic in many ways than one. Most literature suggests that some of the barriers preventing people from testing or acquiring knowledge of their status, seeking preventative measures or accessing services for people living with HIV and AIDS can be linked to the stigma related to this epidemic. This clearly shows that the battle is no longer embedded into the clinical aspects, but rather the psychosocial aspects thereof.

In the foreword of The people living with HIV stigma index: South Africa 2014 summary report (2015:1), the deputy minister of the justice and correctional services department, Mr John Jeffery and the co-chair of the human rights technical task team of the South African National Aids Council (SANAC), Ms Janet Love, emphasised the fact that a multisectoral approach is of utmost importance in order to combat the issue of HIV related stigma.

In order to understand the impact of stigma related to HIV and AIDS, it became significant for the researcher to engage in an in-depth literature review regarding this phenomenon. This was done to get to the bottom of this aspect of HIV and AIDS, to understand the trends, what other authors have written as well as what the arguments are currently within this field of interest. Thus, in the subsequent sections the researcher brings to light a thorough discussion of the issue of stigma. This is done with different subheadings to provide a certain structure. The researcher looks at the conceptualisation of stigma and how it can be linked to HIV and AIDS, the different types of HIV and AIDS related stigma, the prevalence and implication of HIV and AIDS related stigma, the contexts of HIV and AIDS related stigma, stigma as a barrier for voluntary HIV testing and counselling and treatment seeking as well as interventions to reduce HIV and AIDS related stigma.

2.2 CONCEPTUALISATION AND ORIGIN OF STIGMA, LINKED TO HIV AND AIDS

One of the first people to define the concept of stigma is sociologist Ervin Goffman who published a book in 1963 with the title *Stigma: Notes on the Management of Spoiled Identity* in which a lot of research about the nature, sources and consequences of stigma are dealt with (Link & Phelan, 2001:363). Stigma has been further studied and used to explain many chronic illnesses such as leprosy, tuberculosis, cancer, HIV and mental illness as well as physical characteristics or functional loss such as deafness and paraplegia (Reidpath & Chan, 2006:1). Social psychologists have also contributed in the vast pool of stigma research by using social cognitive approach to understand how people construct categories and link them to stereotyped beliefs (Link & Phelan, 2001:364). However, as Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres and Coates (2008:70) sees it, this contribution has impacted on how HIV and AIDS related stigma has been viewed when researching in this field and seeking intervention strategies to reduce the phenomenon. They argue that stigma has been looked at in terms of incorrect societal beliefs and perceptions as well as emotional and cognitive processes of people living with HIV (PLHIV) rather than also looking into structural aspects of stigma such as social, political and economic processes that simultaneously produce and intensify stigma and discrimination (Mahajan et al., 2008:70). Even though so, sociologic and anthropologic disciplines have also contributed to the conceptualisation of stigma by looking into these structural processes.

Parker and Aggleton (2003:13-24) argue that stigmatisation is central to social order. In other words, stigma is linked to the workings of social inequality by its capacity to cause some groups to be devalued and others to feel that they are superior. They further assert that structural power is not only needed to enable stigmatisation but also that stigmatisation plays a role in the manufacturing of relations of power and control (Mahajan et al., 2008:70).

The most quoted definition of stigma is that of the above-mentioned sociologist, Goffman who defined stigma as “an attribute that is deeply discrediting and reduces the barrier from a whole and usual person to a tainted, discounted one” (Link & Phelan, 2001:364). While Goffman’s conceptualisation of stigma argued that individuals can be stigmatised through the unfavourable deterioration of the body, blemishes of individual character and tribal stigma (Major & O’Brien, 2005:394), he further asserted that stigma should be described in terms of relations and not attributes (Earnshaw & Chaudoir, 2009:1161). In other words, stigma is not a product of the ”mark” itself, but of social interactions and relationships in which the “mark” is constructed as a reflection of its possessor’s tarnished character (Earnshaw & Chaudoir, 2009:1161).

In terms of the conceptualisation, it should be accepted that other authors and researchers as prior mentioned have also attempted to conceptualise stigma. Link and Phelan (2001:367) are such authors who have brought a different view in the conceptualisation of stigma by looking at components that occur in order for one to claim that stigma exists. These are distinguishing and labelling differences, associating human differences with negative attribute, separating “us” from “them” and status loss and discrimination (Link & Phelan, 2001:367 and Earnshaw & Chaudoir, 2009:1161). Parker and Aggleton (2003:1) argue that the role of social context in understanding stigma should not be overlooked as it operates within the parameters of culture, power and difference, i.e. sexuality, gender, race and ethnicity as well as class are also important components to be considered as mentioned above.

- **Distinguishing and labelling differences**

It may be of utmost importance to briefly discuss these components in order to be able to position ourselves to how the phenomenon of HIV and AIDS can be related to the issue of stigma. In terms of the first component that is discussed by Link and Phelan (2001:367), the argument is with regards to salient human difference versus differences that are seen as irrelevant in society. An example that is given by these authors is why the colour of one’s eyes or car is treated differently than the colour of one’s skin or sexuality for instance. This means that there is a social selection of human differences that exists in society and that leads to labelling of certain differences that are noticeable than others, hence enduring stigma (Link & Phelan, 2001:368). This can be linked to HIV and AIDS by using Goffman’s tribal stigma, in the sense that people who are from certain ethnic, religious or nationality groups are said to be prone to HIV infection as compared to their counterparts (Castro & Farmer, 2005:55 and Talja, 2005:11).

- **Associating human differences with negative attributes**

In the second component identified by Link and Phelan (2001:368) as a contribution to understand stigma, is that of stereotypes. They argue that stigma also occurs when labelled differences are linked to stereotypes. These authors further argue that this aspect of stigma involves a label and a stereotype, with the label linking a person to a set of undesirable characteristics that form the stereotype. For example people with mental illness carry the stereotype of being “dangerous” together with stigma.

- **Separating “us” from “them”**

The third component that Link and Phelan (2001:370) brings forth is the fact that the process of stigma occurs when social labels connote a separation of “us” from “them.” They also argue that other components of stigma process, such as linking labels to undesirable attributes are the reason for believing that negatively labelled persons are different from those who don’t share the label. In extreme cases the stigmatised person is so different from the “us” that they are not even seen as human and “them” become susceptible to terrible forms of treatment.

- **Status loss and discrimination**

The fourth component that Link and Phelan (2001:370) discusses is that of status loss and discrimination. In this process the labelled person experiences status loss and discrimination. These authors maintain that when people are labelled, set apart and stereotyped there is a reason for devaluing, rejecting and excluding them. In other words, people are stigmatised when the fact that they are labelled, set apart and stereotyped, leads them to status loss and discrimination. In terms of status loss, a person who endures labelling and stereotyping generally gets placed on the lower levels of the status hierarchy, thus their connection to undesirable characteristics reduces their status in the eyes of the stigmatiser (Link & Phelan, 2001:371). When it comes to discrimination on the other hand, it is said that one person’s attitudes and beliefs that are as a result of labelling and stereotyping about another person may lead to certain behaviours that may not be regarded as fair by the person whom it is enacted upon (Link & Phelan, 2001:372).

These components by Link and Phelan, serves as a basis to understand some of the most intricate processes of stigma and discrimination in order to understand the phenomenon holistically. They maintain that for stigma to be present, these components have to co-occur (Talja, 2005:12). In the preceding section, the researcher looks into the structural process of stigma.

- **Culture, power and difference**

Stigma is said to be related to power and domination in all societies. In other words, stigma lies at the manufacturing of power relations among people. Thus, by stigmatising another person one reveals his own superior position in society or group (Talja, 2005:12).

It is important to link stigma to HIV and AIDS so as to contextualise it within this research study. When looking into Goffman's conceptualisation of stigma, three main characteristics have become apparent. These include unfavourable deterioration of the body, blemishes of individual character as well as tribal stigma. These can be linked to HIV and AIDS in the sense that firstly stigma is attached to people living with HIV if they get to the AIDS stage and they have body symptoms such as mouth sores and hair loss, this is linked to unfavourable deterioration of the body, (Herek, 2005:123). Stuenkel and Wong (2013:52), states that many chronic conditions, including HIV and AIDS, create changes in physical appearance or function and this creates a difference in terms of how one sees himself or how they are perceived by others. Stigma is also attached to blemishes of individual character, and this means that it is associated to behaviour that is different from what is known to be normal in society such as promiscuity, homosexuality, alcoholism or other behaviours that are deemed as abnormal in a specific group (Talja, 2005:11). The fact that people are said to become infected with HIV through risky sexual behaviours, attest to the idea of being stigmatised through the weakness of character (Herek, 2005:124). Lastly, stigma is also associated with health care workers who are rendering services to people living with HIV, especially those who are unable to contain their prejudices towards their patients by means of race, religion or nationality (Stuenkel & Wong, 2013:53). This type of stigma is said to be transferred between generations and that one can be born with it (Talja, 2005:11). These characteristics of stigma by Goffman are also referred to as the types of stigma and other types of stigma more common in literature are discussed in the subsequent section.

2.3 TYPES OF HIV AND AIDS RELATED STIGMA

There are different types of HIV and AIDS related stigma. Some authors distinguish between anticipated and enacted stigma, which is also known as internal and external stigma. These are the two most common ones, although other researchers have referred to other types which will also be looked into here such as layered stigma and courtesy stigma. For the purposes of the research study, the two most common will be expanded upon further, as it is the view of the researcher that the others stem from the common ones.

2.3.1 Anticipated stigma

Anticipated or internal stigma is related to fears of being treated differently or being labelled by others. It is also referred to as felt stigma, as the individual undergoing this internalises the perception of being devalued (Stuenkel & Wong, 2013:53). In other words this basically means that a person experiencing this type of stigma feels some sort of shame and perceives themselves as different from other people who do not experience what they are going through, such as an illness like HIV.

According to Talja (2005:12) negative response from other people towards a person in their surrounding can be internalised by someone who sees themselves as different in a negative way. A self-stigmatising person often blames themselves for whatever “difficult” situation they are faced with and this could lead to depression, withdrawal and a sense of worthlessness. This type of stigma is linked to perceived and enacted stigma, i.e. these types of stigma can overlap.

In terms of HIV and AIDS, anticipated stigma refers to the shame that is associated with the disease as well as the fear of being discriminated against which can be felt by people living with HIV. This causes a person who is infected to refuse disclosing their status or the denying it altogether (Lekganyane, 2010:20). An example given by Lekganyane (2010:20) is that of HIV positive mothers who may continue breastfeeding their babies, even if they know that this may infect their children, because of the fear that if they do not breastfeed, their HIV positive status will be revealed to others. However, prior to recent research, the World Health Organisation had advised HIV positive mothers to avoid breastfeeding if they could afford, prepare and store baby formula safely (Langa, 2010:9), but with the prevention of mother to child transmission (PMTCT) programme; mothers who are on antiretroviral (ARVs), and babies who get ARVs at birth, are encouraged to breastfeed exclusively for the first 6 months as “breast milk is best” and to gradually introduce foods while breastfeeding continues for the first 12 months of life (HIV and infant feeding: revised principles and recommendations, 2009:15).

2.3.2 Enacted stigma

The other type of HIV and AIDS related stigma that is more common in literature is called enacted stigma, which is also known as external stigma. It refers to the behaviours and perceptions by other people towards the individual who is perceived as different (Stuenkel & Wong, 2013:53). It also refers to when an individual experiences prejudices, stereotyping, discrimination and exclusion (Bunn, Solomon, Miller & Forehand, 2007:198; Lekganyane, 2010:20 & Visser, Makin, Vandormael, Sikkema & Forsyth, 2009:200). Furthermore, this type of stigma can include explicit expressions such as loss of friendships or social support after disclosing one’s HIV-positive status as well as subtle expressions such as insults, daily hassles or aggressions like those that are experienced by other marginalised groups (Lekganyane 2010:20).

Visser et al. (2009:202), provide gossip, not being treated with respect and keeping distance from people living with HIV, as the most common forms of enacted stigma as reported in a study they conducted in a South African community. Some of the other forms of external stigma are those that arose from the research conducted by the Siyamkela project of the Centre for the Study of AIDS, UP, now the Centre for Sexuality, AIDS and Gender and these include avoidance, rejection, moral judgement, stigma by association, discrimination and abuse as mentioned above (Siyamkela Project, 2003:14). These are expanded upon and discussed as follows:

- **Avoidance**

In terms of avoidance, PLHIV can be avoided by others, due to fear of casual transmission of HIV or due to a perception of PLHIV as immoral and dirty. Avoidance can also take the form of not wanting to share items such as a chair, utensils and toilets with PLHIV as well as avoiding spending time with them or not wanting to be close to them (Siyamkela Project, 2003:14).

- **Rejection**

Many people are said to be rejected by their spouses, families, friends and colleagues following the perception that they deserve to be HIV positive or that the illness is transmitted through casual contact (Siyamkela Project, 2003:15). Some PLHIV are rejected by their partners when they disclose their positive HIV status and are unable to form relationships with a partner because of judgemental attitude. Others are rejected by the faith communities and may be asked to leave their congregations or resign from being a faith leader after disclosing a positive HIV status (Siyamkela Project, 2003:15).

- **Moral judgement**

With regards to moral judgement, people who contract HIV outside societal norms are seen as immoral and promiscuous. They are perceived to be guilty or blamed for their positive HIV status (Siyamkela Project, 2003:16).

- **Stigma by association**

People whose causes of death are unnatural, such as car accidents, shooting or heart attack, are believed to have been killed by AIDS-related illnesses. Thus, stigma in this instance is associated with natural causes of death. Those who are employed in organisations that work with people who are living with HIV, are also stigmatised. In a more overt manner, AIDS activists or those who wear gear such as T-shirts or red ribbons/brooches as a symbol of support to PLHIV have also endured stigma by association (Siyamkela Project, 2003:17). Additionally, people from certain geographical areas, such as rural areas have also been stigmatised due to the perception of high rates of HIV infection in those areas. PLHIV have also shared that their families are stigmatised because of their HIV status. Survivors of sexual assault have also been stigmatised due to the fact that HIV is associated with rape (Siyamkela Project, 2003:18).

- **Discrimination**

People living with HIV have reported the inability to access services based on their HIV status. These services include life cover, medical schemes and blood transfusions (Siyamkela Project, 2003:18). Access to health care services has also proved to be difficult as PLHIV do not receive same care and courtesy as any other person. Discrimination has also been reported in the work place, whereby PLHIV do not trust work place policies that deal with HIV and AIDS because not everyone disclosed their status (Siyamkela Project, 2003:18).

2.3.3 Other types of stigma

As mentioned above, the literature has also referred to other types or forms of stigma mentioned earlier on in this section. These include courtesy, layered, perceived and resource-based stigma. Resource-based stigma is one other type of stigma that appeared in the literature. Though not many authors have written about it, it became interesting to the researcher to include it under this sub-section as it was a relatively new concept. This type of stigma describes stigma that is based on resource concerns due to judgements about the likely social contribution of a person living with HIV and AIDS. Furthermore, this type of stigma occurs when the person who is HIV positive gets to the AIDS stage and they are perceived as a financial burden due to treatment or dietary costs that may be involved in their care. Carers of PLHIV who may have reached the AIDS stage, tend to lose hope and believe that the patient will die anyway, so there is no point in “wasting money” (or any other scarce resources) on them, hence resource-based stigma exists (Maughan-Brown, 2008:32; Deacon, Uys & Mohlahlane, 2009:107).

Courtesy stigma or stigma by association as described above has been observed especially with health care professionals working with PLHIV such as doctors and nurses (Bharat, 2011:142; Siyamkela Project, 2003:17). According to Deacon et al. (2009:107), courtesy stigma has also been referred to as “stigma directed at the families or friends of PLHIV”. This type of stigma is similar to tribal stigma as described by Goffman (1963) in (Major & O’Brien, 2005:394). The People Living With HIV Stigma Index: South Africa 2014: Summary Report (2015:9) describes this type of stigma as “the stigmatisation a person perceives or experiences due to their association with a stigmatised individual or group.”

Layered stigma on the other hand refers to stigma associated with HIV being frequently layered over other forms of social disadvantage which highlights the exclusion and devaluation of PLHIV (Bharat, 2011:142). HIV positive female sex workers, men who have sex with other men (MSM) and transgendered persons, have also been found to endure stigma firstly of being different from other community members and of being HIV positive. In another instance in India, HIV positive MSM chose to “pass” as HIV positive heterosexual in order to avoid being stigmatised (Bharat, 2011:143).

Perceived stigma refers to the fear of how others would stigmatise oneself, the expected reactions of their surroundings (Talja, 2005:12). This type of stigma is in the opinion of the researcher closely related to anticipated stigma. However, what separates it from other types of stigma is the fact that it basically refers to the general perception in society about PLHIV, i.e. how people feel and react towards PLHIV in a particular community. In other words it is a product of social learning and is aggravated by incidents of stigmatising experiences that have been reported (Maughan-Brown, 2008:34).

2.4 PREVALENCE AND IMPLICATION OF HIV AND AIDS RELATED STIGMA

In terms of the prevalence of HIV and AIDS related stigma, the researcher saw it fit to include this aspect in the literature review, in order to comprehend how has this phenomenon transpired in the global and domestic society, as well as what it actually means.

In the Global Report: UNAIDS report on the global AIDS epidemic (2013:85), the prevalence of HIV and AIDS related stigma and discrimination was reported among thirty-five countries across the globe, including South Africa’s O.R. Tambo region in the Eastern Cape province. This report provided a quantified and enhanced understanding of the prevalence and impact of stigma and discrimination with PLHIV reporting incidences of discrimination and denial of family planning, dental and other health services between 2008 and 2013. They also reported the violation of human rights of PLHIV, who sought legal redress. The highest incidences of denial of health and/or dental services were 33% in Pakistan and the lowest incidences were 2% in Cameroon. In terms of denial of family planning services, the highest incidences 88% were found in Rwanda and 1% in Swaziland. With regards to refused employment incidences, the highest was 37% in Rwanda and the lowest being 3% in El Salvador, Guatemala, Russia, South Africa and Swaziland. Concerning the violation of human rights of PLHIV, who sought legal redress, the highest was in Nigeria with more than 60% and the lowest was in Swaziland with less than 20% (Global Report: UNAIDS report on global AIDS epidemic, 2013:85).

The above statistics as cited in the UNAIDS (2013:85), shows the geographical broadness of HIV and AIDS related stigma on a more global scale. This notion is supported by Attell (2013:7) when he argues that research on HIV and AIDS related stigma is viewed as “geographically broad” when attempting to draw broad conclusions about AIDS related studies because of their use of a more representative sample. However, interestingly Attell (2013:7), further argues that such geographically broad studies lack the facet of showing the historical depth of the phenomenon of HIV and AIDS related stigma, rather than when they would have been conducted with smaller samples. He states that the historical depth in this sense would show what changes have taken place over time that may affect HIV and AIDS related stigma (Attell, 2013:7). Thus, in other words what Attell (2013:8) is bringing on this debate is that smaller non-represented population, with specific targeted populations tend to focus social context on their analysis of stigma and are likely to be historically deep and not necessarily geographically broad. On the other hand, the larger representative samples are geographically broad and only sample the prevalence and not the historical depth of the phenomenon.

2.5 CONTEXTS OF HIV AND AIDS RELATED STIGMA

There are multiple contexts in which stigma related to HIV and AIDS has been observed by researchers and widely written about in literature. These include HIV and AIDS related stigma in the health care setting, in the work place, within the family context, community and the socio-cultural context (Bharat, 2011:144; Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, Samson, Daly & Pulerwitz, 2007:617). In the subsequent section the researcher provides a thorough discussion of these.

2.5.1 HIV and AIDS related stigma in the health care setting

HIV and AIDS related stigma in the health care setting is one of the most cited contexts in which stigma has been observed (Bharat, 2011:143). Research has also revealed that stigma and discrimination in the health care setting contributes to keeping people, including health care workers, from accessing HIV prevention, care and treatment services (Nyblade, Stangl, Weiss & Ashburn, 2009:1). According to Living on the outside: HIV stigma and place (2006:13), health care professionals are obligated to be the change agents for reducing stigma through the use of their social and professional authority. This could be achieved through their roles as care givers to PLHIV, as well as educators and roles models for their communities. Furthermore, in this setting, PLHIV discover their status and it is a place where they are taught how to care for themselves and how to prevent transmission to others. Here they also access treatment and care (Mahendra et al., 2007:617). However, as Bharat (2011:143) sees it, discriminatory practices towards PLHIV by health care workers which includes identifying HIV positive patients and minimising contact with them reveals the opposite. Mahendra et al. (2007:617), attests to this notion in that due to stigma, there have been various reports of PLHIV receiving inferior care or being denied care altogether. Hence the perception that within the health care setting HIV and AIDS related stigma is common.

For people living with HIV, the right of access to health care is a major issue, as they raise the concern of treatment by health care workers and see their ill treatment as directly linked to their HIV status (Zuberi, 2005:36). Health care workers tend to moralise the behaviour of PLHIV as other people in society do. Thus, they blame the patient for the disease (Living on the outside: HIV stigma and place, 2006:14). Fear of voluntary counselling and testing (VCT), as well as delay in the access to treatment has also been observed as perpetuated by health care workers (Chakrapani, Newman, Shanmugam, McLuckie & Melwin, 2007:355). Groups that are deemed to be at risk of contracting and transmitting HIV have reported fear of access to VCT due to the fact that they have placed distrust to health care professionals who may disclose their HIV positive status (Meiberg, Bos, Onya & Schaalma, 2008:52).

Even though so, it is also of particular importance to note that the health care setting itself is a stigmatised environment by society. For instance, specially located VCT and HIV and AIDS treatment rooms, can prevent access to treatment as people fear being stigmatised for being identified as HIV positive (Mbatha, 2013:521).

2.5.2 HIV and AIDS related stigma in the family context

In terms of the family context, HIV and AIDS related stigma is also prevalent. In this context, stigma is seen when family members refuse to share intimate spaces or household materials such as utensils or utilization of a common toilet (Bharat, 2011:145). Women are said to be more susceptible to stigma and discrimination especially by in-laws, as well as loss of financial support from their spouses due to knowledge of their HIV status (Paxton, Gonzales, Uppakaew, Abraham, Okta, Green, Nair, Pawarti Merati, Thephthien, Marin & Quesada, 2005:421).

2.5.3 HIV and AIDS related stigma in the community context

Stigma related to HIV and AIDS can also occur on a larger context such as the community. Bharat (2011:144) states that the most common forms of stigma related to HIV and AIDS in the community are labelling and shaming, although there have been other reported forms such as exclusion from social functions, expulsion of children of HIV positive parents from schools, boycotting social visits to homes, physical isolation, denial of rites and burial plot upon death. These are considered extreme instances of stigma and discrimination within the community context (Bharat, 2011:144). Paxton et al. (2005:419), adds that ridicule, insult or harassment are also the most frequent forms of discrimination within the community due to an HIV positive status.

2.5.4 HIV and AIDS related stigma in the workplace and education setting

The workplace and the education setting are also environments in which PLHIV have experienced stigma related to HIV and AIDS (Bharat, 2011:145). In terms of the workplace many people have been tested for HIV in connection to employment, such as loss of jobs because of their status. Those with a positive status often claim that they experience this process as a form of discrimination (Paxton et al., 2005:421). Disclosing one’s status in the workplace can have potentially positive or negative results. Negative results would be due to the fact that PLHIV who works in closed environments have to work closely with other people and the knowledge thereof of one’s status can be detrimental (Living on the outside: HIV stigma and place, 2006:10). With regards to educational setting, stigma and discrimination has also been observed. Children have been denied admission to school due to HIV (Paxton et al., 2005:421). They have also been excluded from other schooling activities and or expelled due to knowledge of their status or their parents ‘status (Brown, Aggleton, Attawell, & Pulerwitz, 2002:5-6).

2.5.5 HIV and AIDS related stigma in the socio-cultural and economic context

The United Nations: News Centre in (2008:1) published an article that discussed the report on some African cultural traditions that influence the spread of AIDS. In the article it wrote that, if we are to fight the spread of HIV, we need to have a better understanding of the cultural factors in Africa, which includes among others gender inequalities, wife inheritance and some sexual practices, as some cultural drivers can fuel the spread of HIV while others have a positive impact. Airhihenbuwa, Okoror, Shefer, Brown, Iwelunmor, Smith, Adam, Simbayi, Zungu, Dlakulu and Shisana (2009:420), agree that the research on HIV and AIDS prevention in South Africa have shown that the social and cultural dynamics of the disease need to be understood better in order to have a broader understanding of the nature and role of stigma in its spread. Hence, stigmatising beliefs about HIV and AIDS have deterred people from seeking voluntary counselling and testing services as well as preventative and treatment services (Kalichman & Simbayi, 2004:573).

Culture plays a significant role in determining the level of health of the individual, the family and the community. This is also true for the African culture, where the values of the extended family and the community influence the behaviour of the individual. In the context of HIV and AIDS, the behaviour of an individual in relation to family and community is a significant cultural factor that has implications for sexual behaviour and HIV and AIDS prevention and control efforts (Airhihenbuwa & Webster, 2004:4). In the South African context, the rates of denial are significantly high and have continued to present a huge challenge when it comes to efforts of tackling this epidemic (Leclerc-Madlala, Simbayi & Cloete, 2009:18).

In many African cultures, South Africa included, illness is attributed to spirits and supernatural forces and such beliefs may be associated with stigmatising the affected persons (Leclerc-Madlala et al., 2009:18). In South Africa for instance, there has been a popular belief that HIV and AIDS is caused by witchcraft, and such traditional beliefs are prevalent in rural communities. Thus, seeing HIV and AIDS as a supernatural phenomenon is a common belief in South Africa that is thought to have an underlying influence on HIV and AIDS related stigma. This belief is said to reflect a common state of misinformation about the facts of the illness and as a result misinformation may be the source of stigma and discrimination related to HIV and AIDS, thus there is a correlation between HIV and AIDS related stigma and traditional beliefs which is measured by knowledge of HIV and AIDS versus HIV and AIDS stigma (Kalichman & Simbayi, 2004:573; Visser, Makin, Vandormael, Sikkema & Forsyth, 2009:198).

In contrast to the traditional evil belief of witchcraft associated with HIV and AIDS, there is also the belief that God and the ancestors may punish an individual to contracting HIV and even die of AIDS, as those who are affected or infected by HIV and AIDS are thought to have brought this upon themselves (Kalichman & Simbayi, 2004:578; Visser et al., 2009:198). The belief held at societal level with regards to God and the ancestors is that if a person has angered these two supernatural systems, they can get punished. In other words, it is believed that ancestors can send the illness to the afflicted person or may withdraw their protection. Thus, attributing this belief leads to stigmatising beliefs about PLHIV that they have brought the illness to themselves and their communities. It is also believed that God is punishing people for their bad behaviour and young people for disrespecting their elders, thus there is a strong link being made between HIV and AIDS related stigma and sex, sin and morality (Kalichman & Simbayi, 2004:578; Campbell, Foulis, Maimane & Sibiya, 2005:810; Visser et al., 2009:198).

Furthermore, HIV and AIDS related stigma has been associated with people who are less educated or less knowledgeable about the illness (Visser et al., 2009:204). Also gender, race, and social class have a significant role in how HIV and AIDS related stigma gets perpetuated (Castro & Farmer, 2005:55). For instance, societies that are said to be marked by profound racism, people of a minority racial group tend to experience stigma as compared to their counterparts. Likewise, gender inequality also determines how sexism marks the course of HIV. In other words, highly sexist contexts, disclosure of HIV can lead to stigma and domestic violence compared to an environment where women enjoy gender equality. In Africa, it has been found that women who live with HIV tend to experience stigma and discrimination related to HIV and AIDS especially by their parents, in-laws and partners (Wyrod, 2013:45). With regards to class, poor communities endure stigma based on their socio-economic standing, i.e. for merely being a poor society. Thus it is inevitable that they will also endure HIV and AIDS related stigma based on that fact (Castro & Farmer, 2005:55).

2.6 STIGMA AS A BARRIER FOR HIV TESTING AND COUNSELLING AND TREATMENT SEEKING

Stigma has been dubbed to have a significant impact in the spread of HIV and this has been widely researched worldwide. Moreover, stigma has also been found to act as a barrier to the prevention of HIV and treatment seeking. In South Africa the state has invested in a significant number of VCT centres as research has revealed that VCT can reduce high-risk sexual behaviour, decrease the rates of sexually transmitted diseases and directing people infected with HIV to highly active antiretroviral therapy (HAART) which is extensively available in South Africa (Meiberg, Bos, Onya & Schaalma, 2008:49). However, delays to the access of VCT services have been observed and these are said to be caused by stigma associated with HIV and AIDS (Brimlow, Cook & Seaton, 2003:8; MacQuarrie, Eckhaus & Nyblade, 2009:5).

As a result of risky sexual behaviour that young people tend to engage into, there is a fear of making use of the VCT services that prevails as well as a variety of other barriers such as worries about confidentiality, fear of being stigmatised and perceptions of the consequences of living with HIV, to mention but a few. The fear of knowing one’s status is the most cited reason for not accessing VCT services by youth. This is followed by the fear of negative social reactions, which is another major barrier for accessing VCT by young people and this pertains to how they fear their friends and family will react when they discover that they have tested positively.

Lastly, another barrier to accessing VCT is the lack of trust of health care workers in the VCT centres, as the fear of being blamed is expected (Chakrapani, Newman, Shanmugam, McLuckie & Melwin, 2007:355; Meiberg et al., 2008:52). This then translates to the right of people accessing VCT being violated as according to National Patient's Rights Charter (2008:2): "… everyone has the right to access to health care services that include counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS."

According to a study conducted by Tshuma, Muloongo, Setswe, Chimoyi, Sarfo, Burger and Nyasulu (2014:7) about the potential barriers to rapid testing for HIV among a commuter population in Johannesburg, South Africa, it revealed that HIV and AIDS related stigma was cited as a barrier to HIV testing, despite the knowledge about HIV transmission, among other factors. Pitpitan, Kalichman, Eaton, Cain, Sikkema, Skinner, Watt and Pieterse (2012:368) also found, in another study conducted in Cape Town, South Africa, that AIDS related stigma is associated with HIV testing and could pose as a significant barrier to testing, especially to men and women who were using alcohol. This also attests to the notion that alcohol and/or substance abuse paired with AIDS related stigma was identified as a barrier to HIV testing (Pitpitan et al., 2012:369). This basically boils down to the fact that HIV and AIDS related stigma has been found to pose as a barrier to voluntary HIV testing and counselling.

Also, some people fear going to the clinic to access treatment because of the stigma attached to this disease (Mbatha, 2013:521). Furthermore, the lack of social support on individuals who are on antiretroviral therapy (ART) leads to the lack of adherence as some people feel that in order to take treatment accordingly they have to disclose to their family members such as partners who may stigmatise them (Katz, Ryu, Onuegbu, Psaros, Weiser, Bangsberg & Tsai, 2013:4).

2.7 INTERVENTIONS TO REDUCE HIV AND AIDS RELATED STIGMA AND THE ROLE OF A SOCIAL WORKER

There has been a need to develop strategies that can deal with the issue of HIV and AIDS stigma and this has been researched and documented quite well. It is the opinion of the researcher that a collaborative effort can be of utmost importance in doing so, thus it is inevitable that the contribution of social workers who often have an encounter with communities of people affected by and living with HIV and AIDS, can also come in handy. Therefore, the following section will discuss intervention strategies described in literature as well as the role of social workers in the mitigation of HIV and AIDS stigma.

Brown, Trujillo and Macintyre (2001:3) state that in order to effectively deal with the issue of HIV and AIDS in any community, be it developed or developing communities, it is imperative that intervention strategies are identified and implemented. Grossman and Stangl (2013:1) agree that stigma and discrimination associated with HIV and AIDS can be reduced through interventions and the global political initiatives have played a major role in working towards an AIDS-free generation through programmes and policies that are aimed at reducing stigma and discrimination as seen through UNAIDS, UN and PEPFAR.

The UNAIDS (2012:7) states that programmes aimed at reducing stigma and discrimination against people living with HIV or those at risk of HIV infection should address actionable causes of stigma and discrimination and empower people living with and vulnerable to HIV. Brown et al. (2001:1), reviewed 21 intervention strategies that were aimed at reducing stigma and discrimination in developed and developing countries. From these, they concluded that these strategies could be divided into four types, namely: information based approaches, coping skill acquisition, counselling approaches and contact with affected people. These are briefly expanded upon in the subsequent section:

- **Information based approaches**

Brown et al. (2001:30), define this type of intervention as information or fact based written and/or verbal communication. They give examples of this type as information packet or leaflet, media advertisement, peer education classroom type factual presentation to mention a few.

- **Coping skill acquisition**

Coping skills are defined by Brown et al. (2001:30), as learning a coping behaviour. The examples of this type of intervention are role play, mastery imagery, reframing and relaxing techniques, group desensitization and scripting.

- **Counselling approaches**

Providing support for positive behaviour is another type of intervention aimed at reducing stigma and discrimination related to HIV and AIDS. Examples here are one-on-one counselling and support groups (Brown et al., 2001:30).

- **Contact with affected people**

The other type of intervention that Brown et al. (2001:30), identified is contact with affected groups. This is defined as interaction between affected groups and general public. The examples to this type are live testimonials, interaction with PLHA and visualisation of being a PLHA.

The above types of interventions were researched intervention strategies and some were published by various authors in different publications over the years with different populations around the world, others were unpublished. Some of the reviewed strategies were not necessarily aimed at HIV and AIDS related stigma reduction alone, it included other diseases as well (Brown et al., 2001:7).

Wolf and Mitchell (2002:165) the social work profession is a critical resource in the community to be used in addressing HIV and AIDS prevention and early detection. Social Workers play a significant role in providing services to people who are directly and indirectly affected by HIV and AIDS (Rodriguez & McDowell, 2014:1).

Spies (2007:134) stated that the current HIV and AIDS epidemic in South Africa in particular poses a major problem to all professions, including Social Work. Thus, the Social Worker who has skills and knowledge in the field of HIV and AIDS is well equipped to play an important role in the multidisciplinary team by assessing and counselling patients regarding adherence to ART, as well as providing support and education.

The researcher is of the view that the involvement of the Social Worker in this field should not be undermined as addressing individual issues with people affected by HIV and AIDS can contribute immensely in efforts aimed at mitigating stigma and discrimination associated with HIV and AIDS.

2.8 COMMUNITY HEALTH CARE WORKERS: THE SOUTH AFRICAN CONTEXT

Community health care workers (CHCW'S) play an integral role in the delivery of primary health care in South Africa and across the world as Schneider, Hlophe and Van Rensburg (2008:179) states that after having declined during the 1980s, the global trend in the use of community health workers, especially in the context of HIV and AIDS re-emerged. It was only fair that the researcher includes a thorough discussion of the involvement of CHCW'S on issues pertaining to HIV and AIDS, and in this context the issue of stigma and/or discrimination. In order to appreciate how they form part of this research study, the researcher reviewed literature with regards to who CHCW'S are and what roles they play in the primary health care system, as well as in the HIV and AIDS field. This would perhaps help to place them within the scope of this study.

In South Africa a rapid increase of lay workers has been observed and they come in the form of (Home based carers, lay counsellors, DOT supporters and community health care workers), where initially their services were sought out to address issues of budgetary constraints and the response to HIV, and more recently, for the roll-out of antiretroviral therapy programmes (Schneider et al., 2008:179). As the South African government dispensed free primary health care (PHC) for all its citizens, the burden of disease, such as HIV infection, in PHC facilities increased and thus a call for more human resource became evident. As a result, the government's response to this as mentioned above was to go via the route of CHCW'S, as part of a solution to the human resource crisis and also to ensure that there is adequate on-going support of recipients of long term treatment and that adherence to treatment is enhanced (Tsolekile, Puoane, Schneider, Levitt & Steyn, 2014:2).

2.8.1 Defining Community health care workers

The answer to the question of who community health care workers might be precisely, can prove to be a difficult task as they differ according to context and demographics (Lehmann & Sanders, 2007:6). Nonetheless, this question can perhaps be answered by firstly defining the term CHCW'S. A widely acknowledged definition is the one which was proposed by the World Health Organisation (WHO 1989), as cited in Lehmann and Sanders (2007:3) which states that:

> “Community health care workers should be members of the community where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily as part of its organisation, and have shorter training than professional workers.”

According to Languza, Lushaba, Magingxa, Masuku & Ngubo (2011:3) community health care workers can be defined as any health care worker delivering health care services and who is trained in the context of the intervention but has no formal professional tertiary training. Lewin, Babigumira, Bosch-Capblanch Aja, Van Wyk, Glenton, Scheel, Zwarenstein & Daniels (2006:5) agree with this definition that lay health care workers (LHWs), which is used as an umbrella term and includes community health care workers, village health workers, cancer supporters and birth attendants), are usually provided with informal job-related training and have no formal professional or paraprofessional tertiary education and can render services with or without pay, i.e. voluntary care. They may also work in communities where they reside (Tsolekile, Puoane, Schneider, Levitt & Steyn, 2014:2). Thus, from the above definitions it becomes pretty clear that community health care workers are individuals who are sought within the community and empowered with skills to serve their communities in return. The researcher is of the view that this is an effort of community development by the health sector which is unified with capacity building to ensure that health care services are delivered effectively.

2.8.2 The roles and functions of community health care workers

Now that a definition of CHWCs has been established, it is inevitable to move on to a description of their role and/or function within the primary health care system, in South Africa in particular. The primary link between the formal health care sector and the households in South Africa is through the engagement of community health workers and they can give a perspective of barriers that hinder the delivery of health services in communities (Suri, Gan & Carpenter, 2007:505). Furthermore, CHCW’S assume different roles which include community empowerment, provision of services and linking communities with health facilities. They also have been understood to assume roles in arears of maternal and child health, as well as infectious diseases such as HIV, malaria and tuberculosis (Tsolekile et al., 2014:2).

In a study conducted in Khayelitsha in Cape Town, it revealed several roles that community health care workers undertook in a certain NGO. These included, advisors, provision of direct services, monitoring of clients, linking clients with the health system, capacity building and administration (Tsolekile et al., 2014:3). These are explained briefly below:

- **Advisor**

As an advisor, community health care workers offer advice to clients ranging from health advice to social issues. This also extended to giving patients information about diet and where to access services relevant to them (Tsolekile et al., 2014:4). This is linked to the role of health educator which is discussed under the subsequent sub-heading:

- **Provision of direct services**

In terms of providing direct services, community health care workers engage in a number of activities which include facilitation support groups, health education, and distribution of medication and rehabilitation services. In terms of group facilitation, CHCW'S run support groups with clients who are suffering from diabetes, hypertension and other ailments and they assume leadership roles within these groups (Tsolekile et al., 2014:4). With regards to health education, CHCW become educators and teach the patients either within support groups or at home about nutrition as well as explain risk factors, symptoms and prevention measures. Lastly, regarding the distribution of medication and rehabilitation services, CHCW'S distribute chronic medication to patients within their support groups or at home during home visits and this is seen as a way to improve access to treatment and benefits both the patient and the health facilities. Rehabilitation services on the other hand means that CHCW'S can also provide physical exercises to patients who have suffered stroke and also encourage them to visit health facilities where they can get further rehabilitation services (Tsolekile et al., 2014:4).

- **Monitoring of clients**

The monitoring of clients includes CHCW'S assisting their group members with information to enable them to better manage their conditions. Further, it also means that while conducting their support groups, CHCW'S also engaged in anthropometric measurements by means of measuring blood pressure, blood glucose and weights of their members (Tsolekile et al., 2014:5).

- **Linking clients with the health system**

Community health care workers refer their clients to the nursing supervisor if they pick up any irregularities in the conditions of their patients. The nursing supervisor will then refer the patient to their nearest health facilities where they can get further assistance. The CHCW'S will then make follow-up visits to the clients in order to establish if they received the necessary treatment as per referral (Tsolekile et al., 2014:5).

- **Capacity building**

An interesting role that became apparent in this literature review was that of the CHCW'S providing on the job training to especially newly recruited CHCW'S. Team leaders are being used in the field to assist newly recruited CHCW'S to gain on the job experience (Tsolekile et al., 2014:5).

- **Administration**

Lastly, when it comes to administration, CHCW'S complete forms with daily stats and information relating to the clients. The information includes patient's medication and their particulars. These are then submitted to the coordinators for record keeping (Tsolekile et al., 2014:5).

- **Generalist versus specialist**

In addition to the above roles that have been singled out by Tsolekile et al. (2014), Lehmann and Sanders (2007:8) brings a different view of the roles and/or functions of community health care workers. They make a distinction between two rather broader terms that are understood to embrace some if not all of the already discussed roles, i.e. the generalist versus the specialist. These authors argue that it is impractical to provide a typology of the roles of community health care worker because of the numerous tasks they perform in different contexts. Therefore, they opted to make a distinction between generalist and specialist (Lehmann & Sanders, 2007:8). A generalist CHCW is someone who engages in a number of activities which include health education, home visits, first aid and treatment of common ailments, maternal and child health, community activities and referrals. A specialist on the other hand, would refer to CHCW'S who address specific health issues. Although, there has been an appreciation of the fact that there are some blurred lines between the generalist and the specialist CHCW'S (Lehmann and Sanders, 2007:11).

2.8.3 Community health care workers in the field of HIV and AIDS

In a study that was conducted in KwaZulu Natal by Suri et al. (2007:507), community health care workers indicated that HIV and AIDS ranked at the top and closely followed by TB and poverty within the community. They further indicated their roles in this field in curbing HIV transmission by means of education and counselling as being of paramount importance. Community health care workers have also expressed their views with regards to HIV and AIDS, in that the underlying causes of poor uptake of VCT and access to treatment among other issues include stigma related to the illness (Suri et al., 2007:507).

2.9 SUMMARY

The phenomenon of stigma related to HIV and AIDS has existed for a very long time since the beginning of the disease. It has been a conundrum that has lingered on the lips of all those who are keen on forming part of the endeavour to reduce the spread of HIV. Many strategies have been developed in order to mitigate stigma and discrimination associated with HIV and AIDS and it has become pretty clear that without a collaborative effort this battle cannot be won. As a result, the above discussion is merely an attempt to reveal the scope of the stigma related to HIV and AIDS and this cannot be solely said to be enough, this problem is probably far deep seated than it appears to be. Even though so, the debates around this issue calls for concern and consequently action to be taken.

The following chapter will focus on the research methodology and findings.

3. CHAPTER THREE: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1 INTRODUCTION

This chapter will provide the research methodology and empirical findings. The former being the research approach, type of research, research design, study population, sample and sampling technique, data collection and data analysis, quality of data and trustworthiness and ethical considerations. The latter part will focus on a presentation of the empirical findings of the study.

3.1.1 Goal and objectives

The goal of this study was: to explore and describe the perspectives of community health care workers regarding the destigmatisation of HIV and AIDS. Thus, the researcher formulated certain steps or objectives, which were followed in order to achieve this purpose (Fouché & De Vos, 2011:94). These are stipulated as follows:

- To describe people infected and affected by HIV and AIDS, with specific reference to stigmatisation within the context of the labelling and attribution theories.
- To explore and describe the perspectives of community health care workers on the destigmatisation of HIV and AIDS.
- To recommend strategies for intervention on the reduction of HIV and AIDS related stigma.

3.2 RESEARCH METHODOLOGY

The research methodology will subsequently be discussed**.**

3.2.1 Research approach

This research study followed a qualitative approach. The purpose for selecting this approach was that the researcher wanted to explore and understand the community health care workers' perspectives in addressing issues of stigma and discrimination relating to HIV and AIDS (Fouché & Delport, 2011:64).

The qualitative nature of the research study allowed the researcher to follow an inductive logic in order to draw conclusions about the proposed study. This implies that the information obtained from the community health care workers in this research project, may lead to the suggestion that explains the phenomenon under study, which could lead to a better understanding of the larger phenomenon (Fouché & Delport, 2011:64 and Creswell, 2009:5).

3.2.2 Type of research

The researcher identified applied research as the relevant type of research, due to the fact that the proposed research study sought to understand the views and opinions of community health care workers on the destigmatisation of stigma related to HIV and AIDS. Thus, the findings could contribute to towards addressing the challenges of the above-mentioned phenomenon, as well as contribute to policy and community development (Durrheim, 2006:45 and Babbie, 2010:26).

The study was explorative and descriptive in nature, where researcher aimed in the former, to explore the perspectives of community health care workers on the destigmatisation HIV and AIDS with the aim of gaining any new insight on this phenomenon (Babbie & Mouton, 2005:80 and Durrheim, 2006:44). With regards to the latter, the research aimed to provide a description of the perspectives of the community health care workers on destigmatisation of HIV and AIDS through their own narratives as well as any relevant observations (Babbie & Mouton, 2005:80 and Durrheim, 2006:44).

3.2.3 Research design

The researcher chose the case study design, namely the collective case study as a research design. The utilisation of the multiple or collective case study design was appropriate, so that the phenomenon being researched could be better understood through multiple cases (Baxter & Jack, 2008:549), namely from more than one case of a community health care worker.

The reason for selecting this type of research design was that the researcher sought to incorporate multiple perspectives of the community health care workers in the study, in order to elaborate holistically on the topic under study (Neuman, 2011:42). This means that different viewpoints regarding the proposed topic were obtained from the participants.

3.2.4 Study population, sample and sampling method

The population for this study were all the community health care workers in the Hammanskraal community, in Gauteng Province, who are employed by various non-governmental and non-profit organisations that render services to people affected by HIV and AIDS. A sample of community health care workers were drawn from this population to which results of the study were generalised (Neuman, 2011:241). The sample included thirteen community health care workers from the targeted population.

The researcher used non-probability purposive sampling with specific selection criteria to identify appropriate non-governmental and non-profit organisations. The selection criteria included the following:

- Organisations (NGO's or NPO's) who render services in the Hammanskraal community, Gauteng Province.
- NGO's or NPO's who render services to people affected by HIV and AIDS.
- NGO's or NPO's who employ community health care workers.

Purposive sampling is described by Strydom and Delport (2011:392) as a technique used whereby a particular case is selected because it shows some feature or process that is of interest for a particular study.

Once the organisations were identified, the researcher applied for and obtained permission to conduct the research study with community health workers from the identified organisations. The organisations that gave permission for the research study became the different strata from which data was collected.

Secondly, after the researcher had ethical clearance from the ResEthics Committee, Faculty of Humanities, UP to conduct the research. The researcher used indirect volunteer sampling to recruit potential participants. Each NGO and NPO that was purposively selected was provided with an information letter by the researcher to inform their CHCW'S of the study. This was done by a manager or direct supervisor in the organisation, who got the contact details of interested community health care workers, i.e. volunteer sampling, which Strydom & Delport (2011:394) assert is a type of sampling which is best with respondents known to one another and who can encourage each other to participate in the study. They also state that participants who volunteer to be part of the study facilitate the researcher’s task and accelerate the process. Furthermore, participants who come forward voluntarily are more skilled and possess specific characteristics than their counterparts. Thus, the following selection criteria were also included in the information letter:

- Community health care workers who speak English and Setswana.
- Community health care workers who have been employed by these organisations for at least a period of two (2) years.
- Community health care workers who worked directly with people living with HIV and AIDS.

Thirdly, the researcher collected the contact details of potential participants meeting the selection criteria from the organisations. Stratified random sampling was then used to select participants, which according to Strydom (2011:228) means that each of the community health care workers in the target population has the same known probability to be representatively selected and this will allow the researcher to estimate the accuracy of the sample to be before the study is done. Stratified random sampling is used to make sure that different segments or groups of a population (organisations in the case of this study) are adequately represented and the population is divided into different strata which have homogeneous characteristics. This method also decreases the probable sampling error. (Babbie, 2010:214 and Strydom, 2011:230).

In this study the researcher used stratified random sampling to ensure that 13 CHCW’S with the same characteristics mentioned above, were represented from the different organisations.

3.2.5 Data collection

Data collection was done through qualitative interview, whereby Babbie (2011:312) states that it is a conversation in which the interviewer leads a general direction for the conversation and pursues specific topics raised by the respondent. This data collection method has the power to elicit information that the researcher seeks from the participants and this can be best achieved by forming a reciprocal relationship between the parties involved (Greeff, 2011:341).

The researcher chose focus group interviews as a method of data collection, in order to obtain multiple viewpoints of the participants, in this study the community health care workers perspectives on the destigmatisation HIV and AIDS (Greeff, 2011:360 and Sagoe, 2012:1-14).

The researcher conducted two (2) focus group interviews in order to shy away from the idea that a single group could not provide for generalizable insights (Babbie, 2011:315). One focus group had 7 participants and the other had 6 participants. Each focus group consisted of participants with common characteristics as mentioned above (Greeff, 2011:360).

The researcher used a focus group interview guide to ask questions and provided clarity where there was a need. The focus group interviews were recorded using a voice recorder. A research assistant was used for the purpose of operating the voice recorder and to make field notes (Greeff, 2011:373). The research assistant signed a non-disclosure agreement. The focus group interviews were conducted at the organisations as this was the most convenient venue for the participants and it took place during working hours, as pre-arranged.

3.2.6 Data analysis

The researcher conducted a thematic analysis, by presenting the data analysed by means of themes and sub-themes that emerged from the responses of the participants during interviews.

In terms of analysing data for the research study, the researcher followed the process stipulated in Schurink, Fouché and De Vos (2011:403) for qualitative data analysis. This is discussed in the subsequent section:

- **Data collection and preliminary analysis**

Data was collected through focus group interviewing. During the data collection process, a voice recorder was used to record the interviews with the permission of the participants. The research assistant took field notes which were used as a preliminary analysis. Once the interviews were done, the researcher transcribed the data verbatim from the audio recordings.

- **Managing the data**

The recorded audio files were transferred electronically to the researcher's computer under specific folders which were labelled with dates after the focus group interviews were conducted. The audio recordings were also stored in the researcher's Google Account's Google Drive storage as a form of backup.

- **Reading and writing memos**

The researcher read thoroughly through the transcripts of the collected data repetitively, in order to make sense of the information that was gathered. He also made notes on the margins of the transcripts by means of phrases and keywords.

- **Generating categories and coding the data**

Themes and sub-themes were generated by means of highlighting text from the transcripts and coding by using keywords to identify common patterns. The coding process was used to generate the themes and sub-themes for analysis and later used as major findings of the study (Creswell, 2009:189).

- **Interpreting and developing typologies**

The researcher consulted the literature study to find support for the findings that came out from the themes and subthemes and to thus substantiate the findings.

- **Presenting the data**

In the subsequent section below, the researcher will present the findings by means of themes and subthemes, as well as quote the exact words of the focus group participants in a verbatim form. In his own words he will then interpret these findings and support it with literature.

3.2.7 Quality of data and trustworthiness

In order to ensure the quality of data and trustworthiness of the research study, the researcher engaged in certain strategies that assisted in ensuring that proper qualitative research processes have been followed. This was done against a backdrop of comprehensive constructs such as credibility, transferability, dependability and confirmability to be used as a criterion to ensure quality (Schurink et al., 2011:419 and Shenton, 2004:64).

- **Credibility**

Credibility deals with the question of compatibility regarding the authenticity of the research findings (Shenton, 2004:64). It employs strategies such as reflexivity, triangulation, peer debriefing and member checking among others.

The first strategy was reflexivity, whereby the researcher acknowledges his own actions and decisions that may have an impact upon the meaning and context of the experience under study (Lietz, Langer & Furman, 2006:447). In other words, the researcher will have to position himself in terms of the impact that his beliefs, perceptions and personal experiences might have with the proposed study, i.e. how this may or may not help the research study. This was done by means of reflection during the research collection and analysis stages.

The second strategy that the researcher chose to ensure trustworthiness was peer debriefing, in order to minimise any effects of reactivity and bias (Lietz et al., 2006:451). This was done by means of consulting and reflecting on the findings with a peer colleague was not immediately involved or did not have any interest in this research study.

- **Confirmability**

These strategies, herewith, also speak to the issue of **confirmability** which in simple terms means that the researcher ought to remain objective (Shenton, 2004:72).

The researcher also made use of member checking, which allowed the participants to review findings from the data analysis either to confirm or challenge the accuracy thereof (Lietz et al., 2006:453). This gave the participants an authentic voice to their meanings, as described in the findings. This was done during the debriefing session after the focus group interviews to clarify if the information gathered was understood correctly. Once the analysis had been done and themes generated, the researcher went back to those participants who researcher could find, to do member checking (Lietz & Zayas, 2010:193-194). At least three (3) members from each focus group were found and were willing to corroborate the findings. Thus, dealing with the issue of credibility rigorously.

- **Transferability**

The issue of transferability basically refers to the extent to which findings of a particular study being applicable to a different situation, either in the same or similar context (Shenton, 2004:69). Although one should be wary of the fact that situations differ, thus “in order to asses that the extent to which findings may be true of people in other settings, similar projects employing the same methods but conducted in different environments could be of great value” (Shenton, 2004:70). Thus, for this study the issue of transferability could be supported by the fact that it followed a qualitative enquiry with an inductive logic where specific cases of the community health care workers that were studied in this research project lead to a suggestion that it is the case with other communities. Also, the fact that these CHCW’S were purposively selected for the study supported the issue of transferability (Lietz & Zayas, 2010:195).

- **Dependability**

Dependability on the other hand, deals with the subject of consistency. In other words, this means that if the same study were to be repeated in the same context, with the same method and participants, the end result would be the same if not similar (Shenton, 2004:71). The researcher is of the view that if a similar process of inquiry were to be carried by another researcher in a similar fashion, it would inevitably bring about the anticipated end result. All data was securely stored and processes noted down and reflected on as part of reflexivity, so that an audit trail can be done in future if needed.

3.2.8 Pilot study

The researcher conducted the pilot study with two community health care workers from Perseverance Rural Development Centre (Prudec) which is one of the organisations that had volunteers who participated in the main study. The researcher went through the questions in the interview guide with the CHCW’S. They understood the questions and also indicated that they were clear and straight forward and also relevant to their daily activities in their line of duty.

3.3 ETHICAL CONSIDERATIONS

Subsequently the ethical considerations in this study will be discussed.

3.3.1 Avoidance of harm

The researcher fulfilled the ethical obligation of protecting participants from any form of emotional harm that may have emerged from the research study. The researcher stated on the informed consent form that the participants can withdraw from the study at any point if they wished to do so, without any negative consequences (Strydom, 2011:115). Since the study focused on sensitive issue of HIV and AIDS stigma, the researcher prior to the research explained the full information regarding the procedure and possible risks including explaining to participants that asking this kind of sensitive information may embarrass or upset them (Neuman, 2011:146-147). This is due to the fact that working with PLHIV may be stressful for or emotionally draining to them and may also mean that they endure stigma too, based on stigma by association (Bharat, 2011:143).

The researcher also avoided any aspects that may put the participants in an emotionally distressful position when talking about their experiences or that could cause any form of stress or discomfort even after the research was done (Neuman, 2012:58). If any participants needed to be referred for counselling services, a social worker from the Department of Social Development (DSD) in Temba, Hammanskraal, Ms Flora Makopo was available. However, it was not necessary to refer any of the participants, as none of them indicated any emotional harm.

3.3.2 Voluntary participation

In this research project, the researcher explained in the informed consent form that participation in the study was be voluntary and no participant was forced to participate involuntarily in the proposed research project (Neuman, 2012:58), and could withdraw without any negative consequences.

3.3.3 Informed consent

A letter of informed consent was provided to the participants prior to the commencement of the focus group, in order for them to make an informed decision about their participation. The informed consent letter clearly outlined the purpose of the study and how the study was to be conducted. It also explained to the participants that they may withdraw at any point and that their participation was voluntary (Kumar, 2005:214). The informed consent also included confidentiality, the avoidance of any harm or discomfort, that the focus group interview was to be voice recorded with their permission, that an assistant was to be used who would adhere to confidentiality agreement, that the data will be stored at University of Pretoria (UP) for 15 years for archival purposes and that the results will be made available to the organisation and in a research report, once the study is complete (Neuman, 2012:59).

3.3.4 Deception of subjects and/or participants

The researcher did not deceive or withhold any information from the participants that would have led them to refuse to participate under false pretences in the study (Strydom, 2011:118-119). As prior mentioned, the purpose of the study was clearly stated in the informed consent letter to avoid any deception.

3.3.5 Violation of privacy/anonymity/confidentiality

In the proposed study, the researcher maintained the issue of confidentiality by explaining to the participants that all the information shared in the focus group would only be known to the researcher and those involved in the study, such as the research supervisor and the research assistant, who signed a confidentiality contract beforehand. He also explained in the letter of informed consent to the participants that their identity will not be made public knowledge (Neuman, 2012:65) and that a pseudonym or false name will be used in the focus group to protect their identity. The researcher also informed the participants that they should also respect the issue of confidentiality, that is, they were also not supposed share anything that transpired in the focus group because of the sensitive issues. Assurance was also given that data would be stored in a safe place.

3.3.6 Debriefing of participants

Strydom (2011:122) states that “a research project must always be a learning experience for both participants and researchers. Debriefing sessions are the ideal time to complete the learning experience that began with agreeing to participate.”

The researcher provided a debriefing session to the participants after the focus group interview had been completed, in order to deal with any misconceptions or harmful experiences that may have emerged during the interview (Greeff, 2011:372). During the debriefing session the issue of trustworthiness was also adhered to, as the researcher did member checking to ensure that the information discussed was understood correctly (Lietz et al., 2006:453).

3.3.7 Actions and competence of the researchers

Researchers have an ethical obligation to be competent, honest and adequately skilled to undertake the proposed study (Strydom, 2011:123). The researcher has the needed competence in conducting research, as he was previously exposed to a qualitative study and an essay as part of his undergraduate degree requirements. His interviewing and group work skills were also beneficial when it came to facilitating the focus group interviews.

3.3.8 Publication of the findings

The findings of the research study must be made publicly available in a written format that is understandable and accessible to the public (Strydom, 2011:126). The researcher compiled a comprehensive research report that presented the findings of the research study in a mini-dissertation format, which is available in the library of the University of Pretoria. A seminar will be held after completion of the study, to share the findings with various organisations in Hammanskraal. A manuscript for possible publication will also be submitted to a professional journal.

3.4 EMPIRICAL FINDINGS

Empirical data was collected in a form of focus group interviews in order to gather a variety of viewpoints from different Community Health Care Workers regarding the issues relating to HIV and AIDS stigma. Two (2) focus group interviews were conducted, recorded and later transcribed verbatim. The transcripts were analysed by the researcher, by coding and identifying themes and sub-themes from the data collected.

The biographical data of the participants is presented in the two tables below with a comprehensive analysis of certain biographic aspects by means of pie charts. This is followed by a thematic analysis of the research findings, which is supported by verbatim quotes from the focus group interviews and literature substantiation.

3.4.1 Biographic profile/data

Table 3.1 and 3.2 shows the biographical data of all the participants who were part of the focus group interviews. Each participant was allocated a pseudonym. FG1 or FG2 shows that the participant was in focus group number 1 or 2 and the M# shows the pseudonym or number a participant was assigned as a focus group member. The tables also show the age, gender and years of experience as a community health care worker for each participant.

Table 3.1: Participants from Focus Group 1

Participant pseudonym	Age	Gender	Years of experience as CHCW
FG1M1	25	Female	7 years
FG1M2	49	Female	7 years
FG1M3	22	Female	3 years
FG1M4	24	Female	2 years
FG1M5	24	Female	2 years
FG1M6	22	Female	3 years
FG1M7	22	Male	2 years

Table 3.2: Participants from Focus Group 2

Participant pseudonym	Age	Gender	Years of experience as CHCW
FG2M1	49	Female	6 years
FG2M2	33	Female	5 years
FG2M3	33	Female	10 years
FG2M4	46	Female	10 years
FG2M5	44	Female	12 years
FG2M6	39	Female	10 years

In the following section the above biographical information of the participants is presented in more detail.

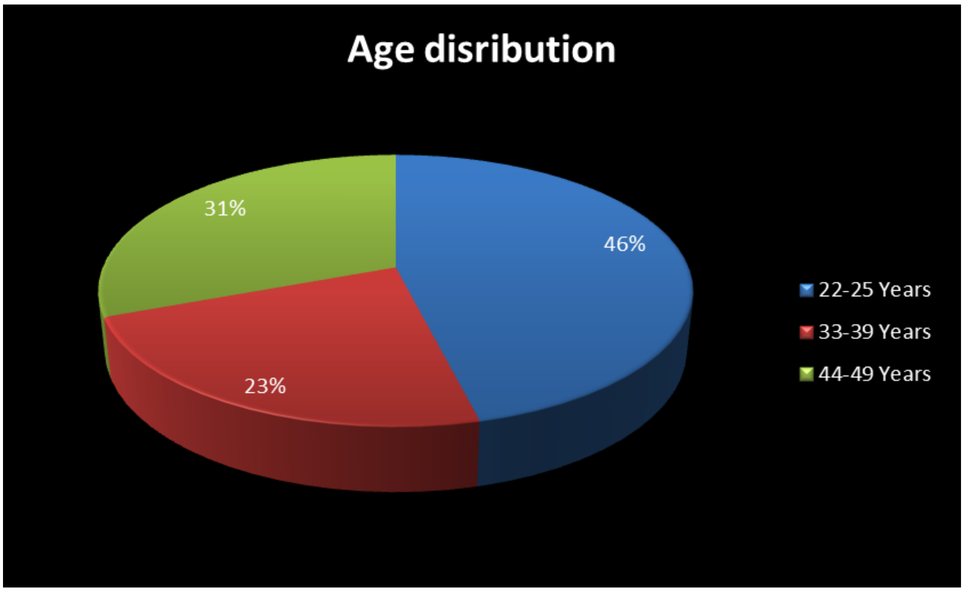

Figure 3.1: Age (n=13)

The above pie chart shows the distribution of the ages of the participants in both focus groups. The total number of community health care workers who participated in the focus group interviews was thirteen (13). The first group consisted of seven (7) participants and the second group had six (6) participants. Of the total number, six (6) of the participant's ages ranged between 22 and 25 years which is 46%, three (3) of them were between the ages of 33 and 39 years which is about 23% and the remaining four (4) were between ages 44 and 49 years which is 31%.

The following figure represents the gender of participants who were part of the focus group interviews:

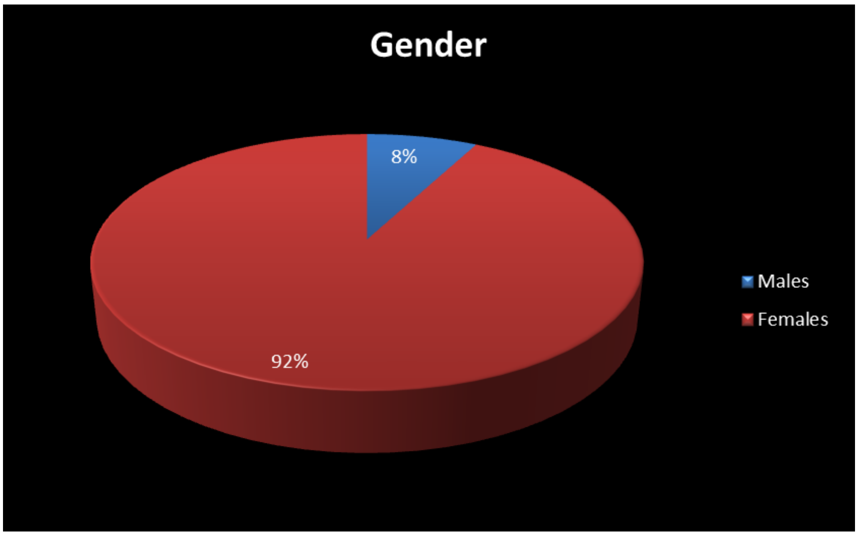

Figure 3.2: Gender (n=13)

There were a total of thirteen (13) participants who took part in the focus group interviews. The first focus group had six (6) females and one (1) male and the second focus group had six (6) females. The 8% represent the one male participant and the 92% represents the rest who were female participants. This reflects the gender of most community health workers in the community.

The next figure shows the distribution in years of experience of the community health care workers who participated in the focus group interviews.

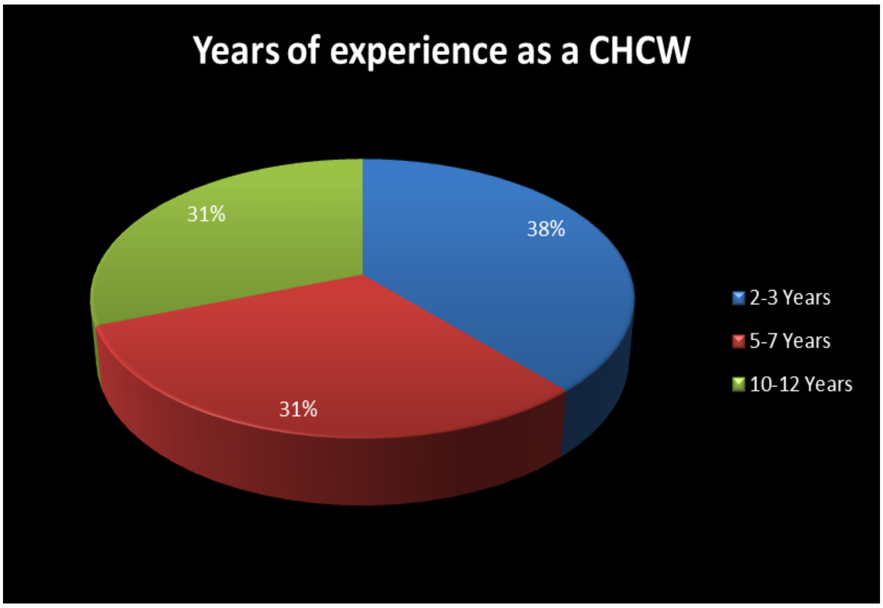

Figure 3.3: Years of experience as a CHCW (n=13)

The above chart shows that there was an equal distribution in the number of years of experience the community health care workers had. Those who were employed for a period of 2-3 years were about 38%, those who had 5-7 years working experience were 31% and those who were employed for 10-12 years were also 31%.

Subsequently, the thematic analysis of the themes and sub-themes are discussed.

3.5 THEMATIC ANALYSIS

The following table depicts the themes and sub-themes generated during the data analysis.

Table 3.3: Themes and sub-themes

Themes	Sub-themes
Fear	• Fear of HIV and AIDS • Fear of stigma and discrimination by health care professionals • Fear of disclosure • Fear of exercising one's rights
Social Support	• Family as a support system • Support groups
Lack of some knowledge and information about HIV and AIDS	• Education about HIV and AIDS
Health care professionals attitudes and behaviour towards PLHIV	• Discrimination through patient's clinical information • Separation of patients in the clinic • Lack of trust between patients and health care professional • Stigma and discrimination by other clinic staff • Strategy to address the attitudes and behaviour of health professionals towards PLHIV
Disclosure	• Disclosing to the public • Disclosing to family • Non-disclosure • Importance of disclosure

The themes and sub-themes as depicted in the above table will subsequently be discussed, using verbatim quotes from the focus group interviews and literature to substantiate the findings.

3.5.1 Theme 1: Fear

Fear is one of the themes that were very significant in the data collected regarding the issue of stigma related to HIV and AIDS as seen by the Community Health Care Workers. Sub-themes that were particularly apparent with regards to fear were: fear relating to HIV and AIDS in general and also particularly with regards to voluntary testing and counselling; fear of stigma and discrimination by the members of the community or health care workers; fear of disclosure to the family or significant others; and fear of exercising one’s own right as a person living with HIV. In the subsequent section these are expanded upon by means of verbatim quotes from the focus group interviews relating to fear as well as literature to support the findings.

Sub-theme 1.1: Fear of HIV and AIDS

The quotes from focus group participants reflect this sub-theme:

> FG2M1: “I think that they are aware about HIV but still there are some people who have fear … they might fear that if they have HIV, people will fear them ….”
>
> FG2M4: “Some of the people I know they say they do not want to test as they do not want to hurt themselves. They say; ‘... I want to be free; I want to live my life freely without knowing my status ….”
>
> FG2M3: “I think they do test but they are still afraid.”
>
> FG2M2: “They should accept themselves first before others can accept them, so they know about testing but eish! That fear makes them not to as they think that their friends will laugh at them when they receive treatment.”
>
> FG1M2: “… they fear to discuss the topic on HIV and AIDS and feel that you will ask them too many questions.”

In terms of fear relating to HIV and AIDS in general as seen by community health care workers, they indicated that some people have fear of voluntary testing or to know of their HIV status due to stigma. The above verbatim quotes attest to this.

Fear in relation to HIV and AIDS stigma and discrimination has been amply documented as one of the strong barriers that prevent people from acquiring knowledge of their HIV status through voluntary counselling and testing (Straus, Rhodes & George, 2015:12). Fear of stigmatisation more importantly has been found to be the most apparent barrier of HIV counselling and testing. This consequently has a negative impact in the course for prevention of HIV and treatment efforts, in South Africa (Meiberg, Bos, Onya & Schaalma, 2008:53).

Thus, fear of HIV and AIDS according to the community health care workers who participated in the focus groups discussions, became an important factor that contributes to stigma and discrimination being perpetuated. Perhaps, if the issues that are accompanying fear which can be seen to fuel HIV and AIDS stigma and discrimination were to be addressed, one might begin to see changes and consequently the mitigation of stigma.

Sub-theme 1.2: Fear of stigma and discrimination by health care professionals

The quotes below substantiate this sub-theme:

> FG1M6: “I also want to add on that issue that mostly when you look at people who are HIV and AIDS are afraid of going to the clinics why because, immediately they enter maybe the person I have to see is the one who gives me pills and it’s my friend, they can…maybe after giving me the pills, they can call someone else and say: “… look at her when she leaves, there she is I told you, she is carrying the pills ….” and you will find that I am definitely carrying the medication, that is why mostly they are scared to go to the clinic because they fear that people, the sisters do not know how to keep a secret and cannot keep confidentiality about people’s health lives, they will distribute their issues everywhere, that is why many people end up killing themselves because their matter is now everywhere.”
>
> FG1M1: “… the admin staff at the clinics are people who live in the same community as everyone, they know everyone, if I enter the counselling…testing room, I test and once I finish I go to counselling, at the end the admin who works in the admin will know that this file belongs to (mentions her name), she’s HIV positive, when she meets me at Thapelo (Local tavern) with my boyfriend, I can’t like disclose my status same day when we meet and say: “…I love you but I’m HIV positive ….” no it will take time. So you find that I have a boyfriend and that guy (clinic staff) will come and say; “… man, how do you feel being with a corpse?” So, that thing you see that at the end it will be like I will default because I will no longer go to the clinic to collet my medication because I fear that admin staff or someone that works at the clinic will meet me at some place and tell the people I’m with that; “… how do you feel being with a ghost?” So that is what makes the community of Marokolong to default and then discrimination and stigma to be high.”

Community health care workers felt that there was also a fear of stigma and discrimination as perpetuated by the community and some health care providers. Some people who live with HIV and AIDS are said to be afraid to visit the clinic on the basis that health care providers such as nurses and other clinic staff stigmatise people who are living with HIV. Furthermore, some PLHIV fear that members of their community might stigmatise them if they know their HIV status, this is according to the views expressed by some community health care workers.

Meiberg et al. (2008:53), also found in their study that participants were afraid of stigma that is perpetuated by health care providers due to a lack of trust of their confidentiality. Nyblade, Stangl, Weiss and Ashburn (2009:2) state that stigma by health care providers hinders the provision of quality care and adherence of patients to treatment. They further stated that in a study conducted in Tanzania, a variety of stigmatising and discriminatory practices were found which included disclosing HIV status without consent and verbal abuse or gossiping. This supports the views provided by the community health care workers above, that health care workers in the clinics and other staff members such as the administrative staff were the reason why PLHIV were afraid of visiting the clinic to get medical attention and consequently defaulting treatment.

Sub-theme1.3: Fear of disclosure

This sub-theme is supported by the following quotes:

> FG2M4: "… parents must not speak about HIV as if it's an illness that is only transmitted through reckless sexual activities, they must explain that it can be transmitted in other ways such as touching someone's blood who is HIV positive if you have a cut in your body, so that their children can be able to talk to them freely because this stigma might prevent them from disclosing because of fear and the more they have fear they will die. That is why it is important that one should disclose within the family so that if it happens that if they get sick then someone knows what treatment they are on and how it is taken. So these negative verbal words are what make children to fear disclosing to their families."
>
> FG2M6: "… people in our community still have that mentality of discrimination. People are afraid of disclosing as they feel that if they do how people will treat them? They think people will judge them that they were promiscuous. They have all the negative thoughts …."

The fear of disclosure was understood by community health care workers as a hurdle for PLHIV. There is the perception that people who live with HIV are afraid of disclosing their status, especially towards their families and the community.

The fear of disclosure in most communities is associated with fear of being ostracised (Lawson, Gardezi, Calzavara, Husbands, Myers & Tharao, 2006:31). Many PLHIV have cited judgement, rejection and avoidance as some of the consequences they are afraid of after they have disclosed their HIV status, especially by the community and significant others such as family. This fear is caused by stigma and discrimination (Siyamkela Project, 2003:18 and Lekganyane, 2010:20). Similarly, this is related to the anticipated or internal stigma as a result of the discrimination that is endured by many PLHIV, i.e. someone will not disclose his or her HIV positive status just because they are afraid of what people will think of them, say about them or how they see themselves in relation to others (HIV negative people), and this can lead to possible psychological consequences such as depression (Ragimana, 2008:25). In a study conducted at Maputo in Mozambique about HIV and AIDS stigma and human rights, some participants cited promiscuity as the cause of fear of disclosing their HIV status or even testing (Talja, 2005:45). This supports the above-mentioned findings as narrated by the community health care workers.

Sub-theme 1.4: Fear of using one's rights

The following quotes from the focus groups reflect this sub-theme:

> FG1M2: "… some people know their rights but they just have fear. They are scared that if they speak out about the treatment they get at clinics. People are afraid and do not know that what is being done to them should not be tolerated. They fear that if they follow the channels for laying their complaints they may be exposed that they are the ones who brought up such a matter. So people know but they have fear."
>
> FG1M1: "… they fear that if they were to lay complaints maybe the staff at the clinic will know that it is them who went to the managers. As ausi (mentions name of CHCW) has mentioned that some people know but they have fear. So I think if they can be made aware that you have a right to go into that office it is meant for this and that and you have a right to go in there and complain about any person who treated you otherwise and I have a right to be treated in a better way. So I believe if we can have awareness campaigns people will receive information and add on the knowledge they have."
>
> FG1M5: "But people are afraid because even if you tell the sister about your rights, they say you know too much and send you back to the waiting area. If you confront the staff they will tell you that you think you know it all and leave you unattended or tell you; … since you think you know better than us and you think you're a nurse go home and treat yourself…"

Exercising one's right also came as a hindrance for people living with HIV as a result of fear. Community health care workers were of the view that PLHIV and many other patients are unable to exercise their rights freely as they have fear of how the same health care providers treat them when they visit the health care facilities such as the clinics. They fear that if they speak out, they might not receive the treatment they deserve. This inability for one to be conscious about his or her rights is seen as one of the things that perpetuate stigma and discrimination, as PLHIV are afraid of confronting health care practitioners.

Stigma, discrimination and human rights violation has been seen to have an inseparable relationship. In other words, in contexts where stigma and discrimination occurs in relation to HIV and AIDS, the violation of human rights is inevitable. Thus, this violation of human rights should not be tolerated and needs to be remedied through programmes such as those that are aimed at alleviating stigma and discrimination (Aggleton, Malcom & Parker, 2005:11). Therefore, the fear of exercising one’s rights is seen to be brought upon by stigma and discrimination that is amplified by pre-existing prejudices and consequently a violation of human rights, within the delivery of services in the field of HIV and AIDS (Nyblade, Stangl, Weiss & Ashburn, 2009:2). The National Patients’ Rights Charter (2008:3) states that every patient has a right to complain about the health care services they receive and these rights do not exclude PLHIV.

This is in support of the labelling theory in the sense that PLHIV endure stigma and discrimination which results in fear, as they are labelled by the community and/or clinic staff. Also, PLHIV can label themselves, i.e. anticipated stigma, in relation to how other people in society perceives them. This consequently leads to fear of disclosure. Their contracting of the virus is also attributed to behaviour deemed as underserving of any pity or sympathy, which in most cases some health care professionals do.

3.5.2 Theme 2: Social Support

The following quotes from the focus groups reflect this theme:

> FG1M5: “I, what I see with this issue of HIV, is that, I used to work somewhere in health and I had a patient who was HIV positive. This person had his own style individually, that he will take treatment at his own time, when he does not feel like it he does not take the treatment, and when he started he was told that he must take treatment properly and when asked why he does not he would say: … my family insults me and say I’m HIV … and when you ask them (family) why they do that they would say he is the one who isolates himself and locks himself in his room and would say people see him that he is sick. I told him that you know what, one day you must just dress up and look into the mirror and say … this is me …” and go outside, you will see no one will see that you are sick because this thing is in you and not on your face and nobody sees it. He tried to go outside and do as I told him so he came back and told me that “… Oh! You helped me ….” Then other family members started gossiping about him to other relative and it affected his life because through families they were talking about him and laughing at him and he decided to stop taking treatment and he passed away.

> FG1M1: "… the problem is the difference between HIV and AIDS. So I think that the people in our community cannot differentiate between the two things (HIV and AIDS), you understand, because at the end if this person gets home and say "… mama I'm positive, I'm HIV …" you will hear the parent themselves, instead of giving support to their child they would say: "… don't come to me with AIDS …." At the end if you as a parent cannot give your child, how will somebody from outside support them?"

The issue of support was one of the themes that came about as community health care workers felt that it is very vital for PLHIV to get support from their family members and the community. The lack thereof was seen as what perpetuates stigma and discrimination related to HIV and AIDS. These are some of the verbatim quotes that deal with this theme.

Li, Lee, Thammawijaya, Jiraphongsa and Rotheram-Borus (2009:1005) view social support as very important to PLHIV and the lack of this is prevented by isolation and stigma, which can hinder treatment seeking and adherence, as well as lead to mental health issues such as depression and the deterioration of one's health status ultimately. Two sources of social support as identified by Folasire, Akinyemi & Owoaje (2014:16) include support by family or friends, as well as community-based support, the state and the health care industry. As a result, community health care workers felt that support was very important to help deal with issues of perceived stigma by PLHIV, especially support by loved ones and support groups.

As a result of enduring labels by community and the society at large, PLHIV become isolated and may delay seeking treatment and/or adhering to treatment as discussed above. Thus, in line with the labelling theory, the above-mentioned can be seen as the negative impact of living with HIV. Therefore, social support is important for PLHIV in order to deal with the many effects of the illness.

Sub-theme 2.1: Family as a support system

The following quotes from the focus groups reflect the sub-theme:

> FG1M5: "They need love from their families and care. They also need support from friends and family …."

> FG1M3: "... so people should be open and talk, as families are not the same, some members might give you support and that might save your life …."

The family and friends were seen as an important form of support for PLHIV by the community health care workers. They thought if people are open to their families they could receive the necessary support they need.

Iwelunmor, Airhihenbuwa, Okoror, Brown and Belue (2006:324) conducted a study in South Africa with regards to family systems and HIV and AIDS. The results showed that the family was regarded as an important source of support for people living with HIV. This is true, especially when a PLHIV discloses their status to the family, as this proved to be important for the family to cope with the illness and to provide the necessary support (Iwelunmor et al., 2006:324), as the community health care workers have mentioned above.

Family support is not the only important aspect of social support as support outside the family system is also seen as important. Support groups were also cited to be very vital for PLHIV in order to cope with HIV and possibly deal with any perceived stigma. In a study conducted by Mabunda (2004:304) that sought to explore the knowledge and practices among people in rural areas in South Africa, it was found that prior to joining a support group; participants indicated that they had no knowledge of HIV and AIDS.

The attribution theory alludes to the fact that PLHIV are placed at fault for acquiring the illness. Thus, as opposed to the notion brought upon by this theory, social support can play a vital role in ensuring that one does not internalise any fault-finding for living with HIV but to rather embrace it.

Sub-theme 2.2: Support groups

The following quotes from the focus groups reflect the sub-theme:

> FG1M2: “They also need support groups.”
>
> FG2M4: “They need support groups … it helps them to realise that they are not the only one who is HIV positive there are other people out there.”
>
> FG2M1: “I think those support groups help them with adherence and they also learn that they should not give their treatment to other people. The support groups also help in (Stutters) the problem is uh in those clubs how do they benefit in terms of food. If there was a way that the government can ensure that in those support groups where should they

> meet? I think they should have a place within the community according to different arrears or municipalities where they will meet in those groups ….”

Support groups were identified by community health care workers to be an important aspect in addressing the issue of stigma. These were seen as a need for PLHIV in order to help them cope with their HIV status and also to understand some dynamics of living with HIV such as adherence to treatment.

Dageid (2014:1) states that psychosocial issues for PLHIV can be addressed in support groups. These groups have been found to be very important in offering ongoing support for PLHIV. The benefits of joining these groups include among other things, coping mechanisms, well-being, social and emotional support, as well as reducing isolation, promoting acceptance, improving self-confidence, encouraging new friendships/networks and assisting in disclosure (Dageid, 2014:2 and Kekana, 2011:6-8). Thus, social support is very crucial in the effort of fighting stigma and discrimination related to HIV and AIDS, as was stated in the focus group interviews in the above findings.

3.5.3 Theme 3: Lack of some knowledge and information about HIV and AIDS

The following quotes from the focus groups reflect the theme:

> FG1M1: “… information can be available in our community, but in Marokolong information on HIV and AIDS is lacking, some they know that okay what is HIV. The problem is the difference between HIV and AIDS. So I think that the people in our community cannot differentiate between the two things (HIV and AIDS) ….”
>
> FG1M3: “… the question is taking us back to the issues of lack of knowledge, because whenever you start to disclose to your family or friends they … like they do not understand what HIV is actually, they take it as if HIV is AIDS and you’re dying. Immediately you start disclosing, they will start saying you he or she is dying with AIDS, he or she is a dead body and there is nothing left, even when you tell your family they will saying this one is dying and interfere in your family matters, that is why a lot of people do not disclose, you see lack of knowledge, not knowing what is HIV.”
>
> FG1M4: “… so I think for instance with people like us community health care workers, we know information and if you were to educate the family about HIV that if someone were to get sick, you could ask them what they think about HIV and if someone in the family were to be infected what would they do. You hear their views as a family and what they think. If they thought of it in a negative way you could still educate them

> to think about it positively, so that if one family member were to be infected with HIV they will be able to support them. A lot of families are not educated and as soon as you tell them that you are living with HIV they will say you want the neighbours to laugh at them, but if they get the right information and you educate them to know better ….”
>
> FG2M4: “… the community as well must be educated as to how they should communicate about HIV in their families. They must be taught that even if they children are sexually active they must not speak badly about HIV. They must not discriminate and stop associating HIV with promiscuity as they might not even know that their children have it. They must be taught how to address the issue of HIV in a sensitive manner ….”
>
> FG2M2: “I remember recently on the workshop we attended they taught us that even with young children you can ask them what is HIV? They will tell you what they know. They will tell you how they are taught about it at school. They have a lot of knowledge about HIV they even know the difference between the male and female condoms...so you see that they have some knowledge although they still need to be educated more but not in a way of shouting at them ....”

The issue of lack of some knowledge and information on HIV and AIDS also came out as an important theme in the focus group discussions with the community health care workers. The lack of some knowledge and information on HIV and AIDS that some people have in the community are what makes stigma and discrimination to remain on the realm. The inability for some people to differentiate between HIV and AIDS shows that there is a lack of some knowledge regarding this illness.

The lack of some knowledge on HIV and AIDS was also seen as what leads some people who are living with HIV to not disclose their status to their families. This means that if people do not understand HIV and AIDS better, they are prone to stigmatising or even thinking the worst about the person living with HIV such as the ultimate death. As Talja (2005:45) states that the lack of knowledge regarding the transmission of HIV denies citizens the right of health education, as well as causes stigma and discrimination as people fear getting tested for HIV.

So community health care workers felt that in order to address the issue of lack of some knowledge and information on HIV and AIDS, it was important to educate people in the community, so they could know better, especially within family settings. This could subsequently be a way in which stigma and discrimination can be stopped. In a study conducted by Visser, Makin, Vandormael, Sikkema and

Forsyth (2009:197) in South Africa, individuals and communities with a lack of knowledge on HIV and AIDS were likely to stigmatise. This is due to beliefs about the illness that are in contrast with the acceptable scientific framework of health and illness. Those who knew someone who is HIV positive or had AIDS, were said to be less likely to stigmatise (Visser et al., 2009:197).

Sub-theme 3.1: Education about HIV and AIDS

The following quotes from the focus groups reflect the sub-theme:

> FG1M1: “Yes education and right information we can achieve what we want because people say they don’t have the right information, so if we can provide that then things will be fine.”
>
> FG1M2: “I was also thinking of education as well as acceptance. People should try and accept their statuses, even though it’s not simple but they should try and they can live better.”
>
> FG1M3: “I think there should be more education, and part of that education should emphasise the issue of disclosure so they can get support because people who don’t disclose don’t get support and end up doing wrong things like taking unnecessary medication ….”

In the focus group discussions with the community health care workers, education was believed to be one of the major needs to address the issue of stigma related to HIV and AIDS. In particular, informal education was cited as a crucial strategy which could be used to help provide the relevant information to the community. This was also understood to assist PLHIV to accept their positive status and that the educational part should focus on disclosure as an important aspect.

Education seems to be a key intervention strategy that can be used to address the lack of knowledge and information that causes stigma and discrimination associated with HIV and AIDS, as seen by the community health care workers. Heijnders and Van Der Meij (2006:358) state that education is used in conjunction with other strategies in order to reduce stigma. The primary purpose of this is to provide information to society by means of increasing knowledge about a specific illness. Facts are being brought to the fore in order to counter fallacious assumptions that are believed to be the basis of stigma. However, in the field of HIV and AIDS some studies have revealed miscellaneous results, when it comes to education being used as a tool to combat stigma, compared to other illnesses (Heijnders & Van Der Meij, 2006:359).

In line with the labelling theory people who lack information or knowledge about HIV are said to stigmatise and discriminate. An underpinned notion of the theory states that deviant behaviour is not an act committed by a person, but a result of what is defined by society as against the norm. Therefore, illness is regarded as a deviant behaviour by society and more so HIV is attributed to the idea that one acquired it through risky behaviour and seen as one’s fault. Thus, such thought processes are of uninformed individuals. This is also in support of the attribution theory.

3.5.4 Theme 4: Health care workers’ attitudes and behaviour towards PLHIV

During the focus group discussions, another issue that came up was that of the attitude of health care workers such as nurses, health care workers and clinic administrative staff who have direct contact with people living with HIV. It appeared that part of the fear that is experienced by PLHIV, is also caused by the attitude and behaviour of the above-mentioned clinic staff in some of the clinics. This is with regards to the manner in which patients’ clinical information is being handled, the separation of patients according to illnesses, a lack of trust between the patient and the healthcare worker and stigma and discrimination by other clinic staff. The community health care workers suggested a strategy that they thought could assist in addressing these above-mentioned issues. This is indicated in the recommendations under theme four.

Sub-theme 4.1: Discrimination through patient’s clinical information

The following quotes from the focus groups reflect the sub-theme:

> FG1M3: “… you know in the clinic they will look for a person’s file and you know the assistants in the clinic are caregivers; they will stand in the middle of the hall and shout that your file is in the side for people who are positive and everybody will turn and look at the person … the problem is the assistants that are working in the clinic they do not treat people well, that is where stigma and discrimination comes in ….”
>
> FG1M2: “… it’s true that the person knows that people know them around and the sisters stay in the same community and knows the person and at the clinic they hear that people are being told to go to a certain room for certain treatment … they default and it becomes a problem because the people who work in the clinics are the ones who must assist the community but they are not to be trusted.”

The manner in which clinical information of PLHIV is being handled did not seem to please the community health care workers in the focus groups. Patients who receive HIV health care, were said to be treated differently from other patients who receive primary health care and this was demonstrated by the manner in which PLHIV were referred to a separate section in the facility by the clinic staff. This was seen by CHCW'S as another way in which stigma is being perpetuated. Also some health care professionals were said to disclose the status of patients in communities where they live.

The Health Professions Council of South Africa (2008:3), states that the disclosure of clinical information regarding an HIV positive patient should be treated with extreme confidentiality and only shared with other health care professionals if there is a need, following a failed attempt to get consent from the patient himself. Thus, contrary to the above-mentioned practice at local clinics in Hammanskraal, this ethical conduct was being disregarded by some health care professionals who were "disclosing" the status of patients by calling a patient's name and indicating that their file is in the room for HIV positive patients. Mathibe, Hendricks and Bergh (2015:7) in their study also found that different types of folders for the clinical records of patients who received HIV treatment were utilized and this lead to a "diagnosis" of PLHIV by the general public. This was seen as stigmatizing and discriminatory and a similar sentiment was shared by the CHCW'S in the current study on how the clinical records of patients are being dealt with in local clinics.

Sub-theme 4.2: Separation of patients in the clinic

The following quotes from the focus groups reflect the sub-theme:

> FG1M2: "… at the clinics they should change the system they are currently using and ensure that no one is separated according to what illness they have and should stop giving people colour coded cards- blue, green, yellow, red- according to their health problems whilst waiting for services, this is wrong as it creates stigma. They should also abolish the system of different consulting rooms, such as containers or back rooms within the clinic, for HIV positive people."
>
> FG2M5: "There are other clinics when you visit there; you're able to see that these people are there for … (Stutters) …these ones are there for hypertension or diabetes and these ones are here for ARVs. If only they could stop that thing."

> FG2M2: "… they put them in different rooms and say these ones are for TB, Diabetes etc. so you can also see that you belong to which side and other people are also able to see that you are there for ARVs. So if they can stop that thing of separating patients according to their illnesses."
> FG2M3: "… the way they do it they separate them to such an extent that you see them being placed in their little corner over there and everyone can see that the ones going that side are HIV positive … people who are taking other treatments go through a different entrance than those who collect ARVs. So they are discriminated and people complain about that …."

Some of the participants in the focus groups felt that the clinics should abolish the system of separating patients and integrate their services, as this creates stigma in itself. They indicated that people being placed according to their illnesses was too obvious and unfair.

Contrary to some of the above narratives, Mathibe et al. (2015:7), found that some patients who attended primary health care facilities in Tshwane, Gauteng, South Africa, showed satisfaction by the integration of ART into primary health care, which was seen to prevent stigma and discrimination, since patients were able to mix with others. While some patients preferred to be kept separate in a facility that had no integration of services. Although the results also showed that some clinicians viewed the integration of services as a way in which stigma and discrimination could be lessened (Mathibe et al., 2005:5).

Sub-theme 4.3: Lack of trust between the patient and healthcare professional

The following quotes from the focus groups reflect the sub-theme:

> FG1M1: "… the admin staff at the clinics are people who live in the same community as everyone, they know everyone, if I enter the counselling…testing room, I test and once I finish I go to counselling, at the end the admin who works in the admin will know that this file belongs to (mentions a name), she's HIV positive, when she meets me at Thapelo (Local tavern) with my boyfriend, I can't like disclose my status same day when we meet and say: "… I love you but I'm HIV positive …" no it will take time. So you find that I have a boyfriend and that guy (Clinic admin) will come and say; "… man, how do you feel being with a corpse?" So, that thing you see that at the end it will be like I will default because I will no longer go to the clinic to collet my medication because I fear that admin or someone that works at the clinic will meet me at some place and tell the people I'm with that; "… how do you feel being with a corpse?" So that is what makes the community of Marokolong to default and then discrimination and stigma to be high."

Likewise, there seems to be a lack of trust by the PLHIV and the community due to the behaviour of nurses at the clinics. Nonetheless, it is not only the nurses who seem to have a stigmatising attitude, but also the assistants who are health care workers and live in the same communities as the people affected by HIV.

Dawson-Rose, Cuca, Webel, Solis Baez, Holzemer, Rivero-Mendez, Eller, Reid, Johnson, Kemppainen, Reyes, Nokes, Nicholas, Matshediso, Mogobe, Sabone, Ntsaygae, Shaibu, Corles, Wantland and Lindgren (2016:577) state that one of the things that strengthens the health of PLHIV, is the trust between the patient and the healthcare provider and that this is a mutual interaction. This provides for the notion that trust between patients and healthcare professionals is of utmost importance, as opposed to the above narrative by the CHCW'S. Thus, stigma and discrimination of PLHIV has been observed through the attitudes and behaviours of healthcare professionals who caused fear by disclosing the statuses of PLHIV or treating them in unjust ways (Nyblade, Stangl, Weiss & Ashburn, 2009:2). This sort of treatment of PLHIV by healthcare professionals, especially nurses, has been seen as some of the factors that inhibit PLHIV to access a variety of services such as testing, counselling and treatment seeking (Dapaah, 2016:1).

Sub-theme 4.4: Stigma and discrimination by other clinic staff

The following quotes from the focus groups reflect the sub-theme:

> FG1M6: "… the sisters do not know how to keep a secret and cannot keep confidentiality about people's health lives; they will distribute their issue everywhere, which is why many people end up killing themselves because their matter is now everywhere."
>
> FG2M3: "… I've heard one sister saying that to patients that; '… whilst you were at home and did not come after 6 months did you think your results would have changed? They haven't changed they are still positive …'so I think that's the view, but others will say if you can go you'll get treatment and be fine, but as people we are not the same, some people can accept even if they have been traumatised and stigmatised and some default and won't continue going to the clinic and will have fear of all the clinics just because of an experience with one person as they think it's all the same."

The administrative staff at the clinic have also been seen as perpetuators of stigma and discrimination for their failure to keep patient's medical information confidential. Some of the participants also felt that even the nurses who work with PLHIV could not keep patient's clinical information confidential. Another participant also added that some nurses did not address people who have defaulted properly.

This was seen to cause fear to the PLHIV and lead to non-adherence due to stigma.

In a study conducted in Vhembe district in the Limpopo province, South Africa by Ramaano (2011:27), health care professionals were found to have less negative attitudes towards PLHIV. Although it was also found that their fear of being infected by HIV and AIDS was an influence to their stigmatising attitudes towards PLHIV. Ndou, Maputle and Risenga (2016:1) conducted a study in an ARV clinic in the Vhembe district in Limpopo province. They inquired into the perceptions of HIV positive patients regarding the care they received at the said clinic. The results showed that there were both positive and negative practices by health care providers (Ndou et al., 2016:3). Of particular interest to this study, is with regards to the negative practices as cited by the patients who received care at the ARV clinic, which correlated with the sentiments of Mlobeli-Dlakhulu (2007) as cited by Ndou et al. (2015:4). The author found that health care providers would shout at PLHIV or send them home without any assistance and that their files would be marked differently to identify them as HIV positive patients. Thus this connects to some of the narratives from the focus group discussions of the community health care workers, who felt that some of the clinic staff are discriminating against PLHIV, including health care providers, as provided above.

Sub-theme 4.5: Strategy to address healthcare workers behaviour and attitudes towards PLHIV

The following quotes from the focus groups reflect the sub-theme:

> FG1M1: "… I think there should be rotation, rotation in the sense that if you stay in Marokolong, you should not work in Marokolong, you should be place in a different community, because at the end of the day people are afraid of collecting their treatment since the caregivers know them. Even their clinic cards are not the same and you get judged on that and the caregivers/staff already know that if a person is carrying this type of clinic card he or she is positive, but if the person if from a different community they wouldn't know who I am even if I am carrying a clinic card for people living with HIV, the person will be able to assist me with passion for his or her job but if they are known to me they can go home and share the information with their mothers who will then share it with their neighbour who will share it with another neighbour …."

> FG1M3: "… maybe this suggestion of rotating the staff might help as if it's someone you don't know you'll have the courage to tell them that what you are doing is unethical."

In order to address these dishonourable behaviours by the health care professionals, the community health care workers recommended that there should be rotation/swapping of staff at the clinics. There was a suggestion that people should not work in the communities that they live in. This was seen as one way in which stigma and discrimination could be lessened, as some of the clinic staff stay in the same community as PLHIV and are said to share confidential clinical information with their family and significant others such as neighbours and it spreads like wild fire.

The literature seems to be silent about rotation of healthcare workers as an exact strategy to address stigma and discrimination related to HIV and AIDS. However, Nyblade, Stangl, Weis and Ashburn (2009:4) provide that in order to reduce stigma in health facilities, the focus must be on individual, environmental and policy level. Healthcare workers must be thoroughly trained about stigma and discrimination related to HIV and AIDS, in order to increase awareness regarding the negative consequences on the PLHIV. The environment must also be conducive enough for the healthcare workers to afford them an opportunity to practice universal precautions and prevent occupational transmission of HIV. Lastly, policies should be created with the aim of ensuring the safety and health of patients and workers in order to prevent discrimination against PLHIV (Nyblade et al., 2009:4). Perhaps the latter could be more fitting with the strategy that was suggested by the CHCW'S above.

To link this theme with the labelling theory, attitudes and behaviours of health care workers towards PLHIV can be aligned with the idea that when applying any form of labelling inter alia stigmatising and discrimination, this is as a result of deviance as seen by others. In other words, health care professionals also condemn PLHIV based on their own prejudices. Those who fear acquiring the illness might be confronted with the notion of the attribution theory that those who are living with HIV failed to protect themselves and are not deserving of compassion.

3.5.5 Theme 5: Disclosure

Disclosure also came out as a theme in the focus group interview, as community health care workers felt that disclosure was very important and the non-disclosure of PLHIV was due to stigma and discrimination.

Sub-theme 5.1: Disclosing to the public

The following quotes from the focus group interviews reflect the sub-theme:

> FG2M5: "… they feel comfortable when they disclose to … (Stutters) like to … maybe if they go disclose at an event somewhere, but it's hard for them to disclose to their family or partner, especially to their partner."

> FG2M2: "… they can disclose to people they don't know because they think if the person doesn't know them they might not recognise them after they have shared their status with them, rather than those who know them. They take time to disclose to their families ...."

> FG2M1: "… at the event you will find that one of the guest speakers must be a person living with HIV to motivate and encourage those who are afraid of disclosing you see. So we find those who are willing to help those who have fear. They will tell you they've even used wheelchairs and people thought they have died but they survived and are able to raise their children. God protected them because they adhered to treatment. So we also want people to talk so they can be treated well and not be discriminated. You'll be able to know when someone say they are in need how do you help them, but when people don't say anything it becomes a challenge because you don't know how to help them .…"

> FG2M3: "I think people living with HIV are very important in the community because they are able to help someone who is still new on the treatment and when they experience side effects they can approach someone who has disclosed and ask them for help and they might be able to assist them, so if they have disclosed people want to be like them and also seek for advice from them, so if you are hiding and not disclosing how will people know that they should come to you for help since you might have knowledge about HIV related information? Disclosing in front of people could give them hope that you might help them before they go to the clinic maybe they are going through similar experiences as you .…"

Some participants thought that people felt more comfortable disclosing to people that they did not know on a personal level to avoid stigma and discrimination. They also thought that disclosing in public was important as it could empower people who have been recently diagnosed as HIV positive to deal with the fears of living with the illness.

Norman, Chopra, and Kadiyala (2007:1775) state that disclosure can be a hard exercise for the PLHIV due to perceived stigma by significant others or the community. However, they can also receive a great deal of support and public disclosure can bring upon elements of empowerment and involvement in the community by PLHIV who can play significant roles in changing the face of HIV in society (Norman et al., 2007:1779). This supports the above narratives from the focus group interviews about PLHIV disclosing in public and the positive outcomes of disclosure thereof.

Sub-theme 5.2: Disclosing to the family

The following quotes from the focus group interviews reflect the sub-theme:

> FG1M1: "… I think that disclosing in the family might not be difficult that much, because in the family you will look at one person that you trust too much, so that at least you know that this one even if I tell them that I have a sore in a particular place it will remain between me and them, but when it comes to partners it becomes difficult, because I don't know that the moment you tell that person that; "… I am HIV positive …" how will their reaction be like. Then when it comes to a friend, as friends we fight…we fight (Puts emphasis) I might tell someone else …."

In the above narrative, one community health care worker felt that disclosing to the family might not be as hard as disclosing to a partner or friends. With regards to family if disclosure is done to those a person trusts, then they might receive support as compared to a partner or friend as one might not know what their reaction would be.

Mkhize (2009:20) discusses the targets for disclosure which include family, friends and sexual partners. The author states that family members are often the targets of disclosure and they are selected based on the quality of the relationship and the level of support required. This is in line with the above finding that PLHIV would rather disclose to their family members than others. However, World Health Organisation (WHO) (2004:3) states that the reasons not to disclose to sexual partners include loss of economic support, discrimination, blame, physical and emotional abuse, abandonment and disruption of family relationships, especially for women. Thus not all PLHIV disclose to their partners for such reasons, which backs the idea that PLHIV would rather disclose to family than others such as partners and friends in fear of their negative reactions and other adverse experiences (WHO, 2004:19; Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007:31).

Sub-theme 5.3: Non-disclosure

The following quote from the focus group interviews reflect the sub-theme:

> FG2M6: "… people in our community still have that mentality of discrimination. People are afraid of disclosing as they feel that if they do how people will treat them. They think people will judge them that they were promiscuous …."

Non-disclosure was also attributed to fear of being seen as a promiscuous person. Some people felt that people fear being judged, hence they do not reveal their HIV status to others.

Rohleder, Swartz, Kalichman and Simbayi (2009:280) noted that disclosure of an HIV status by a positive individual to their sexual partners comes with risks of being rejected and consequently being discriminated. Thus, non-disclosure therefore means that the PLHIV has a responsibility of ensuring safer sexual practices at all times to prevent transmission of the virus to their sexual partners. The decision not to disclose is attributed to the stigma that is associated with HIV (Rohleder et al., 2009:280; Makin, Forsyth, Visser, Sikkema, Neufeld, Jeffery, 2008:908). This supports the above finding that non-disclosure of one's HIV status is associated with stigma and discrimination of any form.

Sub-theme 5.4: Importance of disclosure

The following quotes from the focus group interviews reflect the sub-theme:

> FG1M2: "I think that people do not have to even tell a lot of people about their illnesses they can tell one person and be relieved. Even if it's not the whole family, as long as they tell one person they become relieved … if the person loves you they will keep it to themselves as you would have agreed when you disclose to them …."
>
> FG1M4: "I think that when it comes to the issue of disclosure, it is difficult to just disclose to another person and tell them that you have this kind of an illness, because you understand your family background the way it is, you know if your family members like gossiping, in the sense that if you tell them they will insult you or go around talking about you to other people. People are not the same though, some you know that if you tell them they might support you …."

Furthermore, not everything about disclosure was viewed in a negative angle. Community health care workers also thought that disclosure of one's status might assist in PLHIV shying away from perceived stigma. This might help them to get support from their loved ones like family. However, there was also the perception that disclosing to a stranger might be difficult as compared to family members.

Arnold, Rice, Flannery and Rotheram-Borus (2008:80) state that disclosure is very important as it is associated with reducing transmission of HIV, adhering to treatment and mental health care. They further argue that the importance of disclosure to the family is due to caregiving. In agreement with this are Norman, Chopra and Kadiyala (2007:1775) who state that the importance of disclosure for the individual is to gain support from family and the community in order to deal with the illness from a psychosocial viewpoint. Thus the argument brought upon by these authors supports the belief on the importance of disclosure as was viewed by the community health care workers in this study.

In terms of disclosure, it can be linked to the labelling theory in the sense that due to “societal standards” that when one has engaged in behaviours labelled as deviant, the issue of fear to disclose might emerge. In line with the attribution theory that says PLHIV are at fault of acquiring the illness, one might not see the need to disclose their status, which can be detrimental to their own well-being.

3.6 SUMMARY

This chapter has brought to light the empirical findings of the research study, where five themes and sub-themes were generated. The literature reviewed supported some of the findings more accurately than others. The narratives of the community health care workers from the focus group interviews, provided an idea of how stigma and discrimination related to HIV and AIDS is being perpetuated and consequently how targeting these social ills could address this phenomenon. The key findings speak to the issue of fear, social support, knowledge and information with regards to HIV and AIDS, health care workers’ attitudes and behaviour as well as disclosure.

The following chapter summarises this study and provides the key findings, conclusions and recommendations.

4. CHAPTER FOUR: CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

In this chapter the research goal and objectives will be discussed, as to what extent these were met, as well as the key findings, conclusions and recommendations.

4.2 SUMMARY

The goal and objectives of the study will be discussed, as well as the research question and how they were addressed through this study.

4.2.1 Goal of the study

The goal of this study was **to explore and describe the perspectives of community health care workers regarding the destigmatisation of HIV and AIDS**. This goal was reached by means of the following objectives:

4.2.2 Objectives of the study

The objectives were as follows:

- To describe people infected and affected by HIV and AIDS, with specific reference to stigmatisation within the context of the labelling and attribution theories.
- To explore and describe the perspectives of community health care workers on the destigmatisation of HIV and AIDS.
- To recommend strategies for intervention on the reduction of HIV and AIDS related stigma.

Each objective will subsequently be discussed in terms of how it was met through this study.

4.2.2.1 Objective 1

To describe people infected and affected by HIV and AIDS, with specific reference to stigmatisation within the context of the labelling and attribution theories.

The first objective was met by means of conducting an in-depth literature review on stigma and discrimination regarding HIV and AIDS. The literature review provided a description of the concept of stigma and how it is linked to people who are infected and affected by HIV and AIDS. The theoretical framework provided the context in which stigma related to HIV and AIDS can be understood, i.e. the labelling and attribution theories. The former provided that people who are infected or affected by HIV and AIDS endure stigma and discrimination for deviating from normal sexual practices and/or behaviours among other things. The latter theory alluded that people who are affected by HIV and AIDS have brought upon the illness to their lives and thus are deserving of it, which consequently leads to them suffering stigma and discrimination by society. Furthermore, the literature also suggested that stigma and discrimination related to HIV and AIDS has created barriers for PLHIV to access the necessary assistance that is needed to manage this chronic illness.

4.2.2.2 Objective 2

To explore and describe the perspectives of community health care workers on the destigmatisation of HIV and AIDS.

The second objective was achieved through the key findings revealed in the third chapter of this study. The empirical findings provided the perspectives of the community health care workers on the destigmatisation of HIV and AIDS. The participants revealed that there is a lot of fear among people living with HIV and AIDS which is caused by health care professionals, fear of disclosure and fear of exercising one's rights. The participants also indicated that social support is key in addressing stigma and discrimination experienced by PLHIV, especially family support and support groups. The lack of knowledge and information on HIV and AIDS also emerged as a theme in which the community health care workers indicated it could be addressed through education about HIV and AIDS. Furthermore, the CHCW'S indicated that health care professionals' attitudes and behaviour towards PLHIV. Lastly, the findings also showed that disclosure is also important in addressing HIV and AIDS related stigma.

4.2.2.3 Objective 3

To recommend strategies for intervention on the reduction of HIV and AIDS related stigma.

The third objective was achieved by means of intervention strategies as recommended in the below sections of this chapter. These intervention strategies are outlined under each theme in the recommendation's sub-sections. They speak to reducing anticipated stigma by PLHIV, as well as enacted stigma and discrimination by others, such as family, friends, health care professionals and the community at large.

4.2.3 Research question

The research question that was asked in the context of this study is:

What are the perspectives of community health care workers on destigmatisation of HIV and AIDS?

The above question was answered through conducting a qualitative research study by interviewing community health care workers who are employed at non-governmental organisations that are rendering services to people affected by HIV and AIDS in Hammanskraal. Two focus group interviews were conducted in order to collect data which was later analysed by the researcher, generating themes and sub-themes as discussed in detail in the third chapter. Five themes and sixteen sub-themes emerged to answer the research question.

4.3 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

Key findings and conclusions from the study will be discussed in the subsequent section.

4.3.1 Key findings, conclusions and recommendations regarding literature review

In the succeeding section, the key findings, conclusions and recommendations regarding the literature review are discussed.

- **Key findings**

The two theories that underpin the study were discussed in chapter one, namely the labelling and the attribution theory, which were relevant to this study and could be linked throughout the study. The literature review brought to light the concept of stigma as it was coined by Ervin Goffman, a Sociologist who argued that stigma can be seen to exist when it has the three characteristics which are: unfavourable deterioration of the body, blemishes of individual character and tribal stigma (Major & O'Brien 2005:394). While not totally disregarding Goffman's concept of stigma, other authors also provided differing views of the phenomenon by looking at it from the "us" vs "them" point of view as argued by Link and Phelan (2001:367) and Earnshaw and Chaudoir (2009:1161). They also argued that social context should not be completely ignored when one tries to understand stigma, especially when looked at through the lenses of culture, power, and difference in terms of gender, sex, race and ethnicity (Parker & Aggleton, 2002:1).

The concept of stigma was then linked to the issue of HIV and AIDS in order to fit it into the context of this study, as Herek (2005:123) argues that stigma is attached to PLHIV, especially when they are at the AIDS stage and have visible symptoms on their bodies, which talks to the unfavourable deterioration of the body as stated by Goffman. Also, stigma is said to be attached to blemishes of individual character. This is when it is associated with behaviour that is deemed to be abnormal, such as homosexuality, prostitution or promiscuity. Thus, PLHIV are thought to have brought the illness upon themselves due to their own immoral behaviours (Talja, 2005:11). Lastly, tribal stigma is linked to HIV especially when health care workers are said to be prejudiced towards PLHIV (Stuenkel & Wong, 2013:53).

The literature also revealed the different types of stigma in relation to HIV and AIDS, especially the two most common ones which are anticipated and enacted stigma. With regards to the former, it refers to the type of stigma that is internalised by an individual who is affected or infected by HIV and AIDS, i.e. is by having fears of being judged or labelled by others, while the latter type talks to the type of stigma which refers to the behaviours and perceptions or attitudes by other individuals towards the PLHIV. This type of stigma was also expanded upon by looking at it from other more discernible forms of behaviour such as avoidance, rejection, moral judgement, stigma by association and discrimination. Other types of stigma that were found in the literature study included, curtesy, layered and perceived stigma.

The literature review also looked into the prevalence and impact of HIV and AIDS related stigma and how stigma and discrimination had manifested itself in the society by comparing it through global and local statistics.
The literature review also focused on the different contexts in which stigma and discrimination occurs. The focus was on the health care setting, family, community, workplace and education as well as the socioeconomic context.

With regards to culture, there exists some belief that HIV and AIDS are caused by some supernatural forces of the African culture. This is thought to have some form of influence in understanding and tackling stigma related to HIV and AIDS. In the economic context, stigma and discrimination was said to be prevalent in communities that are deemed as impoverished just because they are poor.

Furthermore, stigma is a barrier to HIV testing and counselling as well as treatment seeking. Delays to VCT or HCT services have been observed to be caused by stigma related to HIV and AIDS. This is coupled with the treatment offered by health care professionals in the health care. Also, the fear of accessing treatment for HIV at health care settings such as clinics was also attributed to stigma and discrimination, which often leads to non-adherence or treatment defaulting.

Interventions to reduce stigma related to HIV and AIDS, as well as the role of the Social Worker, included intervention strategies that can be employed in communities to reduce stigma related to HIV and AIDS. Four types of strategies that can be effective in reducing stigma were found to be: information based approaches, coping skill acquisition, counselling approaches and contact with affected people. The role of the Social Worker was also linked to the efforts aimed at reducing stigma related to HIV and AIDS, as they play a key role in providing support and education to the PLHIV within a multidisciplinary context. The researcher is of the view that this fits well with the strategies mentioned above.

Finally, the literature review also provided a discussion of the community health care workers in South Africa, by looking into their different roles and functions as well as their importance in the field of HIV and AIDS. Their roles could contribute immensely in the curbing of HIV and AIDS stigma.

- **Conclusions**

In conclusion, the literature review gave an overview of the phenomenon of stigma related to HIV and AIDS from looking at it from an individual point of view to a collective one. The literature review also brought an understanding of the concept of stigma linked to HIV and AIDS. It also looked at how and where stigma is most likely to occur and who are the people usually involved. Furthermore, the literature review brought hope regarding this subject in the sense that it provided some strategies that can be used to mitigate stigma as well as who can be the key role players, such as community health care workers.

- **Recommendations**

The researcher is of the view that more research should be conducted regarding stigma and discrimination related to HIV and AIDS. This can help to give a clearer understanding of the phenomenon and how it has manifested itself within the society as well as how it can be addressed. Furthermore, research should also inquire at what has been done thus far to mitigate stigma and discrimination related to HIV and AIDS, especially on the South African context.

4.3.2 Key findings, conclusions and recommendations regarding research findings

Subsequently the key findings, conclusions and recommendations regarding the thematic analysis will be discussed.

4.3.2.1 Theme 1: Fear

This theme revealed sub-themes including the issue of fear in relation to HIV and AIDS, stigma and discrimination, fear of disclosure and of exercising one’s rights as understood by the community health care workers.

- **Key findings**

The participants confirmed that there is a general fear of HIV and AIDS in the communities in which they provide services. They also indicated that there is a fear of stigma and discrimination as perpetuated by health care professionals to PLHIV in primary health care facilities such as clinics and hospitals. They further indicated that there is fear among PLHIV to disclose their HIV status especially towards their families and the community. Lastly, the participants revealed that there is also fear by PLHIV to exercise their rights as patients especially when they interact with health care professionals.

In terms of the fear of HIV and AIDS in general sub-theme, the findings revealed that the community health care workers thought the community has a fear of testing and/or knowledge of their HIV status due to stigma and discrimination respectively.

Under the sub-theme of fear of stigma and discrimination by health care professionals, community health care workers revealed that health care professionals at clinics and hospitals perpetuate stigma related to HIV and AIDS. This in turn caused a fear for PLHIV to access services.

On the sub-theme of fear of disclosure, the results showed that community health care workers were of the view that PLHIV are afraid of disclosing their statuses to their families.

Lastly, another sub-theme under the issue of fear revealed that community health care workers thought that PLHIV are afraid of exercising their own rights as patients. This inability of one to exercise their rights as a patient was thought to perpetuate stigma and discrimination.

- **Conclusions**

It can be concluded that there is a discernible thread of fear that has engulfed people living with HIV and AIDS and the community, which perpetuates the issue of stigma and discrimination. This is also caused by health care professionals in spaces where important health care services and needs for PLHIV are accessed. This hinders the progress made in the sphere of HIV and AIDS. This is in line with the labelling theory which states that deviant behaviour is shunned upon by society and PLHIV are seen to have acquired the illness through behaviour that is dubbed as deviant. Thus, this causes fear as it is a form of stigma and discrimination.

- **Recommendations**

- It is recommended that PLHIV should be educated about their rights and responsibilities as patients who are entitled to accessing health care services without any form of prejudice.
- The health care professionals rendering services to PLHIV in primary health care settings such as clinics and hospitals should be constantly reminded of the rights of patients and their ethical conduct.
- Health care professionals should understand that they have a significant role in addressing issues of stigma and discrimination related to HIV and AIDS, rather than to instigate unnecessary fear.

4.3.2.2 Theme 2: Social Support

Social support in relation to PLHIV also came out as an important theme as was seen by the community health care workers.

- **Key findings**

The issue of social support came out as an important aspect of destigmatisation of HIV and AIDS. Community health care workers indicated that support by family and the community towards PLHIV was very vital. They further indicated that support groups were another way in which PLHIV can support each other. All of this in effort to fight stigma and discrimination related to HIV and AIDS.

The first sub-theme that came out of social support spoke of family as a support system. The community health care workers indicated that family and friends were regarded as an important support system.

The other sub-theme that came out of social support was the issue of support groups. Community health care workers felt that support groups were very vital for PLHIV.

- **Conclusions**

In conclusion, it can be said that social support is very important in order to mitigate stigma and discrimination related to HIV and AIDS. Family members of PLHIV are seen as key role players in providing support emotionally and in many other ways. Support groups are also necessary to address stigma related to HIV and AIDS. This can be linked to the theoretical framework, in the sense that it is conflicting to the attribution theory, which states that PLHIV are not deserving of pity as they brought the illness upon themselves through deviant behaviour as suggested by the fundamental notion of the labelling theory.

- **Recommendations**

- The researcher is of the view that support groups implemented by community health care workers can be a success in reaching the goal of reducing stigma, as they are grass root level role players in the community and seem to have a good understanding of the importance of support systems for PLHIV.
- It is recommended that PLHIV and their families ought to participate in support groups to provide support to each other.

4.3.2.3 Theme 3: Lack of some knowledge and information about HIV and AIDS

This theme focused on the fact that there appeared to be a lack of some knowledge and information about HIV and AIDS in the community.

- **Key findings**

The community health care workers revealed that the lack of some knowledge and information that some people have regarding HIV and AIDS fuels stigma and discrimination. They also indicated that the inability for some people to differentiate between HIV and AIDS proved that there exists this lack of knowledge and information. Furthermore, this lack of knowledge and information was regarded as the reason why some people could not disclose their status to their families which supports the notion that people who lack a better understanding of the illness are inclined to stigmatise. Thus, CHCW'S felt that education is an important factor in ensuring that people get the necessary knowledge and information about HIV and AIDS that will lead them to better understanding of the illness and consequently reduce stigma.

In this theme, the sub-theme that came out spoke to the issue of education about HIV and AIDS. The community health care workers thought that education was an important strategy to address HIV and AIDS related stigma.

- **Conclusions**

Community health care workers view the lack of knowledge and information as what contributes to stigma and discrimination related to HIV and AIDS, especially within families. Thus, in order to mitigate these, they recommended that the community be educated about the illness in order for them to know better.

In line with the theoretical framework, this can be linked in the sense that a lack of knowledge and information is brought upon by the idea that HIV is an illness that is acquired through behaviour that is deemed as risky as suggested by the labelling theory’s intrinsic idea. Thus, when one fails to understand that the illness can be acquired through unfortunate circumstances, it can be concluded that some information and knowledge is lacking.

- **Recommendations**

- The researcher recommends that informal education regarding HIV and AIDS with specific focus to stigma and discrimination should be emphasised and implemented in the community.
- This informal education regarding the issue of stigma and discrimination related to HIV and AIDS can be done through seminars, workshops, community dialogues and mass media.
- The researcher is also of the view that sustained training of community health care workers with specific focus on stigma and discrimination can also assist in equipping them with more knowledge about the phenomenon.

4.3.2.4 Theme 4: Health care professionals’ attitudes and behaviour towards PLHIV

This theme focused on the attitudes and behaviour of health care professionals in health care settings towards PLHIV.

- **Key findings**

The participants revealed that there are negative attitudes and behaviour by health care professionals and support staff such as administrators in health care settings like clinics. It appeared that these clinic staff instigate fear that is suffered by PLHIV when they visit the centres. It also appeared that this is done through the manner in which the clinical records of PLHIV is being handled, such as marking of files of HIV and AIDS patients with different colours from those of other general patients. The dividing of patients within the health care facilities according to illnesses; whereby HIV patients are clearly segregated from the rest also came out as a major concern by the participants. They also spoke of the lack of trust between the patients and the health care professionals due to negative attitude and behaviour towards PLHIV. CHCW’S also pointed out the fact that there was also a salient perpetuation of stigma and discrimination by other clinic staff toward PLHIV. Lastly, the participants provided a strategy which they felt could address this issues of unethical behaviour by the health care professionals towards PLHIV in health care settings.

One of the sub-themes that came out from the theme was that of discrimination through patient’s clinical information as described by the community health care workers. They cited a separation of HIV patients’ clinical files or the files being marked differently from those of other patients. This is against the ethical conduct by health care workers as stated by the Health Professions Council of South Africa (2008:3).

Another sub-theme focused on the separation of HIV patients from other primary health care service patients. They indicated that services should rather be integrated than separated. The literature indicated that there were opposing results in a study that looked into this issue of separation versus integration. While some patients wanted to be integrated into mainstream services of primary health care, others preferred to be separated (Mathibe et al., 2005:5).

The other sub-theme that came out spoke to the issue of the lack of trust between patients and health care workers. They indicated that the negative attitudes of nurses and other clinic staff at the clinics toward PLHIV perpetuated stigma.

Lastly, the other sub-theme that emerged was that of a strategy suggested by community health care workers they thought would assist in the above-mentioned challenges. They suggested that clinic staff such as nurses who work in the same community should be rotated or swapped with others from other clinics outside the community.

- **Conclusion**

In conclusion, stigma and discrimination is not only as a result of negative attitudes by the health care professionals, but also by other support staff at the clinics. Furthermore, stigma and discrimination creates a lack of trust of the health care professionals by PLHIV. The way in which patients and their medical records are being treated in the clinics also appeared to be problematic and a fuel of stigma. This urged the CHCW'S to provide a strategy that they felt could lessen the problem of stigma and discrimination at the clinics.

In support of the labelling theory, one can thus conclude that negative attitudes of health care professionals can be brought upon by the notion that PLHIV have deviated from proper sexual practices such as the use of condoms to prevent the illness. As the attribution theory states that PLHIV are often thought of not deserving of pity compared to their counterparts who are said to have not brought the illness upon themselves.

- **Recommendations**

- Community health care workers recommended that the clinics or primary health care facilities should implement a policy or plan whereby health care professionals are rotated or swapped around health care facilities. They suggested that clinic staff should not work in the same communities where they stay.
- The researcher is of the view that health care professionals should remain ethical in their health care provision duties as they are obliged to adhere to ethics as prescribed by the Health Professions Council of South Africa (HPCSA).
- Disciplinary measures should be taken against health care professionals who explicitly display acts of stigma and discrimination towards PLHIV in order to deter others from committing the same acts.

4.3.2.5 Theme 5: Disclosure

Disclosure was another theme that emerged as an important aspect regarding HIV and stigma.

- **Key findings**

Disclosure was seen by the community health care workers in two parts, i.e. it being an important aspect of PLHIV as well as the lack thereof. The participants revealed that some people are comfortable disclosing to strangers, while others felt comfortable disclosing to their families. The former being for empowerment purposes to those who might not understand the importance of disclosure and the latter for soliciting support from the family system. Non-disclosure was attributed to fear of being judged as someone who acquired the illness through undesired sexual behaviours. The participants also felt that disclosure was important in the sense that it could lessen perceived stigma.

The first sub-theme that came out of the theme of disclosure was that of disclosure to the public. Community health care workers thought that some people were comfortable disclosing in public to people who do not know them personally. They also felt that disclosing in public was a form of empowerment to others.

The second sub-theme spoke to the issue of disclosure to family. Some participants felt that disclosure to family is not easy although it can be of benefit if PLHIV disclose to family members they trust.

The third sub-theme that came out of this theme was that of non-disclosure. Participants indicated that non-disclosure was attributed to fear of being labelled as promiscuous.

Lastly, the sub-theme that emerged from this theme was that regarding the importance of disclosure. Community health care workers felt that it was important for PLHIV to disclose in order to reduce stigma, especially perceived stigma.

- **Conclusion**

In conclusion, the issue of disclosure was seen by the community health care workers as an important aspect in fighting stigma and discrimination related to HIV and AIDS. In support of the labelling theory, it can thus be concluded that when one fears disclosure of their HIV status it is due to fear of being labelled as having acquired HIV through risky sexual behaviour such as promiscuity. This labelling is as a result of one having deviated from “societal norms” of sexual behaviour. This is also in line with anticipated stigma discussed in the literature review chapter.

- **Recommendations**
- It is recommended that PLHIV should be encouraged to disclose their status to people whom they anticipate that they will receive proper support such as family.
- It is also recommended that non-disclosure should not be seen in negative terms, but as a choice that one has.

4.4 RECOMMENDATIONS FOR FUTURE RESEARCH

It is recommended by the researcher that a large magnitude of research of this fashion be conducted in order to get a better understanding of the phenomenon of stigma and its impact on PLHIV in other communities. This will also give a voice to these role players who provide services at grass root level to the HIV and AIDS field. This will ascertain how problematic the issue of HIV and AIDS related stigma and discrimination is, even more so when it is looked at from other people’s perspectives.

It is also recommended that more research be conducted in South Africa concerning stigma and discrimination of HIV and AIDS, as this seems to be a neglected area of this field. This became observable during the literature review phase of the study, as most literature spoke to countries from further afield. The literature was somewhat limited or outdated regarding the South African context and more so the community in which this research was conducted. Thus, continued and relevant research would also help in determining the progress made in eradicating the phenomenon of stigma and discrimination related to HIV and AIDS.

4.5 CONCLUSIVE REMARKS

It became clear from the key findings of this study that stigma and discrimination has manifested itself deeply in society. Its consequences are consistently encumbering the progress made in dealing with the effects of HIV and AIDS.

However, this study gave the platform for the voices of the community health care workers to be heard and that it is important to eradicate stigma. The researcher is of the view that this study has contributed immensely to the subject of HIV and AIDS and destigmatisation.

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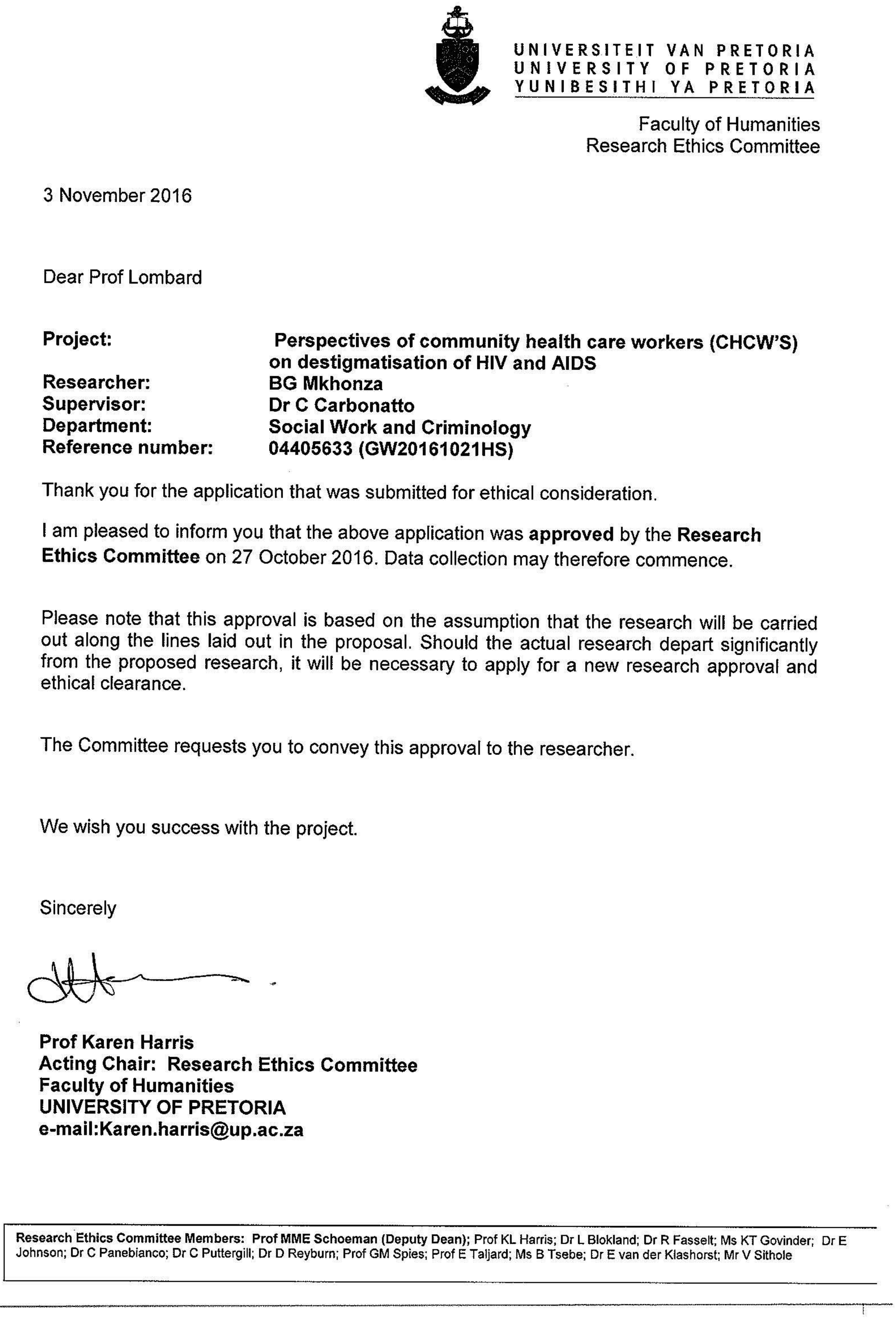
6. LIST OF APPENDICES

6.1 APPENDIX 1: RESEARCH ETHICS CLEARANCE LETTER



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

3 November 2016

Dear Prof Lombard

Project: **Perspectives of community health care workers (CHCW'S) on destigmatisation of HIV and AIDS**
Researcher: **BG Mkhonza**
Supervisor: **Dr C Carbonatto**
Department: **Social Work and Criminology**
Reference number: **04405633 (GW20161021HS)**

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 27 October 2016. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

6.2 APPENDIX 2: REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY

Attention: The Centre Manager/Board of Directors

Modimo O Matla Care Centre

98 G Block Temba, 0407

Dear sir/madam

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY

I am currently a Master of Social Work in Health Care student at the University of Pretoria and the curriculum requires that I conduct a research project and a mini dissertation related to the field.

The topic of interest for my studies is ***Perspectives of community health care workers on destigmatisation of HIV and AIDS***. The research study will be qualitative and the information gathering will be through focus group interviewing of 6 voluntary participants.

The proposal for this research has been approved by Research Committee of the Department of Social Work and Criminology, Faculty of Humanities on 2 October 2015. An application for ethical approval by the ResEthics Committee of the Faculty of Humanities is in process. Copies of the letter of approval from the ResEthics committee, the research proposal, letter of informed consent and the interview guide will provided.

As the researcher, I am fully aware of my responsibility to ensure that this study meets all the ethical requirements, specifically voluntary participation, confidentiality and respecting the privacy of all participants. The researcher will be supervised by Dr C.L. Carbonatto of this department. The results will be available in a research report in the form of a mini-dissertation, of which a copy will be provided to you. These findings could be of benefit to the organisation and the community.

If you have any questions concerning the study, please feel free to contact myself or the supervisor.

I will be grateful if you would grant me the permission and opportunity to conduct this research at your institution, in order to help me comply with the requirements of my MSW (Health Care) degree by completing this study.

Yours sincerely,

Mr B.G. Mkhonza

Researcher

6.3 APPENDIX 3: FOCUS GROUP INTERVIEW SCHEDULE/GUIDE

PERSPECTIVES OF COMMUNITY HEALTH CARE WORKERS (CHCWS) ON DESTIGMATISATION OF HIV AND AIDS

GIFT MKHONZA

Interview schedule/guide

- What are your views about the community regarding HIV and AIDS in general?

Disclosure

- What are your views with regards to people living with HIV and AIDS on disclosing their status to their families/friends/partners?
- What is the general attitude in this community regarding the disclosure of statuses of PLHIV?

Rights

- What are your views about the rights of people who are living with HIV and AIDS regarding the disclosure of their status?
- What are your views about the community's awareness of any rights of people living with HIV?

Stigma

- What are your views regarding the effects of stigma and discrimination on people who are living with HIV and AIDS?
- What are your views regarding the effects of stigma and discrimination on the families or relatives of people who are living with HIV and AIDS?
- What do you think are the attitudes of the community regarding the services (VCT, ART, home-based care) that are available to PLHIV?

Community programmes

- What are your views about people living with HIV and AIDS to participate in community programmes that are aimed at reducing stigma and discrimination?

- What are your views about people or families affected by HIV and AIDS to participate in community programmes that are aimed at reducing stigma and discrimination?
- What are your views about the community's efforts to participate on programmes that are aimed at reducing stigma and discrimination on HIV and AIDS?
- Which services do you think are still needed in the community in order to reduce HIV and AIDS related stigma?
- Who do you think should be involved in programmes that are aimed at reducing stigma and discrimination related to HIV and AIDS? Why?
- Have you ever participated in any programmes that are aimed to destigmatize HIV and AIDS?
- How can the community be involved in programmes that are aimed at reducing HIV and AIDS stigma?

Policies

- Do you know of any policies/legislation that are aimed at reducing stigma and discrimination related to HIV and AIDS?

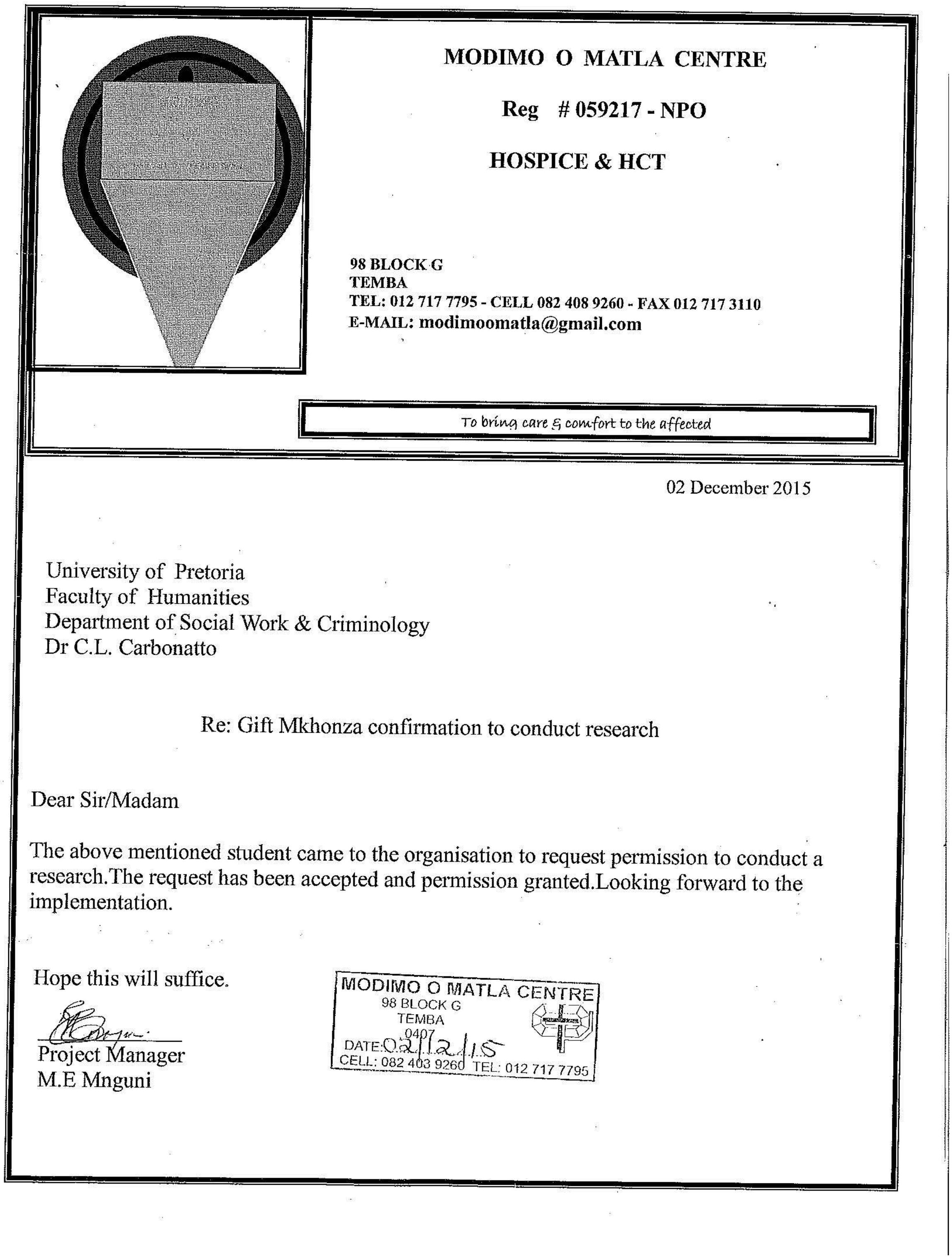
Needs

- What do you think are the needs of people who are living with HIV and AIDS in the community with regards to issues of stigma related to HIV and AIDS?
- What do you think are the needs of the families of people who are living with HIV and AIDS in the community with regards to issues of stigma related to HIV and AIDS?

Recommendations

- What is your recommendation regarding HIV and AIDS related stigma reduction?

6.4 APPENDIX 4: PERMISSION LETTER FROM MODIMO O MATLA CENTRE



MODIMO O MATLA CENTRE

Reg # 059217 - NPO

HOSPICE & HCT

98 BLOCK G
TEMBA
TEL: 012 717 7795 - CELL 082 408 9260 - FAX 012 717 3110
E-MAIL: modimoomatla@gmail.com

To bring care & comfort to the affected

02 December 2015

University of Pretoria
Faculty of Humanities
Department of Social Work & Criminology
Dr C.L. Carbonatto

Re: Gift Mkhonza confirmation to conduct research

Dear Sir/Madam

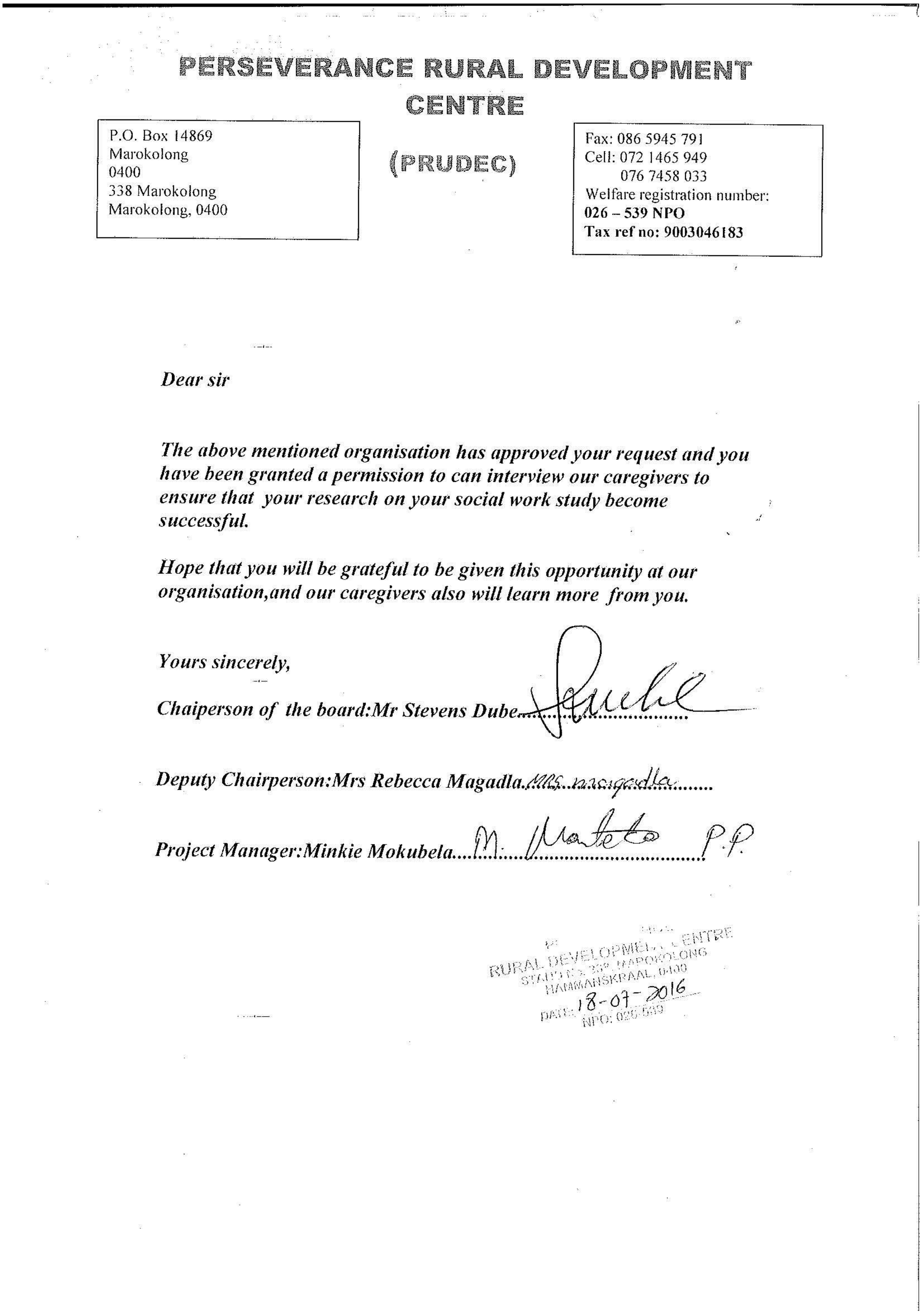
The above mentioned student came to the organisation to request permission to conduct a research.The request has been accepted and permission granted.Looking forward to the implementation.

Hope this will suffice.

Project Manager
M.E Mnguni

MODIMO O MATLA CENTRE
98 BLOCK G
TEMBA
0407
DATE:02/12/15
CELL: 082 403 9260 TEL: 012 717 7795

6.5 APPENDIX 5: PERMISSION LETTER FROM PRESEVERANCE RURAL DEVELOPMENT CENTRE



PERSEVERANCE RURAL DEVELOPMENT CENTRE

(PRUDEC)

P.O. Box 14869
Marokolong
0400
338 Marokolong
Marokolong, 0400

Fax: 086 5945 791
Cell: 072 1465 949
076 7458 033
Welfare registration number:
026 – 539 NPO
Tax ref no: 9003046183

Dear sir

The above mentioned organisation has approved your request and you have been granted a permission to can interview our caregivers to ensure that your research on your social work study become successful.

Hope that you will be grateful to be given this opportunity at our organisation,and our caregivers also will learn more from you.

Yours sincerely,

Chaiperson of the board:Mr Stevens Dube...............................

Deputy Chairperson:Mrs Rebecca Magadla.Mrs magadla.........

Project Manager:Minkie Mokubela....M. Mateto....................... P.P.

RURAL DEVELOPMENT CENTRE
STAND No. 338 MAROKOLONG
HAMMANSKRAAL, 0400
DATE: 18-07-2016
NPO: 026-539

6.6 APPENDIX 6: LETTER OF INFORMED CONSENT

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work and Criminology

LETTER OF INFORMED CONSENT

SECTION A: RESEARCH INFORMATION

1. TITLE OF THE STUDY

The title of the study is; ***Perspectives of community health care workers on destigmatisation of HIV and AIDS*****.**

2. RESEARCHER

The researcher, Gift Mkhonza, is a qualified social worker who is currently working at the Department of Social Development in Gauteng province. He is a registered Master of Social Work in Health Care student with the Department of Social Work and Criminology at the University of Pretoria.

3. PURPOSE OF THE STUDY

Stigma and discrimination related to HIV and AIDS have a significant negative impact on the preventative measures against the illness, access to voluntary counselling and testing, as well as effective care and treatment services. However, something can be done in the community to mitigate the effects of stigma and discrimination. Thus, the purpose of the study is to explore and describe the perspectives of community health care workers regarding the destigmatisation of HIV and AIDS.

4. PROCEDURE

The researcher will arrange a focus group interview with all the voluntary participants to be included in the study, with a suitable date and time for all. The focus group interview will be held at the researcher’s office, which is situated in Temba, Hammanskraal. The focus group will take an estimated maximum of at least two hours and it will be voice recorded with the participants' permission. There will only be six participants in the focus group with similar characteristics. There will be a research assistant who will assist the researcher with operating the voice recorder as well as taking down some field notes. The research assistant will sign a letter of informed consent regarding the issue of confidentiality prior to the commencement of the data collection process. The researcher will then transcribe the discussions from the tape recorder for analysis and pseudonyms or false names will be used to refer to the participants' responses. Thereafter the results will be published in a form of a mini-dissertation, which will be made available to the organisations and the University of Pretoria library. The copies of the letter of informed consent, transcripts and recordings will be stored in a safe place at the University of Pretoria as required, for a period of 15 years and be destroyed thereafter.

5. POTENTIAL HARM

The researcher anticipates that there might be emotional harm as the topic under study might be a sensitive issue for some participants following the nature of their work. Therefore, a debriefing session will be held after the focus group session and if the need arises, the particular participants will be referred for counselling to the Social Worker, Ms. Flora Makopo, at the Department of Social Development.

6. CONFIDENTIALITY AND ANONIMITY

The issue of confidentiality will be adhered to by the researcher at all times and the participants names will not be used, but a pseudonym or false name will be given to each member for the purpose of transcribing data from the voice recorder and to protect their identity. The researcher will only share any information with the supervisor and the research assistant if needed, who will sign a confidentiality contract beforehand. The participants also have an obligation to adhere to the issue of confidentiality with regards to the contents of the focus group, as the topic under study is a sensitive one. Data will be stored in a safe place.

7. VOLUNTARY PARTICIPATION

Participation in the study is voluntary and participants have the right to withdraw from the study at any time. No participant will be obligated to participate in the study. In addition if a participant decides to withdraw from the study, there will be no negative consequences imposed on them.

8. REMUNERATION

The researcher will not remunerate the participant for participating in the study. Participation is voluntary and the focus group will be conducted at a time, which will be suitable for everyone.

9. BENEFITS

The researcher hopes that the study will benefit the community of Temba in Hammanskraal, as well as help to contribute to policy and community development. The participants will not necessarily benefit directly from the study.

10. DETAILS OF THE RESEARCHER

If you have any questions or inquiries about the study, please do not hesitate to contact the researcher in the below details;

Name: Gift Mkhonza

Cell: 073 674 7439

E-mail: giftmkhonza@yahoo.com

SECTION B: INFORMED CONSENT OF PARTICIPANT

I………………………………………………………………. (*Name of participant*) declare that I have read and understood the above information. I was given adequate time to consider my participation in the study. I was also given the opportunity to ask questions and all of them were answered to my satisfaction. I hereby give consent to participate voluntarily in this study.

Signature: ……………………… **Date**: …………………………

Declaration by researcher

I……………………………………………………….. hereby declare that I have explained the above information to the participant and he/she was satisfied with all the answers.

Signature: …………………………… **Date**:

6.7 APPENDIX 7: RESEARCH ASSISTANT NON-DISCLOSURE AGREEMENT

Research Assistant Non-Disclosure Agreement

Research title: ***Perspectives of community health care workers on destigmatisation of HIV and AIDS.***

Researcher: Gift Mkhonza

INTRODUCTION

My name is Bongani Gift Mkhonza and I am currently conducting a study on the above topic as part of the requirements of a Master of Social Work in Health Care degree at the University of Pretoria, South Africa.

PURPOSE OF THE STUDY

Stigma and discrimination related to HIV and AIDS have a significant negative impact on the preventative measures against the illness, access to voluntary counselling and testing, as well as effective care and treatment services. However, something can be done in the community to mitigate the effects of stigma and discrimination. Thus, the purpose of the study is to explore and describe the perspectives of community health care workers regarding the destigmatisation of HIV and AIDS.

PROCEDURE

The researcher will arrange a focus group interview with all the voluntary participants to be included in the study, with a suitable date and time for all. The focus group interview will be held at the researcher's office which is situated in Temba, Hammanskraal. The focus group will take an estimated maximum of at least two hours and it will be voice recorded with the participants' permission. There will only be six participants in the focus group with similar characteristics. You have been approached by the researcher and shown interest to be a research assistant for this study. ***As a research assistant you will assist the researcher with operating the voice recorder, as well as taking down some field notes. You are required to sign a non-disclosure agreement regarding the issue of confidentiality prior to the commencement of the data collection process***. After the focus group the researcher will transcribe the discussions from the voice recording of the focus group for analysis and pseudonyms or false names will be assigned to each participant in the transcription to refer to their responses in order to protect their identity. Thereafter the results will compiled in a research report, namely a mini-dissertation which will be made available to the participating organisations and the University of Pretoria library. The copies of the letter of informed consent, transcripts and recordings will be stored in a safe place at the University of Pretoria as required, for a period of 15 years and be destroyed thereafter.

CONFIDENTIALITY AND NON-DISCLOSURE

The issue of confidentiality will be adhered to by the researcher and you, the research assistant at all times and the participants' names will not be used, but a pseudonym to protect their identity. As a research assistant you will be assisting the researcher with operating the tape recorder and also making field notes during the data collection process. You are required to keep any information discussed in the focus group confidential and not to disclose any names of the participants or any information from the focus group to anyone, even after the study has been completed.

SIGNATURE, CONFIDENTIALITY AND NON-DISCLOSURE AGREEMENT OF RESEARCH ASSISTANT

I ………………………………………………………declare that I have read and understood the above agreement. I was given adequate time to consider my voluntary participation as a research assistant in this study. I was also given the opportunity to ask questions and they were answered to my satisfaction. I am hereby agreeing voluntarily to be a research assistant in this study, to protect the identity of the participants and keep all information shared confidential and not to disclose any information shared or identities of participants to anyone else but the researcher.

Signature: .... **Date**: ....

DECLARATION BY THE RESEARCHER

I declare that I explained the above information to the research assistant, ... who was given ample time to ask any questions and has agreed to keep all data gathered confidential and not to disclose any information or identity of participants to anyone but me the researcher.

Signature: .... **Date**: ....