

Experiences of people living with HIV and people living close to them of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention

H French
12329002

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Promoter: Prof M Greeff
Co-Promoter: Dr MJ Watson

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LANGUAGE EDITOR DECLARATION



Wilna Liebenberg BK/CC

Reg. no. 2010/038585/23

M.A. (Toegepaste Linguistiek - Vertaling)
Taalkonsultant Language Consultant
Geakkrediteerde Vertaler - SAVI/SATI - Accredited Translator
Beëdigde Vertaler - Sworn Translator
SAVI/SATI no. 1000014

✉ 743, STRUISBAAI 7285
☎ (028) 4356906 Fax 0865022074
e-mail: wilna@lieben.co.za
sel/cell: 0828248910

LANGUAGE EDITOR DECLARATION

I hereby declare that I completed the text editing on this thesis, entitled *A comprehensive community-based HIV stigma-reduction and wellness-enhancement intervention*, submitted for the degree Philosophiae Doctor (Nursing Science) at the Potchefstroom Campus of the North-West University, for Heleen French, student number: 12329002.

Wilna Liebenberg

MA Applied Linguistics.

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LITERATURE REVIEW ON STIGMA, STIGMATISATION, DISCLOSURE AND INTERVENTIONS WITHIN THE CONTEXT OF HIV AND AIDS 1 Introduction The research overview provided an introduction to this study, which included the problem statement, the research objectives, the paradigmatic perspective, a comprehensive outlay of the planned research methodology, trustworthiness and ethical considerations. In this section the researcher wishes to provide a review of stigma as described in the literature as well as the process thereof within the context of HIV and AIDS. HIV disclosure as a process closely related to stigma was also explored and will be discussed in terms of noteworthy literature found. Finally the...

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LIST OF ABBREVIATIONS

| | |
|---------------|--|
| AIDS | Acquired Immune Deficiency Syndrome |
| DENOSA | Democratic Nursing Organisation of South Africa |
| FPD | Foundation for Professional Development |
| ART | Anti-retroviral therapy/treatment |
| HIV | Human Immunodeficiency Virus |
| NGO | Non-Governmental Organisation |
| NRF | National Research Foundation |
| NWU | North-West University |
| OSF-SA | Open Society Foundation for South Africa |
| PLC | People living close |
| PLHA | People living with HIV or AIDS |
| PLWH | People living with HIV (for articles) |
| SANPAD | South Africa Netherlands Research Program on Alternatives in Development |
| UNAIDS | United Nations Program on HIV/AIDS |
| UCSF | University of California San Francisco |
| WHO | World Health Organisation |

RESEARCH OUTLINE

The research in this study is presented in an article format and includes the following:

Section A: An Overview of the Research

The objective of the research overview is to provide the reader with a brief review of literature pertaining to the project, the paradigmatic perspective, an outline of the research project and to discuss the methodology in more detail than would be possible within the different articles.

Section B: Literature Review

The objective of the literature review is to present a critical synthesis of aspects that best support the research. The literature review allowed for critical consideration on what literature existed and on identifying gaps within the current knowledge base (Polit & Beck, 2006:147).

Section C: The Articles

These articles each report on the research as it was executed, as well as on the findings thereof.

| Article title | Journal submitted to |
|---|---|
| Article 1: HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting | AIDS Care |
| Article 2: A comprehensive HIV stigma reduction and wellness enhancement community intervention: A case study | Journal of the Association of Nurses in AIDS Care |
| Article 3: Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting | Journal of Social Aspects of HIV/AIDS Research Alliance |

Section D: Conclusions, limitations and recommendations

This section reflects on the executed research project as a whole for a comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Overall conclusions, limitations and detailed recommendations are presented in more depth than is possible in the different articles.

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AUTHOR CONTRIBUTIONS

This research study was planned and executed by several researchers from the African Unit for Transdisciplinary Health Research at the North-West University, Potchefstroom Campus, and a collaborative researcher from the Vrije University, University of Amsterdam. The contributions of specific researchers to these articles are indicated in the table below.

Author and co-authors' contributions

| | |
|------------------|--|
| Mrs H French | PhD Nursing Science student; liable for the review of literature, performance of the study, conducting the research process focusing on the 'Experiences of people living with HIV and people living close to them of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention'. This study focus on qualitatively describing the experiences of people living with HIV and specific groups of people living close to them in a community context. |
| Prof Dr M Greeff | Promoter, project leader, conducting the research process and critical reviewer of the study |
| Dr MJ Watson | Co-promoter and critical reviewer of the study |
| Prof CM Doak | Collaborative researcher from the Netherlands and critical reviewer of the study |

The following are declarations by the author and co-authors to individually confirm their role in the study and the co-authors to agree that the article format is appropriate and acceptable for submission as a thesis.

DECLARATION BY CO-AUTHORS

I hereby declare that I have approved the inclusion of all three (3) articles as mentioned above in this thesis and that my contribution to this study is indeed as stated above. I hereby grant permission that these articles may be published as part of the PhD thesis of Mrs Heleen French.



Prof Dr M Greeff



Dr MJ Watson



Prof CM Doak

DECLARATION BY AUTHOR

I, Heleen French, student number 12329003, declare that:

'Experiences of people living with HIV and people living close to them of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention' is my own work and that all the sources I used are appropriately acknowledged.

This study has been approved by the Ethics Committee of the Institutional Office of the North-West University (Potchefstroom Campus).

The research ethical standards of the North-West University (Potchefstroom Campus) were adhered to during the planning and execution of this study.



Mrs H French

SUMMARY

Human Immunodeficiency Virus (HIV) remains a highly stigmatised condition for people living with HIV or AIDS (PLHA) and people living close to them (PLC) within the African context as well as in other countries. PLC often take part in HIV stigmatisation, but they are likewise often the victims thereof. This research was executed in three phases. The research objectives for the first phase of the study was to explore and describe how HIV stigma and disclosure experiences at present impact on the lives of PLHA in a country where the HIV infection rate is the highest in the world, and to explore whether there are differences between urban and rural settings.

The objective of the second phase of the research was to describe the implementation of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention that focused on PLHA as well as PLC from six designated groups, namely partners, children, family members, friends, spiritual leaders and community members. The objective of the third phase was to gain a deeper understanding of the experiences of both the PLHA and PLC by the six designated groups after they had undergone a comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Attention was focused on their expressed experiences of the workshop and projects executed by them in their communities.

During the first and third phases of the research a qualitative interpretive description approach was followed. A holistic multiple case study design was used for the second phase. Purposive voluntary sampling was used for the PLHA and snowball sampling for the PLC. Data collection during the first and third phases took place using in-depth interviews in an urban and a rural setting in the North West Province, South Africa. The data was manually analysed through open coding. Phase 2 had open coding as well as document analysis.

Findings of Phase 1 indicated that HIV stigma and disclosure themes for experiences in the urban and rural settings were mostly similar, with very few differences. Experiences of stigma were still very prevalent, but also led to negative self-judgement. The intervention proved to have been successful, as was reported during the case study and in participants' expressed experiences. All participants reported a better understanding

of HIV stigma and how to cope with it. Relationships between PLHA and PLC were enhanced. HIV stigma reduction projects developed by PLHA and PLC were executed successfully and the wider community was reached. Leadership skills were developed in order to go out into the community and be part of HIV stigma reduction actions. Some considerations for strengthening the intervention were provided. The intervention in its comprehensive nature was shown to be successful and promising for future use in reducing HIV stigma and enhancing wellness.

Key words: community, community-based, comprehensive, HIV, stigma, wellness

OPSOMMING

In die Afrika-konteks sowel as in ander lande bly die Menslike Immuniteitsgebreeksvirus (MIV) 'n uiters gestigmatiseerde toestand vir mense wat met MIV of VIGS leef, en vir mense wat na aan hulle leef. Laasgenoemde neem dikwels aan MIV-stigmatisering deel, maar hulle is self dikwels ook die slagoffers daarvan. Hierdie navorsing het in drie fases plaasgevind. Die navorsingsdoelwitte vir die eerste fase van die studie was om MIV-stigma- en blootleggingservarings van mense wat met MIV leef te verken en te beskryf asook die moontlike verskille tussen stedelike en landelike omgewings te ondersoek.

Die doelwit van die tweede fase van die navorsing was om die implementering van 'n omvattende MIV-stigmavermindering- en welstandsbevordering gemeenskapsintervensie te beskryf wat fokus op mense wat leef met MIV sowel as mense wat na aan hul leef uit ses aangewese groepe, naamlik lewensmaats, kinders, familieledes, vriende, geestelike leiers en gemeenskapslede. Die doelwit van die derde fase was om die belewenisse van die mense wat leef met MIV en die mense wat na aan hul leef na 'n omvattende MIV-stigmavermindering gemeenskapsintervensie te verken en te beskryf. Aandag is gevestig op hul belewenisse ten opsigte van die deelname aan die werkswinkel en die projekte wat hulle in hulle gemeenskappe uitgevoer het.

Tydens die eerste en derde fases van die navorsing is 'n kwalitatiewe interpreterende beskrywende benadering gevolg. 'n Holistiese veelvoudige gevalstudie-ontwerp is vir die tweede fase gebruik. Doelgerigte vrywillige steekproefneming is vir die mense wat leef met MIV gebruik, en sneeubalsteekproefneming vir die mense wat na aan hul leef. Data-insameling in die eerste en derde fase is deur middel van in-diepte onderhoude in 'n stedelike en landelike omgewing in Noordwes Provinsie, Suid-Afrika gedoen. Die data is per hand met behulp van oop kodering ontleed. Fase 2 het oop kodering sowel as dokumentontleding gebruik.

Die bevindings van fase 1 het aangedui dat die temas te opsigte van MIV-stigma- en blootstellings in die stedelike en landelike omgewings hoofsaaklik ooreengestem het met enkele verskille waarneembaar. Die belewenisse van stigma was steeds 'n algemene verskynsel en het ook tot negatiewe selfoordeel gelei. Die intervensie was

geslaagd, soos in die gevalstudie en in die deelnemers se belewenisse aangedui is. Alle deelnemers het 'n beter begrip van MIV-stigma en hoe om dit te hanteer geverbaliseer. Verhoudings tussen mense wat leef met MIV en mense wat na aan hulle leef het opsigtelik verbeter. Projekte om MIV-stigma te verminder wat deur beide groepe ontwikkel is, is suksesvol uitgevoer en die breër gemeenskap is bereik. Leierskapsvaardighede is in beide groepe ontwikkel om MIV-stigma vermindering in gemeenskappe te bewerkstellig. Die omvattende intervensie het geblyk suksesvol te wees, en toon belofte om in die toekoms gebruik te kan word om MIV-stigma te verminder en welstand te verbeter. Aanbevelings om die intervensie uit te bou is voorgestel.

Sleutelwoorde: gemeenskap, gemeenskapsgebaseerd, MIV, omvattend, stigma, welstand

SECTION A: OVERVIEW OF THE RESEARCH

This study formed part of a larger comprehensive community-based HIV stigma reduction and wellness enhancement intervention study with Prof M Greeff as project leader and aimed at focusing on individuals being stigmatised due to their HIV-positive status or people living close to them (PLC) being stigmatised due to their mere association with them in a community context. The groups of people affected by HIV stigmatisation included in this study are the people living with HIV or AIDS (PLHA) and their partners, children, family members, friends, spiritual leaders as well as community members. In this section an overview of the proposed research is presented in more detail than is possible in the articles.

1 Introduction and Problem Statement

The socio-cultural environment of people affected by HIV (Human Immunodeficiency Virus) can be hostile. Stigmatisation and the contribution thereof to the burden and the spread of this disease is immense (Barradas, 2005:1; United Nations Program on HIV/AIDS [UNAIDS], 2009:5). The sociologist Erving Goffman (1963:13) used the term “stigma” in the early 1960s to refer to attributes that discredit people. Alonzo and Reynolds (1995:304) refer to stigma as a “powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons”. This definition follows upon Goffman’s original definition of stigma in 1963, and it forms the conceptual definition of stigma in this study. Literature regarding stigma is now voluminous, with stigma increasingly being viewed less as concrete traits or features of the individual, and more as a process shaped by structural and cultural forces (Parker & Aggleton, 2003:14; Scambler *et al.*, 2006:269).

In essence, the stigmatised are a category of people who are looked down upon by broader society and who are devalued, shunned, or otherwise lessened in their life chances and in access to the humanising benefit of free and uninterrupted social intercourse (Alonzo & Reynolds, 1995:304). Stigma relating to HIV not only impacts on

the lives of HIV-positive individuals, but also on the individuals, groups and communities to whom they are related (Greeff & Phetlhu, 2007:13; Hilhorst *et al.*, 2006:390).

Closely linked to stigma is the aspect of discrimination. The latter refers to behaviour that leads to unfair treatment and it does not always follow upon the act of stigmatisation. However, the consequence of the negative attitude may still be damaging to PLHA (Campbell *et al.*, 2007:404; Siyam'kela, 2003:6). Some authors differ in this regard and are of opinion that discrimination is always the implication of stigmatisation (Parker & Aggleton, 2003:18; Skinner & Mfecane, 2004:160). Research conducted by Naidoo *et al.* (2007:17) and Hilhorst *et al.* (2006:390) suggests that there are differences in the manifestation of stigma and discrimination concerning individuals from urban communities and those from rural communities. Both studies suggest that the level of literacy mainly influences the act of stigmatisation towards others.

South Africa is the most affected country in the world, with the latest HIV statistics indicating that there are currently approximately 35 million people living with HIV worldwide. More than two-thirds of these infections and deaths are from sub-Saharan Africa. More than 22 million people in Africa, and mostly in southern and East Africa, are infected with HIV (Evian, 2011:3; UNAIDS, 2012:6). The impact of HIV and AIDS reaches all sectors of society, from urban industries to rural villages (Connolly *et al.*, 2004:776). In 2009, more than 25 years into the HIV epidemic, HIV-related stigma and discrimination persist across the globe (UNAIDS, 2009:1). In this context, the necessity of combating HIV-related stigma is undeniable. Literature provides proof of existing HIV stigma reduction interventions, but interventions aimed at reducing stigma at community level, and specifically in the context of Africa, appears to be lacking (Apinundecha *et al.*, 2007:1157; Brown *et al.*, 2003:49; Heijnders & Van der Meij, 2006:353; Lauver *et al.*, 2002:246; Uys *et al.*, 2009:1059). This emphasises the importance of the present study.

For about two decades, discrimination, denial and stigmatisation have been poorly understood, and marginalisation within national as well as international responses has taken place (Parker & Aggleton, 2003:13). In an attempt to conceptualise the process of stigma, Holzemer *et al.* (2007:541) developed a conceptual model of HIV and AIDS stigma from five African countries. According to this model, there are two components, namely contextual factors and the stigma process itself. Contextual factors include the

environment, the healthcare system, as well as agents that have an influence on stigma.

The stigma process includes four dimensions, namely triggers of stigma, stigmatising behaviours, types of stigma, and the outcomes of stigma. Stigma is described as a process that can be activated or triggered by any actions that lead to the labelling of people, whether by themselves or by others, as being HIV positive. The model describes stigma as being one of three types, namely received stigma, internal stigma, and associated stigma. Stigmatisation leads to negative outcomes that compromise quality of life. This conceptual model forms the theoretical framework for this study. The Siyam'kela Project, which ran more or less concurrently with the study by Holzemer *et al.* (2007:541), describes two kinds of stigma, namely external (also known as enacted stigma) and internal stigma (Siyam'kela, 2003:98). Both PLHA and PLC experience stigma, and all three types of stigmatisation will consequently be encountered in this study (Holzemer *et al.*, 2007:547).

Closely linked to HIV stigma is the debate about disclosure. The process of disclosure constitutes a significant dimension of understanding the experiences of stigma (Greeff *et al.*, 2008:312). Most health literature appears to favour disclosure by persons living with HIV (Cusick & Rhodes, 1999:3; Serovich, 2001:355; Serovich & Mosack, 2003:70; Wong *et al.*, 2009:215). Dlamini *et al.* (2007:397) and Greeff *et al.* (2008:312), however, mention that to disclose is not always favourable, as disclosure (or non-disclosure) is often followed by major and life-changing circumstances. Because of the fear of AIDS-related stigma, very few people voluntarily disclose their HIV status (Derlega *et al.*, 2006:758; Elford *et al.*, 2008:519; Kruger *et al.*, 2009:37; Ogden & Nyblade, 2005:35). However, it is widely accepted that holding back one's feelings gives rise to stress, which in turn negatively affects physical as well as psychological well-being (Paxton, 2002:564; Van Dyk, 2002:270).

Greeff *et al.* (2008:318, 319) describe disclosure under three main themes: experiences before disclosure, the process of disclosing, and responses during and after disclosure. Feelings accompanying disclosing or not disclosing include doubt, worry, hurt, acceptance, and courage. Greeff *et al.* (2008:319) found that doubt is a feeling that accompanies the choice of disclosure or non-disclosure. They also found that the

feeling of hurt sometimes causes people to talk openly about their HIV status. It was found that participants in their study tended to disclose their HIV status as soon as acceptance of their positive status had taken place and after they had found the courage from within. Who to disclose to seems to be an important factor when considering disclosure. This consideration forms part of the process of disclosure. It was found that close family members, partners, or healthcare workers were mainly the first choice of candidates to disclose to (Deribe *et al.*, 2010:33; Serovich, 2001:360; Wong *et al.*, 2009:217).

Disclosure outcomes vary from positive to negative. Disclosure can be accompanied by consequences such as problems in relationships, rejection, social discrimination, physical abuse, and verbal abuse (Dlamini *et al.*, 2007:395; Paxton, 2002:563; Van Dyk, 2002:279). Therefore the possible costs of the decision to disclose or not to disclose one's HIV diagnosis should be weighed up against the potential benefits of disclosure. Wong *et al.* (2009:219) found that the most common reason for individuals to not disclose their HIV-positive status was a desire for privacy. The following positive outcomes of disclosure were reported: behavioural changes regarding sexual activities; social support was received; spiritual resilience and community involvement were visible; families provided the most overall support, and community members showed the most increase in support (Wong *et al.*, 2009:220).

As the HIV epidemic is growing among the South African population, it is crucial to develop effective interventions to assist PLHA in disease disclosure decisions (Wong *et al.*, 2009:221). Cusick and Rhodes (1999:14) made the interesting observation that previous disclosure experiences were often used as a basis of confidence by PLHA and the belief that continuous acceptance by others will take place on disclosure of their positive HIV status. The literature indicates that sharing the fact that they were HIV positive with people close to them is important for PLHA in the process of stigma reduction. However, an individual has to feel that he/she is in control of conveying such private information (Greeff *et al.*, 2008:314). HIV stigma plays a major role in HIV-status disclosure, as stigma is often the outcome of the disclosure of a positive HIV status. HIV stigma continues to impact negatively on PLHA and PLC and therefore practically doable and well-thought through interventions are crucial in the process of stigma

reduction, as is evident in the literature on interventions aimed at HIV stigma reduction. The PLHA and PLC form a central element in the HIV stigma reduction process.

In their literature review titled “Interventions to reduce HIV and AIDS stigma: What have we learned?” Brown *et al.*, (2003:49) found that several stigma reduction interventions have been developed and tested in developing countries worldwide. Results indicate that some stigma reduction interventions appear to work, at least on a small scale and in the short term, but many gaps remain, especially in the scale and duration of impact and in terms of gendered impact of stigma reduction interventions. Holzemer and Uys (2004:172) conducted a review of the literature regarding stigma and AIDS care, also with regard to intervention strategies relating to the management of stigma. They found that almost all the research conducted on this matter lacked thorough scientific analysis. Furthermore, few studies have measured stigma or indicated how stigma changes over time. The researcher found that literature regarding interventions aiming at reducing HIV-related stigma is scarce, hence the substance of the present study (Brown *et al.*, 2003:49; Heijnders & Van der Meij, 2006:353; Weiss & Ramakrishna, 2006:536).

In a further study on an intervention in a health setting in the African context, it was found that intervention had a positive outcome in that it gave rise to a better understanding and mutual support between nurses and PLHA. PLHA reported less stigma experiences and an increase in self-esteem (Uys *et al.*, 2009:1059-1061). One community participation intervention to reduce HIV-related stigma in Thailand (Apinundecha *et al.*, 2007:1157) was found in the literature. A brief HIV stigma reduction intervention specifically designed for service providers in China showed to be effective in the healthcare settings in that country. Healthcare providers who had undergone the intervention (which was designed the basis of the findings of lessons from previous qualitative studies) reported a stronger belief in patient confidentiality and the protection of patients’ rights to HIV testing, reduced fear for PLHA, and better knowledge and practise of universal precautions when working with PLHA (Wu *et al.*, 2008:516).

To date, most of the stigma reduction interventions in sub-Saharan Africa have been information-based awareness programmes aimed at reducing ignorance about PLHA (Campbell *et al.*, 2007:404). This emphasises the need for more community-based

stigma reduction interventions, and in particular with regard to the African context. Hence, the importance of this research is obvious.

It is clear that the stigma relating to HIV has not been overcome, despite the immense impact it has on developing countries, and especially South Africa. With this study, the researcher aimed to contribute to a comprehensive understanding of HIV stigma reduction and wellness enhancement interventions that target PLHA and PLC in the community. The “real work” regarding HIV and AIDS and the practices that lead to a rise in the epidemic is likely to occur at community level (Winiarski, 2004:36). Authors differ regarding HIV stigma in rural and urban settings. Naidoo *et al.* (2007:22), for instance, found that there are more stigmatisation and discrimination in urban communities than in rural communities. This research finding contradicts other research studies, which showed the opposite (Bond *et al.*, 2003:7; Bunn *et al.*, 2008:285; Heckman *et al.*, 1998:138; Sliep *et al.*, 2001:61). The act of discrimination and stigmatisation may take different forms within these diverse contexts, as the individuals that make up these areas differ with regard to their economic and educational backgrounds.

Based solely upon the literature on stigmatisation reviewed thus far, specifically with regards to PLHA, as well as on the PLC, one can conclude that the damaging effects thereof have not yet ended. As this pandemic is on the rise, one can predict that stigmatisation will continue to increase if no interventions to combat this are implemented. South Africa, as a country carrying a heavy burden of HIV and AIDS and the associated stigmatisation towards infected and affected individuals, is especially in need of interventions to counteract stigma.

The impact of HIV stigma not only affects individuals, but the community as a whole. The PLHA are part of a community and part of a family, and the disease and the stigma and discrimination that accompany HIV affect them all. Disclosure is another factor that affects the well-being of the PLHA. The higher the level of stigmatisation of PLHA, the higher the likelihood of non-disclosure due to the fear of stigmatisation will be. Research on interventions aimed at reducing HIV stigma is inadequate and there are so few community-based interventions found in the literature that one can conclude that they are virtually non-existent.

2 Research Questions

On the basis of the aforementioned research problem, the researcher asked the following questions:

- What are the HIV stigma and disclosure experiences of PLHA in an urban and rural setting?
- Can a comprehensive community-based HIV stigma reduction and wellness enhancement intervention assist PLHA and PLC living in an urban and rural setting in reducing HIV stigma and enhance their wellness?
- What are the experiences of PLHA and PLC during and after having undergone a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting?

3 Research Objectives

From the abovementioned research questions the following research objectives were formulated:

- To explore and describe the HIV stigma and disclosure experiences of PLHA in an urban and a rural setting.
- To implement and evaluate a comprehensive community-based HIV stigma reduction and wellness enhancement intervention with PLHA and PLC in an urban and a rural setting.
- To explore and describe the experiences of PLHA and PLC after having undergone a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting.

4 Paradigmatic Perspective

The term paradigmatic perspective refers to a worldview, in this case focused upon this research project. It serves as the medium in which the researcher, on the basis of particular theories, knowledge and thought processes, adds meaning to the research and related terms (Young *et al.*, 2001:12). A paradigmatic perspective thus serves as a framework from which the researcher functions and interacts with the research. The paradigmatic perspective includes the meta-theoretical assumptions, theoretical statements and methodological statements. These are discussed below.

4.1 Meta-theoretical assumptions

Meta-theoretical assumptions describe the suppositions of the researcher regarding man and society (Botes, 1995:9; Creswell, 2009:6; Klopper, 2008:67). These are non-epistemic in nature, hence not based on definite researched theory but rather on the personal view of the researcher on objects and processes, and the intention is not to test these statements (Mouton & Marais, 1992:192).

The researcher used aspects from different authors to elucidate her worldview (Brits, 2010:2; Burnett, 1990:208; Frey, 2003:128; Hallett, 1983:214; Kotzè, 1989:1; Milne, 1982:91). Worldviews are not only a philosophy or a theology a person or persons hold, but are the framework in which they find meaning and comprehension (Brits, 2004:76). The researcher as a Christian views the Bible as the textbook of Christian faith. It instructs the way of salvation, clarifying the gospel. The researcher believes in the gospel as being one of grace where those in Him may become the righteous. So it seems that training in righteous living will be linked to life in Christ, grabbing hold of His Spirit to guide those in Him, rather than focusing on one's own abilities and behaviour (Brits, 2004:191). The traditional Christian view of revelation is that the Bible is the authoritative revelation of God to humanity. Faith in God is essential in all circumstances (Bible, 2000:1470; Burnett, 1990:208; Hallett, 1983:214). It seems like the decline in faith in the Living God has something to do with an increase in emotional problems among adults and children (Brits, 2008:2). God is the Alpha and Omega, which are described as the *beginning* and *end*. The researcher agrees with the view of God being the Creator and the ender of life (Kotzè, 1989:1). The meta-theoretical

assumptions of the researcher on human beings, environment, health and illness, as well as nursing will be defined.

4.1.1 Human beings

Human beings, according to the views of the researcher, are naturally introspective beings, capable of creativity and meta-cognition. Human beings were created in the image of God, and the researcher views human life as being precious. The researcher views a human being as a whole person encapsulated in a body, having a soul and a continuously thinking mind. The self-conscious mind cannot be explained by natural phenomena and evolutionism. Much evidence supports the fact that God is the Creator of mind and personality in human beings. Besides intelligence, a human is also an emotional being, perhaps the only emotional being. It is out of emotion that a large proportion of the endeavours of man originate (Brits, 2004:155). Reason is a newly developed capacity of intelligence, associated with the greatly extended development of the cortex of the human brain. Simple deductive reasoning is shown by early primates and may occur in still earlier vertebrates, but to a very minor extent. However, humans have become proficient in its use. It is an imperative ingredient of human motivation, theories, excuses, in the making of plans and decisions (Cooley, 1993:27). If human beings are made within the image of God, they therefore have personality because God is personal. Human beings can act in the cause-and-effect world in a creative way (Burnett, 1990:213).

4.1.2 Environment

The environment can be explained as the sphere in which human beings exist. It is made up of an internal as well as an external component. The internal environment of human beings consists of the body, the mind and the spirit, and includes values, beliefs and morals. The external environment is made up of several forces, namely physical, social and spiritual. The environment in which human beings live can in the main be approved to be the earth as created by God. According to the views of the researcher, human beings were placed within a specific area and in accordance with a unique plan worked out by God prior to existence of the human beings. God has granted human beings the authority to live on this earth, but He also expects respect and protection of the earth.

The world as described by Burnett (1990:214) is not a mere illusion, but a habitat for man in which God has placed him to utilise the resources in a creative and responsible manner. The Bible (2000:9) gives mankind a role as guardian of planet earth, as is shown in the first command given to Adam (Genesis 2:15). The internal environment of human beings has an influence on its external environment, and vice versa (Anna Vaughn School of Nursing, 1990:136-142; Milne, 1982:91). Human beings' beliefs regarding certain aspects of their external environment can cause some reactions from within, for example, if a person views an HIV-infected individual as deviant, their behaviour towards such a person will consequently be expected to be (and usually is) negative. The external environment can also affect the internal environment of human beings, for example when a person infected with HIV (or even merely associated with a person infected with HIV) is being stigmatised, it can negatively impact on the person's physical as well as emotional wellness.

4.1.3 Illness and health

On a physical as well as a psychological level illness can be defined as a dynamic, complex process and experience in the individual. One which occurs if there is a disturbance or failure in the bio-psychosocial functioning of that individual that gives rise to observable or experienced changes, discomfort or inability in that individual. In every ill individual there is the potential to be healthy (Greeff, 1991:9). Illness, according to the researcher, impacts directly on human dignity and it is the duty of the healthcare provider to preserve this at all times during the period of ill health. It is a dynamic condition reflecting in the nature of a human being's patterns of interaction with regard to stress factors in his or her external environment (Anna Vaughn School of Nursing, 1990:142).

4.1.4 Nursing

According to the researcher, nursing is a calling. It is a goal-directed, comprehensive service to the patient. The nurse stands in for those who are not able to sustain their normal activities of daily living due to ill health, whether physical or psychological in nature. Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect. Nursing care is respectful of and unrestricted by considerations of age, colour, creed, culture, disability

or illness, gender, sexual orientation, nationality, politics, race or social status. Nurses render health services to the individual, the family and the community and co-ordinate their services with those of related groups (ICN, 2006:1).

4.2 Theoretical statements

The central theoretical argument and conceptual definitions formed the theoretical statements for this study and are discussed below.

4.2.1 Central theoretical argument

PLHA are often ambivalent when it comes to deciding on whether to disclose their HIV status or not, as HIV remains a highly stigmatised disease and the effects thereof are often traumatic. Hence, one can identify the dilemma in which they find themselves. Stigmatisation negatively impacts on the PLHA, as well as the PLC, through what they do to themselves or through what they receive from others in the form of stigmatisation. PLC also have the potential to be stigmatised due to the mere fact that they are associated with them, for example in a close relationship with such an individual. However, the PLC can also be part of the community that stigmatises the PLHA.

Thus, there is the phenomenon of self-stigmatisation, received stigma as well as associated stigma that occur and that can impact negatively on the well-being of PLHA and PLC. If a comprehensive community-based HIV stigma reduction and wellness enhancement intervention, which targets both PLHA and PLC, and that focuses on HIV stigma reduction, disclosure management and increasing coping, is implemented, it may lead to a reduction in the negative effect and impact of stigma by enhancing relationships between PLHA and PLC, by impacting on the self-esteem of PLHA and PLC, and by empowering them with scientifically based information on stigma and stigma reduction actions.

4.2.2 Conceptual definitions

The main concepts that serve as theoretical grounding in this study are discussed below.

4.2.2.1 Comprehensive

According to the Longman`s Dictionary of Contemporary English (1993:206), the term comprehensive refers to “including a lot or everything”. Comprehensive also specifically means “covering everything or a great deal” (Chambers Pocket Dictionary, 1997:188).

4.2.2.2 Stigma

Alonzo and Reynolds (1995:303) define stigma as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people. Stigma can be divided into three types of stigma, namely received stigma, internal stigma and associated stigma (Holzemer *et al.*, 2007:549).

4.2.2.3 Community

The Longman`s Dictionary of Contemporary English (1993:202) defines community as a group of people living together and united by shared interests, religion, and nationality. In addition, it is the public or society in general (Chambers Pocket Dictionary, 1997:185). The community is a place people identify with, where they sense that they belong and that others care what happens to them (Henslin, 1999:646).

4.2.2.4 Community-based

Community-based denotes the involvement of community members in any integrated approaches to socioeconomic development or the aim to achieve health for all through improving quality of life. Mental and physical health contributes to the social and economic development of a community. It has been acknowledged, though, that health cannot be gained in isolation: it is an integral part of the development process and as such is influenced by all aspects of society (World Health Organization [WHO], 2003:7). According to Rendall-Mkosi (2012:128) it entails that the community members themselves, with their own experiences, commit themselves to active involvement and participation throughout the entire process of co-operation and collective action.

4.2.2.5 Wellness

Subjective wellness or well-being can be defined as life satisfaction, the presence of positive affect, and a relative absence of negative affect (Baumgardner & Crothers,

2010:18). According to Wissing and Van Eeden (2002:32), psychological well-being, also referred to as wellness, can be described as being multidimensional regarding facets of the self that are involved, for example affect, cognition and behaviour. Psychological well-being is also multidimensional with regard to the domains of life in which these facets manifest themselves, for example intra- and interpersonal, social and contextual, in love and at work. A sense of coherence, satisfaction with life and affect balance is a strong indicator of general psychological wellness or wellbeing (Wissing & Van Eeden, 2002:32). Myers, Sweney and Witmer as quoted by Greeff *et al.* (2010:16), further define wellness as “a way of life orientated towards optimum health and wellbeing in which body, mind and spirit are integrated in the individual to live more fully within the human and natural community.”

4.3 Methodological assumptions

According to Botma *et al.* (2010:208), methodological assumptions refer to what the researcher perceives to be good scientific practice. The model for research by Botes (1995:6), as well as the philosophical and methodological grounds of the qualitative interpretive description approach and the case study design, was used as the framework for this research.

The model for research by Botes (1995:1-22) provides a holistic perspective on the research process and is not limited to a specific methodology. Furthermore, its point of departure is that of functional reasoning, which the researcher supports. The activities of nursing are suggested as originating from three orders, according to this model:

- The first order refers to the nursing practice. The activities applicable here are nursing care with the aim of enhancing, repairing and maintaining health (Botes, 1995:6). With regard to this research, nursing practice refers to the researcher being a professional nurse working in the primary healthcare setting and in contact with various HIV-infected and affected individuals on a daily basis and striving towards the reduction of HIV-related stigma in a community context.
- The second order represents nursing research (Botes, 1995:6). The aim of conducting research is to improve nursing practice and to add to the existing body of knowledge. The research process takes place according to a specific research

design. The so-called problem is identified from the first order (nursing practice). The researcher supports the qualitative approach in this research.

The third order is the paradigmatic perspective of the researcher (Botma *et al.*, 2010:207). The meta-theoretical assumptions refer to the philosophical beliefs of the researcher as described under the paradigmatic perspective, referring to the researcher's views on human beings, environment, illness, health, as well as nursing. The researcher stated her theoretical assumptions by providing the central theoretical argument and conceptual definitions in this research study. The researcher's methodological approach favours the qualitative interpretive descriptive approach and the case study design (Botma *et al.*, 2010:208).

5 Research Methodology

The research design and method serve as guidelines for researchers, and according to these guidelines a study needs to be structured, and to collect and analyse information relevant to answering the research question (Polit & Beck, 2006:16). In qualitative research, the choice of design depends on the research problem and questions (Botma *et al.*, 2010:209). The design encapsulates the nature, aims, and context within which the research ought to take place (Klopper, 2008:68).

An overview of the research design and the research method planned for this research follows.

5.1 Research design

The qualitative interpretive description approach (Thorne, 2008:35) and holistic multiple case study design (Yin, 2009:59) have been chosen for this research as it is the most suitable for answering the research questions (Creswell, 2009:129; Polit & Beck, 2006:17). This research was planned to take place in three consecutive phases. The research design for each phase is presented in sequence below.

An interpretive description approach (Thorne, 2008:35) was planned for the first phase to explore and describe the HIV stigma and disclosure experiences of PLHA in urban as

well as in rural communities of the North West Province, South Africa. Interpretive description is not prescriptive, and circumscribed in nature that will dependably lead to new discoveries. It generates questions from the foundation, pushes the researcher into the research field in a logical and systematic way, and creates the context in which engagement with the data extends the interpretive mind beyond the self-evident to discover what else might be there. It provides the potential to look differently at previously accumulated knowledge in order to generate new insights that create new inquiries as well as applications of “evidence” to practice (Thorne, 2008:35).

The second phase is a holistic multiple case study for the implementation and evaluation of the comprehensive community-based HIV stigma reduction and wellness enhancement intervention with PLHA and PLC. A holistic multiple case study design (Yin, 2009:53) was planned in order to implement and evaluate the mentioned intervention. The researcher selected this type of design for the case study because more than a single case would be under investigation and the analytic benefits of having more than one case are significant (Botma *et al.*, 2010:211; Yin, 2009:61). This type of design is useful in the case of exploring in depth a programme such as this intervention with its real-life context (Babbie & Stake, as quoted by Creswell, 2009:13).

The third phase of the research also planned a qualitative interpretive description approach (Thorne, 2008:35) to explore and describe the experiences of PLHA and PLC during and after having undergone a comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Attention was given to experiences of the workshop and the projects that were carried out by the participants.

5.2 The context of the study

The contexts of the population in which this research was planned to take place were Potchefstroom and Ganyesa in the North West Province of South Africa. These urban and rural settings individually were identified as being appropriate, as they were representative of what an urban and a rural context entail. The participants were described as coming from the Ikageng, Mohadin and Promosa suburbs of Potchefstroom. Ganyesa is a village 70 km from Vryburg, 450 km west of Potchefstroom on the highway to Botswana, and 70 km from the Botswana border. It has a good infrastructure (Watson, 2008:34). The people residing in both the urban and

rural settings were mainly made up of Setswana-speaking individuals with a black, African socio-cultural background. They mostly resided in the informal settlements of these regions and hence fell into the category of a lower socio-economic status. As HIV statistics indicate that the rate of HIV infection is high within the African context, this context was identified as being appropriate for this study. The aim of involving both urban and rural settings in the research is not to compare findings from these settings but rather to understand these settings and their people individually so that adaptations can be made to this intervention for future use in each setting, should it be necessary. The researcher hence will purely apply a qualitative approach in this research.

5.3 Research method

As was mentioned before, this research was planned to be undertaken in three phases.

5.3.1 Phase 1: A qualitative interpretive description study to explore and describe the HIV stigma and disclosure experiences of PLHA in an urban and a rural setting

A description of the sample, data collection, data analysis, literature control and trustworthiness as was used during Phase 1 of this research follows.

5.3.1.1 Sample

The sample is described in terms of the population, sampling and the sample size.

- Population

The population included all the elements (individuals, objects or substances) or aggregation of cases that met certain criteria for inclusion in a given world and in which the researcher was interested (Burns & Grove, 2005:40). The population from which the sample was drawn included PLHA in the greater Potchefstroom urban area and rural Ganyesa in the North West Province. Potchefstroom and Ganyesa formed the context of the research. These areas for sampling were identified during the PURE (Prospective Urban and Rural Epidemiological) study.

- **Sampling**

Purposive voluntary sampling was conducted for the initial identification of n = 20–24 PLHA in the North West Province, South Africa (Burns & Grove, 2005:352; Thorne, 2008:90). These 20–24 PLHA had to make up two groups, namely 10–12 PLHA from the greater Potchefstroom urban area, and 10–12 PLHA from rural Ganyesa. The aim of purposive sampling is to identify, in advance of a study, the main groupings or conditions needed for a potentially true reflection of findings. A particular individual is chosen because they illustrate some characteristic or process that is of interest to the researcher and because the person is seen as an expert on the particular lived experience (Botma *et al.*, 2010:201). The participants for Phase 1 of this research had to be selected according to the following inclusion criteria:

The participant had to:

- be 18 years or older and could be male or female;
- be a member of the greater Potchefstroom urban community or the rural Ganyesa community in the North West Province;
- be knowingly HIV positive for a minimum of six months;
- give informed consent to participate in the research;
- be able to understand English or Afrikaans or Setswana;
- be able to communicate freely and to express themselves adequately;
- be literate in order to be able to participate in workshops;
- give consent for the recording of the interview on audiotape;
- be willing to be trained during a workshop in order to go out into the community for implementation of the intervention;
- be willing to take part in a study during which HIV-status disclosure would take place;
- be able to provide people living close to them as participants in this study and according to the set inclusion criteria for each category;
- have undergone a pre-test battery for PLHA.

- **Sample size**

The sample size was as indicated above, namely two groups of between 10 and 12 people, each living with HIV or AIDS, one group originating from the Potchefstroom urban setting and the other from the rural Ganyesa setting. The reason for using a set number of participants was due to the nature of the larger study being an intervention. However data saturation was used as guide and was achieved. Keeping the number of participants limited is especially important in the case of a personal topic such as the one that was studied in this research, where participants most probably sought trusting relationships as a place of departure. Through this means the researcher attempted to create a safe and therapeutic environment during the intervention that may have made a positive contribution for participants with regard to sharing information (Thorne, 2008:91). Data saturation was achieved after approximately 7 interviews.

5.3.1.2 Data collection

The data collection method, the writing of field notes, the physical setting, the selection of mediators as well as the role of the researcher for this research are discussed below:

- **Data collection method**

In-depth interviews (Botma *et al.*, 2010:207; Greeff, 2005:292; Polit & Beck, 2006:291) were conducted with PLHA in order to collect the richest data possible. The interviews were conducted in English but participants who wished to answer questions in another language such as Setswana or Afrikaans were allowed to do so. An interpreter who was fluent in all three languages was available throughout the interviews and in case of translation, the version of the response as provided by the participant and the translator was transcribed and evaluated for correctness during transcription. The main aim of the in-depth interview was to attempt to understand the experience of PLHA and the meaning they added to this experience. It was focused and discursive, and it allowed the researcher and participant to explore certain issues (Botma *et al.*, 2010:207; Greeff, 2005:293). The open-ended questions that were used during the in-depth interview were evaluated by experts in the field and then evaluated for their appropriateness and whether they elicited the content the researcher hoped to obtain (Botma *et al.*, 2010:208).

The following open-ended questions were asked during Phase 1 of this research:

“Tell me about your experience with stigma (le setikima/sekgomaredi) as a person living with HIV.”

“Tell me about your various experiences of having to tell people that you are HIV positive.”

“Tell me about your experience of having this interview with me today.”

Digital voice recordings were made of all the in-depth interviews conducted (Botma *et al.*, 2010:214). The interview commenced with the broad questions indicated above. The researcher familiarised herself with the research questions in order for the process to take place in an organised manner (Botma *et al.*, 2010:207; Greeff, 2005:293).

A combination of communication techniques from Frisch and Frisch, as set out in Botma *et al.* (2010:206), was utilised by the researcher during interviews, for example making use of minimal verbal responses, paraphrasing, reflection, clarification, probing and making use of extensive summarisation.

- **Fieldnotes**

Extensive field notes (observational, theoretical, methodological and personal notes) were made by the researcher directly after the interviews. These notes served as a retrospective overview of the process (Botma *et al.*, 2010:218; Greeff, 2005:298). Observational notes included multiple forms of observed data gathered by the researcher. Three sections were included, namely descriptive notes, reflective notes and demographic information. Methodological notes entailed the methods used in the observation. Theoretical notes were depictions of the researcher’s thoughts about how to make sense of what was going on. Personal notes included the researcher’s personal feelings and experiences while in the field executing the research (Botma *et al.*, 2010:218).

- **Physical setting**

In the case of the Potchefstroom urban community’s participants the interviews took place in an office at the university allocated for this purpose, and in the case of the rural Ganyesa’s participants at a guest lodge. The probable areas for interviewing were

considered in terms of comfort and privacy for participants and the researcher. The areas were as quiet and free from distractions as possible. In both data collection settings the researcher placed a sign on the door that indicated that interviews were in progress (Burns & Grove, 2005:397).

- **Selection of mediators**

During this research a research assistant who was employed by the North-West University was used to link with possible mediators. The research assistant was familiar with the research field as she had been a participant in a previous research study on HIV and AIDS stigma. She was responsible for linking with the mediators, who were responsible for selecting suitable candidates for the study, as per the selection criteria as described above, in the urban Potchefstroom and rural Ganyesa communities. Their role also entailed linking the researcher with participants and establishing the preliminary trusting relationship with them. The research assistant provided the mediators and participants with details regarding the venue and transport to the venue. The research assistant ensured that the participants complied by making contact with them on a regular basis prior to the interviews to remind them about their appointments. She also assisted with interpreting during the interviewing process, as needed.

- **The role of the researcher**

This research project was part of a larger SANPAD funded study and was approved by the Ethics Committee of the North-West University (NWU-00011-09-A1) as well as the provincial Department of Health. Entry into the community was gained via a research assistant who linked with a mediators at non-governmental organisations. Appointments were made for appropriate dates and times for the interviews, and the venues were confirmed. The research assistant assisted in arranging for public transport, paid from the research project funds. Lunch and refreshments were provided for all participants. The researcher conducted some of the unstructured in-depth interviews, while the rest was done by a research assistant who received comprehensive training on the execution of in-depth interviews. Role plays were performed and interviews pilot-tested by an expert in qualitative research to ensure the best quality of data collection possible.

5.3.1.3 Data-analysis

All the digital voice-recorded interviews were transcribed for data analysis (Botma *et al.*, 2010:220; Hek & Moule, 2006:27). Verbatim transcription is a critical step in preparing for the analysis of data. The researcher made use of an external transcriber, and to ensure accuracy of the data, the researcher verified the correctness by listening to the recording and reading attentively through the transcription (Botma *et al.*, 2010:221).

The researcher used Creswell's (2009:185–190) generic qualitative analysis approach, which entailed the collection of qualitative data, analysing for themes or perspectives, and reporting on four to five themes. The six steps necessary for successful data analysis in qualitative research as discussed by Creswell (2009:185–190) are as follows:

- Organise and prepare the data for analysis

The researcher scanned through the material and sorted the data into different types of origin, namely urban and rural.

- Read through all the data

The researcher read through the data in order to get an overall sense of the data gathered. The overall depth, credibility, and use of the information were briefly estimated.

- Begin detailed analysis

The researcher used the technique of open coding as described by Tesch (in Creswell, 2009:186).

- Get a sense of the whole.
- Pick one document (i.e. one interview) – the most interesting one, the shortest, the one on top of the pile. Go through it. Think of the underlying meaning of the information.
- When this has been done for several participants, make a list of all topics. Group topics into major topics, unique topics, and leftovers.
- Take the list and go back to the data. Abbreviate the topics as codes and write the codes next to the appropriate parts of the text. Try this

preliminary organising scheme to see if new categories and codes emerge.

- Find the most descriptive wording for your topics and turn them into categories. Group topics that relate to each other together.
- Make a final decision on the abbreviation style for each category and alphabetise these codes.
- Assemble the data belonging to each category together and perform preliminary analysis.
- If necessary, recode the data.
- Use the coding process to generate a description of the setting or people as well as categories or themes for analysis.
- Representation of the description and themes.

The researcher gave an extensive, chronological overview of themes identified.

- Making an interpretation of the data.

The researcher made use of a co-coder in order to compare findings and interpretations.

5.3.2 Phase 2: Case study for the implementation and evaluation of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting

5.3.2.1 Literature review

The following databases were utilised by the researcher for the initial literature search in this research and were also used in the extended literature review: Google Scholar, Medline, Ferdikat-Library Catalogue, Eric, NEXUS (NRF), SAePublications (Sabinet), PsycINFO, Medline, Science Direct, Ebsco Host: Academic search premier, and Cinahl. A literature review was conducted by the researcher in order to provide a theoretical background for the study and to contextualise core concepts, as well as to explain how the study will add to the existing body of knowledge (Klopper, 2008:64; Silverman, 2004:85). The literature review also contributed to an assessment as to whether the study was doable or not (Botma *et al.*, 2010:216-217). In order to search for the best

descriptive and applicable material, key words or themes such as the following were entered during these searches: HIV stigma; HIV discrimination; HIV stigma reduction; HIV stigma reduction interventions; wellness and HIV; HIV stigma-intervention experiences; urban and rural; HIV and AIDS; HIV status disclosure; and, disclosure experiences.

5.3.2.2 Sample

The population, sampling, data collection and data analysis are discussed below:

- **Population**

The population from which the sample was drawn included two groups: the same group of PLHA as well as PLC in the greater Potchefstroom urban area and rural Ganyesa in the North West Province.

- **Sampling**

Two samples were utilised during the second phase of this research.

Sample 1: PLHA

The first sample included all the PLHA as described under Phase 1.

Sample 2: PLC to PLHA

The second sample, namely PLC to PLHA, was obtained by means of snowball sampling (Strydom, 2005:203). The PLHA, as described during phase one were requested to each invite 6 suitable candidates from specific designated groups to participate, according to the specified inclusion criteria set out above (Burns & Grove, 2005:343). The designated groups included; partner, child, close family member, close friend, spiritual leader and community member.

Each PLHA selected one suitable participant from each of the six designated groups. PLHA and PLC were 120–144 in total. If they did not have a PLC from one of the designated groups they still attended the workshop with the others.

The inclusion criteria for each designated group are set out below. Take note that the first eight criteria as set out under Phase 1, applied to all the rest of the categories and will not be repeated.

- Partner
The participant had to be married to or be in a steady relationship with the particular PLHA for a period of at least six months.
- Child
The participant had to:
 - be a biological child of the PLHA
 - be at least 15 years of age or older
 - obtain consent from parent
- Close family member
The participant had to:
 - be any close family member to the PLHA, apart from a partner or child
 - be 18 years of age or older
- Close friend
The participant had to:
 - be in a friendship relationship with the PLHA for a period of at least six months
 - be someone who was not part of the biological family of the PLHA
 - be 18 years or older
- Spiritual leader
The participant had to:
 - be involved in the spiritual ministering of the PLHA
 - be a traditional or church leader, according to the particular PLHA's beliefs
 - be 18 years or older
- Community member
The participant:

- could be a person with whom they had contact on a regular basis in the community, such as a neighbour
- had to be 18 years or older

5.3.2.3 Data collection

- **Data collection method**

Data was collected during the course of the presentation of the comprehensive community-based HIV stigma reduction and wellness enhancement intervention (Yin, 2009:99). A case study protocol was designed and it was used as a guiding tool by the researcher in order to promote the reliability of the research (Yin, 2009:79-81). The case study record comprised the following: manuals and lectures of the HIV stigma reduction and wellness enhancement intervention; naïve sketches of the participants during the planned three days of the intervention (the planned questions for the participants to answer after each day attended, were posed: “*How did you experience today?*” and “*How do you feel?*”); field notes by the researchers; and project reports as well as project evaluation (Yin, 2009:42).

- **The intervention**

The comprehensive community-based HIV stigma reduction and wellness enhancement intervention was in the form of presentations and small group discussions. The intervention for PLHA and PLC to PLHA was based on the adapted version by Prof. M Greeff of the work done by Uys *et al.* (2009:1059) and was aimed at building knowledge and understanding of HIV stigma and wellness enhancement, coping with stigma, promoting interpersonal trust and familiarity through contact and sharing, as well as empowering PLHA and PLC to them through project development. The facilitators of the workshops were always a non-infected as well as an infected individual. The tenets that these workshops were built on were: increased knowledge, equalising the relationship between PLHA and PLC to them, and empowering them to handle HIV stigma and enhance wellness.

- **Workshop with PLHA**

An initial two-day workshop was presented to PLHA only, focusing on understanding HIV stigma and identifying their personal strengths. Responsible disclosure management was then addressed in order to prepare them for effective participation in the comprehensive community-based HIV stigma reduction and wellness enhancement intervention. The intervention continued in the form of a group of six workshops with PLHA and their partners, followed by children, then family, friends, spiritual leaders and lastly community members. The intervention was aimed at participation in groups and therefore thorough psychological preparation of the PLHA was necessary. PLHA were made aware of the fact that HIV status disclosure would take place during the workshops and that group work would be conducted with fellow PLHA as well as PLC.

- **Workshop with PLHA and PLC**

The initial workshop for PLHA only was followed by six workshops with PLHA as well as the six designated groups of PLC (partners, children, family members, friends, spiritual leaders, and community members). Each of the workshops aimed at providing participants with a better understanding of HIV stigma and a better understanding of the process model of HIV stigma; to maintain more effective relationships between PLHA and PLC; enhance their wellness through a process of coping; and to enhance existing skills to take the lead in the community by learning how to do a project as well as plan an HIV stigma reduction project with a designated group similar to theirs. The workshop was made up of presentations, small group discussions as well as several activities such as role plays and games to enhance understanding of topics presented in the workshop.

During the first day of the workshop the focus was on understanding HIV and how to cope with stigma. The presentation included an overview of the impact that HIV has. This was aimed at giving an idea to participants as to why it was essential to combat HIV stigma. HIV stigma was discussed in terms that were understandable to participants. The conceptual model of the HIV and AIDS stigma process as developed by Holzemer *et al.*, (2007:541) was discussed. This was done by presenting pictures of several scenarios during which HIV stigma was illustrated as can be seen in

communities. This ensured that participants' attention was captured and discussion of the pictures presented was made possible.

Types of stigma were also discussed in order for participants to recognise the categories of stigma that they may have encountered and would encounter in their community. The outcomes of stigma were then also presented in accordance with pictures of scenarios in which PLHA or PLC had been involved and/or affected by HIV stigma. The first day was ended off with a presentation on coping with HIV stigma and some coping exercises intended to make participants aware of their strengths.

The second day of the workshop was aimed at motivating PLHA to use the knowledge gained during the first day of the workshop to move into action and develop skills to be leaders in stigma reduction in the community. The focus was specifically on PLHA and issues such as responsible HIV status disclosure, how to become a voice for the community, how to create an environment of change, and how to create opportunities for experiential HIV stigma reduction interventions.

Each of the six the groups involved in the intervention needed to formulate an HIV stigma reduction and wellness enhancement project with a designated group similar to theirs in the community (e.g. partners with partners) after they had been taught in depth how to plan and execute a project. Each PLHA in this study spontaneously formed part of each of the six groups. The PLHA and their various groups needed to formulate a name, define the vision of the project, define its objectives, and define the activities that had to be conducted. There was a period of one month after the initial days for the implementation of the various projects. The facilitators did follow-up visits to all participating groups per appointment in order to support them and to monitor their progress.

The third day of the workshop took place after a period of one month after the initial two-day workshop. All participants in their designated groups had to give feedback on their executed projects. They needed to focus on the aspects covered in the project; the process followed; the team effort in taking the lead in action within the community; their experiences; and their evaluation of the project. Evaluation of the projects was done by a panel made up of all relevant invited stakeholders in the community and the involved researchers. The evaluation of the projects was based on the feedback provided by

participants. Feedback was then given to participants by the panel on their successes. A prize was awarded to the best project in the urban as well as the rural setting.

- **Role of the researcher**

The researcher made use of the research assistant (as described in Phase 1) to ensure that all participants were reminded in time of the workshops. Transport was arranged for participants who were unable to get to the venues allocated for the workshops. The research assistant paid follow-up visits to participants to ensure adherence to the intervention and to ensure active participation during community projects. The researcher acted as a co-facilitator with senior researchers at some of the workshops.

5.3.2.4 Data analysis

During the second phase of the research, in order to provide the best analytic quality possible, the researcher made use of the five data-analysis strategies for case study research as described by Yin (2009:136-160).

- **Pattern matching**

Pattern matching comprises the comparison of an empirically based pattern with a predicted one. If patterns correspond, the results can help a case study to strengthen its internal validity. In order to apply pattern matching to this research, the researcher was alert during data analysis to a possible repetition of themes by the different designated groups included in the study. Such a repetition could be an indicator of unique findings when compared with existing literature. However it was important to avoid postulating very subtle patterns so that the pattern matching focused on gross matches or mismatches whose interpretation was less likely to be challenged (Yin, 2009:141). The researcher guarded against drawing conclusions based upon insignificant pattern repetition.

- **Explanation building**

The aim of explanation building is to analyse the case study data by building an explanation about the case. To explain a phenomenon is to stipulate a presumed set of contributing links about it, or “how” or “why” something happened. The researcher,

looking into multiple cases (the PLHA and each of the designated groups involved in the research), for example constructed an explanation by means of identifying significant patterns, such as potential changes in stigma experiences. An explanation for these changes as well as the critical set of evidence that supports or challenges these changes was provided in order to enhance the validity and reliability (Yin, 2009:144).

- **Time series analysis**

During time-series analysis, the researcher was able to trace changes over time. It was important that the events over time be outlined in detail and with precision (Yin, 2009:145). The researcher made use of detailed descriptions of the intervention applicable to each of the six designated groups together with the PLHA. Sources such as initial and later descriptions of participants' feelings with regard to the workshops were for example used to trace back any significant changes.

- **Logic models**

The logic model stipulates a complex chain of events over a period of time. The events are staged in repeated "cause-effect-cause-effect" patterns, whereby a dependent variable (event) at an earlier stage becomes the independent variable (causal event) for the next stage (Yin, 2009:149). In this research, for example, the comprehensive community-based HIV stigma reduction and wellness enhancement intervention aimed at reducing HIV stigma and enhancing wellness. The *intervention*, as described under 8.2.2.3 (Data collection), included interactive activities and presentations in order to equip participants with knowledge so that they would be able to go out into their communities and apply the knowledge gained during HIV stigma reduction activities. The provision of knowledge and skills during the workshop could be endorsed as the *immediate outcome*. The result of this immediate outcome was evidence of increased understanding of HIV stigma and how to be an HIV stigma reduction leader within the community (*intermediate outcome*). Eventually, after the project planning process and the knowledge gained during the workshop had been applied, the participants demonstrated their knowledge by presenting their project as executed within their communities. They were now equipped with skills to be leaders in HIV stigma reduction (*ultimate outcome*).

- **Cross-case synthesis**

This technique specifically applies to the analysis of multiple cases, such as in the case of this study. Each individual case study is treated as a separate study. In this way, accumulated findings across a series of individual studies are grouped together and the significance discussed and conclusions drawn (Yin, 2009:156). With regard to this study, the PLHA with their several designated groups of participants' experiences of the intervention in both the urban and the rural groups and the different HIV stigma reduction projects executed by the participants in their communities were analysed and as the dynamics within each of the groups differed, the researcher compared the outcomes in each case.

5.3.3 Phase 3: A qualitative interpretive description study to explore and describe the experiences of PLHA and PLC during and after having undergone a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting

5.3.3.1 Sample

The sample for the third phase of the research was the same as described under Phase 2.

5.3.3.2 Data collection

- **Data collection method**

In-depth interviews were conducted in the third phase of the research process, as discussed under Phase 1. The following questions were asked:

- PLHA:
 - “How did you experience the workshop and project with people living close to you and others in the group?”
 - “How did you feel about telling others your HIV-positive status during the workshop and project?”

- PLC to PLHA:
 - “How did you experience the workshop and project with the PLHA and others in the group?”
 - “How did you feel about hearing the PLHA telling you and others of their HIV-positive status during the workshop and project?”

- **Field notes**

Extensive field notes were made during the workshop as well as afterwards, as was described under Phase 2 of the research (Botma *et al.*, 2010:218; Greeff, 2005:298).

- **Physical setting**

The workshops took place in an allocated hall at the university in the case of the Potchefstroom urban community’s participants, and at a guest lodge, in a conference room, in the case of the rural Ganyesa participants. The setting was chosen with privacy and comfort for all participants in mind.

- **Role of the research assistant**

The same research assistant as described under Phase 2 was utilised during this phase of the research. She was responsible for providing the details regarding the venue and transport to the venue, as well as for ensuring that all participants attended the interview sessions.

- **The role of the researcher**

The role of the researcher was very similar to the role as described under Phase 1. The researcher conducted some of the in-depth interviews during this phase of the research.

5.3.3.3 Data analysis

Data analysis was done as described under Phase 1.

6 Trustworthiness

Trustworthiness, according to Lincoln and Guba (as quoted by Krefting, 1991:215–222) and tabulated by Botma *et al.* (2010:234-235), comprises four epistemological standards, namely truth value, applicability, consistency, and neutrality. These principles were applied in this research as shown in table 1.

Table 1: Standards, strategies and applied criteria to ensure trustworthiness

| Epistemological Standards | Strategies | Application |
|---------------------------|-------------|--|
| Truth value | Credibility | <p><i>Prolonged engagement</i> Prolonged engagement was ensured by the team of researchers as several in-depth interviews were conducted, the comprehensive community-based HIV stigma reduction and wellness enhancement intervention was presented and attended, and follow-up in-depth interviews were conducted.</p> <p><i>Reflexivity of the researcher</i> Reflexivity was ensured by writing extensive field notes throughout the research process. There were also several discussions between the different researchers during the research process.</p> <p><i>Triangulation</i> Methods were triangulated as several methods of data collection were used during this research, namely in-depth interviews, naïve sketches, as well as field notes. Sources were triangulated, as several people were spoken to and information was received from several sources during the research. Investigators were triangulated as the research team was made up of a group of several researchers, some more senior researchers than others, each with their own field of interest and specialisation field. The researchers evaluated each other continuously during the research.</p> <p><i>Member checking</i> During this research a co-coder was used during the data analysis process.</p> <p><i>Peer examination and group discussions</i> The researcher was evaluated throughout the research process by experienced study leaders in the field of qualitative research. The researcher</p> |

| | | |
|---------------|-----------------|---|
| | | <p>also attended meetings with fellow researchers during the research.</p> <p><i>Interview technique</i></p> <p>In-depth training was provided to all researchers and research assistants before they conducted interviews for data collection. Testing of some interviews was done to ensure that the questions were appropriate and understandable.</p> <p><i>Authority of the researcher</i></p> <p>The researcher was a registered nurse working in the field of interest in this research, namely a primary healthcare setting serving vast numbers of PLHA. The researcher was working under a team of senior researchers and group discussions with study leaders were conducted as often as possible.</p> |
| Applicability | Transferability | <p><i>Selection of sources of samples</i></p> <p>During this research thorough consideration was given to the method of sampling in order to gather the richest data possible.</p> |
| Consistency | Dependability | <p><i>Dependability audit</i></p> <p>An audit trail of naïve sketches, field notes, project reports, transcribed interviews and intervention documentation were possible.</p> <p>Stepwise replication of the study was possible due to the thick description of the study. There was made use of an independent co-coder during data analysis.</p> |
| Neutrality | Confirmability | <p>Confirmability audit was executed by the supervisors of this study. All documents required for auditing, including raw data, field notes, and data analysis documents would be available should it be necessary. Reflexivity was ensured as under truth value.</p> |

(Adjusted from Botma *et al.*, 2010:234-235).

7 Ethical Considerations

Ethical considerations, as set out by the Democratic Nursing Organisation of South Africa (DENOSA) (1998:1-7), as well as according to Burns and Grove (2005:181-197) and Polit and Beck (2006:87-99), were taken into consideration throughout the

research. The ethical considerations that were applied in this research are summarised below:

Permission to conduct the research was obtained from the applicable authorities before commencement. This research project, being part of a larger SANPAD funded study, was approved by the Ethics Committee of the North-West University (NWU-00011-09-A1) (30/03/2009-29/03/2014), as well as by the provincial Department of Health. All participants were provided with verbal as well as written information regarding the research project and of what would be expected of them.

7.1 Informed consent

All participants were provided with detailed information regarding the research project and they were allowed time prior to starting any data collection sessions to ask questions. Each participant was requested to sign a consent form prior to their participation in the research. The nature of participation in the research was voluntary and the participants were made aware of the fact that they had the right to withdraw from the study at any time. All parents of children under the age of 18 years gave consent for them to participate in the research, while the children also had to give assent.

7.2 Beneficence

All participants were protected from unnecessary discomfort, whether physical or emotional. They were made aware of the fact that emotional support services would be available if the need should arise. Trained counsellors were available at each data collection site to intervene where necessary.

7.3 Respect for human dignity

Participants had the right to self-determination, which meant that they had the right to be fully informed regarding the nature of the study. Each participant was informed of their right to withdraw from the study at any stage of the research should they wish to do so.

7.4 The right to privacy

The researcher aimed at maintaining the human dignity of each participant throughout the research by keeping documents linking names to data locked up at all times. The only persons who had access to this information were the researchers and the co-coders. Coding was applied throughout the data analysis process and no kind of identity was linked to data. Each participant was treated with respect and they were made aware that all data would be kept anonymous, and at no stage would any personal information be made known to anyone. Data gathered during the research was kept locked away in a cabinet, accessible only to the researchers involved in this research project. Data will be kept locked away for a further five-year period after publication of the research and then destroyed.

8 Article Format

The findings of the research was presented in article format in three articles:

- Article 1: HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting
- Article 2: A comprehensive HIV stigma reduction and wellness enhancement community intervention: A case study
- Article 3: Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting

Referencing is made according to the style requested by the journal but formatting remains uniform.

9 Summary

The research overview presented a brief literature review, the paradigmatic perspective, and a thorough description of the planned research study. In the next section a detailed literature review focusing on the extent of the HIV and AIDS epidemic, understanding stigma, conceptual frameworks of HIV stigma, HIV and AIDS stigma in urban and rural

contexts, HIV disclosure as well as interventions aimed at reducing stigma relating to HIV and AIDS will be presented.

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SECTION B: LITERATURE REVIEW

LITERATURE REVIEW ON STIGMA, STIGMATISATION, DISCLOSURE AND INTERVENTIONS WITHIN THE CONTEXT OF HIV AND AIDS

1 Introduction

The research overview provided an introduction to this study, which included the problem statement, the research objectives, the paradigmatic perspective, a comprehensive layout of the planned research methodology, trustworthiness and ethical considerations. In this section the researcher wishes to provide a review of stigma as described in the literature, as well as the process thereof within the context of HIV and AIDS. HIV disclosure as a process closely related to stigma was also explored and will be discussed in terms of noteworthy literature found. Finally the researcher will present significant literature concerning existing HIV stigma reduction interventions. Bear in mind that all these processes are discussed in relation to the context of the extensive HIV and AIDS epidemic and the stigma attached to having the disease or being associated with it.

2 The Extent of the HIV and AIDS Epidemic

Since 1981, when HIV was first diagnosed in human beings, AIDS has claimed the lives of an estimated 25 million people globally. By 2007 the number of people living with HIV worldwide had increased to 33.2 million, compared to the 29 million in 2001 (UNAIDS, 2008:31). The latest HIV statistics indicate that there are currently approximately 35 million people living with HIV worldwide. More than two-thirds of these infections and deaths are from sub-Saharan Africa. More than 22 million people in Africa, and mostly in Southern and East Africa, are infected with HIV (Evian, 2011:3; UNAIDS, 2012:6). Some of the highest infection rates, an estimated 6 million, are found in Southern Africa. HIV occurrence in Africa varies between 1% (Mauritania) and more than 40%

(Botswana and Swaziland), with areas in Southern Africa (where approximately 2% of the world's population resides) exceeding 30% (Van Dyk, 2005:7). The North West Province, the province in which this study was undertaken, was rated among the top four provinces regarding HIV prevalence in South Africa (AVERT, 2011:1).

AIDS now causes more deaths and suffering in the 18–44 year age group than any other disease (Evian, 2011:3). Unlike other disasters, AIDS is taking more lives, impacting the health of more people and leaving more children and orphans homeless than any hurricane, earthquake or tsunami (Kaleeba & Ray, 2002:20; Kilbourn, 2002:10). Lorentzen and Morris (2003:1) rightfully state that: “The epidemic of HIV and AIDS is changing the history of sub-Saharan Africa. Neither words nor statistics can adequately capture the human tragedy caused by HIV and AIDS”.

In a recent study by Nattabi *et al.* (2011:203) it was found that despite an increase in the number of patients enrolled in ART (antiretroviral therapy), PLHA still experience stigmatisation. In a statement describing reports from community organisations providing prevention services with respect to HIV, AIDS and stigma in South Africa, it was noted that when African NGOs (non-governmental organisations) were asked to portray the three most important challenges to their work, 33% spontaneously described problems relating to stigma. The only other barrier that was mentioned more often by them, was problems regarding funding (Benotsch *et al.*, 2008:336).

Closely linked to this tragedy is the negative influence of HIV stigma that impacts on the lives of people living with and people affected by the disease (Holzemer & Uys, 2004:165). Carr and Nyblade (2007:17) note that stigma and discrimination can be more difficult to cope with than the medical issues associated with HIV for people living with HIV. Yet, although these findings may be significant, it is important to ponder on whether these problems, if addressed, will curb the spread of this devastating condition. We may postulate that the reduction of stigma will allow people suffering from an HIV infection to receive early intervention more freely. This may be the case. It may also allow a better quality of life for PLHA, as the reduction of stigmatisation could reduce psychological stress for these people. Nattabi *et al.* (2011:194) indicate that research that has evaluated the impact of interventions on the reduction or enhancement of stigma is limited.

3 Understanding Stigma

The term stigma as an ancient trend up to the stage of current relevance with regard to the HIV and AIDS epidemic is discussed below.

3.1 The historical development of stigma and stigmatisation

Stigmatisation has occurred since biblical times, as in the case of lepers who were forced to wear ragged clothing and to caution others with the cry “unclean!” (Bible, 2000:161). It is an ancient practice that encompasses the isolation and ill treatment of people with incurable diseases. In the health environment, stigma has been attached to, among other things, diseases such as leprosy, mental illness, tuberculosis, as well as mental and physical disabilities (Brown *et al.*, 2003:64). Sufferers of incurable diseases were held responsible for epidemics caused by these diseases, and they were isolated and treated as social outcasts (Gallo, 1991:129). We may ask ourselves why this intrinsic human behaviour occurs.

In his book “Notes on the management of spoilt identity”, Erving Goffman (1963:15), a pioneer in stigma research, noted that the ancient Greeks used the term “stigma” to refer to bodily signs that were regarded as reflecting something unusual and bad about the moral status of the person concerned. He also wrote that “by definition we believe the person with a stigma is not quite human”. This statement works to approve the discrimination and inhumane treatment of stigmatised people. Stigma is most often defined as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman, 1963:3). Stigma hence spoils the identity of a person by preventing him or her from meeting expectations for particular kinds of social interaction. Goffman emphasised that stigma is not naturally an attribute in itself, but rather in social interactions where the attribute is relevant to the participants’ expectations about what the other person should be (Herek, 1990:2).

According to several authors who wrote specifically on stigma relating to mental illness, stigmatisation involved the ill treatment of a person who was believed to be doing evil (Edgerton, 1967:20; Fink & Tasman, 1992:18; Stengler-Wenzke *et al.*, 2004:88). The person was then burnt with a hot iron on the face, to leave a mark for identification as an “evildoer”. Uys (2004:74) describes stigma as deriving from the mark branded on a

slave and is an imputation that stains or scars a person's reputation. According to Nord (1997:11), the individual carrying the mark of "shame" and "disgrace" was socially discredited. Kleinman (1988:159) stated that diseases that stamp very powerful cultural meanings into the sick person "stigmatise in the same way as the yellow Star of David sewn to the sleeve of a Nazi concentration camp victim". He further emphasised that the disfigurements or markings of a disease stigmatise "because they break cultural conventions about what is acceptable appearance and behaviour, while invoking other cultural categories – of what is ugly, feared, alien, or inhuman".

The various conceptions of what stigmatisation entails seem vague. Can we consider potentially modifiable social statuses such as being a smoker or a person who is overweight as stigmatising? Alternatively, are they simply behaviours that the majority in society disapproves of, and is this disapproval justified because there are potential benefits for the individuals who participate in these behaviours in society? (Stuber *et al.*, 2008:355). Herek (1990:1), in a master lecture delivered at the meeting of the American Association in New Orleans, compared cholera outbreaks during the 1830s with the presence of HIV in the 1990s. In both epidemics, he noted, the social meanings of a disease included stigmatisation of those who manifested its symptoms.

Stigma has thus manifested itself for many years. Christ and Weiner (1985:283) indicated almost two decades ago that because of the stigma attached to AIDS, patients fear the rejection of society, the loss of work colleagues and casual acquaintances, and the abandonment of close friends and lovers. Mann, as quoted by Barradas (2005:1), referred to stigma as the "third epidemic", with HIV being the first and the AIDS epidemic the second. He stated that it was a challenge to our consideration, our judgement and our compassion.

Pleck *et al.* (1988:44) examined what they referred to as the "AIDS phobia". They observed negative attitudes towards AIDS patients and phobia of contracting the disease among hospital staff. They ultimately found that the more contact a staff member had with AIDS patients, the more positive their attitude towards the disease became. Jones *et al.*, as quoted by Herek (1990:3), likewise described the "concealability" of stigma as the extent to which the stigmatised condition is hidden or obvious. Allegedly, more concealable conditions permit their holder to avoid stigma with

greater ease. With regard to the term “AIDS phobia” or “AIDS hysteria”, Herek (1990:7) is of the opinion that labels such as these inappropriately individualise and pathologise this social phenomenon. Instead, he believes that individuals’ hostility toward people with AIDS can best be understood through psychological and sociological perspectives on stigma, prejudice, and attitudes.

In modern society, the stigmatised individual is still isolated and labelled as being different from the rest. Stigma is increasingly seen less as concrete traits or features of the individual, and more as a process shaped by structural and cultural forces (Scambler *et al.*, 2006:269). Stigma represents a construction or deviation from some ideal or expectation and ultimately creates outsiders and social boundaries between the normal and the stigmatised, with the stigmatised condemned to “eternal stigmatization in their own eyes as well as those of society” (Ablon, 1981:8).

AIDS is perceived as a disease of “others” – of people living on the margins of society, whose lifestyles go against social norms and are often considered “wrong” or “sinful” (Mahendra *et al.*, 2007:616). Goldin (1994:1360) in this regard states that this “side-lining” or marginalisation of oneself from these groups poses a serious health threat, as it allows individuals to dissociate themselves from the disease by disowning membership in identified risk groups. When socially distanced from the threat in this way, people are less likely to change their behaviour, for instance by adopting safer sex practices or adhering to medication regimens. It is now recognised widely that HIV and AIDS are not only a concern of biological and medical importance, but also as a social phenomenon (Jean-Baptiste, 2008:1).

3.2 Defining stigma

When stigma is overtly defined it is often in terms of Goffman’s (1963:3) portrayal of stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one”. According to Rahm *et al.* (2006:106), stigmatisation is characterised by an activation of mental wounds that create a feeling of being “singled out as different” or a feeling of being exposed in a negative way, of not being understood and respected. Herek *et al.* (1998:36) used the term “AIDS-related stigma” to refer to prejudice, discounting, discrediting, and discrimination that are directed at people perceived as having HIV or AIDS, and at

individuals, groups and communities with which they are associated. Ignorance about the transmission of HIV, fear of people living with HIV, and lack of access to and understanding of treatment is the very core of HIV stigma (Wingwood *et al.*, 2008:237).

According to Stafford-Clark (1986:80), stigma is a characteristic of a person that opposes the norm of a social unit. In society, stigma is viewed from the perspective of the stigmatising person rather than the stigmatised (Herek *et al.*, 2002:372; Manyedi, 2007:57). Parker and Aggleton (2003:14) describe stigma in the same way when they note that stigma is a negative attribute that is mapped onto people, who in turn, by virtue of their differences, are understood to be negatively valued in society. Goffman (1963:15) explains this notion when he states that in society, a person accepts some behaviour and traits as “normal”, and those that negatively differ from what one considers “normal”, are spontaneously labelled “abnormal”.

Dijker and Koomen (2006:296) describe stigmatisation as some response or other to a wide variety of features and behaviours of others that the stigmatising person may perceive as being undesirable or deviant. Examples are a harelip, illness, lack of intelligence, or some threatening feature of a racial minority. One usually adopts some behaviour and attributes as normal in society, and those that differ from what one considers “normal” are regarded as “abnormal”. The AIDS threat was originally viewed as being the result of deviancy, and was a deserving punishment for promiscuity. There is a sense in some groups that HIV is the result of sin, and those who participate in activities such as homosexuality and drug abuse have nobody else but themselves to blame for contracting the disease (Brandt, 1987:202).

Crocker and Major (1989:609) describe stigmatised individuals as members of social groups “about which others hold negative attitudes, stereotypes, and beliefs, or which, on average, receive disproportionately poor interpersonal and/or economic outcomes relative to members of the society at large due to discrimination against members of the social category”. The definition of stigma by Weiss and Ramakrishna (2001:5) also refers to it as being a social process characterised by exclusion, rejection, blame or devaluation. Herek (1990:7) uses the term stigma to refer to “all unfavourable attitudes, beliefs, behaviours, and policies directed at persons perceived to be infected with HIV,

whether or not they actually are infected and regardless of whether or not they manifest symptoms of AIDS”.

Goffman (1963:152) in a way defends those who are stigmatised as offending against norms of identity or being when he notes: “it is a question of an individual’s condition, not his will; it is a question of conformance, not compliance”. People to whom a stigma is attributed are therefore imperfect beings, possessed of reputed defects that are beyond their capability to correct (Scambler, 2006:293). Deviant relationships, however, as the logic of blameworthiness implies, bear proof of an imputed moral deficit. In this case people are said to be morally responsible for their defects: this is implicit in the inflexible castigation of “guilty” (for instance those who practice unsafe sex) in contrast to “innocent” sufferers from HIV or AIDS (for example those infected through a blood transfusion) (Brandt, 1987:202).

In essence, the stigmatised are a category of people who are looked down upon by broader society, and who are devalued, shunned, or otherwise lessened in their life chances and in access to the civilising benefit of free and uninterrupted social contact (Alonzo & Reynolds, 1995:304). Alonzo and Reynolds suggest that stigma is not simply a characteristic, but signifies a language of relationships, as labelling one person as deviant reaffirms the normality of the person responsible for the process of labelling.

Alonzo and Reynolds (1995:304) refer to stigma as a “powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons”. This definition originates from Goffman’s classic definition of stigma in 1963, and because it refers to both the processes of the community stigmatising and the infected persons’ self-stigmatisation, it is the definition of choice for the researcher in this study.

3.3 Stigma and discrimination

Closely linked to stigma is the aspect of discrimination. The latter refers to behaviour which leads to unfair treatment and the consequence of the negative attitude that may be damaging to the PLHA (Campbell *et al.*, 2007:404; Siyam’kela, 2003:6). Discrimination is described by Jean-Baptiste (2008:2) as the active and passive denial of services, as well as breaches of confidentiality, segregation and isolation, and

selective use of universal precautions in the clinical context. Carr and Nyblade (2007:2) define it as actions or omissions that harm or deny services or entitlements to stigmatised individuals. Skinner and Mfecane (2004:158) depict discrimination as a process arising from any point of difference that can be consistently labelled, for example racial differences or any other factors that set up the person as different from the perceived norm.

Discrimination in the context of HIV may spring from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV and AIDS can or cannot be transmitted. Because the HIV pandemic emerged so suddenly and progressed so quickly, in many countries discrimination could result from people's belief that not enough time remains to weigh carefully the strengths and weaknesses of various alternative solutions to an AIDS-related problem (Herek & Glunt, 1988:888).

Authors differ with regard to whether discrimination follows upon the act of stigmatisation or not. Some are of the opinion that discrimination is always the implication of stigmatisation (Carr & Nyblade, 2007:2; Skinner & Mfecane, 2004:160). Discrimination is normally uttered by force, from avoidance to life threats, lynching and death (Monjok *et al.*, 2009:23). Mawar *et al.* (2005:472) refer to discrimination as severe negative public reactions, ranging from banning entry of HIV-infected individuals to isolating an individual in the family, deserting a pregnant wife on finding out her HIV status in the hospital, or removing a person from his job, or even denying a child access to school. UNAIDS (2003:34) refers to HIV-related stigma and discrimination as "a process of devaluation of people either living with or associated with HIV and AIDS".

UNAIDS (2003:34) indicate that discrimination follows stigma and defines it as the unfair and unjust treatment of an individual on the basis of their real or perceived HIV status. Some authors argue that it is important to distinguish between stigma and discrimination, while others see it as a blend of affective, cognitive and behavioural responses, with the primacy of each factor resulting from variable interactions between the natures of the stigma, the context in which it is encountered and individual differences amongst the interactants (Campbell & Deacon, 2006:414).

According to Campbell *et al.* (2005:2), stigmatisation may result in negative effects without involving discriminatory actions. Discrimination constitutes acts and omissions in

which the content of the stigma is applied either at an individual, a social or a community level. It may arise from any point of difference that can be consistently labelled, for example physical deformity or disfigurement, racial differences or any other factors that set up the person as different from the perceived norm (Skinner & Mfecane, 2004:158).

Bunting (1996:67) describes discrimination as “The actions or treatment based on the stigma and directed toward the stigmatised”. Discrimination is also described as “opportunities denied to people living with HIV or AIDS; the denial of proper medical care or access to medical aid schemes; service providers denying services to people living with HIV or AIDS” (Bunting, 1996:67). It is in essence the unjust distinction in the treatment of different categories of people, especially on the grounds of race, sex, or age (Siyam'kela, 2003:6). Campbell *et al.* (2007:404) prefer to use an inclusive definition, describing stigma as any negative thoughts, feelings or actions towards people infected with HIV or living with AIDS. They believe that irrespective of whether they are at the receiving end of explicit acts of discrimination, people know they are degraded through their more general awareness of the negative social representations of their stigmatised characteristics.

Horizons (1999:1) states that discrimination can often be more easily identified because it frequently includes public restrictions and punishing actions, and that is why some authors prefer to define “stigma” and “discrimination” separately. Ultimately, however, the concepts of stigma and discrimination are closely linked and they are frequently linked together. According to McIntyre (2004:2), countries such as the United States of America even had discriminatory policies where they prohibit HIV-positive individuals from other countries from entering the United States, and this is seen as the most blatant exhibition of discrimination against people living with HIV or AIDS. From the above the assumption can be made that stigma and discrimination against PLHA run concurrently. Stigmatisation is usually the precursor to discrimination against PLHA.

3.4 Conceptual frameworks for HIV stigma

Several authors attempted to conceptualise HIV stigma. Conceptual studies have an important role to play in ensuring that existing knowledge is constantly reviewed. They allow for new vision and a new role for theory. They must be inclusive of and move

beyond the framework of the psychological dimensions of HIV and HIV-related stigma. They should further aim at examining the social, cultural, political and economic determinants and consequences of stigmatisation and discrimination (Parker & Aggleton, 2003:20). Various conceptual studies regarding HIV and AIDS stigma were also found in the literature and will be discussed and compared.

3.4.1 Illness, stigma and AIDS (Herek,1990)

It was stated in a study on HIV-related stigma and knowledge in the United States between 1991 and 1999 that people affected by AIDS and those who were close to them had been highly stigmatised worldwide. This stigmatisation interfered with the responses of society to this pandemic, especially with regard to being cared for by friends or family members, their employment as well as their healthcare.

Herek (1990:3) described that there were five areas to be analysed in order to be able to understand any specific illustrations of HIV stigma. First of all it was essential to understand the characteristic or condition that provided the basis for stigmatisation. He explained that in a disease, this implied understanding its aetiology, symptoms, and course. This process involved a course of social interactions among physicians, epidemiologists, patients and their families (Herek *et al.*, 2002:372).

- (a) The origin of the disease is identified. As knowledge about the illness becomes more common, more complex systems of causes are defined. Responsibility for the disease is assigned and the victim is identified as guilty or innocent.
- (b) In the second place it is important to also examine the processes through which a particular culture attaches stigma to the condition. Both HIV and AIDS are widely viewed as incurable and as posing a risk to others through transmission.
- (c) In the third place, the formation, expression and maintenance of attitudes towards the stigmatised by those who are socially defined as “normal” should be analysed.
- (d) In the fourth place one must analyse the subjective experience of having the stigma: How it is interpreted and understood.

- (e) Lastly, Herek (1990:3) identifies the interpersonal level. One should analyse the interaction processes through which stigmatised individuals are identified, as well as through which the non-stigmatised and the stigmatised negotiate their particular roles in a social interaction. Herek (1990:13) found that public responses to AIDS seemed to be originating from two psychological dimensions, namely “coercion/compassion” and “pragmatism/moralism”. These two dimensions of AIDS-related attitudes were not highly concurrent, signifying that an individual’s position on one dimension did not predict his or her position on the other.

3.4.2 The Explanatory Model Interview Catalogue (EMIC) contribution to cross-cultural research methods from a study of leprosy and mental health (Weiss et al., 1992)

A conceptual model proposed by Weiss *et al.* (1992:820) recognises an insider’s perspective (“emic”) and an outsider’s perspective (“etic”) of the consequences of any illness studied. Originally applied to leprosy, this conceptual view claims to study the relationship between culturally defined experiences (the “emic” perspective) and professionally defined outcomes (the “etic” perspective) relating to the coping strategy of denial, emotional sequel, and compliance with treatment. The “etic” perspective refers to the stigmatising and discriminatory actions and/or responses of others towards the stigmatised (PLHA in this instance). In contrast, the “emic” perspective refers to the possible outcomes of the stigmatising behaviour, as the victims of stigmatisation differ from one another (such as personality and genetic make-up). In the study by Weiss *et al.* (1992:820) of stigma relating to leprosy, significant outcomes included emotional distress and attendance of a particular clinic.

3.4.3 Siyam’kela project (2003)

In 2003, the Siyam’kela project, a joint project of the USAID-funded POLICY project, the Centre for the Study of AIDS at the University of Pretoria and the Chief Directorate: HIV and AIDS and TB in the national Department of Health, aimed at exploring and understanding HIV-related stigma. The project also aimed at developing “indicators of stigma” that could be used in various settings and that would aid in measuring the impact of stigma on PLHA (Siyam’kela, 2003:2). The overall definition of stigma as used

within the project was “a mark of disgrace associated with a particular circumstance, quality or person” (Siyam’kela, 2003:6).

Data obtained during the project resulted in two main categories of HIV/AIDS-related stigma being identified, namely external or enacted stigma and internal or felt stigma. External stigma refers to the experiences of people living with HIV or AIDS of being treated unfairly and differently from others (e.g. avoidance, moral judgement, stigma by association). The project report describes various forms of abuse experienced by PLHA in South Africa. Types of abuse range from name-calling in the community and being called “Satan’s people” by church members, to physical abuse against women by their partners. PLHA are largely cursed by society (Siyam’kela, 2003:6).

Internal or felt stigma is described by Siyam’kela (2003:6) as the way a person feels about themselves, e.g. shame, fear of rejection and discrimination. Some examples of internal stigma are self-exclusion from services or opportunities, low self-esteem, as well as fear of disclosure due to the uncertainty of the consequences.

3.4.4 Stigma and its public health implications (Link & Phelan, 2006)

Link and Phelan’s (2006:367) approach to stigma includes the co-occurrence of labelling, stereotyping, categorical in-group/out-group separation, status loss and discrimination, and emphasising the exercise of power as an essential facet. In their conceptualisation of stigma, they believe, the above aspects should be convergent for stigma to exist. The term stigma is therefore applied when these elements as discussed below co-occur in a power situation (Link & Phelan, 2002:3).

3.4.4.1 Distinguishing and labelling differences

The significance of the differentness of individuals or their circumstances plays a role in determining the call for stigmatising behaviour. It seems as though society is the main determinant of the “normality” and “abnormality” of certain attributes (Link & Phelan, 2006:528).

3.4.4.2 Linking human differences with negative attributes

The second component of stigma involves the process of stereotyping in which the labelled person is linked to some undesirable characteristics. HIV and AIDS are often seen as consequences of promiscuous and reckless behaviour and the stigmatised thus deserving stigmatisation (Link & Phelan, 2006:528).

3.4.4.3 Categorical in-group/out-group separation

A simple illustration of the occurrence of the act of separation in the stigma process is the way a person with certain conditions is referred to or identified. A person has cancer or hypertension, whereas a person suffering from schizophrenia is labelled as “a schizophrenic”. The stigmatiser applies a label to the person involved and the negative attributes that justify that labelling lead to a separation between normal and abnormal individuals (“us” and “them”) (Link & Phelan, 2002:5).

3.4.4.4 Status loss and discrimination

Most definitions of stigma do not include the component of status loss. Link and Phelan (2002:5) are of the opinion that this component is crucial in defining the stigma process.

3.4.4.5 The dependence of stigma on power

The exercise of power is described by Link and Phelan as an essential component in the stigma process. They describe circumstances in which individuals that are viewed as owning power in society, such as physicians, easily capture the idea of stigmatisation and then execute the idea by stigmatising behaviour (Link & Phelan, 2002:5; 2006:528).

3.4.5 HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action (Parker & Aggleton, 2003)

Parker and Aggleton (2003:16) maintain that stigmatisation and discrimination must be conceptualised as social processes that can only be understood in relation to broader notions of power and domination. They view stigma as playing a key role in producing relations of power and control. It is in effect important to recognise that stigma arises and stigmatisation takes shape within specific contexts of culture and power. The construction of stigma involves the marking of significant differences between different

categories of people, and through such marking, their insertion into systems or structures of power.

They further state that stigma and stigmatisation function at the point of intersection between culture, power and difference. Stigmatisation is therefore not simply an isolated phenomenon or expression of individual attitudes or of cultural values, but is central to the constitution of social order. The emphasis on stigmatisation as a process linked to competition for power gives new emphasis to the broader social, cultural, political and economic forces that structure stigma, stigmatisation and discrimination as social processes naturally linked to the production of social inequalities (Parker & Aggleton, 2003:17).

3.4.6 Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory (Alonzo & Reynolds, 1995)

Alonzo and Reynolds (1995:303) attempted to conceptualise how the stages of HIV and AIDS influenced stigma as well as the social processes of experiencing stigma. They refer to it as the “disease trajectory” and the “social trajectory”. The authors describe stigma as a social construction that radically affects the life experience of PLHA and their partners, family and friends. They view stigma as changing and emerging over the course of a single illness trajectory. HIV and AIDS are dynamic conditions and the manifestation of the conditions differs according to the disease stage. Alonzo and Reynolds (1995:303) are of opinion that the progression of the disease brings along several changes in the manner in which the individual and others must address issues of stigma construction and management.

As physiological parameters change and symptoms begin to emerge, there is an apprehension of progression to the later phases in the disease trajectory. There need not be physical signs and symptoms for persons to be victims of the stigmatisation, but even the mere initiation of anti-retroviral therapy can be a causative factor (Alonzo & Reynolds, 1995:310). As the disease progresses a so-called downward decline is experienced during which the individual becomes aware of the isolation by and withdrawal of others who were, in the early stages of the disease, willing to freely interact with and support the individual (Alonzo & Reynolds, 1995:311). During the late stage of HIV infection, the stigma associated with HIV forces individuals to resist

internalised blame. They experience a sense of personal responsibility for their own increasingly fateful circumstances and society offers few resources to deal with these feelings. Hence, stigma is enacted as others shun the person with AIDS, and/or avoid social interaction with him or her (Alonzo & Reynolds, 1995:311).

Stigma is seen by Alonzo and Reynolds (1995:12) as being dynamic. It is often expansive, pervading all corners of one's identity and life.

3.4.7 Lessons from a 10-year global programme against stigma and discrimination because of an illness (Sartorius, 2006)

Sartorius (2006:383–388) proposed a model for stigma that was used in a major programme against stigma towards people with schizophrenia. It was carried out in some 18 countries over a ten-year period and can be applied with slight modifications to the presentations of the vicious cycle of stigmatisation of families of people with mental illness. The model was later adopted for application in a range of other stigmatised conditions.

The model implies that a marker (a visible abnormality or a label) that allows the identification of a person can be loaded with negative contents by means such as association with previous life experiences. Once a marker is loaded in this way, it becomes a stigma. Stigmatisation may lead to negative discrimination. The anticipated stress might worsen the condition of the marked person, and thus intensify the marker (Sartorius, 2006:383).

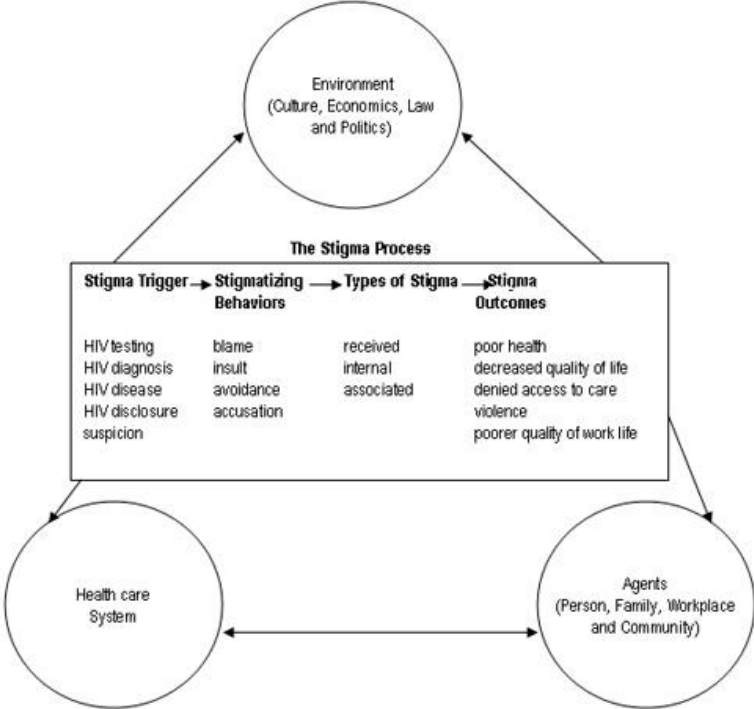
This model also implies that an intervention at any point might stop the vicious cycle of stigmatisation. Therefore, if it proves impractical, for example, to remove stigma, it is often possible to focus on removing discrimination by legal and other means. Sartorius (2006:383) concluded that the impact of stigma on affected individuals should be pursued further, as should the effect that health-related stigma has on health-service utilisation and human rights.

3.4.8 A conceptual model of HIV/AIDS stigma from five African countries (Holzemer et al., 2007)

Most research on HIV stigma lacks meticulous scientific analysis, relying instead merely on testimonials from study participants. The literature lacks studies that literally measure stigma and recognise how stigma changes over time or the impact thereof on the quality of life of people living with HIV or AIDS. The literature still does not distinguish sufficiently between experiences and the causes and outcomes of stigma (Holzemer *et al.*, 2007:541; Parker & Aggleton, 2003:13). No studies provide an understanding of the meaning and effect of stigma as an entity (Greeff *et al.*, 2008b:80). In addition, few studies have focused on Africa, a continent where stigma continues to be a major challenge to addressing the HIV and AIDS epidemic (FPD & UCSF Nursing, 2011:196).

The work by Holzemer *et al.* (2007:541-551) attempted to conceptualise more than just the types of stigma. They aimed at gaining an in-depth understanding of the process of HIV stigmatisation and developed an evidence-based conceptual model of the HIV and AIDS stigma process from five African countries. They describe stigma as being an extremely dynamic process (Foundation for professional development [FPD] & University of California San Francisco [UCSF] Nursing, 2011:196). Two main components of stigma were identified after the analysis of data captured by means of focus group interviews in five countries in Africa. The first component was identified as contextual factors that have an influence on stigma, and the second as the process of stigma itself (Holzemer *et al.*, 2007:545). This model formed the theoretical framework for this study and an impression of the model is provided in order to gain understanding of the variables that influence HIV stigma. Literature supporting or contradicting the various aspects is included under the discussion of each of the components in order to supplement the overview.

Figure 1: The stigma process



(Holzemer et al., 2007).

3.4.8.1 The context of HIV stigma

According to Holzemer *et al.* (2007:541-551) the stigma process takes place within a particular context. Three factors play a role, namely the environment, the healthcare system and specific agents.

- **The environment**

The environmental factors identified by Holzemer *et al.* (2007:545) consist of cultural, economic, political, legal and policy environments. In the sense of power relationships, politics may influence the choice of approach taken towards people living with HIV or AIDS. The authors are of the opinion that there may be secondary achievement for the people involved in stigmatisation. Perceived power may be increased by the mere process of stigmatisation. The authors emphasise that the legal and policy environments are mostly accountable to culture, politics and economics and practically always influence the response to an illness.

Other authors supporting the importance of the environment as context are presented. Mann, as quoted by Rankin *et al.* (2005:1), was described as a physician who was devoted to treating individuals as a whole, including stigma received from or imposed by societies where the oppression eradicates the opportunities of others. He appreciated the healing potential of social justice with respect to human rights. He knew that a civilisation in which various injustices occur routinely is itself not well, and he also knew that respect for human rights made less room for stigma.

Parker and Aggleton (2003:13) approach stigma relating to HIV post-individualistically and describe its functioning “at the point of intersection between culture, power and difference”. They are of the opinion that relationships of stigma and stigmatisation are crucial for the creation of social order while legitimating “ranking” by convincing the dominated to accept existing hierarchies through processes of hegemony.

In a study by Stephenson (2009:407) it was found that the community environment had a definite influence on shaping HIV-related stigma among young people in three different African countries. In various settings, young people living in communities in which a higher percentage of people were employed had considerably more supportive attitudes towards PLHA. Exposure to new ways of thinking, new sources of information and greater social networking automatically result in the attrition of less supportive attitudes toward people with HIV (Stephenson, 2009:408).

The executive director of UNAIDS, Peter Piot, noted that the major causes of personal suffering since the beginning of the AIDS epidemic were stigma, discrimination and gender inequality. Yet, there has never been serious political and programmatic commitment to doing anything about it. He stated that all these efforts had been relegated to the bottom of AIDS programmes, together with human rights, and often without any funding attached to it (Carr & Nyblade, 2007:2).

In India it was proven that legal groups such as the “Lawyers’ Collective” have successfully protected the rights of PLHA. It was noted that policy advocacy and programmes promoting human rights in general can play an important part in broad-based stigma reduction strategies (Carr & Nyblade, 2007:11). With regard to culture, in many African villages people’s lives are intimately intertwined with those of others. Most of the people have always lived closely together and there is a lack of privacy and few

secrets are kept. Inside families, caregivers may fear contracting the virus by means of casual contact and outside the house they may fear gossip in the village. This is due to a lack of education and understanding of HIV and its modes of transmission (Rankin *et al.*, 2005:2).

Campbell and Deacon (2006:414) describe the contexts of stigma as the material, political, symbolic and institutional contexts. They believe that at the material level, poverty and deprivation are forceful drivers of stigmatisation. The psychologically disempowering effect of poverty significantly reduces the probability of stigmatised individuals taking full advantage of any awareness campaigns meant for the public in general or potentially lifesaving HIV and AIDS treatment in South Africa (Campbell & Deacon, 2006:413).

In terms of the political context of stigma, these two authors describe the term “layered stigma” in the sense that stigma may follow existing social fault lines, such as differentiating between rich and poor, men and women (Campbell & Deacon, 2006:413). They warn against crude associations between stigma and existing power differentials, however, meaning that stigma may sometimes affect members of high status groups as well. As such, it is not always a reproduction of existing power relations, but also sometimes a new source of power inequalities. Layers of stigma preserve social structures in the ongoing establishment of insiders and outsiders groups. Institutional contexts of stigma facilitate stigma, according to Campbell and Deacon (2006:413). Examples mentioned by the authors mainly focus on the public health system, for instance posters that may elicit messages that offend and consequently reduce the likelihood of complying or changing (such as smoking being a disgusting habit).

The term “symbolic” is described as the framework of understanding of people’s life experiences (Campbell & Deacon, 2006:414). Several metaphors are used to express stigma (Uys *et al.*, 2005:15). Explorations of the symbolic to the verbal realm alone should be avoided. Visser *et al.* (2009:204) are of opinion that in South Africa, a more committed political reaction to HIV, the active expansion of systems of care and treatment and media coverage of the various community actions of caring for PLHA could probably change the generalised perception that communities are stigmatising towards HIV.

Horizons (2002:8) states that policy and legal contexts of HIV and AIDS stigma and discrimination in society are generally manifested in the form of laws, policies, and administrative procedures. These discriminatory acts are justified as a necessity to protect the general population. A significant example entails prior limitations on travelling outside the country and migration (Horizons, 2002:5).

Employment and the workplace is another aspect of context identified by Horizons (2002:6) as an important context of HIV and AIDS stigma in several developed and developing countries. Discriminatory practices such as pre-employment screening, denial of people who are HIV positive, the termination of employment of PLHA and stigmatisation towards employees who disclose their HIV status as being positive have been identified (Horizons, 2002:2).

Forsyth *et al.* (2008:79) performed a study in a South African township community concerning the decision of postponing the rollout of ARVs by the former president, Thabo Mbeki, whose views had real-time effects and consequences for AIDS policy-making in South Africa, and which finally postponed the implementation of the ARV rollout programme until 2004. The government was consequently criticised in the media for lacking the political leadership to put AIDS at the forefront of the public agenda. Mbeki's decision reinforced HIV and AIDS stigmatisation. The impact of the ARV rollout programme on levels of AIDS-related stigma was investigated in the study by Forsyth *et al.* (2008:79) and it was found that there was a positive correlation between the endorsement of controversial political AIDS views and AIDS-related stigma. Hence, individuals who demonstrated a higher level of agreement with controversial political views were more prone to demonstrate a higher level of stigma than those who disagreed. It indicates some degree of uniformity between the political perceptions people have about AIDS and the response of the government to the epidemic (Forsyth *et al.*, 2008:81).

The work done by the Siyam'kela (2003) project attempted to provide input into national strategy development by the Chief Directorate: HIV and AIDS and TB, national Department of Health. The project indicates that, ideally, stigma mitigation should be related to a national strategy, as it brings together all the key elements involved in addressing stigma and translates this into action.

The protection of the rights, enforcing laws and the implementation of policies are crucial resources for survival in society of PLHA (Siyam'kela, 2003:14). The adoption of a human rights approach assists people vulnerable to the infection and deprived of access to the necessary information and services to protect themselves. There are several examples of international agreements that focus specifically on HIV and AIDS care, such as HIV and AIDS and Human Rights adopted in 1996 by UNAIDS and the UN Office of the High Commissioner for Human Rights (OHCHR), the Tunis Declaration on AIDS and the Child in Africa, which declares a commitment to elaborate a national policy framework to guide and support proper responses to the needs of affected children (Siyam'kela, 2003:15).

The South African government's response to HIV and AIDS and human rights was for the first time seen in 1992 when the National AIDS Coordinating Committee of South Africa (NACOSA) was developed. This policy had no effect as it was not implemented at all. In 2002 the strategic plan was improved and focused on prevention, treatment and support, research, as well as legal and human rights. On the basis of the strategic plan, a Joint Health and Treasury Task Team (JHTTT) was developed by the government, aimed at the examination of issues relating to financing and the improvement of responses to HIV and AIDS, such as care and support. The rollout of ART was a major breakthrough in HIV and AIDS mitigation in the country (Siyam'kela, 2003:16). PLHA are protected by all laws, although there are few that are specifically related to HIV and AIDS.

The Labour Relations Act and the Employment Equity Act do stipulate that PLHA are not to be discriminated against on the grounds of their HIV status. The Promotion of Equality and Prevention of Unfair Discrimination Act (4 of 2000) in addition lists reasons for non-discrimination. The Equality Clause of the Constitution lists 17 grounds for non-discrimination, in which HIV and AIDS are not included, but they have been incorporated into the definition of disability (Siyam'kela, 2003:22). Various institutions deal with human rights violations in South Africa, for example the South African Human Rights Commission (SAHRC), the equality courts, the Public Protector, the Commission for Gender Equality (CGE), the Independent Complaints Commission (ICD), the Commission for Conciliation, Mediation and Arbitration (CCMA), the Legal Aid Board,

legal aid clinics as well as nongovernmental organisations, community-based organisations and paralegals (Siyam’kela, 2003:24).

Cultural or traditional beliefs about HIV and AIDS can also contribute to stigma, and in some cases HIV/AIDS is attributed to witchcraft, spirits and supernatural forces (Visser *et al.*, 2009:199). Nohava (1997:5–6) for instance noted that in exceedingly conservative religious groups, there is even the belief that AIDS is the form that God has chosen to punish deviant behaviour. According to Shilts (1988:347), a religious leader of the “Moral Majority”, Jerry Fallwell, once said: “When you violate moral, health, and hygiene laws, you reap the whirlwind. You cannot shake your fist in God’s face and get by with it.”

- **The healthcare system**

According to Holzemer *et al.* (2007:546) the healthcare system includes settings where healthcare is rendered, such as hospitals and the people working in them, for instance clinicians and nurses. Healthcare workers are perceived as being a major source of stigmatisation. In a study performed in five African countries, Dlamini *et al.* (2007:396) mention that healthcare workers are not universally accepting of their HIV-positive patients. The authors describe them as negligent of their supposed professional ethics.

Stigma has been proven to be prevalent in the healthcare context (Uys *et al.*, 2009:1059; Wu *et al.*, 2008:513; Mahendra *et al.*, 2007:616). Even though the healthcare system can be viewed as a site for stigma as well as an influencing factor, Holzemer *et al.* (2007:546) gave it independent status in the model due to the importance thereof in the healthcare context. It is also a potential area for stigma reduction interventions.

The abovementioned stream of thought is supported by other authors. Jean-Baptiste (2008:21) carried out a study in Rwanda with the aim of quantifying stigma among healthcare providers toward patients, and the evaluation of the relationship between stigma, fears and perceived risks, and discrimination against PLHA among healthcare providers in healthcare settings. Results of the study indicated that there were negative attitudes and beliefs toward PLHA. Reasonably high levels of fear and perceived risks of HIV transmission were expressed. Results indicated both over-estimation and under-

estimation of risk, stressing the need to further educate healthcare providers on precautionary measures in the clinical setting (Jean-Baptiste, 2008:23). The author suggested that interventions for HIV stigma reduction in the healthcare setting should focus on the normalisation of HIV risk, and the establishment of a safe working environment.

Data obtained during a study done in India, focusing on HIV stigma in the healthcare setting, revealed important dimensions of stigma and discrimination specific to the healthcare context (Mahendra *et al.*, 2007:623). Four types of discriminatory acts were identified, namely: HIV testing without consent; disclosing test results to others without consent from the particular patient; labelling of PLHA's belongings or files and unnecessary use of precautions to prevent transmission (Mahendra *et al.*, 2007:620). Like in the case of the study by Jean-Baptiste (2008:1-32), the findings highlighted that stigmatising and discriminatory attitudes by healthcare providers in healthcare settings towards PLHA were a challenge.

An outcome of this particular study was a multi-level intervention that included participatory self-assessment, sensitisation training, development of posters reinforcing appropriate infection control measures, as well as policy reform (Mahendra *et al.*, 2007:625). Busza (1999:12) states that the sensitivity needed from health providers toward PLHA remains critical for the effective delivery of medical services. PLHA often feel unwelcome and disrespected. She mentions an area in the Philippines where HIV was uncommon and where healthcare workers consequently reacted with heightened experiences of fear of treating such patients.

A study by Deetlefs (1998:50), which was aimed at investigating attitudes of nurses towards patients with HIV in their care, concluded that their attitudes can be described as negative mainly due to a lack of knowledge or a lack of the internalisation thereof. It was also found that nurses every so often entertained a biased view of their own risk of contracting HIV, considering risk only from occupational exposure. In accordance with literature already mentioned, the nurse viewed the PLHA as being dangerous in the sense of carrying a life-threatening disease that can potentially be contracted through the performance of nursing care activities (Deetlefs, 1998:63).

In addition, Phetlhu (2005:102) found that stigmatisation and discrimination by health workers in the context of the co-occurrence of HIV and TB posed an unambiguous problem in society and had damaging effects for the stigmatised individual. In a study in Nigeria looking into the discriminatory attitudes of health workers against PLHA, Letamo (2005:715) found that some healthcare professionals (9%) discriminated against and stigmatised PLHA. The study concluded that a noteworthy number of healthcare professionals took part in discriminatory actions towards PLHA and hence were guilty of unethical behaviour.

In a comparative study on understanding health professionals' attitudes toward patients with AIDS and patients with Hepatitis B virus (HBV), Li *et al.* (2006:181) found that HIV-related stigma may stem from specific fears directly relating to disease and death. AIDS patients were believed to be more responsible and deserving of illness compared to patients with HBV. Much less enthusiasm with regard to having casual contact with patients with AIDS was shown than in the case of HBV patients (Li *et al.*, 2006:181).

- **Agents of stigma**

Holzemer *et al.* (2007:546) mention numerous origins or perpetrators, referred to by the authors as agents of stigma. Agents of stigma as recognised from the study data comprise the person who may stigmatise him- or herself, family members, work colleagues and community members of PLHA. People associated with PLHA are often stigmatised, and these people themselves stigmatise others in the community (Greeff, 2011).

Stigmatisation by one's family members, at the very time one most needs their support, is often cited as the most harmful and destructive form of stigma and the form that has the most negative effects on the HIV-prevention struggle (Stigma and AIDS in Africa, 2001:1). In the healthcare context, healthcare workers, as mentioned above, are often the source of stigma from the perspective of many PLHA (Holzemer & Uys, 2004:170). According to Stephenson (2009:408), there is some evidence that young people who lived in communities in which the older people had less supportive attitudes toward PLHA were less prone to have supportive attitudes. The less supportive attitudes towards PLHA held by both young and old individuals may be due to the exposure to

the same environment, for example lack of education. Hence, any prejudiced attitudes among older individuals will have an influence on HIV-related stigma among young people (Stephenson, 2009:408).

Several sources or agents of stigma were identified by Gaudine *et al.* (2010:41) and are described as anger and rejection from healthcare professionals, employers and sometimes family members. The authors noted that even though the diagnosis of HIV within the family was kept secret, the family said that neighbours gossiped about their family, sometimes aware that their family could hear them say things such as people should stay away from that particular family.

According to Skinner and Mfecane (2004:160), children rendered defenceless or orphaned by AIDS are prone to experiencing stigma and discrimination. They face verbal and physical abuse at schools and from community members. Benotsch *et al.*, (2008:342) found that directors of community organisations in South Africa reported sustained stigmatisation of HIV-positive persons by the general population, religious organisations, and family members of HIV-infected persons.

3.4.8.2 The stigma process

According to Holzemer *et al.* (2007:547), the stigma process occurs within any of the contexts as outlined above. It is anticipated to comprise four elements: Triggers of stigma, stigmatising behaviour, types of stigma and outcomes of stigma

- **Triggers of stigma**

Holzemer *et al.* (2007:547) described a trigger of stigma as any action that permits people to label themselves or others as being “HIV positive”. Triggers of stigma are not necessarily based on facts. The suspicion of an HIV-positive diagnosis may also be a trigger of stigma. HIV testing and the resultant positive diagnosis of HIV, physical signs of AIDS, disclosure of one’s HIV positive status and gossip are stated stigma triggers or causes. According to Holzemer *et al.* (2007:547), due to the fear of stigma, people living with HIV or AIDS tend to sidestep situations in which stigma can be triggered or activated. Visiting a particular clinic is an example of a reason for stigmatisation.

Supporting authors mention that medication adherence and quality of life are also affected by stigmatisation due to the stated triggers (e.g. not taking antiretroviral treatment) (Carr & Gramling, 2004:30). Disclosure of one's HIV-positive status can serve as a trigger for received stigma (Wingwood *et al.*, 2008:239). Being in a close relationship in some way with a person who is HIV positive can again be a trigger for associated stigma, and internal stigma can be triggered by going for an HIV test and receiving a positive result (Holzemer *et al.*, 2007:547).

De Bruyn (1999:4) named factors contributing to HIV and AIDS-related stigma, as life-threatening, people fear it, it is associated with behaviour already stigmatised by many societies, for example drug abuse, and that people are seen as responsible themselves for contracting the disease.

In several African countries HIV infection is attributed to supernatural causes or seen as a punishment from God for past sins (Benotsch *et al.*, 2008:339). Siyam'kela (2003:7) also mentions that the fatality of this disease causes fear and often it is associated with misconceptions or lack of knowledge about it. It is further seen as a condition generally associated with promiscuous or irresponsible behaviour and is viewed as preventable (Siyam'kela, 2003:7). Jean-Baptiste (2008:1) states that in fact the very diagnosis of HIV and AIDS makes one susceptible to, and an expected victim of discrimination, disparagement, and denial of basic human rights.

- **Stigmatising behaviour**

According to Holzemer *et al.* (2007:547), triggers of stigma as described above lead to behaviour that is intended to harm, isolate, exclude and classify a person in a negative way. There are various levels of stigmatising behaviour, depending on the perceptions of the person who stigmatises with regard to HIV or AIDS. The intensity can vary from minor discriminatory acts such as asking a person to use particular eating utensils, to major acts such as chasing a person out of his or her home (Holzemer *et al.*, 2007:547). In these authors' view discrimination occurs through behaviour once stigma has been triggered. When a person with HIV is discussed, people tend to ask the question of how the particular person contracted the disease. Shilts (1988:311) mentions that this is

done in order to categorise this person as deserving the infection and accompanying stigma, or as being an innocent victim deserving compassion and support.

Further discussion on studies on stigmatising behaviour follows. In an ethnographic study by Duffy (2005:16) in rural Zambia, where HIV and AIDS is highly prevalent, it was found that people living with AIDS were mostly ill-treated and that nobody liked to be associated with an AIDS patient. In most cases they were considered hideous or revolting. Some findings of the study showed that discriminatory acts such as being given separate eating utensils, towels and left-over food were common. It was further mentioned that people tended to clap hands when greeting individuals infected with HIV instead of the very important handshaking that is the norm among Zambian people.

The experience of stigma is described by Greeff and Phetlhu (2007:22) as being painful and difficult for PLHA. Greeff *et al.* (2008a:80) identified the main forms of stigma as physical and social isolation, gossip and voyeurism, and a loss of rights and access to resources. Language was also mentioned as a potent tool for stigmatisation and also for support purposes.

In the project report, Siyam'kela (2003:89) discusses an array of abuse experienced by PLHA in South Africa. The report indicates that the types of abuse towards PLHA range from name-calling in the community and negligence by the church community, to physical abuse, especially towards women by their spouses. In a study by Dlamini *et al.* (2007:393) it was found that PLHA experience abuse in various forms, for example verbal abuse, neglect and even physical abuse, as mentioned in the Siym'kela (2003) project report. Abuse gives rise to negative feelings such as those of despair, hurt, sadness and shock. Verbal abuse includes blaming PLHA for their infection or infecting other people and revenge by withholding necessities from them, such as access to treatment. Verbal abuse often reflects lack of knowledge with regard to the modes of transmission of HIV. It was found that some people believed that HIV can be transmitted via sheer propinquity (Dlamini *et al.*, 2007:394). Physical abuse is sometimes focused at causing inconvenience and loss, such as by the destruction of personal possessions of PLHA (Dlamini *et al.*, 2007:395).

Various incidents of negligence in the form of denial of access to care and services were mentioned in the study by Dlamini *et al.* (2007:395), for instance the denial of

involvement in community participation projects and denial of access to church gatherings. Kohi *et al.* (2006: 408) propose six forms of discrimination against PLHA or outcomes of stigma. These include denial of healthcare and/or home-care services; verbal abuse; physical abuse; deprivation of food; deprivation of access to loans; and denial of employment.

Uys *et al.* (2005:14) identified a total of 290 references to several degrading words or phrases used to describe HIV as disease or the PLHA in five different African countries. “Eating plastic” for instance, refers to danger to animals that causes internal obstruction and then leads to death due to nutritional deficits. “Winning the lotto” was another term used to refer to the “winning” of HIV/AIDS, as in the case of “playing the dice” by means of a promiscuous lifestyle. It is therefore seen as fate when such people get HIV. Results of the study indicated that there were several categories of statements aimed at causing shame or hurt towards PLHA. These categories of verbal abuse, as described in Uys *et al.* (2005:17), signify the dilapidation and humiliation of stigma in this form towards PLHA.

- **Types of stigma**

The behaviours observed by Holzemer *et al.* (2007:547) were categorised into three types of stigma, namely received, internal and stigma by association. Received stigma entails all types of stigmatising behaviour directed at a PLHA, as experienced by themselves or others (Holzemer *et al.*, 2007:547). Nine dimensions of received stigma were identified, namely neglecting, fear of contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping (Greeff *et al.*, 2008b:86). Internal stigma, in contrast, involves thoughts and behaviour originating from a person’s own negative views about themselves based upon their HIV-positive status (Holzemer *et al.*, 2007:547). Four dimensions of internal stigma were identified, namely perceptions of self, social withdrawal, self-exclusion and fear of disclosure (Greeff *et al.*, 2008b:88). Holzemer *et al.* (2007:547) discovered that associated stigma, which is stigma due to mere association with PLHA, is a third, independent type of stigma that significantly affects various populations as found in the data gathered. It is therefore not merely one of the consequences of received (or external) stigma, which brings about experiences of unfair and different treatment towards PLHA.

After looking into literature defining HIV stigma with regard to types, the researcher found that stigma, although described differently by various authors, is basically divided into themes suggesting stigma directed towards the stigmatised, stigma directed towards the self and stigma directed towards those closely related to the stigmatised (Manyedi, 2007:62–66). Siyam’kela (2003:98) classified stigma as being one of two types, namely internal stigma, which is described as self-stigmatisation, self-judgement and consequential social isolation, and external or enacted stigma, which entails discriminatory acts from others towards the stigmatised individual. As was mentioned earlier, Weiss *et al.* (1992:819–830) distinguish an insider’s perspective (emic) and an outsider’s perspective (etic) of the consequences of a condition such as HIV or AIDS. These types of stigma can each be compared to internal stigma and external or enacted stigma as described by Siyam’kela (2003:6).

Link and Phelan (2001:1) identified three types of stigma: One is direct discrimination at a one-on-one level, where activities devalue, reject, exclude or blame the other person. A second is structural discrimination, in which social contexts, such as a sign identifying an HIV/AIDS clinic, enforce stigma without person-on-person interaction. The third type is self-stigmatisation, a socio-psychological process that operates through the stigmatised person. Stigmatised individuals apply labels to themselves, believe in these labels and live accordingly.

The types of stigma as identified by these authors show some similarities to those of Holzemer *et al.* (2007:547). Direct discrimination, for example, can be compared to received stigma, while self-stigmatisation is the same as internal stigmatisation. Structural discrimination, as the second type of stigma identified by Link and Phelan (2001:1), can be classified in the model of Holzemer *et al.* (2007:545) under the context of HIV stigma.

According to Nyblade (2006:338), stigma associated with PLHA fall into three main categories, namely perceived stigma, experienced stigma and internalised stigma. Several studies focused on measuring the perceptions of PLHA about stigma, in particular, fears of what would happen if others knew about the person’s HIV status. Examples included the possibility of losing friends and/or family, rejection, being blamed, being avoided or “others” being uncomfortable around the PLHA. Secondly,

under perceived stigma, PLHA speculate what “others” would think, or how supportive or unsupportive specific groups such as family, friends, community and healthcare workers would be towards the PLHA. Experienced stigma manifests itself in the form of discrimination, also referred to as enacted stigma, in the form of denial of rights to healthcare, education and employment. Experienced stigma includes acts of discrimination such as refusing to eat with PLHA, children being kept away from PLHA and physical and verbal abuse (Nyblade, 2006:339).

Internalisation of stigma entails the process of external stigma leading to internal stigma in the form of the negative self-image of PLHA. This includes feelings such as sensing that one is unclean or bad (Nyblade 2006:339; Sowell *et al.*, 1997:310; Ware *et al.*, 2006:906). Lorentzen and Morris (2003:22) describe self-stigmatisation as the type of stigma “that can exist without or outside the interactional context”. This implies that self-stigmatisation can take place in the absence of other people. Self-stigmatisation can cause depression, withdrawal, as well as feelings of worthlessness, which reinforce feelings of shame, stigmatisation and social withdrawal.

- **Outcomes of stigma**

The last aspects mentioned by Holzemer *et al.* (2007:547) in the HIV stigma process are the outcomes of stigma. The authors only briefly described this important aspect of the stigmatisation process, which also forms a very significant part of this study. HIV stigma impacts the lives of thousands of individuals infected and affected by this virus. The outcomes of stigma as discovered in the data obtained were suggestive of: poorer health outcomes; decreased quality of life; denial of access to services; violence; and poorer quality of work life. The health outcomes mentioned here not only refer to physical health but also imply mental health, since HIV stigma can certainly impact negatively on a person`s mental well-being (Holzemer *et al.*, 2007:547).

One may assume that this indicates the need for a broader discussion of some probable outcomes of stigma. The researcher attempted to provide more descriptions as found within the literature as barriers to healthcare. The researcher found eight main themes incorporating outcomes of stigma:

- Reduced access to and utilisation of effective services and treatments

Link and Phelan (2002:11) mention that an important way that access to healthcare and treatment is obstructed is when people fear being labelled as having a stigmatised condition. People consequently often delay treatment. Another way stigma may influence access to treatment is by creating undesirable conditions in treatment settings. Phetlhu (2005:69) seconds this with findings from her study, indicating that patients often lack trust, lose hope in the health service, and often do not go back to the clinic at all. These decisions are mainly based on the environment being perceived as negative due to the attitude of healthcare personnel.

In a study by Dlamini *et al.* (2009:382) on HIV stigma and missed medications in HIV-positive people in five African countries it was demonstrated that the participants who reported higher rates of stigma experiences tended to report more symptoms, more medication worries, and more missed medication doses. This may reveal the correlation between being visibly sick, reflected by the increased symptom intensity, and the experience of increased stigmatisation. In a study by Vanable *et al.* (2006:480) research results indicated that lapses in adherence to ARVs were associated with more recurrent episodes of stigmatisation. Siyam'kela (2003:8) mentions that stigma undermines community health by reducing access to treatment and support benefits for PLHA. Isolating behaviours and judgemental attitudes can result in PLHA delaying care until absolutely necessary, when the disease has progressed to a late stage (Siyam'kela, 2003:10).

- Impact on physical and mental wellness

In a study conducted by Wingwood *et al.* (2008:239) among women living with HIV in the Western Cape in South Africa, it was concluded that HIV stigma has a significant, intense, and damaging effect on the mental health status of PLHA. Mak *et al.* (2007:1549) state that HIV impacts on the psychological well-being of PLHA because of the stigma attached to the disease. These statements are confirmed by several authors who are of the opinion that the degree to which a stigmatised individual is deprived of the good things in life and experiences more of the bad things has been identified as a source of chronic stress, with resultant negative effects on mental and physical health (Greeff & Phetlhu, 2007:22; Link & Phelan, 2006:528; Van Brakel, 2006:307). Vanable

et al. (2006:479) confirm that stigma contributes to psychological adjustment difficulties among PLHA. In their study it was found that current symptoms of depression appeared as a strong correlate of stigma frequency.

- Abuse and violence

According to Wingwood *et al.* (2008:237) and Dlamini *et al.* (2007:390), stigma may be manifested through violence towards PLHA. Violence may take the form of physical and/or emotional abuse. Kohi *et al.* (2006:409) found that most of the incidents of abuse towards PLHA in their study included verbal abuse, although some incidents of physical abuse were also reported. Verbal abuse may include words, phrases, shouting, and singing with the aim of insulting (Dlamini *et al.*, 2007:394). Nyblade (2006:5) adds that derogatory and demeaning language is often used to talk about or label PLHA. Gossip was also reported to be one of the most significant outcomes of stigma. Other forms of verbal abuse included expressions of blame and shame, often through scolding and judgement. Physical abuse was described as being aimed at rejecting, dehumanising, and isolating PLHA. In their study, Kohi *et al.* (2006:409) found there were reports of physical abuse on a daily basis, often from family and friends.

- Deprivation of quality of life

Benotsch *et al.* (2008:342) mention that social and economic discrimination towards PLHA is pervasive. PLHA in their study were found to be victims of discrimination in the form of eviction from their homes. Siyam'kela (2003:8) describes stigma as the undermining of human rights. Kohi *et al.* (2006:409) describe incidents of PLHA being deprived of food, the chance to produce food, or to access loans. Some participants in their study even reported denial of employment or income. According to Nyblade (2006:5), PLHA in several countries reported that one of the most intense outcomes of stigma was its impact on their ability to earn a living. People in formal employment, for example, found themselves being dismissed after disclosure of their HIV status. Nyblade (2006:6) describes incidents where PLHA were often treated in an inferior manner in the formal health sector and at home, compared to others and in some places even being denied care altogether.

- Rejection and discrimination

Siyam’kela (2003:8) notes that HIV stigma isolates, divides and breaks down communities. Kohi *et al.* (2006:410) found that societal and familial rejection was often reported by PLHA. Their study found that the human rights of PLHA were disrupted when they were rejected in society as well as in their own homes. Nyblade (2006:5) adds that PLHA find that they are often no longer welcome at important family and community events. A major effect of discrimination is that it forces PLHA into hiding. Disclosure becomes extremely difficult and any association with the disease can be a basis for PLHA being excluded from their community (Skinner & Mfecane, 2004:161).

- Breach of confidentiality

Phetlhu (2005:66) found that most participants in her research study found that they did not trust health workers with their confidential information. This was mostly because they feared that the health workers would disclose their health status to others without their approval. Kohi *et al.* (2006:411) in their study found that disclosure on participants’ behalfs was done by family, friends and other community members on a regular basis. PLHA consequently often felt reluctant on probable consecutive disclosure occasions.

- Impact on PLC to PLHA

Stigma relating to HIV not only impacts on the lives of HIV-positive individuals, but also on the individuals, groups and communities to whom they are related (African Development Forum, 2000; Greeff & Phetlhu, 2007:13; Hilhorst *et al.*, 2006:390; Manyedi, 2007:53; Wingwood *et al.*, 2008:237). According to Chirwa *et al.* (2009:20), there is a predictable amount of variance in the job dissatisfaction of nurses due to the incidence of perceived HIV stigma, which is considered to be the stigma that affects nurses working with PLHA, including the stigma that the nurses attach to themselves as well as the stigma they get as a result of them being associated with PLHA.

4 HIV and AIDS Stigma in Urban and Rural Contexts

According to Chambers Pocket Dictionary (1997:1000) the word “urban” refers to an area situated in a town or city, in contrast to “rural”, which refers to an area situated in a

countryside, or agricultural area (Chambers Pocket Dictionary, 1997:799). Du Plessis *et al.* (2001:1) also define “rural” as the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e. outside the commuting zone of centres with a population of 10 000 or more). There are some evident differences in the lifestyle and circumstances of rural and urban communities. These differences can be seen in elements such as educational background, economic status and social structure and beliefs (Campbell *et al.*, 2005; Relf *et al.*, 2005:14; Visser *et al.*, 2009:197). Naidoo *et al.* (2007:22-2-3) found the influence of social networks (i.e. easier to “gossip”); socio-economic influences (more general knowledge due to higher access to resources such as television, radio and the internet) and higher literacy levels to be evident in the urban community. This is made possible by a higher income per capita.

Naidoo *et al.* (2007:17–23) conducted research in five African countries to investigate whether any differences existed between the HIV stigma and discrimination practices in urban and rural communities. In their study they found that the urban groups described more experiences of stigmatisation and discrimination than did the rural groups. A study by Kruger *et al.* (2009:36), aimed at investigating differences in healthcare-seeking behaviour of people from rural and urban communities, also found similarities to Naidoo *et al.* (2007:22), who found that only 8.7% of participants from the urban areas sought care at a health facility after having been diagnosed as HIV positive, compared to 18.9% from rural areas. This occurrence may be associated with the fear of stigmatisation in more affluent areas, i.e. urban communities. The research finding in Naidoo *et al.* (2007:22) and Kruger *et al.* (2009:36) contradicts other research studies, which showed that stigmatisation takes place more often in rural than in urban communities (Bond *et al.*, 2003:7; Bunn *et al.*, 2008:285; Heckman *et al.*, 1998:138; Sliep *et al.*, 2001:61).

People living in rural communities on average earn a lower income than their counterparts in urban communities. Campbell and Deacon (2006:411) found that poverty and deprivation are potent drivers of the stigmatisation of diabetics in Ghana, of people with tuberculosis in Zambia and African migrants with HIV or AIDS in England. In contrast to people living in rural communities, those living in urban communities tend to stigmatise less.

In a study by Stephenson (2009:408) in three study settings representing differing economic and cultural environments, it was found that participants with access to more economic resources had more supportive attitudes towards those with HIV or AIDS. Young people with high levels of knowledge of the transmission routes of HIV likewise had more supporting attitudes, signifying the role that knowledge plays in reducing the misconceptions that act to create fear and shape stigma. The reason for higher levels of education is due to easier access to tertiary education in urban communities than in rural communities, where distances between dwellings and schools are vast.

Rankin *et al.* (2005:1) are of the opinion that fears of stigma further limit the efficacy of HIV-testing programmes across sub-Saharan Africa, because “in most villages everyone knows – sooner or later – who visits test sites”. This statement indicates that in the rural context privacy is limited, which increases the opportunity for stigmatisation. The authors further note that in many African villages (rural communities), an individual’s and a family’s life is closely intertwined with the lives of others. This conclusion is supported by Hosegood *et al.* (2007:1256) and Sliep *et al.* (2001:14).

The impact of the epidemic on all sectors of society, from urban industries to rural villages, is already being felt and will worsen as more people progress from asymptomatic HIV to AIDS (Connolly *et al.*, 2004:776). HIV and AIDS, especially in the context of poverty, result in considerable suffering. Throughout most of the developing world, bonds and allegiances to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they occur, are social and cultural phenomena linked to the actions of whole groups of people, and not simply the consequences of individual behaviour (Parker & Aggleton, 2003:17). These findings emphasise the effects of rural socio-economic factors on the manifestations of stigma.

Campbell *et al.* (2005:2) looked into a case study of HIV and AIDS management among young people in a rural area named Ekuthuleni in South Africa, where poverty and political marginalisation were common. Within the context of poverty and disempowerment, many people lack access to the conventional social advantages of a highly materialistic society and thus to those objective resources that might assist in increasing their self-esteem. Symbolic resources – such as respectability – come to establish valuable currency in individuals’ efforts to enhance their self-esteem. In the

case of many residents from Ekuthuleni, the openly expressed stigmatisation of people with HIV and AIDS had become a way of asserting claims to respectability (Campbell *et al.*, 2005:2). Hilhorst *et al.* (2006:390) confirm that a lack of knowledge causes higher levels of stigmatisation.

Authors came to contradicting conclusions regarding HIV stigma in urban and rural communities. Nevertheless, a higher prevalence of stigmatisation can be attributed to rural communities. A common thread throughout the literature on urban and rural differences in HIV stigma was that factors such as social structure, economic status and level of literacy probably determined the manner in which such was perceived.

5 HIV Disclosure

HIV status disclosure is generally perceived as a stressful event in the lives of PLHA. Because of the fear of AIDS-related stigma, very few people voluntarily disclose their HIV status (Derlega *et al.*, 2006:758; Elford *et al.*, 2008:519; Kruger *et al.*, 2009:37; Ogden & Nyblade, 2005:35). It is, however, widely accepted that holding back one's feelings gives rise to stress, which in turn negatively affects physical as well as psychological well-being (Paxton, 2002:564; Serovich & Mosack, 2003:76; Van Dyk, 2002:270). Feelings accompanying the choice of disclosure or non-disclosure include doubt, worry, hurt, acceptance, and courage (Greeff *et al.*, 2008a:318–319). The authors found that doubt is a feeling that accompanies the choice of both disclosure and non-disclosure. However, they mention that the feeling of hurt sometimes causes people to talk openly about their HIV status. As soon as acceptance of their positive status has taken place and after finding the courage from within, it was found that participants tended to disclose their HIV status. Who to disclose to seemed to be an important factor when considering disclosure and formed part of the process of disclosure.

5.1 Process of disclosure

Greeff (2013:85-89) formulated a comprehensive framework that describes the disclosure process and makes it easy to understand. She describes disclosure in terms

of the types of disclosure, factors before disclosure, to whom to disclose, the rate of disclosure, enabling factors for disclosure, ways not to disclose, and factors during and after disclosure. This framework was used by the researcher as a basis for the discussion of the disclosure process. The researcher also examined the literature in order to find other authors' opinions and findings in this regard and will describe these as such.

Disclosure is described by Greeff (2013:71) as a complicated process and it involves shared responsibility between healthcare workers and patients. The author is of the opinion that healthcare workers have a major responsibility as "co-managers" of disclosure. She notes that there is a lack of guidelines on responsible disclosure management in the literature and suggests that a practical approach instead of a theoretical approach is essential when dealing with disclosure.

Adedimeji (2010:19) also mentions that the lack of guidelines on the modalities for managing disclosure is a big challenge for healthcare workers. Naeem-Sheik and Gray (2005:48) believe that every healthcare provider should develop a plan with the HIV-infected individual or, in the context of their study, with the parents of HIV-infected children, that will outline the process of HIV disclosure. These authors stress that disclosure is a process that should occur over a period of time and not on the spur of a moment.

Maman and Medley (2004:4) also describe disclosure as being a process rather than a once-off occurrence. They propose a framework to describe the decision-making process accompanying disclosure. The framework consists of six steps, namely adjustment to the diagnosis, evaluation of personal disclosure skills, evaluation of the appropriateness of disclosure, the evaluation of the circumstances for disclosure, anticipation of potential reactions from recipients, as well as the identification of reasons for disclosure. The process of disclosure can be endorsed as clearly unique to each individual. There is an interaction of different factors that influence the progression of the HIV process (Masupe, 2011:67).

5.2 Responsible disclosure management

Responsible disclosure management is described by Greeff (2013:84) as a process during which one should consider various conditions in the area in which the disclosure is planned to take place. She describes it in several steps, which include:

- understanding the meaning of disclosure and non-disclosure;
- gaining knowledge of the total context of the disclosure process before, during and after disclosure;
- knowing the reasons why one chooses to disclose or not to disclose in order to weigh up the advantages and disadvantages;
- positive and negative consequences;
- listing the required circumstances that will accelerate or delay disclosure;
- listing feelings experienced prior to making the decision of disclosure or non-disclosure;
- listing ways in which one should not disclose; deciding on how much one will disclose;
- evaluation of the knowledge of the party to whom there will be disclosed; determining the appropriate time for disclosure, and
- listing potential problems relating to post-disclosure coping.

In a study by Masupe (2011:64) it was found that prior to disclosure of their HIV status, participants in her study claimed to have “pre-disclosure deliberations” during which they prepared themselves for disclosure. According to Masupe (2011:64) this was done by means of “self-counselling” or making positive lifestyle decisions. Individuals should be well prepared to manage the potentially stressful event of disclosure. The environment should be thoroughly evaluated prior to the decision of whether to disclose or not. Social change and a favourable and supportive environment for disclosure form part of responsible disclosure behaviour.

In a study on experiences of disclosure by gay men, Rutledge (2007:1044) describes the process of disclosure as follows: The process starts with the discloser applying his personal disclosure policy to the sex environment, then assessing the prospective sexual partner to try and gauge his potential reaction to disclosure. This is followed by the evaluation of reactions and consequences of disclosing.

With regard to responsible disclosure management the author also agrees that disclosure should take place in a safe environment. The process of disclosure is described as a three-stage process of timing, staging and enacting disclosure. Caughlin *et al.* (2008:656) reason that understanding how others will respond to disclosure is important for the people who deliberate probable disclosure. People making the disclosure may have pre-determined hopes and expectations with regard to the reaction of the people they wish to disclose to. The possibility of negative responses should be kept in mind and the discloser should then be prepared to handle it appropriately. Masupe (2011:83) found that some participants in her study reported more positive outcomes after disclosure than were initially anticipated.

5.3 Categories of disclosure

There are various categories of disclosure, namely voluntary, forced and mandatory disclosure (Greeff, 2013:85). According to the South African AIDS Trust (Southern African AIDS Trust [SAT], 2004:1) there are five types of disclosure, namely involuntary disclosure, voluntary disclosure, full disclosure, partial disclosure and non-disclosure. Greeff (2013:86) in her framework prefers to discuss these types under “degrees of disclosure”. Involuntary disclosure involves the disclosure of a positive HIV status by somebody other than the actual HIV-infected person. This usually happens without the person’s approval or knowledge. Full disclosure entails disclosure of HIV status by the individual themselves to another person, organisation or the media. Partial disclosure is defined as disclosure that occurs when the individual will only tell certain people, such as a partner or spouse, about the positive HIV status. Non-disclosure is when the person does not reveal his or her status to anyone (SAT, 2004:1).

5.3.1 Voluntary disclosure

Voluntary disclosure entails that the choice of whether or not to disclose lies with the PLHA (Greeff, 2013:85; Open Society Foundation for South Africa [OSF-SA], 2009:88). PLHA often disclose voluntarily in order to gain access to treatment and the necessary care.

5.3.2 Forced disclosure

Forced disclosure occurs when the PLHA do not have any other choice but to disclose their HIV status (Greeff, 2013:85). This might happen due to, for example, deterioration in the physical health status, which makes it obvious, and where others disclose the person's HIV status on his or her behalf, without permission. In terms of disclosure by a second or third party, the Bill of Rights, section 14 states that everyone has the right to privacy, which includes the right to not have the privacy of their interactions infringed. In other words, your personal information is confidential and nobody has the right to disclose personal information, such as your HIV status, without consent from the person concerned (OSF-SA, 2009:92).

Moskowitz and Roloff (2007:18) found that a deterioration in CD4 count often causes a sense of urgency to disclose in certain circumstances. In her study, Masupe (2011:67) found a participant who felt obliged to disclose to her family so that they could look after her children should she die. The "disease progression theory", on the other hand (Babcock, and, Kalichman quoted by Serovich, 2001:356), suggests that persons tend to disclose their HIV diagnosis as soon as they become ill with AIDS, as in this phase, due to physical degeneration, it cannot be kept secret any longer. Marks *et al.* (1992:305) suggest that "illness progression heightens anxiety and need for social support, which may motivate disclosure to significant others".

5.3.3 Mandatory disclosure

Mandatory disclosure can be viewed as a form of forced disclosure in that a person who fails to disclose under circumstances in which disclosure is mandatory, may be sentenced according to the particular country's legislation. Notification is mandatory in some countries (Greeff, 2013:85).

In their study based in Ethiopia to assess the effect of gender on disclosure, Kebede *et al.* (2008:87) found fear of legal accusation to be the main reason for disclosure by both men and women. Circcarone *et al.* (2003:949) mentioned that from 1999, 31 states in America had statutes making sexual contact without disclosure of HIV status a criminal offense. Masupe (2011:16) also adds that in the United States and some European countries, “the law requires disclosure of HIV status before engaging in sexual activities”. In their study on disclosure practices between men having sex with men, Gorbach *et al.* (2004:514) found that there were some participants who reported that they absolutely always disclose their status to a partner, as non-disclosure could lead to arrest or legal prosecution. This finding was prevalent in Los Angeles. Some of the terms that were used by participants describing non-disclosure included “murder”, “manslaughter”, “felony rap”. They mentioned that “knowing that disclosure is a legal issue made them feel like they have to disclose” (Gorbach *et al.*, 2004:514).

5.4 Factors prior to disclosure

There are several factors that have an influence on the decision for or against disclosure. These factors are discussed below.

5.4.1 Degrees of disclosure

There are various categories of disclosure, depending on the extent of the disclosure (Greeff, 2013:84; SAT, 2004:1). Greeff (2013:85) divides the degree of disclosure into managed disclosure, during which selective or full realities are expressed; and concealment, during which selective or full concealment or secrecy is anticipated.

5.4.2 Factors that influence decision-making

Factors that influence decision-making for disclosure or non-disclosure are discussed under reasons to disclose, reasons not to disclose, to whom to disclose, rate of disclosure, factors enabling disclosure, and ways not to disclose, as originally indicated by Greeff (2013:86).

Allen *et al.* (2008:196) found that 40% of PLHA do not disclose their HIV status to sexual partners. The rate of non-disclosure also increases disturbingly over time. The impact of gender and sexual orientation does not seem to influence the rate of

disclosure; however, as age increases, the probability of disclosure increases. Emlert (2006:357) states that having a confidant, or affective social support, using formal HIV services and greater amounts of time since diagnosis were important markers for disclosure. The physical, psychological and emotional disbursements are weighed against the negative emotional consequences of disclosure. According to Greene (2006:14), the individual diagnosed with HIV often experiences conflicting thoughts regarding status disclosure. The author found that the individual on the one hand feels the need to disclose their status to their sexual partner on the grounds of loyalty to the relationship, and on the other hand the need not to disclose their status because of the need for privacy. Norman *et al.* (2005:8) mention readiness as a contributory factor to disclosure of HIV status.

5.4.2.1 Reasons to disclose

Several reasons are provided for the act of disclosure of one's HIV status. The motives for disclosure can be seen as advantageous for the discloser and/or the individuals close to them. Greeff (2013:88) divides reasons for disclosure into personal needs, response to the needs of others and fulfilling interpersonal needs.

- **Personal needs**

Greeff (2013:85) includes personal stress and the burden of leading a life of secrecy; the improvement of self-esteem; catharsis; the desire to break the silence; the need for education about the virus; the development of coping mechanisms; access to various forms of support; improvement of mental health; a greater quality of life and forced choice of disclosure, such as in the case of visible signs of disease, under personal needs in HIV-status disclosure. Masupe (2011:68) found that perceived benefits of disclosure to partners were the hope of acceptance and the emotional and financial support; a sense of freedom from the burden of living with a secret; the conviction that the relationship was strong enough to withstand such an issue; and anticipated support in dealing with the physical aspects of the illness. Manyedi (2007:117) found that participants in her study who were in favour of disclosure explained their rationale for taking this step as hoping to prevent gossip. It was, however, revealed that this step only aggravated the situation as those to whom they disclosed and whom they had

trusted, disclosed the news about their positive HIV status to other friends and neighbours. Smith *et al.* (2008:1271) state that when PLHA disclosed their status to more people, they reported more social support. In their study on disclosure patterns in an Indian community, Chandra *et al.* (2003:212) confirmed the findings of support gained.

Other positive outcomes of sharing one's HIV status are the gaining of resources such as assistance with household tasks, health and child care, and the provision of medical information (Serovich, 2001:357). Each of these resources can therefore positively impact on the physical, emotional and social functioning of the individual disclosing. In the case of a study on tuberculosis and self-disclosure among patients in Malawi (Zolowere *et al.*, 2008:6), the authors found that patients gained social and financial benefits from the disclosure of their disease status to significant others. Zea *et al.* (2005:20) also found that increased social support was gained after HIV-status disclosure. Lowered levels of depression and increased levels of self-esteem were also noted by these authors.

Some negative outcomes of disclosure entail that disclosing one's HIV-positive status can provoke feelings of anxiety and threats to personal well-being (Serovich, 2001:357). Fear of disclosure is significantly influenced by fear of stigmatisation. During research on "Coping with stigma by women whose partners died of AIDS", Manyedi (2007:117) found that almost all participants indicated feeling comfortable if their HIV and AIDS status was unknown. This fear of disclosure affected women in this study in such a way that they had to hide when they needed to visit the HIV and AIDS clinic. A life of secrecy and discomfort was therefore anticipated. When discussing the feared disease, cancer, Bolund (1990:130) stated: "There is only one disease, AIDS, that has a similar strong attribution of dread".

- **Response to the needs of others**

Responses to the needs of others when disclosing include fear of what would happen to family members such as children should something happen to them; involvement in preventative activities; the need to reduce stigma and discrimination against PLHA in the community; the need for people to exhibit some genuine respect and understanding;

the duty to educate others; and the need to assist others not to make the same mistakes (Greeff, 2013:85).

In a study by Asander *et al.* (2009:112) it was found that only women talked to their children about their HIV-positive status, where they would go if they were to be orphaned, or both. It was concluded that a sense of isolation made the women more inclined to involve their children. The focus of the study was on HIV-infected African parents who had immigrated to Sweden.

Derlega *et al.* (2006:747) examined the relative importance of reasons for HIV disclosure or non-disclosure. It was found that catharsis, duty, and close relationship were identified overall as important reasons for HIV disclosure. Gorbach *et al.* (2004:514) found that men were much more likely to disclose their status in situations where they had feelings for a partner. A sense of responsibility about HIV transmission was also mentioned as a motive for disclosure to a sexual partner.

Ostrom *et al.* (2006:60, 63), who examined the role stigma plays in women's decisions to disclose or not to disclose their HIV positive status to their children, found that the most powerfully endorsed reasons for disclosure to children included the need for the children to hear the diagnosis from the mother themselves, that the child was entitled to know, wanting the child to be aware of what was wrong with the mother, and wanting to give the child time to prepare for what might happen in the future. The main reason for non-disclosure towards children was the belief that the child had a right to an untroubled childhood. For families living with children infected with HIV, diagnostic disclosure can also be an extremely difficult task. Parents may wish to withhold the diagnosis throughout the child's life in order to protect the child from potentially harmful knowledge (Lester *et al.*, 2002:310). Concealing one's HIV status from a partner is, according to Elford *et al.* (2008:519), in itself a stressful process. It also denies the PLHA and their partner the opportunity of making informed choices together regarding HIV risk reduction.

- **Fulfilling interpersonal needs**

Greeff (2013:85) notes that fulfilling interpersonal needs with regard to HIV disclosure involves readiness to inform others; feeling valuable to be involved in peer or community education and support efforts, and the development of close relationships.

Most health literature appears to favour disclosure by persons living with HIV (Cusick & Rhodes, 1999:3; Norman *et al.*, 2005; Serovich, 2001:355; Serovich & Mosack, 2003:70; Wong *et al.*, 2009:215). Greeff *et al.* (2008a:312) and Dlamini *et al.* (2007:397), however, mention that to disclose is not always favourable, as disclosure (or non-disclosure) is often followed by major and life-changing events. The probable consequences of disclosing are therefore substantial for PLHA (Greeff *et al.*, 2008a:312).

5.4.2.2 Reasons not to disclose

Some PLHA, taking their personal circumstances into account, conclude that the act of disclosure may have negative implications for themselves or for people close to them. On the basis of their assessment of the conditions, they decide not to disclose. Greeff (2013:85) divides reasons not to disclose into protecting the self; protecting others; relationship factors and community factors.

- **Protecting the self**

The loss of privacy; denial; anxiety about the consequences of speaking out; self-blame; vulnerability; rejection or being labelled in a negative way; comfort in rather keeping the illness a secret; ensuring life continues as usual; self-concept difficulties; communication difficulties; fear of physical and verbal abuse; fear of being chased from home; financial and employment implications and the loss of health benefits are identified by Greeff (2013:85) as the main reasons for non-disclosure that PLHA identify. Disclosure outcomes vary from positive to negative. It can be accompanied by consequences such as problems in relationships, rejection and social discrimination, as well as physical and verbal abuse (Dlamini *et al.*, 2007:395; Paxton, 2002:563; Van Dyk, 2002:279). Potential harmful outcomes such as these therefore often play a role in the PLHA rather concealing their status in an attempt to protect the self.

Costs of disclosure, as described by Serovich (2001:360), include fear of a fight, lecture, or blame and overall protection from further hurt and anger by others. Therefore the possible costs of the decision to disclose or not should be weighed against the potential benefits thereof (Derlega *et al.*, 2006:748). Elford *et al.* (2008:519) mention fear of rejection as being a prominent reason for people not to disclose their HIV status to their partner. Gorbach *et al.* (2004:514) found similar tendencies. Norman *et al.* (2005:6) also mention fear of rejection and abandonment as prominent reasons for non-disclosure. In a study in Botswana, Wolfe *et al.* (2006:932) found that fear of the loss of employment was a major factor causing non-disclosure among patients receiving ART in private clinics.

In a study by Wong *et al.* (2009:219) it was found that the most common reason for an individual not to disclose their HIV-positive status was a desire for privacy. Fear of rejection and fear of physical abuse followed this result. Factors that encourage non-disclosure included privacy, fear of rejection, as well as self-blame. It can be concluded that the latter are aimed at reducing negative consequences to oneself.

Sheon and Crosby (2004:2116), who conducted a study among gay men in San Francisco (which is associated with a “golden era” of gay sexual expression and community formation), found that regardless of HIV testing, both HIV-positive and HIV-negative men provided numerous reasons for non-disclosure. The men tended to rationalise their failure to disclose their HIV status (whether positive or negative) with reference to a “macho, barebacking” ethos that discourages disclosure so as not to spoil the mood by invoking “condoms” or “HIV” (Sheon & Crosby, 2004:2116).

In a study conducted by Serovich and Mosack (2003:70) to look into reasons for HIV-positive gay men disclosing or not disclosing their HIV status to their casual sexual partners, it was found the main reason for non-disclosure was shamefulness about having HIV. The “responsibility factor” was a dominant issue in deciding to disclose their diagnosis to a sexual partner (Serovich & Mosack, 2003:75). Zolowere *et al.* (2008:6) also mention that disclosure of a diagnosis of tuberculosis is facilitated by, among other things, a sense of obligation to others. In Dar es Salaam, Tanzania, a study by Maman *et al.* (2003:378) established that the major barrier to disclosing HIV status to sexual partners reported by the women studied was fear of negative reactions. The conclusion

was drawn that the reaction that women feared the most was abandonment and loss of economic support.

- **Protecting others**

PLHA often fear being a possible burden to family members or other acquaintances. They also fear the possible effects of their HIV disclosure on close family members and friends, for example emotional trauma and worry. In addition, they fear associated stigma. They often tend to keep their distance and have only superficial relationships with others in order not to feel obligated to have to share personal information such as being PLHA (Greeff, 2013:87). Gorbach *et al.* (2004:514) also found that PLHA feel a stronger responsibility to disclose their HIV status to partners than to other people.

Diagnostic disclosure to perinatally HIV-infected children is often delayed well into school age. The child's cognitive level may be an indicator of the ability to suitably manage this information. Some of the main reasons for parents not disclosing their children's HIV positive status to them include fear of negative reactions. Lester *et al.* (2002:316) and Naeem-Sheik and Gray (2005:46–48) are of the opinion that these fears may be particularly prevalent in communities that lack HIV and AIDS education and services. This emphasises the importance of proactive education by healthcare providers to schools and communities about HIV as an essential part of the disclosure process. There are, however, duties and obligations to significant others that are also rated highly as reasons for HIV disclosure, such as loyalty towards significant others and a need to have an open and honest relationship (Derlega *et al.*, 2006:761).

- **Relationship factors**

The factors relating to relationships that commend HIV non-disclosure as per Greeff's framework are distrustful relationships with healthcare workers; confidentiality; fear of disruption of close friendships and the fear of being rejected and even chased away (Greeff, 2013:88). During their research, Deribe *et al.* (2010:36) proved that there was no significant difference between men and women regarding the rate of HIV disclosure. However, they found that the contextual barriers as well as reasons for disclosure varied by gender.

A major reason for disclosing to one's sexual partner was that it was natural to tell them such a secret thing. The second reason for disclosure to a sexual partner was seeking support from the partner (Deribe *et al.*, 2010:33). Reasons for non-disclosure varied between males and females: Men were more concerned about the partner's well-being and did not want to worry her; while women were more apprehensive about separation, physical abuse and even murder.

Masupe (2011:70) found that a fear of rejection, loss of self-respect, fear of being blamed for transmitting the virus and possible relationship breakdown as leading factors for non-disclosure. Masupe (2011:97) also found that a previous negative experience after disclosure had a negative impact on future disclosure. In her study it was found that a participant reported non-disclosure to a partner due to the fact that he had had a previous negative experience after disclosing his HIV status to his partner in that he was abused physically and emotionally. He feared losing the relationship and rather kept his status a secret.

Maman and Medley (2004:3) further found that loss of economic support, blame, abandonment, abuse, discrimination and disruption of family relationships were the leading causes of non-disclosure. Norman *et al.* (2005:6) in turn found that fear of abandonment and rejection were the main reasons for PLHA withholding their HIV status from others. Wolfe *et al.* (2006:932) found the fear of unemployment due to an HIV-positive status to be a major contributing factor to non-disclosure.

- **Community factors**

Greeff (2013:86) states that the level of education that PLHA have undergone can have a definite influence on the rate of HIV-status disclosure. She mentions that both uneducated and highly educated individuals have difficulty in freely disclosing their positive HIV status. She further notes that the degree of stigma and discrimination within a community, e.g. rejection and ridicule and blame, is measured and then taken into consideration with regard to non-disclosure.

The final community factor mentioned by Greeff (2013:86) is previous experiences with observing other individuals living with HIV being stigmatised and treated badly within their community. Several studies found that many participants could not disclose their

status mainly due to the stigmatising acts predicted in their minds due to previous observations (Berger *et al.*, 2001:519; Ostrom *et al.*, 2006:63; Yang *et al.*, 2006:722).

5.4.2.3 To whom to disclose

Several individuals are mentioned in the literature as targets of disclosure, and it was concluded that there are no strict parameters in this regard. Individuals such as partners, children, parents, family members, healthcare workers, colleagues and employers, mass media as well as the wider community are some mentioned by Greeff (2013:86). Greeff *et al.* (2008a:314) note that although literature suggests that it is favourable to disclose to the close people in one's life such as those mentioned above, one should be in control of conveying the message. They noted that the literature differs regarding the person to whom to disclose. O'Brien *et al.* (2003:732) found that people with HIV tend to disclose their HIV status most frequently to permanent partners and immediate family members. In their study, only 24,8% of participants with casual sex partners indicated disclosure to these casual sex partners (O'Brien *et al.*, 2003:732). This trend emphasises the fact that HIV disclosure has the potential to offer benefits to the health and safety of the self and others. In their study, Elford *et al.* (2008:519) found that people were less likely to have disclosed their HIV status to their employer than to any other adult due to fear of discrimination and anxiety about losing a job. Greeff *et al.* (2008a:315) note that disclosure to healthcare providers has become crucial, particularly in the developed world with the universal availability of ART.

5.4.2.4 Rate of disclosure

The rate of disclosure involves the correct timing for disclosure. Greeff (2013:87) indicates that the person should be ready for disclosure and the person on the receiving end should be ready to hear and deal with the news. The various timeframes mentioned further are immediately after diagnosis, after having adjusted to the diagnosis, before imminent disclosure to others, or any suitable occasion. Greeff *et al.* (2008a:315) state that it is crucial for health professionals to be alert that cultural factors and the state of the disease can have an impact on disclosure rates and that psychosocial interventions should therefore be planned accordingly.

In a study comparing the HIV disclosure rates of younger and older adults, Emler (2006:355) found that older adults were significantly more likely to disclose their HIV status, specifically to their children. People in the 50+ age group disclosed their HIV status less frequently to individuals such as nurses and partners.

These findings would tend to suggest that disclosure depends on the analysis of the positive and negative consequences of action. In this particular study (Emler, 2006:350-358), the sample indicated the need to disclose one's HIV status in order to receive formal support through an HIV service network. Similarly, having a confidant may provoke the emotional support needed to cope with any consequences of disclosure (Emler, 2006:357; Lester *et al.*, 2002:310; Serovich, 2001:355).

5.4.2.5 Factors enabling disclosure

Greeff (2013:86) divides the contexts and accompanying supportive factors for disclosure into the healthcare system, personal factors and community factors. She emphasises the importance of high-quality care and support for PLHA with regard to counselling and education about HIV and AIDS and ways of living positively with the diagnosis. Personal factors include the acceptance of the disease, disclosure readiness and taking responsibility for disclosure. With regard to the community, factors such as support by people living and working close to PLHA, a facilitating socio-political context, the community being prepared to hear as well as low levels of stigma are mentioned as being important enabling factors for disclosure (O'Brien, 2003:734; Zolowere *et al.*, 2008).

Rutledge (2007:1044) describes a three-phased process of timing, staging and enactment of disclosure. In this research study, a participant described her means of introducing the matter of HIV to her children in a sequential way. She firstly introduced the issue of her needing to take some medication and asked the children to remind her of her medication on a daily basis. She felt that she would then, as time passed, also go on to tell the other younger children. This shows that disclosure needs some emotional preparation, and that circumstances such as the age of the recipient are also important.

5.4.2.6 Ways not to disclose

There are several ways that Greeff (2013:86) describes as unfavourable and most probably leading to negative consequences for the discloser should he or she decide to disclose under these circumstances. These include accidentally, in the heat of anger and when being put on the spot. Naeem-Sheik and Gray (2005:48) also mention these circumstances as being unfavourable for disclosure, but in addition mention that a child should not be left to eventually discover on his or her own their HIV-positive status. It should be done when a child can be assisted to process the information and deal with it positively. Disclosure is therefore a process that needs cautious consideration. It should take place in a responsible manner. Raganya (2003:15) further recommends that situations such as geographical separation or having to use a telephone to convey the message of being HIV positive may create a less favourable context for disclosure to occur.

5.5 Factors during and after disclosure

Disclosure must take place under favourable circumstances, as has already been mentioned, and the discloser has to feel in control of the situation. Greeff (2013:87) mentions three main concepts pertaining to the process of disclosure and thereafter. These are: circumstances necessary for disclosure, feelings accompanying the act of disclosure, and consequences of disclosure.

5.5.1 Circumstances necessary for disclosure

Greeff (2013:87) is of the opinion that it is necessary to disclose if there is a need and a right to know. The PLHA need to be able to tell, that is, they need to be emotionally and physically fit. The person on the receiving end likewise needs to be fit in order to cope with the news disclosed. When there is a risk of HIV transmission, non-disclosure is inadmissible. The researcher has seen this happen on a daily basis, and it is horrific. The target of the disclosure furthermore needs to be trustworthy and must be able to keep a secret.

The risk of harm or rejection needs to be assessed prior to disclosure and needs to be low. This risk also includes the risk and harm to the people living close to the PLHA.

Adedimeji (2010:18) further emphasises the importance of equipped service providers with regard to standardised policies on disclosure co-management. Masupe (2011:72) is of opinion that disclosure should be encouraged, although there have to be appropriate support systems in place to enable disclosure. Ideally, she suggests, an individual risk assessment should be carried out by suitably qualified healthcare professionals so that the person is well equipped for the process. She further notes that despite proclaimed “readiness” for disclosure by a person him- or herself, as soon as they are faced with the actual step of disclosure, it may be hard to carry it through, as it is such a personal issue.

In a study by Ssali *et al.* (2010:7) the researchers recommended measures that could empower people considering disclosure to make the right decisions at the right time by first analysing their personal circumstances carefully. Recommended measures include the adaptation of HIV-disclosure interventions to specifically address concerns about disclosure that may differ between communities. Professional counselling with the emphasis on disclosure issues was suggested as an intervention that could be useful in empowering those who plan to disclose their status to others.

5.5.2 Feelings accompanying the act of disclosure

The feelings of PLHA accompanying the act of disclosure can be limiting or facilitating. Feelings such as hurt, doubt, fear, futility, anxiety, anger and depression may be anticipated. On the other hand, courage, joy, peace, acceptance and relief may be present after disclosure (Greeff, 2013:87). Several authors refer to a prominent sense of fear prior to disclosure. This is mainly the consequence of anticipated stigma and rejection by others (Allen *et al.*, 2008:193; Lester *et al.*, 2002:310; Maman *et al.*, 2003:378).

5.5.3 Consequences of disclosure

There are potentially negative and positive consequences of the act of disclosure. PLHA overall have life experiences and, as was proven in the literature, stigma experiences are real. Greeff (2013:87) describes it as “real consequences”: PLHA anticipate negative consequences of disclosure prior to the act of disclosure due to their past experiences of observing what happens to other PLHA on disclosing their status. Greeff

(2013:87) divides consequences of disclosure into overall consequences, consequences to the self, reactions by PLHA, reactions by family and community, impact on intimate relationships, negative health behaviour and the loss or denial of services.

Some positive consequences are indicated as personal gains, social support and benefits to others, as well as general gains (Greeff, 2013:88). Wong *et al.* (2009:220) mention the following positive outcomes of disclosure: behavioural changes regarding sexual activities; social support was received; spiritual resilience and community involvement were visible; families provided the most overall support, and community members showed the most increase in support. Masupe (2011:72) also found that there were several positive outcomes of disclosure, namely emotional and financial support, improved emotional well-being, strengthening of relationships and an increase in safer sexual practices.

The negative outcomes that were present to a lesser extent were rejection, emotional trauma and abuse, as well as relationship breakdown. Medley *et al.* (2004:303) identified positive outcomes of disclosure such as acceptance, understanding, kindness and relationship preservation in their study on HIV disclosure practices among HIV-positive women in developing countries.

The stigma and secrecy that often surround HIV disclosure in developing countries are potential barriers to psychological support (Menon *et al.*, 2007:349). In a study by the aforementioned authors, there was an indication of evidence of high rates of emotional problems as well as peer problems in HIV-positive adolescents with low rates of disclosure. However, the authors (Menon *et al.*, 2007:349) stated that disclosure can enhance social support from friends and family, which has been proven to play an important role in improving coping, self-esteem and taking part in health-promoting behaviour.

Cusick and Rhodes (1999:14) interestingly noted that previous disclosure experiences are often used as a basis of confidence by PLHA and the belief that continuous acceptance by others will take place on disclosure of their positive HIV status. In addition, Berger *et al.* (2001:519) note that regardless of how well disclosure

experiences have gone previously, many people with HIV fear they risk a stigmatising response with each new disclosure.

Mitchell and Knowlton (2009:614) found that disclosure by caregivers of PLHA (associated stigma) debilitated the relationship between stigma and depressive symptoms to the extent that those individuals with greater stigma who had disclosed their caregiver status to others experienced fewer depressive symptoms. The following quotation illustrates the burden HIV non-disclosure can be in the lives of PLHA. The relief is profound. “A successful disclosure is almost always followed by exhilaration... The patient feels surprised at her own courage and daring. She has broken the secret and survived, no great catastrophe has befallen her or her family” (Schatzow & Herman, 1989:347).

5.5.4 Post disclosure support

Greeff (2013:88) emphasises the importance of looking after the PLHA and their emotional well-being after the act of disclosure. She refers to it as coping and managing post disclosure-related “bumps in the road”. She mentions factors such as repeated disclosure experiences, death of family members who had HIV, negative reactions from the community, medication adherence problems, problematic health-seeking behaviour and spiritual dilemmas.

In a study focusing on diagnostic disclosure to children, Lester *et al.* (2002:310) caution that delays in disclosure may possibly result in negative consequences for the child, for example impaired treatment understanding and adherence. However, they found that there were correlations between child age and increased anxiety, as older children may have a growing awareness of the implications of their illness. Masupe (2011:113) expressed the need to set up personalised local support systems for individuals dealing with the consequences of both disclosure and non-disclosure. She suggests systems such as a 24-hour helpline and local support groups made up of those who have experienced negative outcomes from disclosure of their HIV status.

An explanation of the term intervention and literature regarding stigma reduction interventions follows. The interventions found in the literature are not all necessarily aimed at HIV stigma reduction, but reflect the types of interventions within the broader

context of nursing. The researcher found some target-specific interventions in the literature to be relevant to this research project. These included HIV stigma reduction interventions targeting the partner, child, family, friend, spiritual leader and community member.

6 Interventions Aimed at Reducing Stigma Related to HIV and AIDS

Relatively few HIV stigma reduction interventions have been conducted in developing countries (Bos *et al.*, 2008:450). After an in-depth literature search for HIV stigma reduction interventions, also specifically focusing on explicit target groups within communities such as the partner, child, family member, friend, spiritual leader and community member, the researcher concluded that research in this context was indeed lacking.

Because prevention and care are interrelated, reducing of HIV-related stigma must take these two links into consideration. A holistic view of the barriers posed by discrimination should be considered, as should activities that draw attention to prevention, care and support aspects of HIV experience in a community. Members of a community exist within various “communities” throughout their lives. Successful interventions should therefore target more than one context of discrimination (Busza, 1999:7). With the development of a *comprehensive community-based HIV stigma reduction and wellness enhancement intervention*, the researcher intended to address the various contexts of HIV stigma and discrimination. Six groups, namely partners, children, close family members, close friends, spiritual leaders and colleagues or community members, were incorporated into this intervention. Such a comprehensive approach, according to Busza (1999:7), expands the scope of contributions to the response and also promotes sustainability. The most imperative literature found is presented below.

6.1 Understanding the concept intervention

The term intervention is described by Heijnders and Van der Meij (2006:354) as “the interference to prevent something or to change the result thereof”. In addition, an intervention can therefore be seen as actions or processes planned to come between,

interrupt or alter a course of HIV and AIDS stigmatisation events in order to delay or reduce stigma and ill health, and thereby improve the health and well-being of individuals, families and communities (Cambridge Advanced Learner's Dictionary, 2004; Chambers Pocket Dictionary, 1997:475; Concise Oxford Dictionary, 2001:741; English Usage Dictionary, 1987:434).

Cross (2006:367), who studied interventions aimed at addressing stigma specifically relating to leprosy, concluded that the primary step towards the development of stigma reduction interventions is the promotion of the reality that stigma is a health issue in itself. HIV and AIDS stigma is a definite health issue, as is evident from literature examined so far, It has an immense impact on PLHA and PLC. A considerable amount of research has been done on stigma and related issues in different health fields, and there is proof of some programmes that have implemented stigma reduction interventions (Cross, 2006:372; Lauver *et al.*, 2002:252; Scambler & Paoli, 2008:184; Weiss *et al.*, 2006:277). Yet, the effectiveness and impact of stigma reduction interventions are rarely evaluated (Brown *et al.*, 2003:49).

6.2 Evidence-based stigma reduction interventions

Bos *et al.* (2008:458) argue that theory- and evidence-based stigma reduction interventions are the most probable approaches to deal with AIDS stigma in developing countries. They believe that stigma reduction interventions can be victorious only when based upon a context-specific needs assessment. These interventions should be developed in close association between programme developers, stigma researchers and PLHA. Bos *et al.* (2008:451) further state that community involvement is crucial in the context of HIV and AIDS. Health-promotion planners firstly define objectives for their interventions and they also specify the changes they want to achieve in individual behaviour. Secondly, theory-based strategies to achieve these objectives are identified. These strategies are then combined into an intervention programme (Bos *et al.*, 2008:451)

Twenty-two published studies that were aimed at testing a variety of interventions to reduce AIDS stigma in developed and developing countries were reviewed by Brown *et al.* (2003:49–69). These authors concluded that the main aim of most of these interventions was to increase tolerance of PLHA among the general population. Other

interventions aimed at increasing awareness and knowledge of HIV and AIDS and promoting behavioural change.

The different intervention studies reviewed were divided into three groups on the basis study goals and target populations: information-based approaches, skills building, counselling approaches and contact with affected groups. The authors (Brown *et al.* (2003:49–69) found that only a limited number of stigma reduction interventions have been implemented, although most of them were not scientifically grounded with regard to social stigma and stigma reduction, despite the enormous need for the reduction of AIDS-related stigma. Results of the study (Brown *et al.*, 2003:62-64) show that some of the stigma reduction interventions seem to be effective, at least on a small scale and for a short period of time. However, many gaps still exist with regard to scale and duration of impact and gendered impact of stigma reduction interventions (Brown *et al.*, 2003:53).

In a literature review of 15 additional articles following upon that of Brown *et al.* (2003:49-69), Uys *et al.* (2009:1059) confirmed their findings. Their intervention combined three different strategies, namely sharing of information; increasing contact with the affected group; and improving coping through empowerment. They included PLHA and nurses in a stigma reduction intervention at a healthcare-setting level. The intervention was effective in reducing perceived stigma by PLHA and also increased self-esteem. No significant changes were marked in the stigma experienced by the nurses, but there was an increase in voluntary testing among them (Uys *et al.*, 2009:1064).

Interventions that involve contact with PLHA can be a valuable way to change the reflexive emotional reactions that people have to HIV-related stigma. Personal contact with PLHA appears to be one of the most promising approaches to reduce AIDS-related stigma (Bos *et al.*, 2008:456). When PLHA are involved at all stages of an intervention they exhibit their ability to remain productive members of their community. Both felt and enacted stigma are reduced by normalising and personalising the experience of HIV/AIDS (Busza, 1999:7).

Sengupta *et al.* (2011:1075-1087) subsequently reviewed the literature to evaluate the effectiveness of HIV-related interventions in reducing stigma. The focus of the studies

chosen by them was to evaluate HIV-related interventions in which HIV and AIDS stigma was one of the outcomes being measured. A checklist was used to extract data from accepted studies, assess their internal validity, and overall quality. Data was extracted from 19 studies, and 14 of these studies demonstrated effectiveness in reducing HIV and AIDS stigma. However, only two of these 14 effective studies were considered good studies, based on quality, the extent to which the intervention focused on reducing HIV and AIDS stigma, and the statistics reported to demonstrate some effectiveness. Sengupta *et al.* (2011:1075) found the following inadequacies: insufficient interventions targeting HIV and AIDS stigma, insufficient evaluation measures regarding stigma reduction, whether these stigma reduction intervention trials had public health significance, and lack of good quality studies.

6.2.1 Types of general interventions within the field of nursing and some HIV stigma reduction interventions

The following are descriptions of several types of general interventions that are not necessarily specifically aimed at HIV stigma reduction.

6.2.1.1 Patient-centred interventions

According to Lauver *et al.* (2002:246), patient-centred interventions within the discipline of nursing are highly valued. The authors mention that it is crucial to test whether such interventions actually improve patients' health outcomes. The term patient-centred interventions refers to interventions attentive of and responsive to individual and family characteristics, such as affective states, beliefs, goals and resources. Health messages during interventions are selectively based on the assessment of an individual's needs, for example a particular health behaviour that needs to be addressed, or the health condition of importance (Lauver *et al.*, 2002:248). The aforementioned authors conclude that there are four types of patient-centred interventions, namely personalised, targeted, tailored, and individualised interventions. They describe it within a general context in the field of nursing and regarding health behaviours that need change in general (Lauver *et al.*, 2002:252).

6.2.1.2 Counselling as an approach toward stigma reduction

Counselling assists people with various stigmatised conditions such as TB, leprosy, HIV infection or mental illness to protect themselves from the impact of stigma, which they may either come across or anticipate. Individual and group interventions aim to minimise susceptibility and enhance resilience in response to stigmatising encounters or stressful situations (Weiss *et al.*, 2006:538). Counselling programmes are used to provide information on HIV and AIDS, allocate time for intimate discussion of concerns, and provide social support for behaviour change or maintenance of safe behaviours (Brown *et al.*, 2003:53).

6.2.1.3 Cognitive interventions

Patients are not passive agents in the stigma reduction process (Heijnders & Van der Meij, 2006:361). Abel *et al.* (2004:510) developed a model, the Integrated Model of Health Promotion (IMHP), which integrates the contextual elements of living with HIV or AIDS. This model proved to be an effective means of reducing the perception of stigmatisation cognitively. Elements of the model include the context of the intervention, the intervention, and outcomes. The model suggests that emotional disclosure through a writing intervention will reorganise patients' perceptions of the meaning of HIV or AIDS diagnosis and the requisite treatment, and will therefore result in psychological, physiological and behavioural health benefits.

In his paper "One starfish at a time: Reducing HIV and AIDS stigma using fundamentals in Sociology", Moremen (2008:11) describes the positive outcomes gained from incorporating HIV and AIDS stigma reduction efforts in a course on sociological fundamentals. He found that after attending the course, students had significant positive changes in their attitudes and approach towards PLHA.

6.2.1.4 Health sector-based interventions

In the literature there is evidence of some interventions aimed at HIV and AIDS stigma reduction in the healthcare context (Mahendra *et al.*, 2007:616; Uys *et al.*, 2009:1059; Wu *et al.*, 2008:513). The study by Uys *et al.* (2009:1059–1061) was aimed at exploring the results of an HIV stigma intervention in five African countries, specifically in

healthcare settings. A brief HIV stigma reduction intervention designed for service providers who had undergone the intervention (that was designed on the basis of the findings of lessons from previous qualitative studies) reported a stronger belief in patient confidentiality and protection of patients' rights to HIV testing, reduced fear for PLHA, and better knowledge and practice of universal precautions when working with PLHA (Wu *et al.*, 2008:516).

6.2.1.5 Information-based interventions

The main approaches identified by Brown *et al.* (2003:49) were information or fact-based, focused on skills acquisition, counselling, resource provision, and contact with affected individuals, as well as the multiple intervention programmes. Information-based approaches included providing individuals or groups with facts relating to a disease or its preventative measures and may be in writing in the form of booklets, or in multimedia, and were usually presented in a formal educational set-up (Brown *et al.*, 2003:53). Uys (2003:10) is of opinion that the provision of information plays an important role in stigma reduction, as it may be used to change attitudes and increase coping. Skills acquisition programs aim at training PLHA in some coping skills (Ogden & Nyblade, 2005:10). This kind of intervention is generally used to enhance the coping strategies of participants in order for them to be able to deal effectively with situations in which they are stigmatised (Brown *et al.*, 2003:53).

6.2.1.6 Combination approaches

A combination approach implies the combination of information about stigma, the acquisition of coping skills, or empowering, prevention, counselling and support (Busza, 1999:9; Uys, 2003:28). Examples of some promising interventions that are broadly descriptive of different approaches to stigma reduction are presented in Carr and Nyblade (2007:24) in the form of case studies.

One programme in Vietnam (Carr & Nyblade, 2007:16), called "Reducing HIV and AIDS-related stigma and discrimination", was born from research conducted between 2002 and 2007. The focus of the research was the identification of drivers of stigma in order to design a strategy to challenge stigma from various angles. A project to tackle stigma and discrimination in policy, the mass media and communities, was also

developed (Carr & Nyblade, 2007:24). The project proved to be valuable in that the project activities changed attitudes among decision-makers, reporters, community members and others. It also motivated anti-stigma and discrimination action at national, provincial and community levels (Carr & Nyblade, 2007:25).

In a literature review of mostly unpublished studies on community-based HIV stigma reduction interventions in Southeast Asia, Busza (1999:7) states that the projects target stigmatisation manifested in a wide variety of community contexts, namely family and immediate community, the workplace, health services, religion and the media. The author found that the interventions described tend not to be “stigma and discrimination projects” as such, but rather limit the negative attitudes as a “side effect” of other goals through innovative approaches.

6.3 Target-specific interventions

The researcher conducted a literature review to investigate the extent of existing HIV stigma reduction interventions targeting specific groups within communities as a secondary study in this research project. The groups included a partner, child, family, friend, spiritual leader and community member. A description of some existing HIV stigma reduction interventions targeting these groups as found in the literature is presented below.

6.3.1 Stigma reduction interventions targeting the partner

After an in-depth literature search the researcher realised that studies focusing on the partner within the context of HIV and AIDS stigma were limited. The studies found in the literature focused more often on the partner with regard to HIV status disclosure (Allen *et al.*, 2008:192–100; Maman *et al.*, 2003:373–382; Serovich, 2001: 355–364; Serovich & Mosack, 2003:70–80; Sheon & Crosby, 2004:2105–2118).

Manyedi *et al.* (2010:39) confirmed this finding. They developed an intervention for coping with stigma for women whose partners had died of AIDS. This intervention was in the form of three successive sessions during which participants in the study took part in role plays, played card games on HIV and AIDS facts and knowledge about the modes of transmission, shared experiences of voluntary confidential counselling and

testing, and watched a DVD about stigma and its manifestations. They also did an exercise on the experiences of stigma, effective ways of reacting to the effects of stigma and the identification of support mechanisms for PLHA. The programme proved to be a useful tool for assisting women whose partners had died of AIDS to cope with the stigma associated with their having had a partner who had been infected and had died of AIDS (Manyedi *et al.*, 2010:43–50).

The International Centre for Research on Women (ICRW, 2006:8) developed a manual focusing on HIV and AIDS stigma and violence reduction. This manual is a guide for community-based organisations to facilitate a community-led process addressing stigma and gender violence in HIV and AIDS prevention efforts. Sallar and Somda (2011:279) suggest a communication strategy such as entertainment education to raise awareness and tolerance and to promote action in the fight against HIV and AIDS stigma towards male partners engaging in sexual activity. These authors are of the opinion that entertainment education is a communication strategy that could assist in creating awareness and reduce stigma, although the intervention message has to be culturally adjusted in order for it to be successful (Sallar & Somda, 2011:304).

6.3.2 Stigma reduction interventions targeting the child

Children of PLHA are prominent targets of HIV stigma and discrimination in their communities. The researcher recognised that children often suffer in silence, as was evident in the literature on the urgent need for anti-bullying in the HIV and AIDS stigma context. Some of the HIV stigma reduction interventions found in the literature are discussed below.

Children affected by HIV and AIDS experience high levels of stigma, including teasing, name calling, negative comments, chronic abuse and neglect. It has been suggested that programmes aimed at reducing HIV stigma should not single out children orphaned or affected by HIV and AIDS, since this might increase stigmatisation. The “Save the Children” study in China in 2005 indicated that taking children seriously, having fun with them, treating them with admiration and using group activities were found to provide psycho-social support and promoted personal development. This study also suggested implementing general anti-bullying campaigns in schools (Children in distress network [CINDI], 2007:3-14).

Another example of an HIV stigma reduction intervention is entitled “Engaging youth to provide care and tackle stigma in rural Zambia” (Carr & Nyblade, 2007:31). The aim of the programme was to involve school-aged children in the care and support of PLHA. The project took place in a rural area in Zambia, among members of school- and community-based anti-AIDS clubs. According to the findings there were intense attitude changes for the good among family members and the wider community in general. Results indicated that these attitude changes were mainly due to the home visits of the youth caregivers. There was evidence of an increase in home visits by neighbours and friends after observing the children visiting the PLHA and their families (Carr & Nyblade, 2007:31).

Benotsch *et al.* (2008:344) mention that some educational efforts focusing on children and HIV stigma reduction in Africa were undertaken. Fawole *et al.*, as quoted by Benotsch *et al.* (2008:344), conducted six weekly information sessions for secondary school children in Nigeria. The intervention mainly focused on the provision of information, but also included interactive components that captured the children’s attention. Results indicated significant increases in tolerance for PLHA.

Various media campaigns are being conducted in some African countries to raise awareness of HIV (Benotsch *et al.*, 2008:344). An example of such a local awareness programme focusing on children as target group is Sesame Street, better known as “Takalani Sesame”, which includes a puppet who is HIV-positive. The puppet discusses HIV-related issues with the young audience, whom she addresses as her friends (UNAIDS, 2005).

Another edutainment television series aimed at addressing issues relating to AIDS, including living positively and AIDS-related stigma, was presented in South Africa since 1992, with children as the main audience (UNAIDS, 2005). The storylines concerning AIDS were designed to make this an open topic, describing it as an illness that can affect anyone. The series, known as “Soul Buddyz”, was found to be a rewarding production in that some children said that they talked about the things that they had seen on “Soul Buddyz” with other people. Many of those with high exposure to “Soul Buddyz” on television were also found to be willing to be friends with someone living with HIV (UNAIDS, 2005).

In attempting to reduce HIV stigma and discrimination amongst adolescents in Hong Kong, Lau *et al.* (2005:88) designed an intervention during which a video was shown to the participants, followed by a discussion session, knowledge-based quiz and active participation in the form of a creativity exercise session during which greeting cards were designed and made specifically for PLHA. Prior to the cognitive intervention, participants (mainly high school students) revealed high levels of stigmatisation and discrimination towards PLHA. Research results suggest that the intervention was efficient in HIV stigma reduction towards PLHA.

Moletsane *et al.* (2009:18-28) conducted a research study on Grade 8 to 12 learners in a school in rural KwaZulu-Natal in South Africa. Visual as well as voice aids were used during the study. The study aimed at exploring current perceptions of HIV and AIDS by asking participants to make drawings and take photographs of their views of HIV and stigma in their communities. They had to present their captured views on HIV stigma. A dramatisation on their views of HIV stigmatisation was also presented. This intervention proved to be effective, as it improved awareness of HIV and AIDS stigmatisation and assisted in lowering perceived stigmatisation.

6.3.3 Stigma reduction interventions targeting the family

Within society, the family structure is originally viewed as the first line of support for any given challenging situation. It is also true within the context of HIV and AIDS. Many studies have proven that close family members are often the first line of choice for disclosure (Hosegood *et al.*, 2007:1251; O'Brien *et al.*, 2003:731). One can envision that stigmatisation by one's family members would be particularly distressing. However, the family is frequently the co-target of HIV stigma and discrimination, in which case it would be associated stigma (Holzemer *et al.*, 2007:542, 547; Watson, 2008:234). The family and their well-being are therefore directly affected by the punishing and divergent acts towards their HIV-infected family member. A study by Ferreira (2004:14) on HIV and AIDS and family well-being in South Africa strongly recommends that the national government, NGOs, and local communities work together in order to meet the needs of affected communities and their families. Here are few examples of studies focusing on the family in HIV stigma reduction.

An example of an intervention aimed at HIV stigma reduction in the community is the “FARM project” (Foundation for Agricultural and Rural Management) in Thailand, which provides training for family members and community members on home-based care that will aim at reducing HIV stigma in the family context by combating myths and reducing cases of isolation. This intervention proved to be of benefit to the family and community, as an increased willingness among PLHA to disclose their HIV status was noted (Busza, 1999:10).

Another example of a study focusing on close family members and HIV stigma is that of Krishna *et al.* (2005:483). The authors attempted to understand the impact that stigma had on the family system, as the family in the Indian context usually represents emotionally strong bonds. Mohanan and Kamath (2009:8) conducted a study on the effect of family support on morbidity, mortality, quality of life and economics within a family in a developing country, with at least one person being HIV infected. They found that more rigorous studies were necessary in order for them to be able to draw conclusions regarding the effect of family support on the reduction of mortality and morbidity in PLHA.

In a study that included PLHA, close family members, leaders and other community members, Gaudine *et al.*, (2010:1) found that each of these included groups experienced HIV-related stigma differently, and that no intervention aimed at stigma reduction had been implemented. However, their study should assist in the development of culturally sensitive approaches to reduce HIV-related stigma.

6.3.4 Stigma reduction interventions targeting the friend

When one considers the literature on associated HIV stigma studied so far, it is undeniable that a person who is closely associated with PLHA through friendship will be stigmatised and perhaps ill-treated due to their mere association with these individuals. It is therefore important to include a friend in an HIV stigma reduction intervention such as the one designed by Greeff (2010) in this research project.

In no portion of literature found during the search of literature on HIV and AIDS stigma reduction interventions did the researcher find any interventions specifically targeting the “friend” of PLHA. It is assumed that the friend would form part of the community

group of stigma reduction programmes. This emphasises the significance of this comprehensive intervention, individualising stigma reduction programmes. Individuals such as neighbours living together in a community could be friends for that matter.

Nyblade *et al.* (2009:1), for example, describe an HIV stigma reduction intervention that was implemented in two urban communities in Vietnam that was attended by several individuals, some of whom knew each other, for example neighbours. The main aim of the intervention, which was presented in the form of workshops, was to increase awareness of HIV stigma, reduce fear-driven stigma (i.e. explanation of the fact that HIV cannot be transmitted by merely sharing a toilet), reduce value-driven stigma (counteract blaming of PLHA), as well as discrimination. The intervention was successful if the qualitative research results are considered. It was found that the most common behaviour changes were an increased willingness to communicate freely with and sit close to PLHA and drink and eat in their homes (Nyblade *et al.*, 2009:2).

6.3.5 Stigma reduction interventions targeting the spiritual leader

Spiritual leaders are mainly viewed as individuals carrying authority within a community and they are usually respected by multitudes. Spiritual leaders with regard to the context of this study may entail a religious leader or a traditional healer. The researcher found a few interventions in the literature aimed at HIV stigma reduction involving spiritual or religious leaders and these will be discussed.

While many outreach projects that convey their messages through valued members of the community help to reduce stigma against PLHA, when such reinforcement comes from spiritual leaders, the impact can be significantly greater, as it carries the added authority of an accepted ethical system (Busza, 1999:13). An example of a stigma reduction programme is the Malaysian AIDS Council managing to gain the support of the Minister for Islamic Affairs for its activities, and 9 of 14 state religious authorities attending the initial workshop. After attending discussions that included technical information, presentations by PLHA Muslims, and philosophical debates about HIV and the Koran, religious authorities in Malaysia introduced their own working groups to continue investigating the issues raised.

The Sangha Metta (“Compassionate Brethren”) project was introduced by a lay Buddhist teacher in Northern Thailand in 1997. The aim was to respond to community needs involving HIV prevention and care. The motivation was to make use of existing community resources and extend the traditional role that Buddhist monks and nuns play in social welfare in the region. Reported outcomes showed that training and support were being provided to an expanding body of Thai monks and nuns. As a result monks have assisted in the promotion of acceptance of PLHA. Monks also became a source of support for PLHA with disclosure difficulties. PLHA also started to take more part in religious and community festivals. The Sangha Metta project has further assisted in founding similar programmes in six neighbouring countries. The Sangha Metta training model has also been used effectively with Christian, Hindu and Islamic leaders from Sri Lanka, Nepal, Pakistan and Afghanistan (UNAIDS, 2005:23).

Focusing narrowly on small-scale church-based interventions, Hartwig *et al.*, as cited by Campbell and Deacon (2006:9), highlight the value of workshops in providing opportunity for reflection in a complex and conflicting environment, and for the construction of narratives about ways in which individual religious leaders can create opportunities to combat stigma. There is a lack in literature within the African context.

6.3.6 Stigma reduction interventions targeting the community member

Interventions that reduce stigma and discrimination at the level of the family and most immediate community generally rely on outreach activities with the aim of demonstrating the low risk associated with caring for or coming into close contact with PLHA. In Cambodia, for example, there are home visit care teams that visit suspected PLHA on a weekly basis and then train their primary caregivers via demonstration that close contact does not cause HIV transmission. The members of the team use educational messages to clarify what activities do or do not carry risk of transmission (Busza, 1999:9).

The community as a whole has an important role to play with regard to enhancing their collective health and socioeconomic well-being (WHO, 2003:7). It is therefore important to implement community-based projects for actual matters such as HIV and AIDS stigma. This “disease” in itself affects a community as whole and not mere individuals.

According to Siyam'kela (2003:26) it is sensible to make use of communities in HIV and AIDS stigma work, as they typically understand the local needs and can therefore ensure that interventions are responsive to the particular needs of their community. It is also here where the PLHA live and this results in PLHA participating in services and programmes aimed at them.

In a study by Watson (2008:5) on a community-based collaboration to support the older person in the world of HIV/AIDS, the author focuses on this vulnerable group (previously disadvantaged elderly community) affected by HIV/AIDS. She looks into the particularly important group's needs on a physical and psychological level and the importance of collaboration by services to sustain these individuals comprehensively. Groups such as particular stakeholders within the community are addressed and recommendations for future sustainability are provided. Although the main aim of her research is not merely the reduction of HIV and AIDS stigma, she certainly addresses this problem as being part of the detraction of their overall well-being.

In a study by Blignault *et al.* (2009:231) on stigma reduction it was found that by using personalised community education sessions in conjunction with meetings with community leaders, increased self-reported knowledge of participants about and attitudes towards the stigmatised illness were anticipated.

A community participation intervention for the reduction of HIV-related stigma in Thailand (Apinundecha *et al.*, 2007:1157) was found in the literature. The approach utilised in this study was action research to develop and implement an intervention to reduce HIV and AIDS stigma. The intervention improved the levels of accurate HIV and AIDS knowledge among participants and also reduced the level of community stigma in the intervention group compared to the control group.

This study demonstrates the usefulness and effectiveness of a community-based intervention with the aim of empowering the community with regard to HIV and AIDS stigma (Apinundecha *et al.*, 2007:1163). Winiarski (2004:36) emphasises this statement when he writes that the "real work" regarding HIV and AIDS and the practices that lead to a rise in the epidemic is likely to occur at community level.

The Academy for Educational Development (AED, 2007:3) designed a toolkit for action against HIV stigma. It was designed by and for HIV trainers in Africa to assist them in the planning and organisation of educational sessions to raise awareness and promote practical action to challenge HIV stigma and discrimination. The toolkit has been translated into several languages. The toolkit contains information on HIV stigma that is comprehensible to the lay person in the community; some illustrations with scenarios of manifestations of HIV stigma that are easily identifiable and based on research findings. Some of the topics discussed are “the family and stigma”, “children and stigma” and “thinking about change: Developing skills for advocacy”. It is therefore an elementary, comprehensive educational tool for the lay person in the general community (AED, 2007:5).

Numerous community-based interventions with multiple activities demonstrated substantial changes in stigma at the community level in Thailand, Tanzania, Vietnam, and Zambia. Each of these programmes focused on community participation. Although all these programmes included awareness-raising and sensitisation and HIV knowledge awareness, the exact content and modalities of these programmes are too diverse to easily gather which approaches are most responsible for success. Intervention studies in Vietnam and Tanzania suggest that opportunities for ongoing discussions about values and beliefs are imperative for reducing more than fear-based stigma and combating other drivers of stigma (UNAIDS, 2009:3; ICRW, 2006:8).

7 Summary

Stigmatisation within the context of the AIDS epidemic was described in this literature review, together with several interdependent terms. The pandemic is reaching epic proportions and people are still dying at a high rate, despite the fact that it has been almost three decades since the first case of HIV was reported. The fact that HIV and AIDS are highly stigmatised conditions makes the task of curbing the disease difficult.

Stigmatisation has been taking place since ancient times, as was noted in the Bible, where lepers were discriminated against and treated as outcasts. The original definition of stigma by Erving Goffman (1963:3) was the definition of choice within this study and

encompasses “an attribute that is deeply discrediting”. Alonzo and Reynolds (1995:304), following Goffman, refer to stigma as a “powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons”.

Discrimination entails behaviour that leads to unfair treatment. Some authors suggest that discrimination always follows upon stigmatisation. Others are of the opinion that stigmatisation can occur without involving discriminatory actions.

The terms stigmatisation and discrimination are mostly described together, and the researcher concluded that the act of discrimination is almost inevitable within the context of HIV and AIDS stigmatisation. Several HIV and AIDS stigma conceptual frameworks as found in the literature were described, and the conceptual model of HIV and AIDS stigma from five African countries (Holzemer *et al.*, 2007:541–551) was introduced as being the theoretical ground for this study. The authors attempted to conceptualise stigma as a dynamic process with more to it than merely the types of stigma. They came to the conclusion that stigma is an extremely dynamic process.

Stigma seems to be manifesting itself differently, depending on the context (urban or rural). Literature suggests that it is important to take into account the broader context of culture when comparing stigma within urban and rural settings. Some studies found that stigmatisation is highly prevalent within the rural setting, while others indicated that urban settings are more likely to cause stigmatising behaviour.

HIV status disclosure as a major and life-changing event in the lives of PLHA was explored in terms of the process of disclosure and categories of disclosure, as well as enabling and debilitating factors for disclosure. The importance of responsible disclosure management was discussed. Potential disclosure outcomes were investigated and the importance of postdisclosure support was accentuated. Interventions with the aim of reducing HIV and AIDS stigma found in the literature were described, and the researcher concluded that there is a lack of HIV stigma reduction interventions, especially within the context of the broader community targeting both PLHA and PLC. The sustainability of the positive effects of the interventions is also rightly being questioned.

The three articles reporting on the present research follow. The first focuses on the experiences of HIV-related stigma of, and disclosure by people living with HIV or AIDS in an urban and a rural setting, with the last two presenting results of the comprehensive community-based HIV stigma reduction and wellness enhancement intervention.

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SECTION C: ARTICLES

ARTICLE 1: HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting

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HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting

Heleen French¹, Minrie Greeff¹, Martha J Watson¹ & Colleen M Doak².

¹North-West University, Potchefstroom Campus, South Africa

² Vrije University, Amsterdam

Corresponding Author:

Prof Minrie Greeff, North-West University, AUTHeR, Private Bag x 6001, Potchefstroom, 2520, South Africa. Tel: 27 18 299 2992. Fax: 27 18 299 2088.

Email: Minrie.Greeff@nwu.ac.za

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Bios

Heleen French, MCur (Clinical Nursing) is a PhD candidate completing her studies with the African Unit for Transdisciplinary Health Research at the Potchefstroom Campus of the North-West University, South Africa.

Prof Minrie Greeff, PhD (Psychiatric Nursing) is a professor in research in the African Unit for Transdisciplinary Health Research at the Potchefstroom Campus of the North-West University, South Africa.

Dr Martha J. Watson, PhD (Nursing Science) is a senior lecturer for the School of Nursing Science at the Potchefstroom Campus of the North-West University, South Africa.

Dr Colleen M Doak, PhD (Nutrition) is an Epidemiologist and assistant professor in the Section of Infectious Disease, Department of Health Sciences, VU University in Amsterdam.

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HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting

Abstract

Human Immunodeficiency Virus (HIV) remains a highly stigmatised condition for people living with HIV (PLWH) and people living close to them (PLC) in the African context, as well as in other countries. PLWH fear stigmatisation and its consequences and are therefore reluctant to freely disclose their HIV-positive status. The research objectives for this study were to explore and describe how HIV stigma and disclosure experiences at present impact the lives of PLWH in a country where the HIV infection rate is the highest in the world, and to explore whether there are differences between experiences in urban and rural settings. A qualitative interpretive description approach was followed and participants were selected through purposive voluntary sampling. Data collection took place using in-depth interviews with 23 PLWH, 11 of whom resided in an urban setting in North West, South Africa, and 12 resided in a rural setting in the same province. The data was manually analysed through open coding. Findings indicated that HIV stigma and disclosure experiences in the urban and rural settings were mostly similar, with very few differences. The HIV stigma experiences expressed by PLWH depicted negative behavioural patterns and attitudes towards them; fear from the community of being infected by PLWH, and lastly negative self-judgment by PLWH themselves. During disclosure PLWH were unsure and they described it as a stressful event. They cautiously considered to whom to disclose their condition and what benefits disclosure will hold. They further had to handle forced disclosure due to being identifiable in healthcare settings. HIV stigma and related disclosure practices remained a problem, which detrimentally affected treatment and support efforts. Recommendations focused on HIV stigma reduction in the community that needed to involve PLWH and PLC. Responsible disclosure management should form an essential part of HIV stigma reduction programs.

Keywords: AIDS; disclosure; HIV; rural; stigma; urban

HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting

1 Introduction and Problem Statement

This study formed part of a larger 'comprehensive HIV stigma reduction and wellness enhancement community intervention' study and built on the findings of Holzemer et al. (2007), who intensively studied the context of HIV stigma in Africa. From their findings a conceptual model of HIV/AIDS stigma from five African countries was developed, focusing on both the context and process of stigma. Two validated stigma scales specifically for use in the African context were developed. A health setting-based intervention to reduce HIV stigma was also conducted (Uys et al., 2009). The current larger study was aimed at adding to the body of knowledge on HIV stigma by focusing on people living with HIV (PLWH) and people living close to them (PLC) in a community context.

The focus in this article is on a comparison between the HIV stigma and disclosure experiences of PLWH in an urban and a rural setting, as well as on gaining an understanding of the present form it displays in a country like South Africa, which has the highest infection rate in the world (United Nation Programme on HIV/AIDS [UNAIDS], 2012). However, literature on international level also indicates that HIV stigma still remains an issue everywhere (Charles et al., 2012; Galvan, Davis, Banks, & Bing, 2008; Lewis, 2011; National AIDS Manual [NAM], 2012; Rochkind, DuPont, & Ott, 2009; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; UNAIDS, 2012). The conceptualization of stigma as described by Alonzo and Reynolds (1995, p. 304) as a "powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons" served as definition of choice in this study.

HIV remains a pandemic that defies comprehension, as is evidenced by statistics that indicate that there are currently approximately 34 million people living with HIV worldwide. Sub-Saharan Africa remains the most affected region (UNAIDS, 2012). Recent evidence shows that the incidence of HIV is declining, yet the prevalence is

increasing due to the fact that more people are now living with the disease (Department of Health, 2011; Khumalo, 2012). However, HIV remains a highly stigmatised condition mainly due to people's perceptions of the probability of immoral behaviour that may have been the cause thereof (Brandt, 1987; De Bruyn, 1999;). This leads to many people being affected by the stigma of HIV.

The prediction by Jonathan Mann, founder of the World Health Organisation (WHO) Global Programme on AIDS in 1987, has undeniably become a reality. He identified three phases of the HIV and AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the last phase: the epidemic of stigma, discrimination, and denial, in which we find ourselves today. He noted that the third phase is "as central to the global AIDS challenge as the disease itself" (Mann 1987, p. 2). Parker and Aggleton (2003) mention that for nearly two decades, issues surrounding HIV and AIDS such as stigma, discrimination and denial have been poorly understood and often marginalised within national and international responses.

Several models describing various aspects of HIV stigma were found in the literature (Alonzo & Reynolds, 1995; Herek, 1990; Link & Phelan, 2006; Parker & Aggleton, 2003; Siyam'kela, 2003). Few have focused on Africa, however, where HIV and stigma continue to pose a major challenge (Holzemer & Uys, 2004). The work by Holzemer et al. (2007) that was mentioned earlier attempted to provide an in-depth understanding of the process of HIV stigma within an African context. Stigma is referred to by them as a complicated process that occurs within a context of the environment, healthcare system and different agents. The stigma process itself includes triggers of stigma, stigmatising behaviours, types of stigma and outcomes of stigma. The stigma process is triggered by a variety of factors, of which HIV disclosure is an example. Stigmatising behaviour towards PLWH in various degrees then follows, and can be classified into types of stigma, namely received stigma, internal stigma and associated stigma, with outcomes of stigma being the last aspect mentioned in the process of the model.

The literature regarding types of stigma contains various authors referring to it in a variety of terms. Received stigma (Holzemer et al., 2007), for instance, is also referred to as enacted stigma (Siyam'kela, 2003), or the etic view (outsider's view) (Weiss et al., 1992). Dimensions of received stigma are summarised by Greeff et al. (2008b) as

neglecting, fear of contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping. Similarly, internal stigma (Holzemer et al., 2007) is also referred to as felt stigma (Siyam'kela, 2003) and the emic view (insider's view) (Weiss et al., 1992). Perceptions of self, social withdrawal, self-exclusion and fear of disclosure are mentioned by Greeff et al. (2008b) as dimensions of internal stigma. Associated stigma (Holzemer et al., 2007), the third type of stigma, was seen as a mere theme under external stigma by Siyam'kela (2003), and was also referred to as secondary stigma (Ogden & Nyblade, 2005). Authors therefore mainly agree that there is stigma directed towards the stigmatised, with PLWH stigmatising themselves, and stigma attached to those associated with PLWH, such as family, spouse and healthcare workers.

As was mentioned, the last phase in the stigma process as described by Holzemer et al. (2007) refers to stigma outcomes: poor general physical and mental health, violence, poor quality of life and reduced access to care. Other authors mention additional aspects or confirm those mentioned by Holzemer et al. (2007): reduced access to and utilisation of effective services; mental and physical wellbeing; physical abuse; rejection and discrimination; breach of confidentiality and impact on people living close to PLHA (Link & Phelan, 2002; Phetthu & Watson, 2011; Siyam'kela, 2003; Vanable, Carey, Blair, & Littlewood, 2006; Wingwood et al., 2008). Stigma further negatively impacts on aspects such as ART adherence, lifestyle adaptation; life satisfaction and HIV disclosure (Dlamini et al., 2009; Greeff et al., 2010; Makoae et al., 2009; Shacham, Small, Onen, Stamm, & Overton, 2012).

HIV stigma occurs in both urban and rural settings and authors differ as to whether stigma is the highest in urban or rural settings. It is also part of the focus of this article to determine whether any differences exist between the experiences of stigma in an urban and a rural setting. Although it was found in research done by Naidoo et al. (2007) that the urban groups described more experiences of stigmatisation and discrimination than did the rural groups, other studies showed that stigmatisation more often occurs in rural than in urban communities (Bond et al., 2003; Bunn et al., 2008; Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; Slied, Poggenpoel, & Gmeiner, 2001). The difference boils down to factors such as social structure, economic status and literacy levels. According to Duffy (2005), HIV and AIDS in the context of poverty result in considerable suffering. The issues surrounding prevention, transmission and alleviation

are complex, but one very important concept sustaining the epidemic is stigma. Poverty has been shown to increase susceptibility to HIV, while HIV aggravates poverty (Parker, Easton, & Klein, 2000).

As was indicated earlier and found in the literature, HIV disclosure forms a significant dimension of understanding HIV stigma and is often spontaneously discussed in HIV stigma research (Greeff et al., 2008a; Holzemer et al., 2009; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009). Such disclosure is generally perceived as a stressful event and many people prefer to keep their HIV-positive status a secret or avoid seeking healthcare due to the fear of being stigmatised (Derlega, Winstead, Greene, Serovich, & Elwood, 2006; Elford, Ibrahim, Bukutu, & Anderson, 2008; Kruger, Greeff, Watson, & Fourie, 2009).

Disclosure is described by Greeff (2013) as a complicated process and it involves a shared responsibility between healthcare workers and patients. A lack of guidelines on responsible disclosure management was identified in the literature and is currently a challenge for healthcare workers (Adedimeji, 2010; Greeff, 2013; Naeem-Sheik & Gray, 2005). These authors, as well as Maman and Medley (2004), stress that disclosure is a process that should occur over a period of time and not on the spur of the moment. The process of disclosure is unique to each individual, as there is an interaction of different factors that influence the progression thereof (Masupe, 2011). Negative outcomes such as verbal and physical abuse are mostly the reason for non-disclosure by PLWH (Dlamini et al., 2007; Elford et al., 2008; Gorbach et al., 2004; Paxton, 2002; Van Dyk, 2002). "Costs of disclosure", as it is described by Serovich (2001, p. 356), should be weighed against the potential benefits thereof (Derlega et al., 2006).

Disclosure practices in the African context seem to differ from those in other countries mostly because cultural differences are prominent factors influencing disclosure practices (Greeff et al., 2008a; Masupe, 2011; Raganya, 2003). It was found that collectivist societies such as in India and Africa would rather disclose their status to close family members due to the high value placed on relationships within families (Greeff et al., 2008a), whereas individualist societies such as in the United States of America (USA) would more easily disclose their status to someone such as a friend (Vira, 2003). It is crucial for PLWH to be equipped with skills to manage their disclosure

practices effectively despite their cultural background. Greeff (2013) refers to fixing more attention on responsible disclosure management.

From the literature reviewed it was evident that HIV stigma and non-disclosure are still durable problems at national as well as international levels. Both these aspects negatively affect PLWH. However, HIV stigma manifests itself in different ways and could differ in contexts. It also still remains a question whether urban and rural differences are clear. The choice of disclosure or non-disclosure is further often influenced by the presence of HIV stigma and discrimination. Knowledge of the aspects mentioned with regard to both HIV stigma and disclosure experiences can impact on the nature of interventions in this arena.

2 Research Question

What are the HIV stigma and disclosure experiences of PLWH in both an urban and a rural setting and do these experiences differ in the two settings?

3 Research Objectives

In this research the main objectives were to explore and describe the current HIV stigma and disclosure experiences of PLHA within the context of both an urban and a rural setting in the North West Province, South Africa. The researcher further aimed at exploring any associations between the HIV stigma and disclosure experiences and whether there were any differences in these experiences between urban and rural settings.

4 Research Design

A qualitative interpretive description research approach (Thorne, 2008) was used to explore and describe the HIV stigma and disclosure experiences of PLWH. The research was based in both urban Potchefstroom and rural Ganyesa. Both settings

mainly included individuals from an African background with Setswana as home language, living in poverty due to high rates of unemployment (North West Provincial Government, 2013). The aim of including individuals from both urban and rural settings is mainly to recognize, if any, differences from these groups that could necessitate adaptations in the intervention for future use. It is not a comparative study in essence.

5 Method

5.1 Sampling and recruitment

For the purpose of this study, the population from which participants were identified included HIV-infected people residing in the greater Potchefstroom area as the urban group, and those from Ganyesa as the rural group. Purposive voluntary sampling was utilised in this research. The recruitment of participants was based on a set of inclusion criteria: they needed to be aware of being HIV positive for a period of at least 6 months; they had to be 18 years or older; and had to be able to communicate in English, Afrikaans or Setswana. A standing relationship with the community facilitated entry into the community. The research assistant linked with local non-governmental organisations (NGOs) as mediators and identified PLWH who were prepared to participate. The sample size was 23 PLHA, 11 (10 female, 1 male) of whom were from the urban Potchefstroom setting, and 12 (9 female, 3 male) of whom were from the rural Ganyesa setting. Data saturation in both settings was achieved at approximately seven interviews.

5.2 Data collection

The research assistant made appointments with each potential participant, informing them of the arranged date, the time of interviews and the venue of their choice that would afford them privacy and no interruptions. They were told what to expect during interviewing and were assured of confidentiality and anonymity, as well as made aware of their right to withdraw at any stage. All computer systems used were only accessible by directly involved researchers using access codes, and documents were kept in locked cabinets (Burns & Grove, 2005; Polit & Beck, 2006).

The risks and benefits of participating in the study were also explained to participants. The risks included that they would be making their HIV-positive status known to all the people from the various groups; some of their privacy would be lost during the intervention, though not during the reporting of the research results; and sharing experiences might cause discomfort. Benefits included learning about HIV stigma, and how to cope with stigma and become empowered to become leaders in HIV stigma reduction. Participation would also assist researchers to develop a comprehensive community-based approach to reduce HIV stigma. The researcher, aware of the participants as a vulnerable group, made them aware of the availability of counselling should they be in need thereof. The participants then gave written informed consent.

The two open-ended questions for use in the in-depth interviews were formulated beforehand and evaluated by experts for appropriateness and understandability. The questions were further assessed by conducting an interview and then included in the data set. The participants were asked to respond to the following two open-ended questions: “Tell me about your experience with stigma as a person living with HIV” and “Tell me about your experiences of having to tell people that you are HIV positive.”

The interviews individually took approximately one to one-and-a-half hours to complete. Several communication techniques were applied, such as making use of minimal verbal responses, paraphrasing, reflection, clarification, probing and making use of summarisation. Field notes (observational, theoretical, methodological and personal notes) were made by the researcher directly after the interviews. These notes served as a retrospective overview and verification of the process and findings and enhanced trustworthiness (Botma, Greeff, Mulaudzi, & Wright, 2010; Greeff, 2005). Data saturation was achieved after approximately seven interviews and this principle is also a determinant contributing to trustworthiness.

5.3 Data analysis

All the digital voice-recorded interviews were transcribed verbatim for data analysis (Botma et al., 2010; Hek & Moule, 2006). The researcher made use of Creswell’s generic qualitative analysis approach, which was thematically driven (Creswell, 2009). Data analysis was done manually. The steps taken by the researcher involved the reading of the data, followed by a detailed analysis during which themes were grouped

under major topics and topics that stood out as leftovers that did not really fit into a specific category. From the different topics identified, the data was then assembled into categories and themes. Data was interpreted and conclusions were drawn. Analytical bias was dealt with through the use of a co-coder to reach consensus.

6 Protection of Human Participants

In addition to aspects already mentioned regarding ethical considerations, this research project was approved by the Ethics Committee of the North-West University (NWU-00011-09-a1), as well as by the Provincial Department of Health.

7 Trustworthiness

Principles as set out by Lincoln and Guba (in Krefting, 1991), were applied in order for trustworthiness to be ensured. Truth value was guaranteed through prolonged engagement during the in-depth interviews and reflexivity applied through the writing of extensive field notes and having regular discussions with study leaders. The sampling was well thought through, with a specific urban and rural demography. Thick description of the methodology and data ensured applicability. Consistency was ensured in that an audit trail as well as stepwise replication was possible due to a thick description of the methodology. The use of a co-coder further enhanced consistency. As was mentioned before, neutrality was ensured with the audit trail and triangulation of investigators due to the presence of more than one researcher executing the research, and reflexivity confirmed the results. The research was authentic in that it gave a sense of the reality of HIV stigma and disclosure experiences to the reader.

8 Results

In contrast to the literature, the findings of this research showed no real differences in the findings for both the urban and the rural groups in their expressed experiences of

HIV stigma and disclosure. The research findings were pooled due to the similarity. In a few specific cases differences were observed, and these were mentioned specifically. The discussion of findings was enriched with applicable quotes from participants during the study.

It was noteworthy that the overruling experiences expressed by PLWH were negative in nature. Stigma experiences by PLWH were described as focusing on negative behavioural patterns towards them; negative attitudes towards them; fear of the community of being infected by PLWH; and negative self-judgment by PLWH. The expressed disclosure experiences revealed the following themes: disclosure as an unsure and stressful event in the lives of PLWH; the decision by PLWH of whom to disclose to; benefits of disclosure for both discloser and receiver; and forced disclosure due to distinguishability in healthcare settings.

8.1 Expressed stigma experiences by PLWH

The first three themes focused on stigma experiences due to other people's behaviour or attitudes towards PLWH, but the last theme indicated how strongly PLWH also judged themselves. The first theme reflected on the *negative behavioural patterns towards PLWH*. Both verbal and physical actions were noted. The participants mentioned that the act of *gossiping* took place in an extremely obvious fashion. "They scratch each other. If you look back, you find them talking about you." Blaming was used as a form of *verbal abuse*: "I always told you don't do this and this and this you do it. Now is your time. It is your result now." However, calling them by derogatory terms was more prevalent in the urban setting: "You are a slut"; and "You are a prostitute". Openly rejecting PLWH was evident: "That one I don't like him because he is positive." PLWH were constantly *pestered* regarding their weight loss and the probability of dying soon: "Why did you lose weight like that?" and "Have you bought a coffin yet?" So much was lost by PLWH when they were *chased from their houses* and seen as not deserving a home: "You see now. Go outside of my house. You can't sleep in my house." From this theme it was evident that negative behavioural patterns towards PLWH in their various forms remained a shocking reality and mainly took the form of gossip, verbal abuse, pestering and PLWH being chased from their houses.

The second theme focused on the *negative attitudes towards PLHA*. *Rejection* by the community was a generally expressed experience: “Not coming to me because of my status”; “They don’t want to sit with me anymore.” The participants from the urban setting specifically mentioned being *dehumanised*: “Because I feel that they are classifying me as a non-living person.” *Judgmental attitudes* towards PLHA showed that the community felt they deserved their HIV-positive status due to promiscuous sexual behaviour: “This one changes different partners. Maybe she is having different partners; that is why she is HIV.” They mentioned that the people look at them with *disgust*: “You can see because he or she doesn’t look you with a nice eye.” The fact that the community *looked down upon them* made them feel that their social status was one of not being “good enough” to be involved in friendships anymore: “They were good friends. Every time they are with me. When I becoming HIV they are away from me.” The attitudes towards PLWH mainly became obvious through rejection, by dehumanising and judging them, as well as by looking down on them in disgust.

Theme 3 was about PLWH’s expressed experiences of the *community fearing to be infected*. *Fear of contagion* was still notably high in the community, leading to most PLWH being treated as people suffering from a disease that is extremely contagious. Even just *talking to PLWH* was seen as risky, despite all the current educational efforts in society: “The other people they don’t want to talk to you because they are scared because they can get positive and they can get HIV when they talk to someone that is positive.” *Not sharing eating utensils* was still an issue: “Because people they don’t want to eat the same dish with you. They don’t want to drink the same cup with you.” If PLWH were involved in *food preparation*, for example during weddings and funerals, they experienced that they were either denied the task or overtly watched when dealing with food. This experience was prominent and described by practically all participants: “Other people when see that you are HIV, or other people when you cook food, they can’t eat that food. They think that you have put – what is it? – that virus inside.” From the above it is clear that ignorance and/or a lack of education was still astonishingly prevalent and was expressed through not talking to PLWH, sharing eating utensils and – very prominent in this study – not wanting them involved in food preparation.

The previous three themes focused on what the community did to stigmatise, but the fourth theme focused on how *PLWH also self-stigmatised through negative self-*

judgment. They perceived themselves as being *useless or not respectable* enough to be part of society's normal gatherings: "You feel like you can stay in the house, not going outside to meet with people." *Embarrassment* was a notable experience: "It makes you feel small to go to the street." They indicated that they often *socially withdrew or self-isolated* once their HIV status was known and the reality kicked in: "After you have tested positive, you stay indoors." *Suicidal ideation* was expressed by various PLWH, indicating a strong sense of *hopelessness*: "I even thought of committing suicide." Experiencing the harsh behaviours and attitudes of people in the community and seeing the fear of their community becoming infected by them led to the negative self-judgment displayed by PLWH feeling useless, not respectable and embarrassed, wanting to socially isolate themselves or even expressing suicide ideation. The impact of HIV stigma was therefore intense, leaving PLWH often disheartened and desolate.

8.2 Expressed disclosure experiences by PLHA

The second main area of expressed experiences focused on PLWH's expressed disclosure experiences in both the urban and the rural settings. Theme 1 reflected on findings expressed by PLWH on disclosure as *an unsure, emotional and stressful event* in their lives. They expressed *worrying about disclosure* a lot: "Firstly I was afraid of telling them. I feel like they are going to cry and they are going to treat me bad or asking me how do you get that illness, where did you get it?"; "I've been asking myself those questions before I told them." It was acknowledged that it took a *great amount of courage and bravery* to disclose one's HIV-positive status: "I needed the courage. I prayed to God: God, give me the strength and courage to tell my status."

A strong sense of *fear of various losses* was expressed by PLWH, mostly referring to loss of friendship, loss of a partner, and loss of security in the form of housing: "So maybe when I have to tell everybody that I have HIV, at the last minute I will be alone"; "The most people I've told, I tell them, my boyfriends the first time. Now I've lost four because I am just talking to them"; "Maybe they can say I must go and have another place to live." *Fear of disclosure by others without their consent* came through strongly. Friends and healthcare providers were identified the most: "I told them because I trusted them. Then they (friends) went and disclosed on my behalf to others"; "I am afraid the nurse is talking about me. She was at the street and she was talking about me." *Anger*

was expressed after finding out that others had disclosed without their consent: “I feel so angered. I feel so angered because I think it is my secret to know that I have got HIV positive, and don’t go and tell the persons.”

Because of the negative experiences mentioned, PLWH expressed their *preference to not disclose their HIV status* to others anymore as a means of coping with previous negative experiences post-disclosure: “Until now he didn’t come back. So now I am feeling a bit scared to tell someone to tell people about.” It was therefore evident that PLWH worried a lot about disclosure and had to build up courage to disclose. Fear of several losses inhibited disclosure practices. Having others then disclose without their consent led to anger, not wanting to disclose and constantly having to cope with negative experiences post-disclosure.

The second theme mentioned by PLWH was the decision by PLWH *with regard to whom to disclose to*. PLWH in this study *avoided disclosure to friends*, mainly due to a fear of disloyalty and loss of friendship: “Even my friends, those people I was going to school with. I never told them what was going on.” The people that they actually decided to disclose to were *mainly family members*. Their *mothers* were almost unanimously mentioned as the first person to whom they disclosed due to the fact that she was such an important figure in their lives: “Your mother is your mother. She is going to get hurt. But after, she will accept what is going on.” *Other family members* were also identified as people to whom PLWH disclosed: “The first person who welcome me home was my mother. After that my uncle, my sister.” It was, however, noted that there was a tendency to *delay disclosure to children*. They did not want to expose their children to negative and distressing news such as that a parent or parents were infected with HIV: “I don’t want to affect my child because he’s at school now. I want to finish at the school. He can hear from me when he is grow up enough for I’m positive.” It therefore seemed that deciding to disclose involved a lot of thought about who it should be done to, and seemed to take the order of avoiding disclosure to friends and rather disclosing to specifically mothers first, and then other family members. Delaying disclosure to children became evident.

In theme 3 PLWH expressed the *benefits of disclosure for both discloser and receiver*. By disclosing to neighbours, PLWH felt that they *secured their children’s future*: “My

neighbours they are older but I've told them. I've told them I have HIV now, if I can die, they must help me with my children." Many PLWH expressed *achieving a sense of freedom and emotional healing* through disclosure. Taking the step to disclosure and having had the strength to carry it through made PLWH feel truly free and proud of themselves: "When I tell a person that whether I know the person or do not know the person, I feel that I move it away from me"; "I heal myself by speaking about it"; "I am free myself." PLWH saw disclosing as a means of *protecting others from getting infected with HIV* and felt obliged to do so: "Then I tell my mother because I didn't want to when I didn't tell her maybe I use a knife to cut, it cut me maybe on the finger. Then when I didn't tell her he will take my blood with her hands, then maybe he will have that thing." HIV disclosure could therefore be beneficial to both the discloser and the receiver. The benefits were linked to securing PLWH's children's future but achieving true freedom and a sense of healing once they had disclosed. Disclosing to protect people close to them against becoming infected by accident was an important reason for disclosing.

The fourth and last theme focused on *forced disclosure due to distinguishability in healthcare settings*. PLWH reported that there were some incidents in their daily lives of so-called forced disclosure, as they were often *seen at healthcare service sites* by people, for instance during collection of anti-retroviral treatment (ART). People seeing them there then automatically knew that they were infected with HIV: "Because some of them, they can see me at the hospital when I am going to take those treatment. But they didn't know I have got HIV positive". The rural group of PLWH specifically mentioned the discriminatory way in which their *files were labelled*, giving away their diagnosis and disclosing their HIV status: "If you drink ARV, they give you the black file at the hospital. I said why this black file because this black file take out your secret." Forced disclosure due to links with specific healthcare settings or practices in healthcare settings remained an issue of concern for PLWH.

9 Conclusions

In this study no notable differences between urban and rural settings were noted, except for the calling of PLWH by derogatory names in the urban setting, as well as the experience of being treated as inhuman. In the rural setting, on the other hand, the issue of their filing system revealing PLWH's status without their consent was prominent. Negative behavioural patterns towards PLWH in the form of gossip, verbal abuse, pestering and PLWH being chased from their houses remained a reality. Attitudes towards PLWH that were identified were also overwhelmingly negative and were noted through rejection, dehumanisation, negative judgment and looking down upon PLWH in disgust. PLWH were shockingly also abruptly ignored in the community, and sharing of eating utensils with PLWH was avoided. PLWH were also not allowed to be involved in food preparation.

It seemed as though ignorance and/or a lack of education was still the reason behind PLWH being treated this badly. Experiencing the pain associated with harsh behaviours and attitudes in the community towards PLWH often led to self-judgment by PLWH and intense negativity, which often led to suicide ideation. In a study by Greeff et al. (2008b) the negative behavioural patterns and attitudes towards PLWH discussed in this study were mainly summarised as dimensions of received stigma. Five years later it is evident that HIV stigmatisation is still a dreadful reality that needs urgent attention in the community.

Some differences noted were that pestering in this study mainly took the form of questioning about weight loss and provocation about the probability of dying soon, whereas in the study by Greeff et al. (2008b) it took the form of persistent questioning about PLWH's behaviour and illness. In this study, avoidance of involving PLWH in food preparation at gatherings such as funerals and weddings was extremely prominent, while in the study by Greeff et al. (2008b) mere avoidance of sharing eating utensils was identified. Dimensions of internal stigma as described by Greeff et al. (2008b) encapsulated the issue of negative self-perception, and social withdrawal and suicide ideation were also mentioned.

Fear of disclosure was one of the dimensions of internal stigma identified by Greeff et al. (2008b). In this study it was found that disclosure was a major issue for PLWH and required a lot of courage and consideration. It was found that the mother figure was the first person to whom PLWH disclosed their HIV status, followed by other family members. This finding confirmed that by Greeff et al. (2008a), who found that, in Africa, family members were the first people to whom disclosure was made. Disclosure without consent remained a problem that was also previously identified (Greeff et al., 2008a).

The benefits and disadvantages of disclosure for both discloser and receiver were often weighed against each other in order to make an informed decision. PLWH feared losses in various forms and often avoided disclosure due to the prominence of stigmatisation in the community and its probable negative effects. This finding was confirmed by Serovich (2001). Disclosure was often forced, as there were several associations within the community that can be attached to being infected with HIV. Examples were visiting healthcare facilities for treatment collection and review, and practices such as filing systems revealing HIV status. PLWH experienced it as being discriminated against and being denied the right to a stress-free environment like anyone else. Greeff (2013) confirmed that disclosure was often inevitable, for example when the need arose to visit the healthcare facility. From the above findings it was clear that the stigma process as described in the conceptual model of HIV/AIDS stigma from five African countries (Holzemer et al., 2007) indeed took the form of triggers of stigma, stigmatising behaviours, types of stigma and outcomes of stigma. Several recommendations can be made upon the basis of the findings of this study.

10 Limitations of the Study

The fact that this study was conducted in urban and rural settings within the North West Province only makes it difficult to confirm with certainty that there are truly no significant differences between HIV stigma and disclosure experiences in urban and rural settings.

11 Recommendations

Research in several provinces across South Africa may be meaningful in investigating differences in HIV stigma and disclosure practices between urban and rural settings. Educating people within a community setup on HIV and its modes of transmission is necessary to avoid misconceptions and discrimination against PLWH due to issues such as fearing contagion. Providing guidelines for PLWH on coping with HIV stigma and discrimination constructively is important as it is a reality that is part of their daily lives, as was evident in this study. HIV stigma and disclosure should be addressed together as these issues are intermingled and are often discussed together in HIV stigma literature. Managing HIV disclosure wisely should further be taught to PLWH, as disclosure is a prominent issue in their daily lives. It can be meaningful to bring PLWH and PLC together when addressing HIV stigma and disclosure issues in order to equalise the relationship between these groups. HIV stigma reduction interventions focusing on the community are important. The research findings can also be utilised in the development of workplace policies such as in the primary healthcare setting. Healthcare professionals should be trained on HIV stigma reduction and -management as well as on disclosure counselling. HIV stigma reduction and responsible disclosure management are essential aspects within current primary healthcare re-engineering.

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ARTICLE 2: A Comprehensive HIV stigma reduction and wellness enhancement community intervention: A case study

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A comprehensive HIV stigma reduction and wellness enhancement community intervention: A case study

Mrs H French, MCur

PhD Candidate

North-West University

Potchefstroom Campus

Private Bag X6001

Hoffman Street

Potchefstroom

2522

South Africa

Tel: +27 13 690 2201

E-mail: heleenfrench@gmail.com

Prof. Dr M Greeff*, Research Professor in the Africa Unit for Transdisciplinary Health
Research (AUPHeR), North-West University

DCur

Potchefstroom Campus

Private Bag X6001

Hoffman Street

Potchefstroom

2522

South Africa

Tel: +27 18 299-2092

E-mail: minrie.greeff@nwu.ac.za

***Corresponding author**

Dr MJ Watson,

PhD Nursing Science

Senior Lecturer, School of Nursing Science

North-West University

Potchefstroom Campus

Private Bag X6001

Hoffman Street
Potchefstroom
2522
South Africa
Tel: +27 18 299-1838
E-mail: mada.watson@nwu.ac.za

Dr CM Doak

PhD Nutrition
Assistant Professor, Department of Nutrition and Health Institute of Health Sciences
Vrije University
Amsterdam, The Netherlands
Tel: +31 20 59 83502
E-mail: colleen.doak@falw.vu.nl

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The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities) whose products or services are related to topics covered in this manuscript that could be construed as a conflict of interest.

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A comprehensive HIV stigma reduction and wellness enhancement community intervention: A case study

Abstract

This study aimed at describing the implementation of a comprehensive HIV stigma reduction and wellness enhancement community intervention that focused on people living with HIV (PLWH), as well as people living close to them (PLC) from six designated groups, namely partners, children, family members, friends, spiritual leaders and community members. A holistic multiple case study design was used in both an urban and a rural setting in the North West Province in South Africa. Purposive voluntary sampling was used for the PLWH and snowball sampling for the PLC. Data analysis was in the form of open coding and text document analysis. The intervention proved to be successful. All participants reported a better understanding of HIV stigma and of coping with it. Projects developed were executed successfully and the wider community was reached. Some considerations for strengthening the intervention, clinical considerations for nursing practice and further research were provided.

Key words: community, comprehensive, HIV, intervention, stigma

1 Introduction and Problem Statement

This study formed part of a bigger, comprehensive HIV stigma reduction and wellness enhancement community intervention study and focused on describing the implementation of the intervention within both an urban and a rural setting in the North West Province, South Africa. This study aimed at building upon existing HIV stigma-intervention research, as well as the work initiated by a group of researchers that executed a broad HIV-stigma study in the African context, working over a five-year period (Holzemer et al., 2007; Uys et al., 2009).

For the purpose of this research the definition of stigma as conceptualised by Alonzo and Reynolds (1995) and supported by Holzemer et al. (2007) was used. They refer to stigma as a “powerful discrediting and tainting social label that radically changes the

way individuals view themselves and are viewed as persons” (Alonzo & Reynolds, 1995, p. 304). In the literature there are various models describing HIV stigma (Alonzo & Reynolds, 1995; Herek, 1990; Link & Phelan, 2006; Parker & Aggleton, 2003; Siyam’kela, 2003; Weiss et al., 1992).

Alonzo and Reynolds (1995) describe stigma as a social construction that radically affects the life experience of PLWH and their partners, family and friends. They view stigma as changing and emerging over the course of a single illness trajectory. Herek (1990) explains that with any stigmatised disease, it is important to understand its aetiology, symptoms and course, as this process involves a course of social interactions among physicians, epidemiologists, patients and their families. Link and Phelan’s (2006) approach to stigma includes the co-occurrence of: labelling, stereotyping, categorical in-group/out-group separation, status loss and discrimination, emphasising the exercising of power as an essential facet.

Parker and Aggleton (2003) point out that stigmatisation and discrimination must be conceptualised as social processes that can only be understood in relation to broader notions of power and domination. They view stigma as playing a key role in producing relations of power and control. Siyam’kela (2003) describes two main categories of HIV/AIDS-related stigma, namely external or enacted stigma, as well as internal or felt stigma. External stigma is the type that is directed at the stigmatised, while internal stigma refers to the stigma as felt by the stigmatised persons themselves. Weiss et al. (1992) recognise an insider’s perspective (“emic”) and an outsider’s perspective (“etic”) of stigmatisation of any illness studied.

However, few of these models focus specifically on the African context (Holzemer & Uys, 2004). The conceptual model of HIV/AIDS stigma from five African countries was designed to ensure a better understanding of HIV stigma in Africa (Holzemer et al., 2007). The model focuses on the context and process of HIV stigma in an African context. According to this model stigma is a complicated process that arises within a context of the environment, healthcare system and different agents. The stigma process itself comprises triggers of stigma, stigmatising behaviours, types of stigma and outcomes of stigma. The stigma process can be triggered by a variety of factors, of which HIV disclosure is an example. The types of stigma identified in the conceptual

model include received stigma, internal stigma and associated stigma. Outcomes of stigma are mainly negative in nature and form the last aspect discussed in the model. This model formed the theoretical framework for this study.

The abovementioned group (Uys et al., 2009) also developed a health setting-based HIV stigma reduction intervention focusing on people living with HIV (PLWH) and nurses. They found that their intervention led to mutual support between nurses and PLWH and created momentum in the settings involved for continued activity. PLWH reported fewer stigma experiences and an increase in self-esteem. Nurses did not report a reduction in stigma or increased self-esteem, but their HIV-testing behaviour increased significantly.

The present study extended this work into an HIV stigma reduction and wellness enhancement intervention in the community focusing on PLWH and people living close (PLC) to them in both an urban and a rural setting.

A considerable amount of research has been done on stigma and related issues in different health fields and there is proof of some programmes that have implemented stigma reduction interventions (Lauveret al., 2002; Scambler & Paoli, 2008). Yet, the effectiveness and impact of stigma reduction interventions are rarely evaluated (Brown, Macintyre, & Trujillo, 2003). Some of the HIV stigma reduction interventions found in the literature seem to be focusing on segmented areas of HIV stigma, such as skills building, counselling, contact with affected groups, as well as awareness campaigns (Brown et al., 2003).

Sengupta, Banks, Jonas, Miles, and Smith (2011) consequently reviewed the literature to evaluate the effectiveness of HIV-related interventions in reducing stigma. The focus of the chosen studies was to evaluate HIV-related interventions, in which HIV and AIDS stigma was one of the outcomes being measured. Data was extracted from 19 studies, and 14 of these studies demonstrated effectiveness in reducing HIV and AIDS stigma. However, on the basis of quality, the extent to which the intervention focused on reducing HIV and AIDS stigma, and the statistics reported to demonstrate some effectiveness, only two of these 14 studies were considered to be good studies. They found the following inadequacies: insufficient interventions targeting HIV and AIDS stigma, insufficient evaluation measures regarding stigma reduction, whether these

stigma reduction intervention trials had public health significance, and lack of good quality studies (Sengupta et al., 2011).

There is also evidence of some target-specific HIV stigma interventions such as those focusing on partners (Manyedi, Greeff & Koen, 2010; Sallar & Somda, 2011); children (Benotsch et al., 2008; Carr & Nyblade, 2007); family members (Gaudine, Glen, Thuan, & Dung, 2010; Mohanan & Kamath, 2009); and friends. The latter category is limited and does not specifically refer to “friends”, but does include them (Nyblade, Stangl, Weiss & Ashburn, 2009). There were also stigma reduction interventions focusing on spiritual leaders (Busza, 1999), as well as community members (Blignault, Woodlands, Ponzio, Ristevski & Kirov, 2009; Ogden & Nyblade, 2005; Siyam’kela, 2003). However, none included PLWH and PLC in a comprehensive manner within a community context.

Even if these interventions exist, stigma still negatively impacts on various aspects of the lives of PLWH. It also impacts on the individuals, groups and communities to whom they are related (Greeff & Phetlhu, 2007). The need for comprehensive approaches towards HIV stigma reduction is hence undeniable at national and international level. In a current qualitative research study looking into the HIV stigma and disclosure experiences of PLWH in the context of the North West Province, South Africa (French, 2013), it was confirmed that HIV stigma indeed remains a major problem impacting on various areas in the lives of PLWH. The fact that HIV stigma remains a problem is also reflected in current literature at international level (Charles et al., 2012). It was also established that PLC play a major role in the stigma process in that they are mostly the parties involved in the act of stigmatisation (Greeff et al., 2008; Holzemer et al., 2007). They are, however, also often stigmatised due to their mere association with PLWH (Greeff & Phetlhu, 2007; Holzemer et al., 2007; Siyam’kela, 2003).

The outcomes of stigma thus have a devastating effect on both PLWH and PLC. Negative attitudes and behaviours towards PLWH are due to fear (Greeff & Phetlhu, 2007), mainly relating to possibly getting infected with HIV (Greeff et al., 2008). The negative attitudes and behaviours of PLC towards PLWH often give rise to negative self-judgment by the PLWH (Greeff et al., 2008; Simbayi et al., 2007). The PLWH are affected negatively in areas of their lives such as disclosure, healthcare-seeking

behaviour, antiretroviral therapy (ART) adherence, emotional wellness, as well as life satisfaction (Charles et al., 2012; Greeff et al., 2010; Simbayi et al., 2007).

According to Wissing and Van Eeden (2002), psychological well-being is multidimensional and involves the affect, cognition and behaviour, as well as the domains of life in which these facets manifest themselves, for example, intra- and interpersonal, social and contextual, in love and at work. A sense of coherence, satisfaction with life and affect-balance are strong indicators of general psychological wellness or well-being (Wissing & Van Eeden, 2002). Several research studies suggest that HIV stigma has a definite negative impact upon psychological well-being (Greeff et al., 2010; Holzemer et al., 2009).

HIV stigma and disclosure are often spontaneously discussed in literature as interrelated aspects affecting each other (Greeff et al., 2008). Disclosure is described by Greeff (2013) as a complicated process and unique to each individual, as there is an interaction of multiple factors that influence the progression of such disclosure. Disclosure is a process that should occur after intense consideration. "Costs of disclosure" should be measured against the potential benefits thereof (Derlega, Winstead, Greene, Serovich & Elwood, 2006, p. 160).

Disclosure practices in the African context appear to be different from those in other countries. Cultural differences are prominent factors influencing disclosure practices (Greeff et al., 2008). Collectivists as found in Africa would rather disclose to close family members, as family ties within the African culture are important, whereas individualists as found in the United States of America (USA) would more readily disclose to someone such as a friend (Greeff et al., 2008). When stigma is high, disclosure is low (Greeff, 2013). Disclosure management is therefore an important matter that needs to be addressed to assist in HIV stigma reduction (Greeff, 2013).

International literature about HIV stigma tendencies in urban and rural settings differs. Several differences in the living conditions of people living in these settings seem to be the driving forces behind their HIV stigmatisation tendencies. Differences are evident in elements such as educational background, economic status as well as social structure and beliefs (Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009). Naidoo et al. (2007) found the influence of social networks (i.e. easier to "gossip"); socio-economic

influences (more general knowledge due to higher access to resources such as television, radio and the internet) and higher literacy levels in the urban community affecting stigma. They found that the urban groups described more experiences of stigmatisation and discrimination than did the rural groups. A study by Kruger, Greeff, Watson and Fourie (2009) aimed at investigating differences in healthcare-seeking behaviour between people from rural and urban communities found similarities to Naidoo et al.(2007) in that only 8.7% of participants from the urban areas sought care at a health facility after being diagnosed HIV positive, compared to 18.9% from rural areas. The reasons expressed included the fear of stigmatisation in the more affluent urban communities.

The research findings by these two groups of authors contradict those in other research studies, which found that stigmatisation takes place more often in rural than in urban communities (Bond et al., 2003; Bunn et al., 2008). People living in rural communities, on average, earn a lower income than their counterparts in urban communities. Campbell and Deacon (2006) found that poverty and deprivation are potent drivers of the stigmatisation of diabetics in Ghana, of people with tuberculosis in Zambia and African migrants with HIV or AIDS in England. In contrast to people living in rural communities, those living in urban communities tend to stigmatise less. In a study by Stephenson (2009) in three study settings representing different economic and cultural environments, it was found that participants with access to more economic resources had more supportive attitudes towards those with HIV or AIDS. Young people with high levels of knowledge of the transmission routes for HIV likewise had more supportive attitudes, signifying the role that knowledge has in reducing the misconceptions that act to create fear and shape stigma. The reason for higher levels of education is easier access to tertiary education in urban communities than in rural communities, where distances between dwellings and schools are vast.

Rankin, Brennan, Schell, Laviwa, and Rankin (2005, p. 2) are of the opinion that fears of stigma further limit the efficacy of HIV testing programmes across sub-Saharan Africa, because “in most villages everyone knows – sooner or later – who visits test sites”. This statement indicates that in the rural context there is a restriction on privacy, which increases the opportunity for stigmatisation. The authors further note that in many African villages (rural communities), the lives of individuals and families are closely

intertwined with those of others. Authors therefore came to opposing conclusions regarding HIV stigma in urban and rural communities. Nonetheless, it seems as though a higher prevalence of stigmatisation can be attributed to rural communities. A common thread throughout the literature on urban and rural differences in HIV stigma was that factors such as social structure, economic status and level of literacy probably determined the manner in which HIV was perceived.

PLWH and PLC likewise are affected by HIV stigmatisation in their communities. PLC often take part in stigmatisation but are also often stigmatised due to their association with PLWH. HIV stigma reduction interventions in the literature seem to focus largely on PLWH, often concentrating on improving only fragmented areas identified, such as skills building or education. Due to high levels of stigma in the community, PLWH are often reluctant to disclose their HIV status mainly due to the fear of being stigmatised.

Stigma further also severely impacts on people's lives, e.g. their psychological well-being. Hence, a need for more comprehensive approaches towards HIV stigma reduction and wellness enhancement by involving PLWH as well as PLC from various areas of their lives was identified. There should be a focus on responsible disclosure management by PLWH and becoming aware of their personal strengths. For both PLWH and PLC there should be knowledge building regarding HIV stigma and coping with it. PLWH and PLC should be brought together in an intervention in order to equalise the relationship between them and enhance their relationships. Personal leadership skills should be developed in order for them to become activists of HIV stigma reduction in their own communities.

Following an extended literature review the researcher asked the following questions: Would a comprehensive community-based HIV stigma reduction and wellness enhancement intervention help to enhance responsible disclosure management by PLWH and reduce their experiences of HIV stigma? Will it make a difference in stigmatisation by PLC? Will the intervention enhance the wellness of both PLWH and PLC? Will there be any differences in the intervention outcomes of an urban and a rural setting?

2 Research Objective

The objective of this study was to describe the implementation of a comprehensive HIV stigma reduction and wellness enhancement community intervention with PLWH and PLC in both an urban and a rural setting, and to see whether there are differences in the outcomes of the urban and the rural settings.

3 Research Design

A holistic multiple case study design (Yin, 2009) was applied in this study, as this was the most suitable to provide a meaningful description of the execution of the intervention.

4 Research Method

The case study method was used to capture data during the intervention.

4.1 Sample

The sample consisted of PLWH and PLC originating from the urban greater Potchefstroom and the rural Ganyesa in the North West Province, South Africa. For the PLWH, purposive voluntary sampling was applied (Burns & Grove, 2005). PLWH were recruited through local healthcare facilities and non-governmental organisations (NGOs). Mediators who had a trusting relationship with PLWH and were working in those organisations were used to link the research assistant and the researcher with potential participants. They provided the research assistant, who was employed by the North-West University, with the names and addresses of possible participants fitting the inclusion criteria and willing to participate. The inclusion criteria for PLWH were that they had to have been knowingly HIV infected for a period of at least six months; they had to be able to communicate freely in English, Afrikaans or Setswana; be willing to take part in a study during which HIV status disclosure would take place; and give

consent to be interviewed and recorded. The final sample size of PLWH was N = 18 (10 = urban and 8 = rural). See Table 5.

The second sample, namely the PLC, consisted of six designated groups, namely: partners, children, close family members, close friends, spiritual leaders and community members. PLC were obtained by means of snowball sampling (Strydom, 2005). Each of the PLWH was asked to identify suitable participants of their choice from the six designated groups of people living close to them to take part in this study. The inclusion criteria for all six groups were that they had to be at least 18 years of age; be able to communicate freely in English, Afrikaans or Setswana; and give consent to be interviewed and recorded.

Each designated group also had some specific inclusion criteria, namely: the partner had to have been married to or in a stable relationship with the PLWH for a period of at least six months. The child had to be a biological child of the PLWH, be at least 15 years of age, and had to obtain consent from the parent to take part in the study. The close family member could be any close family member of the PLWH apart from a partner or child. The close friend had to have been in a friendship relationship with the PLWH for a period of at least six months and be someone who was not part of the biological family of the PLWH. The spiritual leader had to have been involved in the spiritual ministering of the PLWH and could be a traditional healer or a religious leader; and the community member had to be a person with whom PLWH had had regular contact, such as a neighbour. The sample size for the PLC was N = 60, consisting of the six designated groups. See Table 2.

Table 2: Sample outlay of PLWH and PLC

| PLWH | | | | COHORTS | PLC | | | |
|-----------|---|-------|---|-------------------|----------|----|--------|----|
| URBAN | | RURAL | | | URBAN | | RURAL | |
| M | F | M | F | | M | F | M | F |
| 1 | 9 | 3 | 5 | Partners | 2 | - | - | 1 |
| | | | | Children | 1 | 3 | 2 | 5 |
| | | | | Family | - | 2 | 1 | 4 |
| | | | | Friends | - | 2 | - | 6 |
| | | | | Spiritual leaders | 4 | 2 | 3 | 7 |
| | | | | Community members | 1 | 6 | - | 8 |
| 1 | 9 | 3 | 5 | TOTALS | 8 | 15 | 6 | 31 |
| n = 10 | | n = 8 | | | n = 23 | | n = 37 | |
| PLWH = 18 | | | | | PLC = 60 | | | |

4.2 Data collection

The research project was approved by the research committee of the School of Nursing Sciences, the Ethics Committee of the North-West University (NWU-00011-09-A1), as well as the Department of Health. The researchers had been extensively involved with both the urban and rural communities over the past 15 years and therefore had community access and involvement. The research assistant linked up with the willing participants who had been identified to arrange their participation in the intervention. Participants were informed of the date, time and venue of the workshops and transport was organised for them and light meals were provided. They were made aware of the fact that they would be taking part in an intervention involving various PLWH and PLC.

PLWH were made aware of the fact that disclosure of their status would happen, but that they would be trained in responsible disclosure management beforehand. They were made aware of the fact that sharing experiences during the workshop maybe painful and cause psychological discomfort. Participants were also informed of the fact that they would be enriched as they would gain knowledge about HIV stigma and coping with it. Their relationships with one another could be enhanced and they would develop skills in how to plan and implement an HIV stigma reduction project. They were allowed time to decide about whether they felt comfortable to participate or not. They were requested to give written informed consent and made aware of their right to withdraw at any stage during the research.

Participants were informed that their privacy would be respected as far as possible through partial confidentiality and that the research would be conducted in an anonymous fashion. All computer systems used were password coded and documents were kept in a safe, locked cabinet that was accessible only to researchers who were directly involved (Burns & Grove, 2005; Polit & Beck, 2006).

A case study protocol was designed and it served as a guiding tool to the researchers to collect data and add to the reliability of the research (Yin, 2009). The case study records consisted of: manuals and lectures of the HIV stigma reduction and wellness enhancement community intervention; naïve sketches of the participants during the planned two-day workshop with PLWH only, as well as during the three days of the workshops with the PLWH and PLC together. The introductory sentences to activate the

naïve sketches were: *"I experienced this day of the workshop as..."* and *"I feel..."* Field notes of the researchers, the project reports of the community projects of the PLWH and PLC, as well as the project evaluation by the researchers and community members, all formed part of the case study records (Yin, 2009).

4.3 The intervention

The intervention consisted of an initial two-day workshop with only the PLWH, both in the urban and rural setting. This was followed by six three-day workshops in both settings with the PLWH and a specific designated group of PLC, namely a partner, then a child, then a close family member, close friend, spiritual leader and lastly a community member. Each group had an HIV stigma reduction project running over a period of one month with a group similar to theirs (e.g. partners with partners).

The intervention for PLWH and PLC was adapted from the work done by Uys et al. (2009). The workshops were presented in the form of presentations and small group discussions and activities. The facilitators of the workshops were always a non-infected as well as an infected individual. The trans-disciplinary researchers who acted as facilitators during the workshops received in-depth training on the presentation of the workshops beforehand. The tenets that these workshops were built upon were: sharing of information on HIV stigma and coping with it, equalising the relationship between PLWH and PLC through increased interaction and contact between them, and empowering them towards leadership in HIV stigma reduction through practical knowledge and experience of project planning towards HIV stigma reduction and implementation in their communities.

The workshop with the PLWH was an initial two-day workshop presented to the PLWH only in both the urban and the rural settings, focusing on understanding HIV stigma, identifying their personal strengths and handling disclosure in a responsible manner in order to prepare them thoroughly on a psychological level for the next phase of the intervention involving various PLC and the other PLWH. PLWH were made aware of the fact that HIV status disclosure would happen due to the nature of the workshops and that group work would be conducted with the various designated groups of PLC and fellow PLWH.

The six workshops with PLWH and PLC in both the urban and the rural settings followed the initial workshop with PLWH and consisted of a series of three-day workshops with the six designated groups of PLC linked together with the PLWH. The workshops aimed at bringing PLWH and PLC together, building relationships between them and providing them with knowledge. The first day of the workshop focused on understanding HIV stigma and coping with it. The second day of the workshop aimed at motivating PLWH and PLC to use the knowledge gained on the first day to move into action and develop skills to become leaders in HIV stigma reduction in their own community. Participants were taught how to plan a project followed by them in planning their own projects with designated groups similar to theirs, e.g. partners with partners. PLWH spontaneously formed part of each of the six groups of PLC.

There was a period of one month after the initial two-day workshop for the implementation of the various projects in the community. The researchers facilitated all groups per appointment in order to support them and to monitor their progress. The third and last day of the workshop took place one month after the initial two-day workshop and each group had the opportunity to present their executed projects. Evaluation of the projects was done by a panel consisting of invited relevant stakeholders in their community and the researchers involved. The evaluation of the projects was based on the feedback by researchers during facilitation as well as the presentation by participants. Feedback on their successes was then given to participants by the panel.

5 Trustworthiness

Licolen and Guba's model (in Krefting, 1991) was used to ensure trustworthiness in this research. *Truth value* was guaranteed by prolonged engagement in the research field during the implementation of the intervention. Reflexivity was applied through the writing of comprehensive field notes during and after the intervention, as well as in discussions with study leaders. Triangulation of various trans-disciplinary investigators and a variety of methods took place. The methods mentioned as the case record were included.

Applicability was ensured by the well thought through sampling with a very specific urban and rural demography, as well as the thick description of the methodology. *Consistency* was ensured by the availability of an audit trail and the possibility of stepwise replication due to a thick description of the methodology and availability of data. The use of a co-coder further enhanced consistency. *Neutrality* was ensured by the availability of an audit trail, triangulation of investigators and methods, as well as reflexivity, as was previously mentioned.

6 Results of the Study

During data analysis no noteworthy differences were marked between themes of the groups from the urban and the rural settings. Data was therefore pooled and any noteworthy differences were specified individually. The results integrated the findings from the various data sources. The discussion of the findings is enriched with quotes made by participants during the intervention. See Table 3 for a detailed outlay of the various projects.

6.1 The workshop with PLWH only

The workshop presented only to PLWH to prepare them for their involvement in the rest of the workshops and to enable them to handle disclosure in a responsible manner proved to be successful, as they felt more in control and more prepared to disclose their HIV status: “I am going to go and talk about my status.” They felt they had the final choice: “I became broad minded about stigma and disclosure;” “When it comes to me and my status, it’s only me. So I can speak.”

A strong sense of bravery and courage was reported regarding disclosure by some PLWH: “God who gave me the strength in this workshop.” “I can stand up and disclose and how to cope.” Some of the PLWH from the urban group specifically described their experience of uncertainty of having to later in the project disclose their HIV status: “As a difficult thing because the project is to disclose to other people who don’t know you.” This was a necessary part of the intervention to prevent traumatic experiences by PLWH.

6.2 The workshop with PLWH and partners

Both the PLWH and the partners from the urban and rural groups mentioned truly gaining knowledge on how to cope with stigma and self-acceptance: “I experienced how to cope with stigma, to accept yourself.” Partners indicated their initial ignorance about caring for an infected partner and felt a strengthening of their relationship: “The presenters taught me something important today... I learned things that I did not know, care, sympathy and love”; “When I saw someone stigmatising in the group I was able to say no, what you’re saying is actually very hurtful and for me to also know how to speak to others so my partner and I learnt a lot on how to support each other as well as other partners.”

PLC felt enlightened and a realisation set in that PLWH should be treated with dignity: “They have opened up my eyes. I experienced the different types of encouraging people in the community and to support other partners” and “So this also made us improve our support group and home based care groups. There was stigma within those groups they would stigmatise the patients so I was able to learn this and to be able to teach them when you have a person with HIV you shouldn’t treat them in a bad way.”

To the PLWH the workshop facilitated healing by helping them to feel supported: “Talking to other people as a support group healed me and turn me back to where I am today.” They indicated having gained knowledge about stigma: “I learned quite a lot about stigma” “I didn’t know about stigma.” Both the PLWH and their partners felt motivated, and ready to go out and share their knowledge gained with the community to bring about change. The PLWH stated: “I learn how to take the stigma reduction further” and partners expressed it as: “To teach the people about stigma reduction, I feel strong.”

The *project* of the urban PLWH-and-partner group focused on teaching other partners in intimate home settings about the HIV stigma types and the effects thereof, while the project of the rural group entailed a door-to-door action aimed at teaching people in their homes about HIV stigma. The groups of urban and rural PLWH and partners reached 20 other partners in the community. See Table 6 for a more detailed description.

PLWH from both the urban and rural groups described how planning and executing the project were initially extremely challenging: “It was difficult today but I understand the way to organise the campaign but it is not easy.” However, they felt so committed to the project that they did not allow themselves to be discouraged: “It was hard to get partners but we got them and learned many, many things about the project”; “We told ourselves that what we are intend to do is going to happen even if we are only two.” The project built their confidence: “I am not afraid of the people or others in the community” and they really felt happy with the outcome: “...happy we have achieved our goal.”

Partners in the urban group struggled with their project but said that with courage everything was possible: “How to deal with partners is not easy but if you want something you can do it.” Although reaching fewer partners, the rural group saw their project as advantageous to the community. Partners in both settings expressed how honoured they felt at having been involved in the projects. Pride and a sense of hope were noted among both the urban and rural groups of partners: “I even saw that there is life”; “I am proud of myself of being able to talk to people.”

6.3 The workshop with PLWH and children

The PLWH in this group reported gaining knowledge on specifically coping with stigma and stigmatisation: “...how to cope with stigmatising behaviour”; “I learned how to handle people who are stigmatising and learned how to cope.” The children rather reported on gaining knowledge regarding HIV stigma: “I was having a lack of knowledge about the stigma”; “The workshop gave me more knowledge about HIV and stigma.” They were happy about getting this opportunity: “A happy day because I got the information about stigma and HIV/AIDS that I never knew.”

The children expressed a sense of initial fear of the unknown but realised that in the end it was worthwhile to continue to take part: “The first day was a bit scary because I knew no one but I am glad I was part of this whole workshop”; “I dealt with my inner being.” The children indicated that they had developed a sense of belonging within the group: “We were accepting each other for who and what we are”; “Honoured and respected.” A strong sense of pride in their realisation of their ability to interact with PLWH was expressed among the children: “Proud about the first step I took of handling people with HIV and AIDS.”

Children were able to realise what hurt they had caused with their stigmatising behaviour in the past and felt ashamed about it: “I wasn’t aware that I was stigmatising people. How sad they were when people talked about them, I felt like, I’m sorry. I shouldn’t have done that”; “I myself was a thrower of rocks, I was one of those who stigmatised.” They expressed a sense of now being prepared to relate to PLWH in their community: “I now know how to treat and cope with people who are infected.” PLWH however expressed their surprise at feeling supported by the children: “I did not think that children are so supportive and share ideas...”

Being together empowered PLWH to talk to their children about their HIV status: “Thank you to this workshop to give me power to talk to my kids.” Both the PLWH and the children experienced the second day, when they had to plan the project, as challenging and exhausting, yet interesting and exciting: “Very difficult and tiring...how to understand everything about intervention” and “I felt great because I applied all the knowledge that I had learnt.” The children expressed their sense of delight in taking part in the preparation of their project: “...exciting plans that we are determined to implement.” They further expressed intense excitement and pride to go out and share the knowledge gained during the intervention in their communities: “Maybe people haven’t seen what is stigma. Let me spread out the message. Spread out and disseminate. I was proud”; “Like everywhere, everywhere, I have to spread this message.”

The *project* of the urban group of PLWH and children involved targeting an entire school of 980 children, while the project of the rural group involved giving lectures to HIV-affected children, and reached 39 children. Both the urban and rural groups of children aimed at raising awareness against HIV stigma against children affected by HIV. See Table 6 for a more detailed description.

PLWH from both the urban and the rural groups felt thrilled to be part of the project and content with the outcomes of their projects: “The school kids didn’t really know anything. That is why I am very proud of the project”; “I wanted to shout and scream and jump. It was fine. I felt good about it.” Both the PLWH and the children recognised that knowledge should be shared in the community: “I know about stigma... I learned that in life you have to share what you have with others who don’t have.” They further

expressed pride in their role in HIV stigma reduction in the community and recognised it as being important. They felt that they were able to bring about change in their communities: “What we have taught really changed their perspectives as though they want to teach others.”

The children experienced the disclosure they saw in the workshops as a positive thing in that it united people: “This experience unite a lot of people. You realise that you aren’t alone”. They also experienced that disclosure brings about a sense of relief for the PLWH and support from others is then possible: “It’s like a burden, like when you have something weighing heavy on your heart. If a person discloses and comes across people who are welcoming and loving, then you are also able to love yourself back.” The children of the urban group won the prize for the best urban project.

6.4 The workshop with PLWH and family members

The PLWH expressed a sense of how to handle people that stigmatise you: “I learned how to handle people who stigmatises people who are living with HIV.” They realised that stigma also affects family members: “How difficult it is in the family when someone has HIV.”

The family members came to realise that PLWH should be treated with respect and stigmatisation was unacceptable: “We should stop undermining people with HIV because we stigmatise them and that is not fair that we do so”; “...see the light about the other people’s feelings when they sick of being called names.”

The PLWH and family members reported to an equal extent that planning a project on the second day was challenging. “It is difficult to plan a workshop and to be committed to something.” The PLWH and family members also described a sense of readiness to empower others with knowledge gained in order for change to come about: “I go tell everyone what I hear from this workshop and I know they go change as I am changed.” They also reported that they were taught how to be a leader in the community: “Getting more information about being a leader of community.”

The *project* of the urban group of PLWH and family members was in the form of a teaching and discussion session at the house of one of the PLWH. The focus of the

discussion was on HIV stigma and coping with stigma, and they reached 13 people. The project by the rural group entailed two *shows* in the form of a psychodrama groups on HIV stigma and coping with it. They reached 127 people. See Table 6 for a more detailed description.

The urban group had real difficulty getting their project started and expressed a sense of disappointment in people who were not committed to the project and were less involved. However, this motivated them more to make the project work: “For me I know I am going to do it no matter the people that we invited disappoint us.” The importance of teamwork when approaching stigma reduction was also described: “That if all of us can be committed we will conquer this stigma.”

The family members from the urban group that continued with the project despite poor commitment by team members described feeling proud of their success. The PLWH from the rural group felt motivated to take their project even further due to its success and continue with it in future: “I experience this project was very strong and we’ll do more than this today”; “We are going to be the light of the community.” They felt extremely proud of their project. Both the PLWH and the family members experienced that the project assisted them in going out into the community and bringing about change: “So I have experienced that this project is helping us to come closer to the people so that they must know about their stigma.” Some realised that they could be leaders, playing an important role in bringing about change: “I didn’t realise I can be a leader for change, but here I am.” The rural family group won the prize for the best rural project.

6.5 The workshop with PLWH and friends

The group of friends reported truly gaining new knowledge and expressed the fact that they never knew about HIV stigma before and that the workshop had made them aware of the pain stigma caused: “...knowing more about stigma”; “I knew nothing about stigma so I learnt that it is when people call other people with HIV all sorts of bad names and that is painful because there is no person who likes being sick.”

The PLWH likewise reported gaining knowledge on HIV stigma but also specifically on coping with stigma: “The professor, she gave us a light about that stigma’; “I can see

that people can cope with the stigma. People are really positive.” The group of friends also came to realise that they were able to make a significant difference in the community with regard to HIV stigma reduction: “I can make a change in the community by reducing stigma”; “At the workshop I learnt so much like even out there we can be able to teach people and let them know what can or cannot be done as well as about stigma and how to handle that.”

The friends explicitly reported pride in knowing that they were able to teach others what they had learned and taking the lead in their communities in HIV stigma reduction efforts: “I am very proud because I will teach my support group;” “And I can hold a workshop and teach people about stigma.” The PLWH expressed a sense of freedom with regard to being able to disclose their status to friends as well: “It was a light on how to disclose to other people;” “I changed. I told myself that I have been released”; “I was still feeling scared, but as it went, I felt free, and my heart opened up.”

The PLWH and friends from both the urban and the rural groups described that planning a project was difficult but that they were motivated to do so: “That is a challenge, I am not afraid of it. Let’s keep punching.” They noticed that they were able to make use of knowledge gained and go over to action and bring about change. They were also empowered to be leaders in stigma reduction: “My experience is to go to the people teaching them about that disease because another people they don’t know about only HIV and AIDS but they don’t know more;” “Now I can educate people about stigma and I also can teach a person how to cope with stigma.”

The *project* of the urban group of PLWH and friends first presented a lecture about HIV stigma and coping with it, followed by a march in the community for raising awareness of the negative impact of stigma. They then went from door to door, aiming to befriend friends and community members. They reached 36 people.

The rural group planned to address the discriminatory filing system with the management of the hospital and to hold a march. They spoke to hospital management about the files, but management was not prepared to make the changes. They group was also not allowed to march on the hospital premises. However, they eventually presented lectures at the local hospital, focusing on the types of stigma and its meaning and impact. They reached 66 people. See Table 3 for a more detailed description.

Some of the PLWH and friends of the urban group stated that despite poor commitment they had carried out their project successfully: “We did all the best we can. It’s easy to talk but to do it’s hard.” The PLWH from the urban group seemed to have been unhappy about their project. It was not well organised and group members were not fully committed: “I feel sad and unhappy in this project.” However, they expressed motivation to continue to practice what they have been taught.

The PLWH from the rural group also reported that the project was difficult to execute. The rural group of PLWH and friends reported that they could not successfully execute all their planned tasks as they did not know what further steps to take to when they were refused some of the requests by hospital management, such as to get the colour coding of files of PLWH changed. However, they were motivated to go out into the community and teach others what they had learned about HIV stigma: “And not getting tired for it – also to speak with our mouths spreading the word stigma which form the project.”

6.6 The workshop with PLWH and spiritual leaders

PLWH from both the urban and the rural groups were surprised to see that people with different talents and personalities could work together: “I didn’t realise that people with different gifts can work together.” The PLWH and spiritual leaders felt empowered to be leaders of HIV stigma reduction. They realised the need for them to assist in reducing HIV stigma: “I feel to need the help people”; “From today I am going to fight for HIV-positive people that they must not be segregated.”

Spiritual leaders strongly expressed their experience of a deep realisation of their ability as people in pastoral office to actually have an impact with regard to HIV stigma within their communities: “I’ve learned that I can encourage people who are positive not to be discouraged by other people who are not sick and treat them well.” They noted that in the past they had not wanted to get involved in HIV and stigma issues, as they did not feel that it was part of their duty to get involved: “Because in the past I was a pastor just because I have a ministry, I was ignoring what was happening.”

All the groups expressed an intense awakening to go out and work on changing the community regarding HIV stigma: “That was giving me a burning desire was to see the people the way that they are live and sometimes they are things happening in front of

my eyes”; “I am supposed to be taking out and reach out to the people and giving what I have”; “The experience of giving back what I have learnt as I said these things is not for me, it’s for us and to help other people.” Both the PLWH and the spiritual leaders experienced that to design a project was a difficult task, but they were driven to try and give it their best. They described that they felt equipped to act as leaders against stigma in the community: “I feel that I can now be a leader teaching people about stigma and coping and I can educate them that to stigmatise people is not a good thing to do.”

The *project* by the urban group of PLWH and spiritual leaders entailed a variety of activities in church context focusing on HIV stigma and the impact thereof in the community. They reached 52 people. The project by the rural group involved three different events: a teaching session on HIV stigma and the types of stigma; a psychodrama showing HIV stigma, as well as a candlelight ceremony. They reached 271 people. See Table 6 for a more detailed description.

The PLWH and spiritual leaders reported a sense of motivation to continue with HIV stigma reduction in the community: “I will keep on telling people about what I know about this stigma;” “I will proudly go out and teach people about it.” They learnt that they could work together in a group with people from different religious groups, as well as with traditional healers: “...learnt a lot about integration and working with pastors and traditional healers.” The spiritual leaders worked in groups with people from varying religious groups but they realised the commonality in their cause to assist in reducing HIV stigma, no matter what religion they followed.

The PLWH from both the urban and the rural groups realised that working as a group was important for a project to be successful. Both PLWH and spiritual leaders expressed their sense of contentment with the outcomes of the projects. The urban group of spiritual leaders presented to their communities tangible, touching expressions of what stigma does to PLWH, and people attending the projects were touched: “The people who attended said it opened their eyes about the problem with the HIV stigma”; “If you look at it, it feels as if she touched your heart. After that you will say that I will never let my love ones go through that.”

The rural group of spiritual leaders also felt equipped and enriched with knowledge: “You have enlightened me and put much knowledge in my thoughts and my ears can

hear.” They felt motivated to share the knowledge. Both groups expressed a sense of gratitude for being part of the intervention and to be able to assist others in HIV stigma reduction: “One of the best educations in my life, we use to deny our own people and make to feel small... Since I learn about stigma is when I started to see my mistake...”

6.7 The workshop with PLWH and community members

The community members realised that HIV stigma impacts negatively on PLWH and that it was important to fight stigma: “How people fear to disclose because of people don’t treat them well and ... if they accepted themselves and take their ARVs together we can beat this stigma.” Others felt motivated to go out and equip others with knowledge in order to assist in HIV stigma reduction: “We need to take this information to our people so we intend to go to the churches, the schools and our village.”

Both the PLWH and the community members learnt the process of designing a project and realised the importance of commitment and group participation to carry it out successfully: “If you want to do the project you must be committed if you are committed and hard work you are going to enjoy this project”; “...everything is possible if we do things as a team or group.” They were motivated despite the fact that it was going to require effort: “Planning the project is not just a simple thing.” Experiencing a sense of freedom and seeing a way forward were reported: “I feel free and I can see the light.”

The *projects* of the PLWH and community members were the culmination of all the work done during the intervention. Community halls were used for these events. The important stakeholders in the community were invited, as were all the various designated groups involved in the intervention. Both groups did an initial march standing up against HIV stigma in their communities. Two PLWH then gave a talk on how stigma affected them and a psychodrama depicting stigma was presented. A certificate ceremony for all the successful participants followed, and prizes for the best urban and rural projects were awarded.

The PLWH from the urban group indicated that the project had equipped them with HIV disclosure management skills: “I experience when, how and why to disclose...and after disclosing how to support, love and care for someone who is HIV.” The PLWH from the rural group likewise reported pride and achievement: “In the last project I am a big

persona because I have done all things very well”; “Today I was glad and very happy because I am the queen of stigma.”

The task was not easy for the PLWH and community members, but perseverance made it possible in the end: “It was hard but we tried to do the task. This group did a wonderful job.” Both the PLWH and the community members felt proud and a sense of achievement was reported: “...very happy after all the work that we have done and I learn how to stand front of people to talk and teach people about people who stigmatised people.”

Table 3: The various projects conducted by PLWH and the six designated groups in both an urban and a rural setting

| Designated cohort group | Name of project | Target | Activities | Quantity people reached |
|-------------------------|---|--|--|-------------------------|
| Partners | Urban <i>Tlosa Letshwao</i> (Remove the label) | Partners of PLWH | <ul style="list-style-type: none"> Lecture: Types of HIV stigma presented at portable classes at a local primary school allowing for intimate discussions Psychodrama depicting the outcomes of different types of stigma encouraging partners to stop labeling and blaming | 13 |
| | Rural <i>Tshwaraganang lo dirisane</i> (Coming together and working together) | Partners and direct family of partners | <ul style="list-style-type: none"> Door-to-door activity on three different days, during which teaching about HIV stigma and personal experiences thereof were discussed. The targeted groups were also taught on the importance of knowing one's HIV status Handmade flyers distributed advocating importance of knowing one's HIV status | 7 |
| Children | Urban <i>Stop stigma bullying</i> | Children affected by HIV stigma | <ul style="list-style-type: none"> Act as stigma ambassadors: wearing t-shirts, carrying posters showing their disgust at bullying children affected by HIV Lecturing all the children at a local school over four days in Life Orientation classes using colorful visual aids on the effects of HIV stigma Composed a song and performed a psychodrama on HIV stigma Launched a campaign against HIV stigma bullying: handing out stickers to all children to wear on their uniforms Held a march through the school grounds singing their newly composed song Held a candlelight ceremony in honor of children infected and affected by HIV | 980 |
| | Rural <i>Stigma ambassadors</i> | Children affected by HIV stigma | <p>Lectures over a four day period at the tribal hall:</p> <p><i>Session One:</i> HIV and its modes of transmission</p> <p><i>Session Two:</i> HIV stigma and its effects and coping with stigma</p> <p><i>Session Three:</i> Games played covering commonly asked questions regarding HIV and stigma</p> <p><i>Session Four:</i> Evaluation day where children were asked to describe concepts covered during the previous sessions</p> | 39 |
| Family members | Urban <i>Thusanang malapa ka stigma</i> (Helping families with stigma) | Close family members | <ul style="list-style-type: none"> Teaching session at one of the family members' houses focusing on HIV stigma and coping with it. This was followed by discussions Intimate context enabled sharing of personal HIV experiences and enhanced relationships | 13 |
| | Rural <i>The Kopano Show</i> (The 'Together' show) | All members of the community | Presenting a psychodrama at the tribal hall on two different days: drama performed depicting HIV stigma and how to cope with it | 127 |
| Friends | Urban <i>Ditsala di rata ditsala tse di tshwaetsegileng</i> (Friends love HIV friends) | Friends of PLWH | <p>Three aspects presented on three different days:</p> <ul style="list-style-type: none"> Lecture about HIV stigma and how to cope with it through an intimate context enabling sharing of personal HIV experiences held at a local 'development and support center'. A march through the township to the local police station raising awareness of the negative impact of HIV stigma and how to unite people to fight HIV stigma Door-to-door action befriending community members to encourage acceptance of PLWH and raising awareness that a person with HIV can be a friend. Brief teaching sessions about the impact of stigma took place during the door-to-door action | 36 |
| | Rural <i>Friends of PLWH speak out against stigma</i> | Friends of PLWH | <p>One of three planned tasks executed:</p> <ul style="list-style-type: none"> Address visible discrimination within the healthcare setting where files of PLWH are being labeled in a different manner from others: Change not possible to execute since feedback from the particular healthcare setting indicated this as not possible. March against HIV stigma through the hospital grounds which was not allowed. | 66 |

| | | | | | |
|---|-------|---|--|---|-------------|
| | | | | <ul style="list-style-type: none"> Lectures presented at the local hospital. Split into three groups to teach people about different types of stigma were taught as well as the meaning and impact of stigma: <ul style="list-style-type: none"> Group 1: people in the consultation line; Group 2: people waiting for other assistance; Group 3: people waiting at the pharmacy. | |
| Spiritual leaders | Urban | <i>Areageng</i> (Let's build) | Spiritual leaders of PLWH from the area | <ul style="list-style-type: none"> Teaching session at one of the local churches during a scheduled church service with specific invitation to other local spiritual leaders Interaction in church setup with singing and prayer Taught about HIV stigma and the impact thereof in the community HIV stigma posters displayed in the church enriching the message conveyed during the event Special song encouraging united fight against HIV stigma performed followed by psychodrama depicting the painful effects of stigma at the church | 52 |
| | Rural | <i>Modimo O rata bothle</i> (God loves everyone) | Spiritual leaders of PLWH in different sections of the community | <ul style="list-style-type: none"> Three different events executed on three different occasions: <ul style="list-style-type: none"> <i>First event:</i> Teaching session on HIV stigma and the types of stigma, with practical examples describing the types as well as coping with stigma at the tribal hall <i>Second event:</i> Psychodrama describing HIV stigma and a teaching session on HIV stigma at a local primary school <i>Third event:</i> A teaching session on HIV stigma and a candlelight ceremony where group stood united against HIV stigma and discrimination at a local hall Dances were also performed and professional nurses took part in the project by providing voluntary counseling and testing services | 271 |
| Community members | Urban | <i>Silencing the voice of HIV stigma</i> | People living close to PLWH in the community and those reached during the projects | <ul style="list-style-type: none"> Project entailed a march standing up against HIV stigma in the community through Ikageng End of intervention gathering in community hall A <i>stigma talk</i> by people infected with HIV and living positively with the virus Event was concluded with a psychodrama portraying discriminating situations of community against PLWH Songs sung uniting people against HIV stigma as it prevents PLWH from living a normal life Certificates handed to all PLWH and PLC who actively participated in the entire intervention The prize for the best urban project was handed to the group of children | 132 |
| | Rural | <i>Silencing the voice of HIV stigma</i> | Community members of PLWH | <ul style="list-style-type: none"> A march against HIV stigma with group members carrying posters saying "<i>Silence the voice of HIV stigma</i>" A HIV stigma talk at the tribal hall A song "<i>Down with stigma</i>" was sung A psychodrama demonstrating the painful effects of stigma was performed A beauty contest with the name "<i>I am HIV positive and I am beautiful</i>" was presented with the main message that PLWH are just the same as anyone else Certificates handed to all PLWH and PLC who actively participated in the complete intervention The prize for the best rural project was handed to the group of close family members A candlelight ceremony where all present took an oath to respect PLWH and to stop stigmatizing behavior in the community | 123 |
| Total number of people reached by the projects | | | | | 1793 |

7 Conclusion

From the discussion of the comprehensive HIV stigma reduction and wellness enhancement community intervention case study one can conclude that the intervention was on the whole successful for the PLWH and all the designated groups of PLC. Two-weekly sessions took place, with the intensive intervention stretching over a three-month period. Preparing PLWH through training in responsible disclosure management and identifying their personal strengths did prepare them for the rest of the workshops and gave them back control over their disclosure decisions and some form of self-acceptance. Most of them felt that disclosure was a means of freeing themselves of the burden of carrying secrets.

The set goals of bringing the PLWH and PLC together, sharing information on HIV stigma and coping with it through increased communication between the PLWH and PLC, and empowering them towards leadership in HIV stigma reduction were met. The relationships in all the groups showed a marked improvement. Bringing PLWH and PLC together in such an intimate workshop environment where personal experiences with stigma were shared enhanced a deeper understanding for PLWH, and the damaging effects of stigma were realised. Specific knowledge on stigma and coping with it led to courage and pride.

Executing the HIV stigma reduction projects with specific designated groups in their own communities gave them a sense of achievement and of gaining personal leadership. The methods of facilitating the intervention by using a non-infected and infected facilitator, with the presentation providing specific knowledge followed by activities and discussions to ensure contact and skills building were successful. The contact and method of presentation facilitated the achievement of the tenets on which the intervention was based.

The number of people reached through the projects showed that using the “stone in a pond” ripple effect was much more effective than targeting this problem on an individual basis. In the end the 18 PLWH and 60 PLC reached a further 1793 people in the community with specific HIV stigma reduction activities.

The results were mainly the same for both the urban and the rural groups, and only small differences were observed and were expressed as being denied the opportunity to bring about change regarding the discriminatory filing system in the hospital. The similarities between the experiences of the urban and the rural groups may be attributed to the fact that the Setswana culture is so powerfully present in the North West Province.

8 Limitations

There were groups, e.g. the partners and family members, in which there were either no relationships or low attendance, and this contributed to the sample size not being as big as had initially been planned. The choice given to the PLWH of whom to invite also added to this. The therapeutic nature of the intervention, however, did not allow for bigger numbers.

9 Clinical Considerations

- The comprehensive HIV stigma reduction and wellness enhancement community intervention in its totality as presented in this study can be meaningful in future, but it can also be presented to any PLWH and PLC, and not only separately to designated groups.
- Preparing PLWH to manage disclosure and find some form of personal strength is essential before including them in such an intervention.
- The tenets upon which the intervention was built (sharing of information, equalising the relationship between PLWH and PLC, as well as enhancing existing strengths for leadership development) proved to be useful and should not be separated.
- The timeframe of the intervention need not to be as long as in this study, as workshops could be with PLWH and any PLC, and still have a positive outcome.

- It could be meaningful to present this intervention in other provinces and cultural groups in both urban and rural settings to gain a better understanding of possible differences.
- This intervention can also be applied in the re-engineering of primary healthcare services by not merely presenting the course to PLWH and PLC in workshops, but to present it in primary healthcare clinics to newly diagnosed PLWH and allow them to invite a PLC of their choice to join them.
- The intervention can be extended to include communities through stigma “hub” networks that work on a variety of levels in reducing stigma..
- The intervention proved that empowering PLWH and PLC to target HIV and AIDS stigma together on a community level is much more effective than empowering mere individuals. Bigger numbers of people are reached in this way and HIV stigma reduction hence easier to advocate for. This has direct implications for policy development in the primary healthcare setting where re-engineering is an important current movement in South Africa.

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ARTICLE 3: Experiences of People Living with HIV and People Living Close to Them of a Comprehensive HIV Stigma Reduction Community Intervention in an Urban and a Rural Setting

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Appendix

Figure captions

Tables and figures. Do not import figures or tables into the main text. Footnotes are to be listed separately at the end of the text and not at the bottom of each page.

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All publications cited in the text should be presented in a list of references following the text of the manuscript. In the text refer to the author's name (without initials) and year of publication (e.g. 'Since Shisana and Simbayi (2002) have shown that...' or 'This is in agreement with results obtained later (Uys, 2002)'). For 2 – 6 authors all authors are to be listed at first citation, with '&' separating the last authors, for more than six authors, use the first six authors followed by '*et al.*'. In subsequent citations for three or more

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Shisana, O., & Simbayi, L. (2002) *Nelson Mandela/HRSC study of HIV/AIDS: South African national HIV prevalence, behavioral risks and mass media household survey 2002*. Cape Town: Human Sciences Research Council Publishers. (full text: www.sahara.org.za).

Hall, E., & Shisana, O. (2003) The impact of HIV/AIDS on health workers employed in the health sector. In O. Shisana, & E. Hall (Ed.), *The impact of HIV/AIDS on the health sector: National survey of health personnel, ambulatory and hospitalized patients and health facilities, 2002* (pp. 57-84). Cape Town: Human Sciences Research Council Publishers. (full text: www.sahara.org.za)

Streefland, P.H. (2003). Introduction of HIV vaccine in developing countries: social and cultural dimensions. *Vaccine*, 21(13-14), 1303-1309.

Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting

Heleen French

Africa Unit for Transdisciplinary Health Research (AUTHeR), Faculty of Health Sciences, North-West University, Potchefstroom Campus, South Africa

North-West University, AUTHeR, Private Bag X6001, Potchefstroom, 2522, South Africa. Tel: +27 13 690 2201.

Heleen French, MCur, is a doctoral candidate at the North-West University, Potchefstroom Campus.

Minrie Greeff

Africa Unit for Transdisciplinary Health Research (AUTHeR), Faculty of Health Sciences, North-West University, Potchefstroom Campus, South Africa

North-West University, AUTHeR, Private Bag X6001, Potchefstroom, 2522, South Africa. Tel: +27 18 299 2092. Fax: +27 18 299 2088. Email: Minrie.Greeff@nwu.ac.za

Professor in Research, Africa Unit for Transdisciplinary Health Research.

Martha J Watson

School of Nursing Sciences, Faculty of Health Sciences, North-West University, Potchefstroom Campus, South Africa

North-West University, School of Nursing Sciences, Private Bag X6001, Potchefstroom, 2522, South Africa. Tel: +27 18 299 1838.

Senior Lecturer, School of Nursing Science.

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Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting

HIV stigma remains high globally. Although there is a selection of HIV stigma reduction interventions discussed in the literature, there is a paucity of research about the effectiveness of these interventions. This study aimed at gaining a deeper understanding of the experiences of people living with HIV (PLWH) and people living close to them (PLC) from six designated groups during and after having undergone a comprehensive HIV stigma reduction community intervention in both an urban and a rural setting. Attention was focused on their expressed experiences of the workshop and projects executed. A qualitative interpretive description approach was used.

PLWH as participants were selected through purposive voluntary sampling and through snowball sampling for PLC. Recruitment was from both urban and rural settings in the North West Province, South Africa. Data collection was via in-depth interviews with 23 PLWH and 60 PLC from specific designated groups. The data was thematically analysed through manual open coding. The results from the urban and the rural settings were pooled, as there were no noteworthy differences in the themes between them.

The results indicated that there was an increase in knowledge in all the groups, as well as experiences of enhanced relationships and of being equipped with leadership skills in order to go out into the community and being part of HIV stigma reduction actions. The intervention in its comprehensive nature was shown to have been successful and promising for future use in reducing HIV stigma.

Keywords: community, comprehensive, HIV, intervention, stigma

L'Expérience de personnes vivant avec le VIH et de leur entourage au regard d'une intervention communautaire globale de réduction de la stigmatisation liée au VIH, en milieu urbain et rural

La stigmatisation liée au VIH est répandue dans le monde. Bien que la documentation sur le sujet aborde un ensemble d'interventions en faveur de sa réduction, les recherches sur l'efficacité de telles interventions restent limitées. Cette étude vise donc à mieux comprendre l'expérience des personnes vivant avec le VIH (PVVIH) et de leur entourage dans six groupes sélectionnés pendant et après une intervention communautaire globale de réduction de la stigmatisation liée au VIH, en milieu urbain et rural. L'on a accordé une attention particulière aux expériences partagées sur l'atelier et les projets entrepris. Une approche de description qualitative et interprétative a été adoptée. Les PVVIH participantes ont été sélectionnées grâce à un échantillonnage dirigé et volontaire, et un échantillon boule de neige pour l'entourage. Les personnes recrutées provenaient de milieux urbains et ruraux de la province du Nord-Ouest, Afrique du Sud. La collecte de données s'est faite par des entretiens approfondis avec 23 PVVIH et 60 personnes de leur entourage, toutes issues de groupes spécifiques désignés. Les données ont été analysées thématiquement par codage ouvert et manuel. Les résultats des milieux urbains et ruraux ont ensuite été regroupés car il ne semblait pas y avoir de différence remarquable entre les thèmes soulevés dans les deux milieux. Dans tous les groupes, les résultats indiquaient un accroissement des connaissances, de l'amélioration des relations, et des compétences de leadership pour prendre part à la vie communautaire et participer aux activités de réduction de la stigmatisation. La réussite de la nature globale de l'intervention est prometteuse pour les activités futures de réduction de la stigmatisation du VIH.

Mots-clés : communauté, global(e), VIH, intervention, stigmatisation

1 Introduction and Problem Statement

This article reports on the in-depth experiences of people living with HIV (PLWH) and people living close to them (PLC) of a comprehensive HIV stigma reduction community intervention. PLC comprised partners, children, close family members, friends, spiritual leaders and community members. The research forms part of a larger SANPAD-funded study focusing on HIV stigma reduction in both an urban and a rural setting in the North West Province, South Africa.

South Africa is known to be the country with the highest HIV rates globally, but fortunately there is evidence that its incidence is decreasing. The persistency of the disease is, however, strengthened with current advances in HIV medicine and the free access to antiretroviral treatment (ART) (Department of Health, 2011; South Africa.info, 2013). These advances make HIV a manageable condition in the long term. However, the stigma attached to HIV remains a major problem, mainly due to the probability of immoral behaviour associated with its cause (De Bruyn, 1999; Pape, 2005). This perception has led to a great number of people being negatively affected by HIV stigma.

A group of researchers (Holzemer, et al., 2007; Uys et al., 2009) conducted intensive research on HIV stigma within the African setting over a five-year period. They aimed to understand HIV stigma within the African setting, formulating a conceptual model for HIV stigma, and developing and validating two stigma scales for the African context (Holzemer et al., 2007). Their study also had a component focusing on HIV stigma reduction in healthcare settings, including both PLWH and nurses (Uys et al., 2009). The current study proposed to extend this previous research into the community.

According to the conceptual model of HIV stigma in five African countries, stigma is a complex process and it occurs within a context consisting of the environment, the healthcare system and different agents. The stigma process itself involves triggers of stigma, stigmatising behaviours, types of stigma and outcomes of stigma (Holzemer et al., 2007). Stigmatising behaviour comprises discriminatory acts towards PLWH in different degrees. The types of stigma identified in the conceptual model include received stigma, internal stigma and associated stigma. This model formed the theoretical framework for the current study. The definition of HIV stigma as compiled by

Alonzo and Reynolds (1995, p. 304) is supported in this study. They describe stigma as “a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons”.

Despite the negative impact on PLWH and PLC, there have been a surprisingly limited number of intervention studies aimed at reducing HIV stigma. The most prominent HIV stigma reduction studies as summarised in recent literature reviews by various authors mainly focused only on PLWH (Brown, Macintyre & Trujillo, 2003; Heijnders & Van der Meij, 2006; Sengupta, Banks, Jonas, Miles & Smith, 2011). Brown et al. (2003) reviewed twenty-two studies that evaluated HIV stigma reduction interventions. They described them as being one of four types: information-based approaches, skills building, counselling approaches and improvement of contact with the affected group. Results of these interventions indicate that there are some that seem to be effective, at least on a small scale and in the short term, but this is inadequate, especially in relation to the scale and the duration of the impact of stigma reduction.

The review done by Heijnders and Van der Meij (2006) did not focus specifically on HIV and AIDS-related stigma reduction but it was significant, as it described related stigma reduction strategies focusing on individuals at interpersonal as well as community level. Sengupta et al. (2011) also did a literature review, focusing on evaluating the effectiveness of HIV stigma reduction interventions in which HIV and AIDS stigma was one of the outcomes being measured. Data was extracted from 19 studies, 14 of which demonstrated effectiveness in reducing HIV and AIDS stigma. However, only two of these 14 effective studies were considered good studies on the basis of their quality and the extent to which the intervention focused on reducing HIV and AIDS stigma.

The intervention studies were mainly quantitative, and the literature lacks qualitative reflection on experiences of these interventions that could be good for future HIV stigma reduction intervention development. It was further noted that there is a serious need for more comprehensive approaches towards HIV stigma reduction. Some target-specific interventions were found, for example focusing on people, like the designated groups in the current study. Uys et al. (2009) executed an HIV stigma reduction intervention focusing on the healthcare setting. The study proved to be successful in that it led to enhancing contact with PLWH, increasing knowledge of HIV and stigma, as well as

coping through empowerment. It instigated an increase in voluntary HIV testing by the nurses in the group, and was effective in reducing perceived stigma by PLWH and improved self-esteem (Uys et al., 2009).

HIV stigma reduction interventions targeting partners, like in a study by Manyedi, Greeff and Koen (2010), developed a programme to empower women whose partners had died of AIDS to cope with the accompanied stigma. The International Centre for Research on Women (Duvvury, Prasad & Kishore, 2006) developed a manual aimed at providing strategies for the reduction of HIV and AIDS stigma and violence against women. Sallar and Somda (2011) suggest a communication strategy such as entertainment education to raise awareness and tolerance and to promote action in the fight against HIV and AIDS stigma towards male partners engaging in sexual activity. It seemed from the literature that stigma reduction interventions targeting the partner mostly focus on disclosure issues and health education approaches with regard to safe sexual practices.

HIV stigma reduction interventions targeting the child also showed to be individual-based and in most cases did not include PLWH. The “Save the Children” study in China in 2005, for example, indicated that taking children seriously, having fun with them, treating them with admiration and using group activities were found to provide psychosocial support and promoted personal development (Children in Distress Network [CINDI], 2007).

Another example of an HIV stigma reduction intervention is entitled “Engaging youth to provide care and tackle stigma in rural Zambia”. The aim of the programme was to involve school-aged children in the care and support of PLWH. The findings showed intensely positive attitude changes by family members and the wider community in general. Benotsch et al. (2008) mention that some educational efforts focusing on children and HIV stigma reduction in Africa were undertaken and were effective, as they enhanced knowledge. Their sustainability and effects have not yet been evaluated though.

Fawole et al. as quoted by Benotsch et al. (2008), similarly applied educational approaches in the form of six weekly information sessions for secondary school children in Nigeria. Results indicated significant increases in tolerance for PLWH. A television

series known as “Soul Buddyz” was found to be a rewarding production for children, as they talked about things that they had seen on “Soul Buddyz” (UNAIDS, 2005). It seems as though HIV stigma reduction interventions targeting the child are mainly focusing on education and entertainment, and none were found that involved PLWH.

HIV stigma reduction interventions focusing specifically on family members of PLWH are uncommon in the literature. An example of an intervention aimed at HIV stigma reduction in the community is the “FARM project” (Foundation for Agricultural and Rural Management) in Thailand, which provides training for family members and community members on home-based care that aims to reduce HIV stigma in the family context by opposing myths and reducing cases of isolation (Busza, 1999). Another example is the study by Krishna, Bhatti, Chandra and Juvva (2005). These authors attempted to understand the impact that stigma had on the family system, as the family in the Indian context usually represents emotionally strong bonds.

There is a significant gap in the literature regarding family member-oriented HIV stigma reduction interventions in particular. Likewise, HIV stigma reduction interventions with friends are minimal. In no portion of literature the researcher reviewed could any interventions specifically targeting the “friend” of PLWH be found. This emphasises the significance of this comprehensive HIV stigma reduction intervention.

Nyblade, Stangl, Weiss and Ashburn (2009) describe an HIV stigma reduction intervention that was implemented in two urban communities in Vietnam that was attended by several individuals, some of whom knew each other, for example as neighbours. The main aim of the intervention was to increase awareness of HIV stigma and reduce fear-driven stigma, value-driven stigma, and discrimination. Qualitative studies depicting experiences of HIV stigma reduction programmes are scarce. The literature review also suggests that there is no comprehensive approach towards stigma reduction.

Limited HIV stigma reduction studies focusing on spiritual leaders were found in the literature. An HIV stigma reduction programme by the Malaysian AIDS Council managed to gain support from the Minister for Islamic Affairs (UNAIDS, 2005). The religious authorities of nine out of 14 states attended the initial workshop. The SanghaMetta (“Compassionate Brethren”) project was introduced by a lay Buddhist

teacher in Northern Thailand in 1997. The aim was to make use of existing community resources and extend the traditional role that Buddhist monks and nuns play in social welfare in the region to HIV prevention and care. The SanghaMetta training model was also used effectively with Christian, Hindu and Islamic leaders from Sri Lanka, Nepal, Pakistan and Afghanistan (UNAIDS, 2005). The outcomes of these interventions mentioned were education-focused and partially assisted in stigma reduction, as they enhanced disclosure and also assisted in reducing fear of interacting with PLWH.

HIV stigma reduction interventions focusing on the community as a whole were generally found in the form of outreach activities aimed at demonstrating the low risk associated with caring for PLWH. In Cambodia, for example, there are home-visit care teams that visit suspected PLWH weekly and then train their primary caregivers via demonstration that close contact does not cause HIV transmission (Busza, 1999).

In a study by Watson (2008), a community-based collaboration to support the older person in the world of HIV and AIDS, the author focused on this vulnerable group (previously disadvantaged elderly community) affected by HIV and AIDS. Although the main aim of her research was not merely to reduce HIV and AIDS stigma, she certainly addressed this problem as being part of the detraction from their overall well-being.

A community participation intervention for the reduction of HIV-related stigma in Thailand (Apinundecha, Laohasiriwong, Cameron & Lim, 2007) improved the levels of accurate HIV and AIDS knowledge among participants and also reduced the level of community stigma in the intervention group compared to the control group. The Academy for Educational Development (AED) (2007) designed a toolkit for action against HIV stigma. It was designed by and for HIV trainers in Africa to assist them in the planning and organisation of educational sessions to raise awareness and promote practical action to challenge HIV stigma and discrimination. It is an elementary, comprehensive educational tool for the lay person in the general community (AED, 2007).

Numerous community-based interventions with multiple activities demonstrated substantial changes in stigma at community level in Thailand, Tanzania, Vietnam, and Zambia. Each of these programmes focused on community participation. Intervention studies in Vietnam and Tanzania suggested that opportunities for ongoing discussions

about values and beliefs were imperative for reducing more than fear-based stigma and combating other drivers of stigma (Duvvury et al., 2006; UNAIDS, 2009).

The literature on HIV stigma reduction interventions targeting specific groups of PLC strongly suggests that the increasing of knowledge is the main objective. There is, however, a need to move outside information and education approaches and to rather integrate the necessary elements for an effective response to sustainable stigma reduction outcomes (Eba, 2007). There is furthermore a paucity of research on the experiences of the participants after they had undergone HIV stigma reduction interventions.

Authors also seem to come to opposing conclusions with regard to HIV stigma manifestations in urban and rural contexts, making effective intervention planning difficult. Naidoo et al. (2007) found that PLWH from urban contexts were often being stigmatised more than their rural equivalents. However, there are studies that found that the opposite was true (Bunn et al., 2008; Heckman, Somlai, Kalichman, Franzoi & Kelly, 2006). It is argued that the social background of the people involved as well as their economic status may influence their way of comprehending HIV, and hence their behaviour with respect to stigmatisation and discrimination.

From the literature reviewed it was evident that there are gaps in scientifically based HIV stigma reduction interventions aimed at curbing the phenomenon on a long-term basis (Sengupta et al., 2011). There are insufficient HIV and AIDS stigma reduction interventions, measurement tools evaluating the effects of HIV stigma reduction interventions are lacking, and the impact of the interventions on public health is not taken into consideration. It is important to provide proof of whether a reduction in HIV and AIDS stigma is associated with better health outcomes. It is therefore important to look into the experiences and outcomes of HIV stigma reduction interventions in order to improve future interventions. It is also useful to see whether there are any differences in HIV stigma reduction experiences between urban and rural contexts.

2 Research Objective

In this study the aim was to compare the expressed experiences of PLWH and PLC in an urban and a rural setting after they had undergone a comprehensive HIV stigma reduction community intervention.

3 Research Design

The research followed a qualitative interpretive description approach (Thorne, 2008) in order to explore and describe the expressed experiences of PLWH and PLC after they had undergone a comprehensive HIV stigma reduction community intervention. The research took place in urban Potchefstroom and rural Ganyesa. Both settings mainly included individuals from an African Setswana background. The living conditions in these areas are mainly poverty-driven due to high rates of unemployment (North West Provincial Government, 2013).

4 Research Method

4.1 Sample

The sample was drawn from two main groups, namely PLWH and PLC originating from the urban greater Potchefstroom and the rural Ganyesa in the North West Province, South Africa. PLWH were gathered by means of purposive voluntary sampling (Burns & Grove, 2005). PLWH were recruited through mediators with trust relationships with PLWH from local healthcare facilities and non-governmental organisations (NGOs). The research assistant was informed of the willing participants and given their contact information. For PLWH, the inclusion criteria were that they had to have been diagnosed with HIV for at least six months; they had to be able to communicate freely in English, Afrikaans or Setswana; willing to take part in a study in which HIV-status disclosure is imminent; and give consent to be interviewed and recorded. These PLWH were all actively involved in the workshops as well as projects with their designated groups. The final sample size of PLWH was $n = 18$.

The second main group, namely the PLC, consisted of six designated groups, namely: partners, children, close family members, close friends, spiritual leaders and community members of the PLWH. They were gathered through snowball sampling (Strydom, 2005). Each of the PLWH was asked to identify appropriate participants of their choice. The inclusion criteria for all six PLC groups were that they had to be at least 18 years of age; able to communicate freely in English, Afrikaans or Setswana; give consent to be interviewed and recorded. Each designated group also had some specific inclusion criteria, namely: the partner had to be married to or had to have been in a stable relationship with the PLWH for a period of at least six months; the child had to be a biological child of the PLWH, be at least 15 years of age or older, and had to obtain consent from the parent to take part in the study and provide consent themselves. The close family member could be any person apart from a partner or child. The close friend had to have been in a friendship relationship with the PLWH for a period of at least six months. The spiritual leader could be a traditional healer or religious leader. The community member had to be a person with whom the PLWH had regular contact, such as a neighbour. These people all had to actively participate in the entire intervention. The sample size for the PLC was $n = 60$, comprising the six designated groups.

4.2 Data collection

The research project was approved by the Ethics Committee of the North-West University (NWU-00011-09-A1) and the local Department of Health. For this study all participants were already involved in the overall study and have given their consent before. Consent was re-confirmed and they were informed that they could withdraw at any stage.

The researcher initially gained access to the community through a mediator and a research assistant. The research assistant made appointments with each potential participant and informed them of the arranged date, time and venue of interviews. They were thoroughly prepared for the interviews, and allowed time for queries prior to starting. They were assured of confidentiality and anonymity. All documents were kept in locked cabinets and were accessible only by researchers who were directly involved (Burns & Grove, 2005; Polit & Beck, 2006).

The participants were made aware that sharing experiences may cause discomfort.

Participants were further made aware of the availability of counselling and emotional support afterwards should they need this. Benefits included an opportunity to share their experiences of the intervention. Participation would also assist researchers in executing a comprehensive HIV stigma reduction community intervention.

Two open-ended questions for use in the in-depth interviews with PLWH as well as PLC were formulated beforehand and evaluated by experts for appropriateness. The questions were further assessed by conducting an interview and were then included in the data set. The PLWH were asked to respond to the following two open-ended questions: *“How did you experience the workshop and project with people living close to you and others in the group?”* and *“How did you feel about telling others your HIV-positive status during the workshop and project?”* The two open-ended questions that were asked to the various groups of PLC were: *“How did you experience the workshop and project with the PLWH and others in the group?”* and *“How did you feel about hearing the PLWH telling you and others of their HIV-positive status during the workshop and project?”*

The interviews individually took around one to one-and-a-half hours to complete. Various communication techniques such as the use of minimal verbal responses, paraphrasing, reflection, clarification, probing and making use of summarisation were utilised. In-depth field notes were made after the interviews (observational, theoretical, methodological and personal notes) for future reference and verification of the process and findings (Botma, Greeff, Mulaudzi, & Wright, 2010; Greeff, 2005).

The intervention for PLWH and PLC was adapted from the work done by Uys et al. (2009). The intervention consisted of an initial two-day workshop with PLWH, both in an urban and a rural setting, focusing on understanding HIV stigma, identifying their personal strengths and ability to handle disclosure in a responsible manner in order to prepare them thoroughly on a psychological level for the next phase of the intervention involving various PLC.

This was followed by six three-day workshops in both settings with PLWH and a specific designated group, namely partners, children, close family members, close friends, spiritual leaders and community members. Each group had a project running over a

period of a month. The workshops were presented in the form of presentations and small-group discussions and activities.

The facilitators of the workshops were always a non-infected as well as an infected individual. The researchers who acted as presenters during the intervention received in-depth training on the presentation of the course material beforehand. The tenets that these workshops were built upon were: increased knowledge and understanding of HIV stigma, equalising the relationship between PLWH and PLC, and empowering them to handle HIV stigma and enhance their wellness. The workshops aimed at bringing PLWH and PLC together, building relationships between them and providing them with knowledge.

The first day of the workshop focused on understanding HIV stigma and coping with it. The second day of the workshop aimed at motivating PLWH to use the knowledge gained on the first day to move into action and develop skills to become leaders in HIV stigma reduction in their own community. Participants were taught how to plan a project, followed by them planning their own projects with designated groups similar to theirs, e.g. partners with partners. PLWH spontaneously formed part of each of the six groups.

There was a period of one month after the initial two-day workshop for the implementation of the various projects. The researcher facilitated all groups by appointment in order to support them and to monitor their progress.

The third and last day of the workshop took place one month after the initial two-day workshop and each group had the opportunity to give feedback on their executed projects. They had to give a summary of the outcomes of their projects. Evaluation of the projects was done by a panel made up of invited relevant stakeholders in the community and the researchers involved. The evaluation of the projects was based on the feedback by researchers during facilitation as well as the presentation by participants. Feedback was then given to participants by the panel on their successes and a prize was awarded to the best project in the urban as well as the rural setting. The 18 PLWH and 60 PLC reached 1793 people with their projects.

4.3 Data analysis

Digital voice-recorded interviews were accurately transcribed verbatim in order for data analysis to take place (Botma et al., 2010; Hek & Moule, 2006). Data analysis was done manually by means of Creswell's generic qualitative analysis approach, which was thematically focused (Creswell, 2009). The steps taken by the researcher involved reading the data, making a detailed analysis, with grouping of themes under major topics, unique topics and leftovers. The data was then assembled according to identified topics and into categories and themes. Data was interpreted and conclusions drawn. Analytical bias was avoided through the use of a co-coder to reach consensus.

5 Trustworthiness

The researcher applied Lincoln and Guba's model (in Krefting, 1991) to guarantee trustworthiness in this research. *Truth value* was assured by prolonged engagement in the research field during the workshops as well as by conducting the in-depth interviews. Reflexivity was achieved through the writing of comprehensive field notes during and after the interviews. The researcher received in-depth training and did simulated interviews in advance. Triangulation of investigators took place. Regular discussions with study leaders took place, improving credibility. *Applicability* was guaranteed by the well-thought through sampling in urban and rural settings, as well as the thick description of the methodology. *Consistency* was ensured in that an audit trail as well as stepwise replication was possible due to a thick description of the methodology. The use of a co-coder further enhanced consistency. *Neutrality* was ensured by the availability of an audit trail, triangulation of investigators and reflexivity.

6 Results of the Study

The results are based on the in-depth interviews conducted with PLWH as well as the six designated groups who attended the intervention in its totality and took part in the implementation of their HIV stigma reduction projects. During data analysis it was established that there were no major differences in the themes between participants

from the urban and rural groups and data were therefore pooled. If any noteworthy differences are identified, they will be indicated. The experiences of the participants in the comprehensive HIV-stigma community intervention, which included the workshops and the projects, will be presented in the following sequence: PLWH, partners, children, family members, friends, spiritual leaders, and lastly community members. The discussion will be enriched by quotes of responses by participants. The main aim of reflecting on these experiences is to form an understanding of whether the intervention was successful and to identify gaps for possible improvement for future implementation.

6.1 Experiences of PLWH

The PLWH with each of their designated groups uniformly expressed a strong sense of a shift in perception regarding HIV stigma experiences. They became enlightened by the fact that they could, with the support of PLC, live in a positive manner with HIV: “When I was with the partners, I was able to talk to them about HIV. Before you stigmatise, think first about our life;” “At the workshop I experienced when a person lives with that illness and you have a partner don’t point fingers and say it’s their fault; ... you should come together and fight this together.”

Most of them reported feeling out of place and unsure initially, especially due to the imminent disclosure that was to take place: “I felt lonely;” “I was so afraid. So scared to talk about it.” PLWH felt empowered regarding disclosure choices: “...an eye opener, it teaches me a lot. Because I learned how to disclose my status and how to trust people I disclose to.”

The eventual outcome for most of the PLWH was that of freedom after disclosure and acceptance and comfort received during the intervention. PLWH experienced strengthening of relationships during the intervention. They felt supported and their human dignity enhanced during the intervention: “We didn’t judge each other, and there was openness. It felt like a blanket that keeps you warm.” Disclosure brought along a sense of self-determination and freedom: “I feel free. And more appreciative:” “I shouldn’t hide my status, I’m free;” “I was free. I was confident to disclose myself”. “It means that after we attended the workshop I learned a lot, so I’m not afraid to talk about it.”

The PLWH, like all the other designated groups that were part of the intervention, described gaining important knowledge regarding HIV stigma and coping with it. “In the workshop I experienced how to cope and what is stigma;” “At first ... I didn’t understand what the meaning of stigma is. When I came to the group, I learned more about the stigma.” They described a sense of realisation of how the community was discriminating against them: “...we get undermined and discriminated against by the community;” “They undermine us, and this results in us being side lined.” PLWH were reminded of the severe emotional pain that was caused by HIV stigma towards them: “I was feeling very, very sad and lonely, my family doesn’t accept me because I’m HIV positive;” “My sister used to beat me.”

PLWH felt enabled to take part in HIV stigma reduction in their community. They reported that designing a project was not always an easy task, but by joining hands the fight can be successful: “It was difficult to plan and organise all of those things, but the support you get from your group members it’s what count. That gives you strength to do what you planned to do.” A strong sense of pride about being part of the intervention was also reported “I felt so proud to be part of the project.” They expressed their desire to reach more people so that HIV stigma reduction can be an active reality within the broader community: “If we can reach more people, stigma will reduce in the community, people will rush to the clinics, they will not fear to go to the clinics because of stigma.”

6.2 Experiences of partners

Partners gained knowledge about HIV stigma and they became strongly aware of their own role in stigmatising PLWH: “Like I didn’t understand that these things of pointing fingers at people with HIV or going around talking about them that they have HIV or AIDS I didn’t realise that doing that is stigmatising a person.” Partners reported a strong sense of learning how to cope with stigma: “Like it taught me to accept myself and whatever obstacles and challenges that come my way to be able to face them”. They became empowered to share the knowledge as leaders in HIV stigma reduction in their own community. “Because I saw that it does happen to other people in the community. When a person sees that his wife is sick then he blames her, so I was able to talk to my neighbours and guide them”; “I am able to encourage people to go and test and share my knowledge with them.”

Partners expressed a sense being united during the workshops and the projects with the goal of reducing stigma: “I experienced that we got together, the community as well as people living with HIV, and we got to teach them about stigma and that people living with HIV are just like any other person who is living with any other illness”; “The project taught me to interact with people and to come together as a group and talk about this illness as partners and not fear anything.”

Partners felt empowered to disclose their own HIV-positive status after observing partners in the group doing so. “Sometimes when I was around others and they talked about people with AIDS I used to be ashamed and leave the room but now I am able to talk to them and tell them that we can live with AIDS and take our medication”; “I would fear being excluded because I had AIDS so I wouldn’t tell people. I couldn’t express my feelings but after the workshop I am able to talk to them and tell them that I am still living.”

Partners felt enlightened, enthusiastic and proud to go out and share their knowledge gained. “I felt like I could go around and teach other people so that they can also live good lives”; “So that the knowledge can move forward”; “I was very proud that I got that knowledge to teach the community”. Partners experienced the intervention as an enriching and uplifting experience: “It was a life-changing experience and it was the first time hearing about stigma”; “My spirit felt supported to hear about stigma”.

They experienced designing a project as challenging yet extremely satisfying and building confidence. “Well I didn’t even know what a project was. I learnt that if you want to do a project you should work hard.” “I felt like I could in front of a nation and tell them that a person with HIV is also a person”; “And I now feel that I am a stronger person and I can tell someone to go forward and tell people about stigmatising.” Through their group effort they made a success of their projects and felt fulfilled: They learned that group effort ensures success: “I learnt that as a group you can be able to reduce stigma as a group if we work together.”

6.3 Experiences of children

Children initially felt nervous and unsure of what to expect of the workshops, but as the time went by they reported more self-confidence: “I was quite a shy person and I

couldn't speak in front of an audience. So, after I attended the workshops that's when I started to feel free"; "I learnt to accept yourself." People from different age groups were involved in the intervention, which initially made it somewhat intimidating for some children: "The workshop was quite scary for me at first because there were older people there". They also felt scared and unsure of how to react towards PLWH: "At first I was scared because I did not know how to react to PLWH."

However, they got to know the PLWH better and acknowledged a positive kinship between them: "We have to embrace the PLWH". They learned to treat PLWH with dignity and not to discriminate against them: "It taught me to accept them and love them and be able to touch them and we can even share a glass." Children reported that they had experienced a learning curve during the intervention and that they had gained valuable knowledge throughout: "It was kind of a pathway that I had to learn (the project). At some points, I told myself now you need to focus and learn".

They realised the extent of HIV stigmatisation against PLWH and felt hurt by it. Some felt ashamed as they noticed that they were taking part in stigmatisation: "I felt hurt by what these kids were doing because I also taught myself about what stigma was and that how it affected people emotionally and physically"; "Because to be honest I was a thrower of rocks, I was one who stigmatised."

Children noted that people with HIV were often rejected and negative labels attached to them in their communities: "Some people in the community say very bad things about people living with HIV. This makes people living with the disease ashamed." The children had a common goal of advocating against HIV stigma: "...because I know my community wasn't aware the stigma attached to HIV. So now they will start being aware." "These people should be taught that people with HIV are people too."

They felt that stigma reduction can have a positive outcome for PLWH, as they then did not need to hide from people due to their status: "It would really help because people wouldn't have to hide the fact that they have HIV and they would be free." They reported forming positive relationships with the other children in the group. The children came to the realisation that there were other children in the community with the same circumstances as themselves. It elicited a sense of belonging and comfort: "Knowing

other children and understanding how they feel, of being affected by HIV and getting to know their situations at home...”; “We were working like a group and like a family.”

Children reported gaining self-confidence to achieve success through participation: “We were working as a team working hard. We told ourselves that we are going to achieve the project.” They felt excited about completing their project: “So we felt great about it.”

6.4 Experiences of family members

The group of family members expressed that they got a much better understanding of stigma and that they had not realised what stigmatisation was and how bad it was: “I didn’t know about this stigma before until I heard all these people;” “I wasn’t okay because it was still us who hurt people with our words.” The family members realised the hurt they caused by stigmatisation and that it was unacceptable and that they should change their behaviour: “The workshop and the project made a difference in my life...I learned that I must respect and love people who have been infected with this disease;” “I am no longer going to stigmatise people.”

Leadership was enhanced and stigma activists formed during the intervention: “After attending that workshop I can stand in front of the people telling or teaching about stigma and how to handle the people who are living with HIV;” “I learn too many things and it made me feel good because I was a leader...;” “I feel very happy because right now I can become something. I can teach people what is the stigma.”

The group of family members from the rural setting indicated the presence of blatant discriminatory acts within healthcare settings directed at PLWH. In Ganyesa, almost all participants indicated that they were aware of discrimination at the local healthcare facilities in the form of differentiation by means of colour coding between files of PLWH and people who were not infected: “Their files are separate, the colour is not the same as others;” “And I realised that people are afraid of these files because when people see your file that’s when they start talking about you.”

The project was described as a difficult task but yet fruitful in the end. Participants from the urban group experienced a challenge regarding commitment, but the group members who persevered succeeded: “When the time goes on, the project broke into

two pieces;” In the end they felt proud of succeeding and expressed a sense of achievement: “I teach people what is the stigma and understand it very well.”

The rural group of family members also experienced that they had achieved their goals with their project: “People are happy about the information and people are promising not to do what they did last.”

6.5 Experiences of friends

A strong message of a fear of contagion was reported by friends. Some indicated how their distorted ideas had been corrected during the intervention: “I was scared of people with HIV. And even to touch them I was scared to touch them. But right now I can touch her; I can do anything for her”. Friends came to realise how painful the effects of stigma were: “I knew nothing about stigma so I learnt that it is when people call other people with HIV with all sorts of bad names and that is painful...” They became skilled in helping PLWH cope with HIV stigma: “...learnt how to cope and how to deal with the stigma”; “how to treat people with HIV and how to make them comfortable with their status”.

Friends felt proud of being part of the projects and sharing the knowledge they had gained. “I feel proud and happy teaching something that is important;” “We were able to teach others”; “Very proud and also that I still hold what I’ve taught and I am able to give people information.”

Friends from the rural group, like the group of family members, specifically noted the discriminatory acts within the healthcare setting. The rural group of friends, like the family members, indicated that they disapproved of the issue of colour coding the files of PLWH: “Because some of the people are faced with difficulty when they have to get treatment;” “...if they carry those black files, people know that they are HIV positive. And they don’t want people to know...”

One of their objectives planned initially was to address this, but this could not succeed due to refusal by the hospital authorities: “And the management said that it was not possible. We can write to the district, they give us the address. They said we can write to the district manager to ask them to change the files”. They felt that HIV stigma

reduction was imperative and should continue in the community: “Because this workshop were very important for other people outside so they will teach us how to make an organisation so that we can help the people outside.” They felt that standing together in unity against stigma in the community was possible: “I share that if we can work together, we can reduce this stigma thing.”

6.6 Experiences of spiritual leaders

During the workshops, spiritual leaders gained knowledge that brought them to a shocking reality of their role in applying the knowledge they had gained on HIV stigma: “I’m supposed to take the knowledge to be a spiritual leader or pastor and put it aside and also use this knowledge of stigma.” They described coming to the realisation of how wrong they had been in the past in ignoring the issue of HIV stigma in their communities: “In the past...I am a pastor, these things are not my problem”; “I was taught in my college to read the Bible and telling the people do that and that, singing and praying then other things they not for me.”

They were brought to realise the negative impact stigma has on PLWH and that, as people with a standing in their community, their active involvement in stigma reduction was undeniable: “I am supposed to take the knowledge to be spiritual leader or pastor and put it aside and use this knowledge of stigma;” “I am supposed to be taking out and reach out to the people and giving what I have.”

Spiritual leaders indicated that it had initially been a strange yet fulfilling experience to be placed together in a group of people from different religious and traditional standpoints. However, they realised that they were there for a common goal, wanting to get a better understanding of HIV stigma: “...pleased to see us all as traditional healers as well as pastors being grouped together”; “working together especially people who are different in religions is totally something very difficult ...but what I like is that we’re serving one goal.”

The rural group of spiritual leaders were proud that people had gone for HIV testing spontaneously during the project hosted by them: “...were willing to get tested because they used to fear being tested but they did at that time;” “...and those that were afraid to go and test ended up having the courage to go...” They further expressed a sense of

pride and motivation to continue with the important task of HIV stigma reduction: “I saw what we were doing was something very good and important...our community is still happy because they ask us when next are you coming;” “...very excited to learn about stigma so that I could be able to explain it to my peers as well as the community.”

The realisation of being of support to PLWH was marked: “They feel free because people accepted them the way they are;” “I can lead the people who are living with HIV and also those who do not have HIV.” One of the spiritual leaders from the urban group felt able to disclose his own HIV status during the intervention due to other participants doing that comfortably within the group: “I met other spiritual leaders, the community. They made me stronger because I was able to disclose.” They saw the success story by working together: “...after the drama the whole thing was a success. So if everyone works together we will achieve.”

6.7 Experiences of community members

The community members described the intervention as initially frightening due to its unfamiliar nature, yet significant: “...hard because I saw new faces that I didn’t know but eventually I got used to them and we went and got taught and at the workshop I learnt things that I didn’t know.” They received knowledge about stigma and coping with it and realised the importance of sharing the knowledge with others: “...knowledge I gained from the workshop like HIV stigma, coping...;” “...take this information that I had and use it in my community with my friends and share it with my people and my peers.”

They were able to work in close proximity with PLWH during the intervention and realised that they were equal to everyone else: “I was able to deal with and working with people who are positive. I was able to put myself in their shoes;” “I didn’t see them as the outsiders. I started to see them as people just like us.” During the intervention, the community members became aware that dedication is necessary for a project to be successful: “Even if you must stay up the whole night, it doesn’t matter because it is you that is going to have the fruits behind it. You will get the fruits.” The projects were successful and well received in the communities: “It was so fruitful because the impact we get from the people were very good;” “Even though it was a good thing, it was a success for me.” They were also able to realise how important and satisfactory it was to

share gained knowledge: “I can also help some people gaining knowledge because with the little they gain we can at least do something more in helping the next person.”

Community members expressed feelings of motivation after the intervention. Some felt inspired by the passion from presenters to also step out and act against stigma: “I can see that these people are really serious and these people they are not here to play these people are here to help others;” “...I’m going to join them and I’m going to help also to make a difference.”

7 Conclusions

There were no remarkable differences between the experiences expressed by the PLWH and the PLC after they had undergone the comprehensive HIV stigma reduction community intervention in urban and rural settings. This could be due to the Setswana culture that is prominent in the North West Province. After they had taken part in the intervention in its totality with the designated groups of PLC the PLWH expressed a sense of being accepted and respected. Bringing the people together had made them aware that they still had human dignity, and that they could still live positively with the virus.

The workshop was described as emotionally demanding mainly due to the imminent disclosure, but support and the eventual disclosure actually brought freedom for PLWH. Responsible disclosure management was discussed and truly capacitated PLWH for the management of HIV disclosure in a responsible manner.

They received knowledge about HIV stigmatisation as well as skills for coping with it. They felt enabled to actively take part in HIV stigma reduction in the community. The PLWH also reported that designing a project as part of the intervention had been difficult, although it had proved to be successful in the end and had instilled a sense of pride. The PLWH strongly agreed that they wished to reach many people with the important message of HIV stigma reduction.

Partners gained knowledge on HIV stigma, but they reported a strong realisation of their stigmatising behaviour towards PLWH. They could accept themselves better.

Relationships between partners were enhanced during the intervention. Disclosures that took place during the workshop as part of the intervention empowered some partners to also take that step. The knowledge gained empowered them to share their status and also to change their stigmatising behaviour. The partners experienced the intervention as an uplifting and enriching experience.

Children were initially nervous when they started the intervention but they learned that it was an enriching experience and they gained confidence. They were saddened by the severity of HIV stigmatisation and they became aware of their damaging deeds as participants in stigmatisation. There was a common goal amongst them to advocate against HIV stigmatisation and a strong sense of cohesion was reported. The children gained self-confidence with the success of their projects.

The family members reported gaining an enhanced understanding of HIV stigma. The prominent theme reported by family members was the positive change in the attitudes of family members brought about by the intervention. Leadership was enhanced and HIV stigma activists formed. The rural group of family members experienced noticeable discriminatory acts within the healthcare environment. The projects were experienced as difficult but meaningful.

The group of friends experienced gaining knowledge regarding HIV stigma, but they prominently indicated the realisation of the painful effects of stigma. Initially there was a strong sense of fear of contagion in this group, but that changed. They also reported gaining skills on how to help PLWH cope with stigmatisation. They further felt proud of the useful knowledge received and their being able to share it. The rural group of friends, like the family members, reported their dismay at realising the visible discrimination in the healthcare settings where PLWH were being marginalised by the existing filing system. The friends uniformly described their strong belief in the importance of applying HIV stigma reduction in a continuous and sustainable manner in the community.

Spiritual leaders realised that HIV stigma knowledge was important and should be applied in their work as spiritual leaders. They acknowledged their negligent behaviour in the past with regard to HIV stigma reduction and also that they had the capacity as respected figures in the community to assist in HIV stigma reduction. They reported that

being placed in a group of people with varying religious and traditional viewpoints was strange and challenging, but eventually they worked towards a common goal of HIV stigma reduction and recognised how fulfilling the experience actually was. It made them to feel proud of being part of the project and motivated to reduce HIV stigma in the community. There was a strong sense of being a support system to PLWH. The spiritual leaders acknowledged the importance of working together to achieve set goals.

Community members experienced the workshops as being frightening due to the unknown nature thereof, but they eventually found them meaningful. They gained knowledge about HIV stigma and coping with it and they reported the strong realisation of the importance of sharing gained knowledge. The community members were reminded that PLWH were equal to any other human being and that they should not be treated differently. They also realised that dedication was an important aspect of ensuring success in a project. They felt motivated to go out and assist in HIV stigma reduction in their community.

From the discussion of the results it can be concluded that not only was there an increase in knowledge, but all designated groups as well as the PLWH reported an experience of enhanced relationships and being equipped with leadership skills in order to go out into the community and being part of HIV stigma reduction actions. However, the PLWH reported more prominently on being enlightened about being accepted and that they were able to live a normal life in a community with PLWH as well as non-infected individuals. Responsible disclosure management was identified as a very meaningful guideline for future disclosure decisions.

Partners realised what a major role they were playing in stigmatising PLWH and they were reminded of the fact that PLWH should be treated with respect and dignity. Children commonly reported on a sense of enhanced relationships and cohesion with other children in the group. They further became aware of how painful HIV stigmatisation is for these children. They became motivated and actively took part in HIV stigma reduction efforts in the community.

In the group of family members there was a uniform report that the intervention had brought about changes in negative attitudes from family members towards PLWH. Friends reported on their realisation of how prominent their role in HIV stigmatisation

was. They often feared contagion unnecessarily and they became aware of the pain that they were causing by their stigmatising behaviour.

Spiritual leaders noted that they had been negligent in the past with regard to HIV stigma reduction by saying that it was not part of their duty as spiritual leaders to assist in HIV stigma reduction. However, they understood the important role they could play in HIV stigma reduction, as it was a prominent problem in the community, and that they as figures carrying authority in the community could make a significant difference in fighting HIV stigma.

8 Limitations

Some of the designated group members' groups were smaller than anticipated because the PLWH had a choice to bring a specific member of a designated group, or they did not have someone that represented the designated group, e.g. partner or child.

9 Recommendations

Although the intervention in its entirety was successful after it had been implemented, it could be meaningful to take the specific needs of the different groups involved in this study into consideration, as a greater awareness of these needs was created. With regard to partners, it may be meaningful to also specifically address HIV stigmatisation in the context of the PLWH being in intimate relationships with the partners.

Children may gain from preparing them emotionally to be part of a group of PLWH who maybe older than they are. Family members can be placed together with more family members from the same family to intensify the effect of the intervention on more people. Friends in this study seemed to have been strongly taking part in stigmatising behaviour, and fear of contagion remained an issue. It may be worthwhile bringing friends together and providing them with knowledge on HIV modes of transmission and advocating friendships with PLWH, as they are the same as anyone else.

Spiritual leaders could be specifically trained on HIV stigma and the religious community, e.g. on the application of biblical norms in HIV stigma reduction education. Applying the intervention in its totality with the projects is effective, as many people were eventually reached due to its ripple effect. Further quantitative research to strengthen the findings of this study could be meaningful – also to evaluate its long-term effect. It can also be useful to take the intervention further into the community on a permanent basis, for example by establishing HIV stigma reduction hubs in the broader community. Additional research involving other cultural groups and urban and rural populations would be meaningful.

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SECTION D: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

1 Conclusions

In this section, conclusions are presented as compiled from all the sections of this research presented in article format. A summative conclusion for the study as a whole is also presented.

1.1 Conclusions on HIV stigma and disclosure experiences of PLHA in an urban and a rural setting

No noteworthy differences between urban and rural settings were noted with regard to HIV stigma and disclosure experiences. This outcome could be due to the fact that both the urban and the rural groups were mostly Setswana speaking and that the cultural contexts were the same. Differences were noted with the really bad name calling in the urban setting, as well as the experience of being treated as inhuman, whereas in the rural setting the issue of their filing system revealing the status of people living with HIV or AIDS (PLHA) without their consent was prominent.

In general it can be concluded that negative behavioural patterns towards PLHA in the form of gossip, verbal abuse, pestering and PLHA being chased from their houses remained a reality. Attitudes towards PLHA were also overwhelmingly negative and were noted through rejection, dehumanisation, negative judgment and looking down on PLHA in disgust. PLHA were still ignored in the community and sharing of eating utensils with PLHA was avoided, with not PLHA not being allowed to be involved in food preparation. It seemed as though ignorance and/or a lack of education was still the reason behind PLHA being treated this badly. Experiencing the pain associated with harsh behaviours and attitudes towards PLHA in the community often led to self-judgment by PLHA and intense negativity, which often led to suicide ideation.

In a study by Greeff et al. (2008b) the negative behavioural patterns and attitudes towards PLHA discussed in this study are mainly summarised as dimensions of

received stigma. Five years later it was evident that HIV stigmatisation was still a dreadful reality that needed urgent attention in the community.

Some differences noted in the shift in contexts were that pestering in this study mainly took the form of questioning about weight loss and provocation about the probability of dying soon, whereas in the study by Greeff et al. (2008b) it took the form of persistent questioning about PLHA's behaviour and illness. Avoidance of involving PLHA in food preparation at gatherings such as funerals and weddings was further extremely prominent in this study, whereas in the study by Greeff et al. (2008 b) only avoidance of sharing eating utensils was identified.

Dimensions of internal stigma as described by Greeff et al. (2008b) encapsulate the issue of negative self-perception and social withdrawal and suicide ideation was also mentioned. Fear of disclosure is one of the dimensions of internal stigma as identified by Greeff et al. (2008b). In the current study it was found that disclosure was a major issue for PLHA, and that it took a lot of courage and consideration. It was found that the mother figure was the first person to whom PLHA disclosed their HIV status, followed by other family members. This finding confirmed that by Greeff et al. (2008a), who found that family members are the first people to whom PLHA in Africa disclose their status.

Disclosure without consent remained a problem and was also previously identified (Greeff et al., 2008a). The benefits and disadvantages of disclosure for both discloser and receiver were often weighed against each other in order to make an informed decision. PLHA feared losses in various forms and often avoided disclosure due to the prominence of stigmatisation in the community and its probable negative effects. This finding was confirmed by Serovich (2001).

Disclosure was often forced, as there were several associations within the community that could be attached to being infected with HIV. Examples were visiting healthcare facilities for treatment collection and review and practices such as filing systems revealing HIV status. PLHA experienced these as being discriminated against and being denied the right to a stress-free environment like anyone else. Greeff (2013) confirms that disclosure is often inevitable, for example when the need arises to visit the healthcare facility.

From the above findings it is clear that the stigma process as described in the a conceptual model of HIV/AIDS stigma from five African countries (Holzemer et al., 2007) indeed takes the form of triggers of stigma, stigmatising behaviours, types of stigma and outcomes of stigma. It remains a reality that PLHA experience high degrees of stigma in a variety of ways. The close link between disclosure and stigma was once again evident in this study.

1.2 Conclusions on the outcomes of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention on PLHA and PLC

The comprehensive HIV stigma reduction and wellness enhancement community intervention was successful as a whole for PLHA and all the designated groups of PLC (people living close to them). Preparing PLHA through training in responsible disclosure management did prepare them and gave them back control over their disclosure decisions. Most felt that disclosure was a means of freeing oneself of the burden of carrying secrets.

Two-weekly sessions initially took place, with the intensive intervention covering a three-month period. The method of facilitating the intervention by using a non-infected and an infected facilitator, presentations providing specific knowledge followed by activities and discussions to ensure contact was successful. The contact and method of presentation facilitated the achievement of the tenets on which the intervention was built. The set goals of bringing PLHA and PLC together, sharing information on HIV stigma and coping with it through increased communication between the PLHA and PLC and empowering them towards leadership in HIV stigma reduction was effective. Executing the HIV stigma reduction projects with specific designated groups in their own communities gave the PLHA and PLC a sense of achievement and of gaining personal leadership. Bringing PLHA and PLC together in such an intimate workshop environment where personal experiences with stigma were shared, enhanced a deeper understanding for PLHA and the realisation of the damaging effects of stigma were identified.

The number of people reached through the projects showed that using the “stone in a pond” ripple effect was much more effective than targeting this problem on an individual basis. In the end the 18 PLHA and 60 PLC reached a further 1793 people in the

community with specific HIV stigma reduction activities. The results were mainly the same for both urban and rural groups, and only small differences were observed and expressed as being denied the opportunity to bring about change regarding the discriminatory filing system in the hospital. The similarities between experiences of the urban and the rural groups may be attributed to the fact that the Setswana culture is so powerfully present in the North West Province.

1.3 Conclusions on experiences of PLHA and PLC of a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting

There were no noteworthy differences between the expressed experiences of the PLHA and the PLC after they had undergone the comprehensive HIV stigma reduction community intervention in the urban and the rural settings. This could be due to the Setswana culture that is prominent in the North West Province. Through their participation the intervention in its totality, The PLHA taking part in workshops and projects with their designated groups experienced a strong sense of being accepted and respected. Bringing PLHA and PLC together made the PLC aware that the PLHA still had human dignity, and of the fact that they can still live positively with the virus.

The workshop was endorsed as being emotionally demanding mainly due to the imminent disclosure by the PLHA, but support and the eventual disclosure actually brought about a strong sense of freedom for the PLHA. The preparation for responsible disclosure management was an important aspect of the intervention that was discussed and truly empowered the PLHA to manage HIV disclosure in a responsible manner in future.

The PLHA received important knowledge about HIV stigmatisation and acquired important skills for coping with it. However, it was also true that they were once more made aware of the fact that HIV stigma causes a great amount of emotional pain. They felt enabled to actively take part in HIV stigma reduction in the community through the projects. They also reported that designing a project as part of the intervention was difficult, although it proved to be successful in the end and gave them a sense of pride. The PLHA strongly agreed that they wished to reach many people with the important message of HIV stigma reduction.

Partners gained knowledge on HIV stigma but they reported a strong realisation of their stigmatising behaviour towards PLHA. They could accept themselves better. Relationships between partners were enhanced during the intervention. Disclosure that took place during the workshop as part of the intervention empowered some partners to also take that step to disclose their own status. The knowledge gained empowered them to share the knowledge with others and also to change stigmatising behaviour and hence become leaders against HIV stigma in the community. A strong sense of pride at being part of the intervention but also being enabled to educate others was reported. The partners were uplifted and enriched.

Children were initially unsure and nervous when they started with the intervention, but they learned that it was enriching and they gained confidence as the workshops and projects progressed. They were saddened by the severity of HIV stigmatisation in the community, especially towards children affected by HIV stigma. They became aware of their own damaging deeds as participants in stigmatisation. There was a common goal among them to advocate against HIV stigmatisation and they became passionate about fighting stigma. In the group of children there was a strong sense of cohesion. They gained self-confidence with the success of their projects.

The *family members* reported gaining an enhanced understanding of HIV stigma and a positive change in attitude was brought about by the intervention. Leadership was enhanced and HIV stigma activists developed. The rural group of family members spoke up against the noticeably discriminatory acts within the healthcare environment. The projects were experienced as difficult but meaningful in the end and completing them gave the family members a sense of pride.

The group of *friends* gained knowledge regarding HIV stigma, but they prominently indicated the realisation of the painful effects of stigma. There was a strong sense of fear of contagion in the group of friends, which changed. They also reported gaining skills on how to help PLHA to cope with stigmatisation. They became motivated to take it further. The rural group of friends also reported their dismay at realising the visible discrimination in the healthcare settings where PLHA were being marginalised by the existing filing system. The friends uniformly described their strong belief in the

importance of applying HIV stigma reduction in a continuous and sustainable manner in the community.

Spiritual leaders realised that HIV stigma knowledge was important and should be applied in their work as spiritual leaders. They acknowledged their negligent behaviour in the past with regard to HIV stigma reduction and also that they had the capacity as a respected figure in the community carrying authority to make a significant difference regarding HIV stigma reduction. Being placed in a group of people with varying religious and traditional viewpoints was strange and challenging to them, but in the end they recognised how fulfilling the experience actually was. It made them feel proud of being part of the project and they became truly motivated to reduce HIV stigma in the community. There was a strong sense of providing a support system for PLWH.

Community members experienced the workshops as being frightening due to the unknown nature thereof, but they eventually found them meaningful and significant. They strongly reported the realisation of the importance of sharing gained knowledge. The community members were reminded that PLHA were equal to any other human being and that they should not be treated differently. They also learned that dedication was an important aspect in ensuring success in a project. They became motivated to go out and assist in HIV stigma reduction in their community.

1.4 Summative conclusion

From the discussion of the results it can be concluded that the execution of the comprehensive HIV stigma reduction and wellness enhancement community intervention was successful. PLHA as well as six designated groups were involved, and the results of the reported experiences of the intervention as a whole reflect that not only was there an increase in knowledge, but the participants also reported an experience of enhanced relationships and being equipped with leadership skills in order to go out into the community and be part of HIV stigma reduction actions:

The PLHA more prominently reported that they had been enlightened about being accepted and that they were able to live a normal life in a community like non-infected individuals. Responsible disclosure management was identified as a very meaningful guideline for future disclosure decisions. Partners prominently came to realise what a

big role they were playing in stigmatising PLHA, and they were reminded of the fact that PLHA should be treated with respect and dignity.

Children commonly reported a sense of enhanced relationships and cohesion between other children in the group. They further became aware of how painful HIV stigmatisation was for these children. They became motivated and actively took part in HIV stigma reduction efforts in the community.

In the group of family members there was a uniform report that the intervention brought about changes in negative attitudes from family members towards PLHA. Friends reported on their realisation of how prominent their role in HIV stigmatisation was. They had often needlessly feared contagion, and they became aware of the pain that they had been causing by their stigmatising behaviour. Spiritual leaders noted that they had been negligent in the past with regard to HIV stigma reduction by saying that it was not part of their duty as spiritual leader to assist in HIV stigma reduction. However, they realised the important role they could play in HIV stigma reduction, as it was a prominent problem in the community, and that they as a figure carrying authority in the community could make a significant difference in fighting HIV stigma. The community members had closer contact with PLHA and realised their role in the reduction of HIV stigma.

All the set goals for the study were met. The intervention can be applied in its totality as it was done in this study, but it is also adaptable with regard to target groups. It can be applied to any group of people living close to PLHA who are affected by HIV stigma.

2 Limitations

The fact that this study was conducted in urban and rural settings within the North West Province only makes it difficult to confirm with certainty that there are truly no significant differences in HIV stigma and disclosure experiences between urban and rural settings. In groups such as the partners, children and family members there were in some cases either no significant others present in the lives of PLHA, or low attendance by them.

This contributed to the sample size not being as big as it was initially planned to be. The choice given to PLWH of who to invite also added to this.

3 Recommendations

The following recommendations follow from the literature review, findings and conclusions:

- The comprehensive HIV stigma reduction and wellness enhancement community intervention in its totality as presented in this study can be meaningful in future and it can also be presented to any group of PLC.
- The tenets upon which the intervention was built, (sharing of information, equalising the relationship between PLHA and PLC, as well as enhancing existing strengths for leadership development) were proven to be useful and should not be separated.
- The timeframe of the intervention does not need to be as long as in this study to have a positive outcome. The focus can be only on specific groups identified by PLHA.
- Disclosure should always be addressed together with HIV stigma reduction intervention efforts.
- It can also be useful to take the intervention further into the community on a permanent basis, for example by establishing HIV stigma reduction hubs in the broader community.
- This intervention can be applied in the re-engineering of primary healthcare services by presenting the course to newly diagnosed PLHA and PLC. Nurses and healthcare workers should be included in this strategy.
- Although the intervention in its entirety was successful after it had been implemented, it could be meaningful to take the specific needs of the different groups involved in this study into consideration now that they have become more aware of the problem of HIV stigma. With regard to partners, it may be meaningful to

also specifically address HIV stigmatisation in the context of being in an intimate relationship with the partner. Children may gain from being prepared emotionally to be part of a group of PLHA who may be older than they are. Family members can be placed together with more family members from the same family to intensify the effect of the intervention on more people. Friends in this study seemed to be strongly participating in stigmatising behaviour and fear of contagion remaining an issue. It may be worthwhile bringing friends together and providing them with knowledge on HIV modes of transmission and advocating friendships with PLHA, as they are the same as anyone else. Spiritual leaders could be specifically trained on how to integrate HIV stigma and the religious community, e.g. through the application of biblical norms in HIV stigma reduction education.

- Further quantitative research to strengthen the findings of this study and to evaluate its long term effect could be meaningful.
- Additional research involving other cultural groups and urban and rural populations would also be meaningful.
- The successes achieved during the comprehensive HIV stigma reduction community intervention, is a positive motivation for development of workplace policies for the primary healthcare setting.

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APPENDIX A: ETHICAL APPROVAL FOR THE STUDY



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Prof M Greeff

Ethics Committee

Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za

2009-03-31

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|----------------|---|---|---|---|---|------|---|--------|---|---|---|---|---|-------------|--|--|----------------|--|--|--|--|--|------|--|--------|--|--|--|---|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| Project title: A Comprehensive Community-Based HIV Stigma Reduction and Wellness Enhancement Intervention | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Ethics number: | <table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>0</td><td>1</td><td>1</td><td>-</td><td>0</td><td>9</td><td>-</td><td>A</td><td>1</td></tr><tr><td colspan="3">Institution</td><td colspan="6">Project Number</td><td colspan="2">Year</td><td colspan="4">Status</td></tr><tr><td colspan="15">Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</td></tr></table> | N | W | U | - | 0 | 0 | 0 | 1 | 1 | - | 0 | 9 | - | A | 1 | Institution | | | Project Number | | | | | | Year | | Status | | | | Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation | | | | | | | | | | | | | | |
| N | W | U | - | 0 | 0 | 0 | 1 | 1 | - | 0 | 9 | - | A | 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Institution | | | Project Number | | | | | | Year | | Status | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Approval date: 30 March 2009 | Expiry date: 29 March 2014 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

APPENDIX B: CONSENT TO BE A RESEARCH PARTICIPANT

THE NORTH-WEST UNIVERSITY AND VRIJE UNIVERSITEIT AMSTERDAM

CONSENT TO BE A RESEARCH SUBJECT

A COMPREHENSIVE COMMUNITY-BASED HIV STIGMA REDUCTION AND WELLNESS ENHANCEMENT INTERVENTION

1 PURPOSE OF THE STUDY

A team of researchers from various disciplines of the North-West University and the Vrije Universiteit, Amsterdam are conducting a study on a comprehensive community-based HIV stigma and wellness enhancement intervention in the North West province, South Africa. You are being asked to participate in this study because you are a person living with HIV or a person living and working close to a person living with HIV.

2 PROCEDURE

If you agree to be in this study the following will occur:

- A set of questionnaires will be completed by you prior to a workshop.
- If you are a HIV positive person an in depth interview will be conducted with you at the beginning of the research and you will be expected to join an initial two day workshop followed by six workshops with people living and working close to you.
- If you are a person living or working close to a person living with HIV you will be expected to join a two day workshop followed by a project that you will be involved in for a month that will be evaluated during a further one day session.
- After the workshops interviews will be conducted with you asking you about your experiences during the intervention.
- This will be followed by questionnaires completed by you on a three monthly basis for four times during 2011.

3 RISK/DISCOMFORTS

As people living with HIV and people living and working close to such persons the HIV status of the person will be made known to all the people in the various groups. In the workshops you will be joined by other people similar to yours. Sharing experiences could be painful and uncomfortable. Some of your privacy might be lost during the intervention, however your data will be handled as confidential as possible. Your name will never be made known and no individual identifiers used in any publications resulting from the survey. Only the team of researchers will work with your data.

4 BENEFITS

By being involved in this research project will become knowledgeable about HIV stigma, learn to cope with the situation and become empowered to be leaders in the field of HIV stigma reduction. Your participation will help the researchers to develop a comprehensive community-based approach to reduce HIV stigma.

5 COSTS

There will be no cost to you as a result of your participation in the study.

6 PAYMENT

You receive no payment for participation. You will receive a meal and refreshments during the workshop days and will be transported to the site.

7 QUESTIONS

You can talk to Prof Greeff (project leader) or Poncho (research assistant) if you have any further questions concerning your consent. They can be reached at 018 299 2092.

8 CONSENT

You will be given a copy of this consent to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point.

Should you be willing to participate you are requested to sign below.

I.....hereby voluntarily consent to participate in the above-mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study, that the information will be kept confidential and not linked to my name at any stage. I also understand that I might benefit from the intervention. Should I experience any emotional discomfort I will be referred for counseling.

Date

Signature of the participant

Date

Signature of the person obtaining consent

APPENDIX C: EXAMPLE OF A NAÏVE SKETCH

Participant:

Code: 201

I experienced the project as:

I experienced much in this speak out project because we have already teach people about stigma and we will go forward to nearest place to teach people about stigma.

I feel:

So happy and lightly exited

God will give us the power to reach our goals

APPENDIX D: EXAMPLE OF A FIELD NOTE

Field notes

Group: Family
Rural

Day-1

Demographic and Methodological notes:

The stigma intervention for family members at the rural site (Ganyesa) took place on the 14th September 2010 at Setlhare Guest house. Only 3 family members came for the interviews on day 1. On day 1 of the workshop, another 5 family member participants were interviewed by the facilitators. One participant of the previous day did not come back for the workshop. The participants were 9, (2 male and 7 female) People Living with HIV or AIDS (PLHA), and 7 family members (1 male and 6 female). The workshop started at about 09H00 with 16 participants, (1) facilitators, (2) co-facilitators and (1) fieldworker. The room was quiet, with enough ventilation and light, with sufficient chairs and tables. The seating arrangement was semi-circular but with tables in front of the participants. Although there were tables between the facilitator and the participants, it caused no barrier as the participants were close to each other. Smaller groups sat around the tables when engaged in activities. The atmosphere was very stiff at the beginning but got better as the workshop went on. The workshop on day 1 finished at 16h00.

The facilitator used the designed manual to guide her through the implementation of a “comprehensive community-based intervention in HIV stigma reduction and wellness enhancement for PLHA and people living and working close to them (PLC)”. In this workshop the family members of PLHA attended together with the PLHA. The described activities that form the core of this workshop were followed in the sequence indicated. The workshop activities comprised of:

PowerPoint presentations
Interactive activities
discussions

During the workshop, focus was on mobilising participant participation contact and collaboration, through a range of workshop participatory activities and inputs by the facilitators. A laptop was used to present the PowerPoint presentations during the workshop. All the activities done by the participants were noted down on white paper and were presented by each group. These notes were kept to use for further information when data analysis will be done.

Observational notes:

Prof Kruger started the workshop by welcoming every one and explained what the workshop was about. Everyone was given the opportunity to introduced themselves and explain why they were here. One of the family members said that she does not know why she was here. Only 3 PLHA mentioned in the introduction that they were HIV positive while the others did not. Group rules were set and little participation was given, as some just stared in front of them, not participating. One of the participants asked about confidentiality as he was afraid that the other participants will leak confidential information as disclosure of status to the community. The participants were asked again to commit to confidentiality. The atmosphere was one of non interest at this early stage of the workshop. Their expectations of this workshop ranged from to learn about stigma, how to cope with stigma and how to live and deal with a HIV+ person. Participation during the different activities was very slow and information had to be drawn from them especially about their understanding of stigma, but once they started with examples it went very well. Their stigma experiences were the same as in the urban area, e.g. rejection by family members, friends disappeared, people do not want to share food, cups etc and refuse to hug them (something that came out as so important and needed by PLHA), blaming each other especially in relationships. Experiences came from the PLHA and the family members did not actively participated in this activity. Interesting was that all the participants except one who could not write well, took notes during the workshop and referred back to it during activities. At 12H00 we all enjoyed lunch. After lunch the groups worked together and participation was more relaxed and spontaneously. Although a lot of information had to be translated in Tswana during the workshop, it did not had an effect on the time set aside for this 1st day of the workshop and one of the participants thanked the facilitators that the workshop was not so long. The participant, that mentioned in her introduction that she

do not know why she has to attend, reported that she was glad that she came and that she understand HIV/AIDS and the stigma the people experienced and that she will support any person who disclose to her with love, care and understanding.

Personal Notes:

Although the participants was experienced as non interested and very observed early in the workshop it did got better as the day went on. Other observations made during the workshop is that PLHA and family members did not sat together, no relationship or bonding were experienced between them, it seemed as if they were not knowing each other well and I wondered if the family members that were asked to come to the workshop actually knew that the person who asked them to attend, is HIV+. One of the family members was recognized by one of the facilitators as a participant in the PURE study with a positive HIV status, but during the workshop it became evident that he did not disclose his status to his family, as it was not mentioned. He appeared to be a very important person in the family, someone to whom they come for advice etc. and by disclosing his status it will lower his status within the hierarchy and will bring back the stigma mentality. The person that asked him to attend the workshop is normally a very outgoing person, but within the workshop she was very still and when asked what was wrong she just pointed in his direction and said it is because he was there, she must behave. It seems that family support in Ganyesa was really a problem as we struggled to find family members to participate in the workshop. A commend made by one of the family members about her feelings around stigma after day 1, that she will support and care for any of her children, or any family member who is HIV+, left the feeling that she maybe of probably is not aware that her daughter who asked her to attend the workshop, is actually HIV+.

APPENDIX E: SECTION OF AN IN-DEPTH INTERVIEW

- Respondent** Friends as well yes
- Moderator** This knowledge that you have learnt can you tell me a little more about it?
- Respondent** With this knowledge that I learnt, I was happy to know that if a person is sick with this disease it doesn't necessarily mean death. If they take their treatment the right way it will be managed and also that if a person has it they must use protection
- Moderator** It's not a death sentence?
- Respondent** It's not a death sentence.
- Moderator** Coming to the workshop, this experience educated you?
- Respondent** It educated me a lot and I had to spread my knowledge in the community.
- Moderator** You took this knowledge and they taught you to spread it in the community.
- Respondent** But first I started in my own home,
- Moderator** You gained knowledge, you were happy to learn about stigma. You then spread the word in your home and there after in the community, but you thought it best to start
- Respondent** At home
- Moderator** At home. The decision to start at home can you tell me what
- Respondent** The decision to begin at home came when I remembered my child who had past on because of this disease so I wanted the rest to know that if ever some day they were to have this illness then they have all the knowledge and necessary information
- Moderator** So you used this information to teach others so that they wouldn't have to go through the same thing as you did, am I correct?

Respondent Yes you are.

Moderator So you thought that its best if taught at home first?

Respondent Yes

Moderator Could you please tell me the experience of teaching your family? How did you feel to come with this and teach it to them because you said they taught you how to teach and you saw it best to start at home, so how was it like to teach at home first?

Respondent When I taught at home, everyone listened and accepted what I was saying and there was even one child whop told me that he doesn't like using condoms because they were sore but after that he understood the importance of using them

Moderator So it was like an awakening for your entire family because it not only changed your perceptions

Respondent But also of the children

Moderator But also your children perception. Now when you realized that what you were saying was changing their perceptions of certain things how did that make you feel?

Respondent I felt a lot of joy in me

Moderator This joy you had could you maybe try and explain it to?

Respondent After I explained it them and they received what I was saying and I realized that I also understood this better then I was truly a mother

Moderator So it brought back that confidence and strength to you?

Respondent Yes

Moderator And you felt proud?

Respondent I felt proud and confident

Moderator It gave you self-worth and made you feel important to change the mindset of your children and to teach them and wished that the

knowledge you gained at the workshop would have come before your child and his friends had past on because then you would have taught him

Respondent I would have because he didn't accept himself

Moderator I hear you speaking of the knowledge you had after the workshop and also that you felt happy and that just because you live with this disease doesn't mean death. Are there any other things that we have not spoken about because you only talk about the education you got which you then spread at home as well as in the community and you say it brought you happiness and made you feel proud? And you said it made you to be able to change the mindset of the children in your house. What did it mean or say to you when you saw yourself receiving this knowledge and helping you as you said it was helpful?

Respondent For me it was just simple happiness

Moderator So you say it was happiness because you got to use it?

Respondent To use it on the children and the community and then we came and formed groups and spread it in the churches and the people we were teaching were asking us questions and we explained to them and they were also happy. Now at that time I had also invited nurses and they were very pleased with our work because they asked us to also come to the clinic

Moderator You were happy that you got to spread the word

Respondent Yes

Moderator And the nurses thanked you?

Respondent They thanked us, even the local municipality and teachers they were also there and they thanked us and they encouraged us go forward with what we were doing

Moderator When you hear all these grateful people, the nurses, the schools and the municipality, what was it like for you to receive all these thank you from them all?

Respondent It felt like they were just helping me grow from within

Moderator I can see you're thinking it through

Respondent It was powerful

Moderator It was powerful?

Respondent Yes

Moderator You felt that they were giving some form of strength

Respondent They gave me confidence

Moderator They gave you a position?

Respondent They were giving me praises

Moderator They were lifting you up with what they were saying to you?

Respondent Yes

Moderator At the time when you heard how grateful they were to you and singing your praises what was it like for you to hear that?

Respondent I even felt in my soul that even God was happy. I'm the type of person who sometimes gets fear when I pray but now when I pray I could feel myself being stronger as if God was also just pushing me forward

Moderator That is agreeing with what you are going to do?

Respondent Yes

Moderator So you experienced that God was with you?

Respondent I could even feel it in my blood that God was with us because when I would encourage people with the word I just felt free.

Moderator You felt free. So tell me about this time when you would pray and become free, just tell me about this freedom because I'm trying to understand it, what kind of freedom was it?

Respondent It was something very powerful like God was a part of it

Moderator I can even see with your hand movements that you fell strongly about this because your fists are about to knock me over. When they were asking you questions at the time when you were at the project and you were with the spiritual leaders and the people living with HIV, that experience how was it for you?

Respondent Even the people who were living with HIV were very happy and they wished to join us because they still had fears that they were HIV positive

Moderator You received feedback that was good and you saw that you had now even recruited people who were living with it

Respondent Who were sidelining themselves but were now becoming free and telling us

Moderator When you saw the people of the community and even the spiritual coming out and speaking and for them to also gain that strength how did you experience that to have someone come out and speak to you and even ask to join your group?

Respondent I felt like there was healing when we came together

Moderator So there's healing in doing things in a group and just coming together?

Respondent And joining forces, yes.

Moderator This healing, what kind of healing was it? Can you maybe explain it to me so that I can understand it better?

Respondent It's just that I realized just how free they were to just talk they were happy as if we were giving them medication they were just happy to realize that they were just like us

Moderator Let me try and sum up what you're saying