

**A community-based HIV stigma reduction and wellness enhancement  
intervention for people living with HIV and a close family member**

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## LIST OF ABBREVIATIONS

<b>CFM</b>	=	Close Family Members
<b>HIV</b>	=	Human Immunodeficiency Virus
<b>AIDS</b>	=	Acquired Immune Deficiency Syndrome
<b>PLC</b>	=	People living close
<b>PLHA</b>	=	People living with HIV and AIDS
<b>WHO</b>	=	World Health Organization

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## RESEARCH OUTLINE

The research is presented in an **article format** including the following

1. An overview of the research: The purpose of the overview is to give a brief literature review that led to the project, the paradigmatic perspective, an outline of the research project and a discussion of the methodology in detail.

Literature review: The purpose of the literature review is to present a critical synthesis on aspects that best support the case study and interpretive description approach. The literature review allows for critical reflection on what does exist and what does not in the literature, commentary on the strengths and weaknesses within the overall body of knowledge, as well as identifying gaps in the knowledge base.

A further literature control was conducted as part of the article by using the same databases as mentioned above. The focus was on comparing the findings of the study with existing literature in order to draw conclusions about (1) confirmation that the findings have been reported on before in a similar way; (2) identification of other findings in the literature closely related to the study but not evident in the present study; or (3) findings of the present study as being truly unique and not found in the literature (Bothma, *et al.* 2010:197).

2. One (1) article as follows:

ARTICLE TITLE	JOURNAL SUBMITTED TO
A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and a close family member	<i>Journal of the Association of Nurses in AIDS Care</i>

The article reports on the conducted research and findings. Brief recommendations are included.

3. Conclusion, limitations and recommendations for a community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and a close family member. In this section overall conclusions are drawn, limitations of the study discussed and detailed recommendations for further research presented.

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## AUTHORS' CONTRIBUTION

This study was planned and carried out by a team of AUTHeR (African Unit for Transdisciplinary Health Research) and an international collaborator at the Potchefstroom Campus of the North-West University. Each researcher's contribution is listed in the table below:

Ms. J.B. Pretorius	M.Cur. student, responsible for the literature study, conducting the pilot study, implementing the research process and writing the text on people living with HIV or AIDS and close family members.
Prof. M. Greeff	Supervisor, project leader and critical reviewer of the study.
Dr. F.E. Freeks	Co-supervisor, member of the research team and critical reviewer of the study.
Prof. A. Kruger	Research team member and critical reviewer of the study.

The following statement is a declaration by the co-authors to confirm their role in the study and agree to its nature as being in the article format for submission as a dissertation.

Declaration:

I hereby declare that I have approved the inclusion of one (1) article mentioned above in this dissertation and that my role in this study complies with what is described above. I hereby give consent that this article may be published as part of the M.Cur.-dissertation of Ms Johanna Beatrix Pretorius.

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Ms J.B. Pretorius

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Prof. Dr. M. Greeff

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Dr. F.E. Freeks

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Prof. A. Kruger

## SUMMARY

The diagnosis of HIV is a life-changing event that requires people to deal with the disease, as well as cope with HIV stigma. Both people living with HIV or AIDS (PLHA) and their close family members (CFM) are stigmatized, but CFM also stigmatizes PLHA. This interaction affects the relationship between PLHA and their CFM.

The aim of this study was to evaluate the effect of a comprehensive community-based HIV stigma reduction intervention on PLHA and their CFM as well as to explore and describe their experiences during and after the intervention.

A holistic multiple case study design as well as a qualitative description approach was used. The study was conducted in both an urban and a rural setting. Purposive sampling was used for the PLHA and snowball sampling for the CFM. The case record for the case study consisted of several sources. In-depth-interviews were used to explore their experiences. The data was analysed using open coding and text document analysis. Both groups gained a richer understanding of HIV stigma and coping with it. The relationships enriched by PLHA feeling more supported and CFM realizing how they stigmatized and that they should be more supportive. Leadership was activated through the project. Bringing PLHA and CFM together during an intervention, proved to be affective,

Recommendations focus on the inclusion of HIV-related stigma reduction awareness interventions in the curriculum of student nurses and the implementation thereof in the community, through community based nursing. It would be of benefit if the programme could also be offered as a workshop to traditional healers in the community. Nurses in clinics working with PLHA should invite PLHA and CFM to participate in groups to support each other in reducing HIV-related stigma and share problem-solving coping strategies. The researcher believes that the results of the current study have important implications for further research in HIV-related stigma reduction interventions in other countries and demographic groups. It has the potential to be used for long-term monitoring studies of HIV stigma reduction interventions and the change over time.

**Keywords:** HIV; AIDS; Community-based; Intervention; Stigma; Close family member

## OPSOMMING

Die diagnose van MIV is 'n lewensveranderende gebeurtenis wat vereis dat die persoon aandag gee aan die siekte en leer om die stigma wat aan HIV kleef, die hoof te bied. Mense wat met MIV en VIGS leef (MMVL) asook hul nabye familieledede (NF) word gebrandmerk, maar familieledede brandmerk ook diegene wat met MIV of VIGS lewe. Hierdie interaksie affekteer die verhouding tussen persone wat leef met MIV en VIGS en hul nabye familieledede.

Die doel van hierdie studie is om die effek wat 'n omvattende gemeenskapsgebaseerde MIV-stigma-verminderingsintervensie op MMVL en hul NF het te evalueer, en terselfdertyd ondersoek in te stel en hul ervarings gedurende en na die intervensie te beskryf.

'n Holistiese meervoudige gevallestudie-ontwerp en 'n kwalitatiewe beskrywende benadering is gebruik. Hierdie studie is in 'n in beide 'n stedelike en 'n landelike gebied onderneem. Doelbewuste steekproefneming is vir die MMVL gebruik en 'n sneeubal-steekproefneming vir die NF. Die gevallerekord vir die studie het bestaan uit verskeie bronne. Deurtastende onderhoude is gebruik om hierdie ervarings te ondersoek. Die data is ontleed deur van oopkodering- en teksdokument-analises gebruik te maak.

Die ontmoeting van die MMVL en NF tydens 'n intervensie het ontroerende resultate tot gevolg gehad. Alle deelnemers het aangedui dat hul 'n beter begrip het van die MIV-stigma en hoe om dit die hoof te bied. Die verhoudinge is verryk omdat die MMVL gevoel het hul ontvang meer ondersteuning en die NF besef het dat hul stigmatiseer en eerder ondersteunend moet wees. Leierskap is deur die projek geaktiveer, aangesien die projek wat ander NF as teikengroep gehad het, inisiatief getoon het en 'n groter aantal mense binne die gemeenskap deur hul eie inisiatiewe bereik het. Hulle was trots om as leiers op te tree wat ander opvoed.

Aanbevelings het op die insluiting van MIV-stigma-verminderingsintervensies in verpleegstudente se kurrikulum gefokus, asook die implementering daarvan in die gemeenskap deur middel van gemeenskapsgebaseerde verpleging. Verpleegsters wat in 'n kliniek met MMVL werk, behoort deur indiensopleiding opgelei te word om die stigmaverminderingsprogramme te hanteer. Dit sal 'n aanwinst wees indien die program as 'n werkwinkel vir tradisionele genesers in die gemeenskap aangebied kan word. Die aanbeveling is gemaak dat MIV-stigma-verminderingsintervensies ingesluit behoort te word by klinieke se opvoedkundige programme wat vir MMVL en hul NF aangebied word. MMVL en hul NF kan uitgenooi word om aan ondersteuningsgroepe deel te neem om sodoende mekaar te ondersteun in die vermindering van MIV-stigma en om hul probleem-oplossingstrategieë te deel. Opvolgintervensies met gemeenskapsgroepe kan volhoubaarheid verseker. Die resultate van die huidige studie het belangrike implikasies vir verdere navorsing oor MIV-verwante stigmaverminderingstrategieë vir MMVL en NF in ander lande en demografiese groepe. Die potensiaal bestaan dat dit vir langtermyn-monitoringstudies vir MIV-stigma-

verminderingsointervensies gebruik kan word en die verandering aan MMVL en NF met verloop van tyd.

**Sleutelwoorde:** MIV; VIGS; Gemeenskap gebaseerde; Intervensie; Stigma; Nabye Familielid

**OVERVIEW OF RESEARCH:  
A COMMUNITY-BASED HIV STIGMA REDUCTION AND WELLNESS  
ENHANCEMENT INTERVENTION FOR PEOPLE LIVING WITH HIV AND A CLOSE  
FAMILY MEMBER**

The overview that follows gives an overview of the study and discusses the paradigmatic perspective and methodology in more detail than in the article.

The article that follows the overview reports on the completed research and findings, and follows the guidelines prescribed by the Journal of the Association of Nurses in AIDS Care.

This study is embedded in and funded by the **SANPAD** Project: *A Comprehensive Community-based HIV stigma reduction and wellness enhancement intervention* (Reference number: 09/15) with Prof. M. Greeff as project leader.

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**Core concepts:** HIV; AIDS; Community-based; Intervention; Stigma; Close family member.

## 1 INTRODUCTION AND PROBLEM STATEMENT

This study is part of a bigger comprehensive community-based HIV stigma reduction and wellness enhancement intervention study. The focus of this study is on the intervention as well as on the experiences of people living with HIV or AIDS (PLHA) *and a close family member (CFM)* during and after the intervention. The focus in this study is on both the PLHA and their CFM who are stigmatised due to their diagnosis or association with the disease. Members of the latter group themselves may be involved in stigmatising the PLHA. Ogden *et al.* (2005:31) support the view of stigma by association but refer to “secondary stigma”. They argue that the consequences of HIV and AIDS-related stigma do not begin and end with PLHA, but extend to include families, children, and even friends and caregivers. Ming-Chu *et al.* (2009:487) mention that family members of PLHA experience many of the same expressions of stigma as PLHA. The interaction between being stigmatised as family member and stigmatising PLHA becomes a complex process with many consequences. In this study *close family member* refers to a member who is part of the biological family but excludes the husband/wife or children of the PLHA. The latter are included in other parts of the broader study.

To focus on a better understanding of HIV stigma, and for the purpose of this study, the researcher refers to one of the oldest definitions of stigma as described by Goffman (1963). Goffman (cited by Uys, *et al.*, 2009:150) defines stigma as a “significantly discrediting” attribute and he describes three types of stigma: (1) “abominations of the body,” or stigma related to physical deformities; (2) stigma related to “blemishes of individual character,” such as people who are considered to be weak-willed, to have unnatural passions, or to be dishonest; and (3) “tribal stigma,” or stigma relating to race, nation or religion, or membership of a despised social group (Ogden, *et al.*, 2005:7). Alonzo and Reynolds (1995) (cited by Greeff, *et al.*, 2008:312) define the same concept as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people. The latter will be the definition of choice for this research.

Being diagnosed with HIV or AIDS remains a life-changing event that requires people to deal with the disease and its associated stigma and isolation (Abel, *et al.*, 2004:510). In the African setting, HIV stigma remains a powerful barrier to people living with HIV or AIDS as it inhibits testing and disclosure of HIV status, that would in most cases be accompanied by fear, i.e. fear of accusations of unfaithfulness, rejection, discrimination, and violence (Dlamini, *et al.*, 2009:378). The stigma also inhibits access to anti-retroviral medication, access to care services, and it limits the availability of support for PLHA (Bell, *et al.*, 2007:114, Greeff, *et al.*, 2008:311-324). Phaladze *et al.* (2005) (cited by Makoe, *et al.*, 2009:1357) found that in sub-Saharan Africa, stigma and discrimination have had a considerable influence on PLHA, and according to

Aggleton and Parker (2002) (cited by Holzemer, *et al.*, 2004:169), the real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends.

Results of the Ogden *et al.* (2005:31) and Holzemer *et al.* (2007:547) studies imply that as soon as the diagnosis becomes known, spouses, children and family become targets of stigmatisation. Effects on the family may result in shock, anger and disappointment, fear of caring for PLHA as well as fear of infection (Toolkit for action, Module D: 2007:4). Judgment from family members can be one of the worst personal struggles to PLHA (Muhomba, 2007:16). Greeff *et al.* (2008:322) reported on the important role of support the family plays within the African context and that the family is the first the PLHA discloses to. Stigmatisation from family members often leave the infected individuals with existential questions about the meaning of their infection, their behaviour, as well as their HIV-positive status as it relates to their family relationships (Muhomba, 2007:12).

In Southern Africa the virus has long been regarded as enigmatic, difficult to explain and imbued with cultural meaning (Gilbert, *et al.*, 2009:1128). Over a six-year period, the Holzemer and colleagues team studied HIV stigma intensively in five African countries (Kohi, *et al.*, 2006:404-415; Dlamini, *et al.*, 2007:389-399; Naidoo, *et al.*, 2007:17-23; Chirwa, *et al.*, 2008:14-21; Greeff, *et al.*, 2008:78-108; Makoe, *et al.*, 2008:137-146; Uys, *et al.*, 2009:150-159; Uys, *et al.*, 2009:1059-1066; Dlamini, *et al.*, 2009:377-387; Kohi, *et al.*, 2010:134-143; Makoe, *et al.*, 2009:1357-1362; Greeff, *et al.*, 2010:475-486). The researchers found that stigma was more intense and more frequent in certain countries and settings than in others and that it remained a serious problem to PLHA (Uys, *et al.*, 2009:1059). From their findings pertaining to Africa, they conceptualised a model to understand the stigma process (Holzemer, *et al.*, 2007:541- 551). The Conceptual Model of HIV or AIDS Stigma outlines that stigma is a very specific process within a context of three contextual factors:

- *Environment*, including cultural, economic, political, legal and policy aspects
- *Health care systems*, including settings such as hospitals, clinics and home-based care settings, and health care workers such as physicians, nurses and others
- *Different agents or people*, including the individual who may self-stigmatise, family members, work colleagues, or community members

Within these contexts the **Stigma Process** takes place and includes four elements: 1) *triggers of stigma*; 2) *stigmatising behaviours*; 3) *types of stigma*; (received; internal; and associated stigma) and 4) *outcomes of stigma*. This “Conceptual Model of HIV or AIDS Stigma” by Holzemer *et al.* (2007:546) provides the theoretical grounding for the present study.

In reviewing the literature on HIV stigma reduction programmes or interventions (Abel, *et al.*, 2003:510-525; Heijnders, *et al.*, 2006:353-363; Bos, *et al.*, 2008:450-460; Sheng, *et al.*, 2008:513-518) it was found that a few HIV stigma reduction programmes have been developed and implemented, but not one rigorously evaluated. However, several researchers (Mahendra, *et al.*, 2007:616-625; Murphy, *et al.*, 2000:73-88; Pisal, *et al.*, 2007:32-43; Chirwa, *et al.*, 2008:20) supported the argument that HIV-related stigma reduction interventions can be effective.

Brown *et al.* (2003:52-53) reviewed 22 published studies that tested a variety of interventions to decrease AIDS stigma in developed and developing countries. The aim of many of the reviewed interventions was not exclusively the reduction of AIDS stigma, but many other components (i.e. increasing awareness and knowledge of HIV and AIDS, promoting behaviour change, etc.) were involved. The studies reviewed, were classified into three categories based on study goals and target populations. A variety of interventions tested across these three categories, were divided into four groups: (1) information-based approaches, (2) skills building, (3) counselling approaches, and (4) contact with affected groups. The study focused on the stigma component within these comprehensive interventions. According to Brown *et al.* (2003:52) only a few stigma-reducing interventions have been done, but most of these interventions were not based on scientific insights on social stigma and stigma reduction, despite the big need to reduce AIDS-related stigma.

Results suggest some stigma reduction interventions appear to work, at least on a small scale and in the short term, but many gaps remain especially in relation to scale and duration in impact and in terms of gendered impact of stigma reduction interventions. A follow-up study was done by Uys *et al.* (2009:1059-1066) to explore the possibility of an HIV stigma intervention in five African health care settings. This group studied a further 15 intervention articles that included articles earlier than 2001, including illnesses such as leprosy and cancer. Their findings about interventions were similar to the study of Brown *et al.* (2003: 52-53) with the exception that this group further researched the development and implementation of an intervention focusing on one health care setting and involving both nurses and PLHA together in a workshop. The intervention combined three strategies: (1) sharing information on HIV stigma, (2) improving coping through empowerment and leadership development, and (3) increasing contact with the affected group. PLHA and nurses were engaged in a project to reduce stigma in a health care setting. PLHA had to address stigma directly rather than concentrate on accepting it or living with it. Results suggest that the intervention was very effective in reducing perceived HIV-stigma by PLHA.

The mentioned study, based on health-care settings in five African countries, encouraged Greeff (2009) to expand the intervention to a comprehensive community-based HIV stigma-

reducing and wellness-enhancing intervention. The current study on PLHA and their family members forms part of this broader study.

From the discussion above it is clear that interventions could make a difference but that research in this field is essential to increase the understanding of HIV stigma and the impact that HIV stigma-reduction interventions can have. Greeff (2010:3), in her SANPAD proposal for this study, argued that although several HIV stigma-reduction programmes, workshops and interventions have been launched in Africa, the focus was on either the PLHA on a personal level, parts of the community, health care professionals, or media. Most of the programmes involved the sharing of information and strengthening of specific skills.

These interventions were health-care based and did not include people living and working close (PLC) to the infected person. Greeff (2009) proposed a comprehensive community-based HIV-stigma reduction and wellness enhancement intervention that would focus on the PLHA and PLC (partners, close family, adolescent children, close friends, ministers and work colleagues) to empower PLHA and PLC in becoming leaders in stigma reduction, and to enhance their and others' wellness. This comprehensive intervention will lead to a better understanding of the HIV stigma process and how to manage it (SANPAD RESEARCH PROPOSAL: 15 September 2009, Reference number: 09/15).

In focusing the review of literature on specific interventions with family of PLHA very little could be found. Studies found focused more on the experiences of family members. A study done by Mohanan *et al.* (2009:8) on the effect of family support on morbidity, mortality, quality of life, and economics in families with at least one HIV-infected member, in developing countries, came to the conclusion, from this review, that more rigorous studies are required in developing countries before substantive conclusions can be drawn about the effects of family support in reducing morbidity and mortality in HIV-infected persons. A qualitative study by Gaudine *et al.* (2010:1) on HIV-related stigma in Vietnam, including PLHA, family members, and community members and leaders came to the conclusion that HIV-related stigma was experienced in a different manner by each of these groups, that no interventions to reduce stigma had been implemented and they stated that findings of their study should help in developing culturally sensitive strategies to reduce HIV-related stigma. Krishna *et al.* (2005:483) aimed to understand the impact of HIV on the family system in an Indian context. Indian families have strong emotional ties and sentiments that connect them together, and these include links with the extended family.

Results of a study done by Naidoo *et al.* (2007:22) on *Urban and rural differences in HIV and AIDS stigma in five African countries*, indicate that in general the urban groups described more

incidents of stigmatization and discrimination than did the rural groups. Although their findings contradict the results of some other research (such as the Rural Center for AIDS/STD Prevention, 1994; Sliep, Poggenpoel & Gmeiner, 2001; Duffy, 2005)(cited by Naidoo, *et al.*, 2007:22; Campbell, *et al.* 2008:510), who stated that issues of anonymity and confidentiality are major difficulties in rural areas, and that many people avoid seeking help out of fear that they will be suspected of having HIV and so will be stigmatised and ostracized, they argued that such an exploration is important for planning interventions for prevention, treatment and care, since such programmes might need to be specifically structured for an urban or rural population should stigma significantly differ between the two settings.

Reviewing the above-mentioned literature the researcher would like to argue that close family members experience the same forms of associated stigma as participants in these studies and that the impact of the process of associated HIV-related stigma is significant to both the PLHA and the close family members and could furthermore severely influence the relationship between them, adding the possibility that family members also stigmatise PLHA. This has a serious effect on the relationship between PLHA and their close family members who, within the African context, play an important role. It is also not clear whether there would be differences in urban and rural communities with regard to stigmatisation and the experiences surrounding it. The literature review showed no evidence of available HIV-related stigma reduction interventions for PLHA and their CFM.

The above-mentioned-problem leads to the following questions:

In what way can a community-based HIV stigma reduction and wellness enhancement intervention reduce stigma in PLHA and their close family members in an urban and a rural setting?

What are the experiences of PLHA and their CFM during and after a community-based HIV stigma reduction and wellness enhancement intervention in an urban or a rural setting?

## **2 OBJECTIVES OF THE RESEARCH**

- 2.1 To evaluate the effect of a community-based HIV-stigma reduction and wellness enhancement intervention on PLHA and a CFM through a case study method in both an urban and a rural setting in the North West Province.
- 2.2 To explore and describe the experiences of PLHA and a CFM during and after a community-based HIV stigma-reduction and wellness-enhancement intervention through a qualitative interpretive description strategy in both an urban and a rural setting in the North West Province.

### **3 PARADIGMATIC PERSPECTIVE**

The paradigmatic perspective explains the beliefs and assumptions of a researcher about the world and how these views will influence the research that is to be conducted. The paradigmatic perspective includes meta-theoretical, theoretical and methodological assumptions.

#### **3.1 Meta-theoretical Assumptions**

The following sources inspire the meta-theoretical assumptions underlying the study: The Word of God (Bible, 2004), different theology-based nursing theories, and other philosophers such as Ray (2004), Martinsen (2001) and Eriksson (1988) (cited by Tomey, *et al.* 2006:435).

##### **3.1.1 Person**

The researcher sees a person as someone who was created by God, an entity of body, soul, and spirit. This person is a holistic being who has freedom of choice and movement, with a sense of identity and self-worth as described by Levine (1991) (cited by Tomey, *et al.*, 2006:232). For the purpose of this study the researcher agrees with Orlando (1972)(cited by Tomey, *et al.*, 2006:435), that each person is unique and individual and that responses to the same situation may differ from individual to individual. She further states the same behaviour in different persons, can signal different needs.

##### **3.1.2 Environment**

The environment involves both internal and external factors that can be negative or positive. King (1981) (as cited by Tomey, *et al.*, 2006:303) believes that it is essential to understand the ways that human beings interact with their environment to maintain health. The researcher agrees with King (1981) that the environment is the context in which individuals live their lives. The researcher's challenge is to give each participant dignity in particular situations. Benner *et al.* (1989) take it further and argued that each person's past, present, and future have an influence on current situations as they have their own personal meanings, habits, and perspectives (cited by Tomey, *et al.*, 2006:151).

##### **3.1.3 Health**

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organisation, 1948). According to Levin (1969b) (cited by Tomey, *et al.*, 2006:232), health is the ability to function in a reasonably normal manner, as socially determined. The researcher agrees with Neuman (1995b) (cited by Tomey *et al.*,

2006:325) that health is dynamic in nature and can constantly change. The person is either in a state of wellness or illness in varying degrees, at any given point in time

### **3.1.4 Nursing**

The American Nurses Association (ANA) (2003:6) (cited by Burns, et al., 2009:2) described nursing as follows: “Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations”. According to Orlando (1950) (cited by Tomey, et al., 2006:434), the purpose of nursing is to identify the needs of patients and supply the necessary help they need, either directly by her own activity or indirectly by referring to another professional in the multi-disciplinary team. As a Primary Health Care Practitioner, the researcher supports these definitions as it is the core business of her everyday practice.

## **3.2 Theoretical Statements**

### **3.2.1 Central theoretical argument**

HIV stigma has an impact on PLHA who suffer from both internal and received stigma, as well as their close family members who suffer from associated stigma. The impact can influence the relationship that exists between them influencing the support and understanding experienced by PLHA from their close family members. The family members might find themselves in a position of being stigmatised due to their association with the PLHA or stigmatising the PLHA themselves. A community-based HIV-stigma reduction and wellness enhancement intervention could contribute to a process that enhances an understanding of the stigma process by both parties, enhance their wellness and empower them to become leaders in stigma reduction on an urban and rural community level.

### **3.2.2 Conceptual definitions**

#### ***Community-based***

The dictionary of PSYCHOLOGY (2001) corroborates Cookfair’s (1991)(cited by Skidmore, 1997:76) definition of a community as a settlement of people concentrating in one geographical area. For the purpose of this study community-based intervention can therefore be defined as an intervention taking place within a specific community defined by a geographical area e.g. the greater Potchefstroom district for the urban community and Ganyesa for the rural community.

#### ***Intervention***

Interventions involve contact with an individual or group, offering support, education or counselling that is intended to change the conditions which have negative impact on the well-

being of the patient (Doull, *et al.*, 2009:4; Brown, *et al.*, 2003:53). Sidani & Braden (1998)(cited by Burns, *et al.*, 2009:317) define intervention as “treatment, therapies, procedures, or actions implemented by health professionals to and with clients, in a particular situation to move the clients’ condition toward desired health outcomes that are beneficial to the clients”. For the purpose of this study, the intervention will be a community-based HIV stigma reduction and wellness enhancement intervention for PLHA and a close family member in both an urban and a rural setting.

### **Stigma**

The traditional definition of stigma is that of Goffman (1963) which was further expanded by Alonzo and Reynolds (cited by Dlamini, *et al.*, 2009:390), as ‘*a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons*’. Within these contexts the Stigma Process, Holzemer *et al.* (2007:547), identified *three types of stigma*: received (or external) stigma, internal (or self-devaluing) stigma, and stigma by association (or secondary stigma).

### **Close family members**

Referring to CFM that are part of the biological family but exclude the husband, wife or children of the PLHA.

## **3.3 Methodological Statements**

According to Greeff (2008:320) methodological assumptions refer to good scientific practice. The research model of Botes (1992) is supported in this research. She formulated the methodological assumptions according to three orders (Botes, 1992:36-42). This study takes place within these three orders: The first order according to the Botes model (Botes, 1992:38) is about the *practice of the discipline*. This study will explore and describe experiences of PLHA and their close family members during and after a community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting.

The second order is the *research order* and develops from without the first order. A case study and qualitative interpretive descriptive research design will be followed to explore and describe the implementation of a community-based HIV stigma reduction and wellness enhancement intervention and evaluation as well as the experiences during and after of the PLHA and family close to them of the intervention (Botma, Greeff, Mulaudzi & Wright, 2010:188-189).

The third order represents the *paradigmatic perspective* of the researcher, and includes the following:

- Meta-theoretical assumptions underlying the study referring to the researchers' views of person, environment, health, and nursing
- Theoretical assumptions, referring to the central theoretical argument and conceptual definitions based on theory
- Methodological assumptions: the researcher will approach the study using the qualitative research paradigms of both case study (Yin, 2009:3-24) and interpretive description (Thorne, 2008:50-51).

## **4 RESEARCH METHODOLOGY**

### **4.1 Literature Review**

For the purpose of the initial literature review the following databases were used: Ebsco Host, Pro Quest, SA publications, Google: Scholar, Internet – Google.

The purpose of the comprehensive literature review is to gain information on aspects that will best support the case study and the interpretive description approach to gain relevant data as well as insight and understanding from existing knowledge pertaining to the topic(s) under discussion in the present field of study. A literature review also allows for critical reflection on what does exist and what does not in the literature, commentary on the strengths and weaknesses within the overall body of knowledge, planning and establishing of an appropriate context for the study as well as for formulation of the problem statement, research questions and objectives (as adjusted from Thorne, 2009:61).

A further literature review and control will be conducted as part of the article, by using the same databases as mentioned above. The focus is on comparing the findings of the study with existing literature in order to draw conclusions about (1) confirmation that the findings have been reported on before in a similar way; (2) identification of other findings in the literature closely related to the study but not evident in the present study; or (3) findings of the present study as being truly unique and not found in the literature (Botma, *et al.* 2010:197).

### **4.2 Design**

The design of the study is qualitative in nature using both the holistic multiple case study design (Yin, 2009:59) and interpretive description approach (Thorne, 2009:50) designs, to evaluate the effect of a community-based HIV-stigma reduction and wellness enhancement intervention on PLHA and their CFM, in both an urban and rural setting, as well as to explore and describe PLHA and their close family members' experiences during and after having undergone the community-based HIV stigma reduction and wellness enhancement intervention in both an urban and a rural setting.

### **4.3 Research Method**

This research has two 2 phases. The 1<sup>st</sup> Phase is the holistic multiple case study of the community-based HIV stigma reduction and wellness enhancement intervention in both an urban and rural setting and the 2<sup>nd</sup> phase a qualitative interpretive description of the experiences of PLHA and their close family members during and after the community-based HIV stigma reduction and wellness enhancement intervention at both an urban and rural setting.

#### **4.3.1 Phase 1.**

A holistic multiple case study of the community-based HIV stigma reduction and wellness enhancement intervention at both an urban and rural setting. The qualitative, holistic multiple case study on the effect of the community-based HIV-stigma reduction and wellness enhancement intervention will be conducted in both an urban and a rural setting in the North West Province.

##### **4.3.1.1 Sample.**

###### ***Population:***

The population consists of two groups: PLHA and CFM.

###### *PLHA:*

The population of PLHA for this study is PLHA who were diagnosed with HIV in both the Potchefstroom and Ganyesa districts of the North West Province, South Africa.

###### *CFM:*

The population of CFM includes family members who are part of the biological family, excluding the husband, wife or children of the above-mentioned PLHA.

###### **Sampling:**

###### *PLHA:*

For PLHA purposive voluntary sampling (Burns, *et al.*, 2009:355) was used. Ten to twelve PLHA from the greater Potchefstroom urban district were included for the Potchefstroom group, and 10 -12 PLHA from the rural Ganyesa group, N=20-24. The interactive nature of the intervention is used as guideline in determining the size of the groups (as adjusted from Thorne, 2008:94).

###### *Inclusion Criteria for the PLHA participants:*

They must be older than 25 years and may be male or female; Have been diagnosed with HIV for at least 6 months; Be able to communicate freely and express himself/herself; Participants must be literate in order to participate in the workshops; Must have the ability to speak and write Afrikaans or English and Setswana; Would need to be willing to participate in the study and to be prepared to disclose his/her HIV status; Would have to give consent to be interviewed and recorded.

*CFM:*

Snowball sampling (Burns, *et al.*, 2009:356; Rossouw, 2005:113) to identify a further group of a CFM was used. Each person was requested to bring one CFM should they feel comfortable to do so. The nature of the intervention prescribes the size of the group during the intervention. Ten to twelve close family members from the greater Potchefstroom urban district for the Potchefstroom group, and 10-12 from the rural Ganyesa district, for the Ganyesa group, N=20-24, were included.

*Inclusion criteria for the CFM participants:*

The following exclusion criteria were used: Not the partner and children of the PLHA. According to the inclusion criteria the selected CFM must be: a close family member of the identified PLHA; part of the extended family; older than 18 years (male or female); able to communicate freely and express himself/herself; literate in order to participate in the workshops; able to speak Afrikaans or English and Tswana; willing to participate in the study; and willing to be interviewed and recorded.

During the intervention, both groups, PLHA (10- 12) and CFM (10 – 12) formed the intervention group in both Potchefstroom and Ganyesa.

**Sample size.**

According to Thorne (2008:94) the sample size can be justified by the background literature and disciplinary wisdom that would suggest that a certain phenomenon occurs commonly within clinical populations and what is needed is a more in-depth exploration of its underlying subjective experimental nature. Engagement with a small number of individuals experientially familiar with a specific phenomenon and willing to share their lived experiences with the researcher could produce something worth documenting.

Due to the nature of the intervention (interactive workshop) in this research it was decided that a manageable size of 10-12 PLHA per site and 10-12 close family members per site would suffice for purposes of the present study. Accordingly the sample size was 20-24 participants per site, *i.e.* N = 40-48.

#### **4.3.1.2 Data collection.**

##### ***Data collection method.***

For data collection, the case study method to record the community-based HIV stigma reduction and wellness enhancement intervention with PLHA and their CFM was used.

##### *The intervention:*

The intervention consists of a three-day workshop with PLHA and their close family members. The workshop consists of an initial two-day workshop focusing on understanding HIV stigma, coping with HIV stigma and project planning. The project focuses on other family members in the community and was run over a one-month period, followed by a third day for the presentation and evaluation of the project.

The underlying tenets of the intervention are: to increase knowledge about HIV stigma and emotional wellness; to equalize the relationship between PLHA and CFM; and to empower PLHA and CFM to become leaders in stigma reduction and wellness enhancement.

##### *Field notes:*

For the purpose of this study, the following field notes were written down: Methodological notes that are a reflection of strategies and methods used during the observation. Observational notes that document the researcher's thoughts about the meaning of observations while in the field. Personal notes that were made about the researcher's own feelings and perceptions while in the field.

##### *The case record:*

The case records include a detailed description of the HIV stigma reduction and wellness enhancement intervention, naïve sketches of participants during and after the intervention, field notes of the researchers during and after the intervention, as well as a detailed description and evaluation of the project. This documentation will be collected for both the urban and rural groups.

##### *Role of the researcher:*

The researcher gained entry into the community through the PURE study that had been done previously, as well as through other Non-Governmental Organisations (NGOs). Appointments were arranged with community leaders and gatekeepers to obtain permission from them to conduct the study in Potchefstroom and Ganyesa communities, and to gain and build trust within the community. Ethical approval for this study was gained from the School of Nursing, and the Ethics Committee of the North-West University. The appointed research assistant in

AUTHeR for this project, together with fieldworkers in the PURE study, acted as 'go-between' persons or mediators. As soon as the study-related activities commenced transport was arranged for participants to be at venues on time. Arrangements for light meals during these days were made. Appointments were confirmed during the weekend before the interviews were scheduled to take place.

#### **4.3.1.3 Data analysis.**

Data analysis involves an intensive analysis of the various aspects of the case record. According to Yin (2009:126) data analysis of a case study consists of examining, categorising, tabulating, testing, or otherwise recombining evidence, to draw empirically-based conclusions.

#### **4.3.2 Phase 2:**

##### **A qualitative interpretive description of the experiences of PLHA and their CFM during and after the community-based HIV stigma reduction and wellness enhancement intervention.**

A qualitative interpretive description approach (Thorne, 2008:90) was followed to explore and describe the experiences of PLHA and selected CFM during and after a community-based HIV stigma reduction and wellness enhancement intervention in both an urban and a rural setting in the North West Province, by means of in-depth interviews.

##### **4.3.2.1 Sample.**

The sample in this phase consisted of the same two groups described under phase 1.

##### **4.3.2.2 Data collection.**

###### *Data collection method.*

It stands to reason that certain observations would be made all along, e.g. during the workshops, but the main focus of data collection and recording was on in-depth interviews with both PLHA and CFM after the intervention. Open-ended questions were formulated for the in-depth interviews and reviewed beforehand with experts in the field. These questions were field-tested with participants and viewed as a form of piloting.

The following questions were asked during the in-depth interview:

###### *To the PLHA:*

How did you experience the workshop and project with your close family members and others in the group?

###### *To the close family members:*

How did you experience the workshop and project with the PLHA and others in the group?

Participants were informed that the researcher would make use of digital tape recordings and written permission was obtained from them. The recording was explained, and the digital

recorder placed unobtrusively. The digital recorder was checked beforehand for any defects. Communication techniques like paraphrasing, summarizing, reflection, minimal verbal response and probing, as described by Okun (1992:70-71) were utilised during the interview, and the setting was private, as negotiated, and disturbance-free.

*Role of the researcher:*

Interviews were conducted at a place that was private and safe as indicated to participants and acceptable to all. They were informed that the researcher would make use of audio tape recordings and written permission was obtained. The recording was explained and the digital recorder placed unobtrusively. Communication techniques as described by Okun (1992:70-71) were utilized during the interview, and the setting was private, as negotiated, and disturbance free. After each interview, the field notes by the researcher focused on methodological, observational and personal notes.

*Field notes:*

For the purpose of this study, field notes during the 2<sup>nd</sup> phase were the same as discussed in phase 1.

**4.3.2.3 Data analysis.**

The steps that were followed in this research are those described by Creswell (2009:184).

- Step 1: Organise and prepare the data
- Step 2: Develop a general sense of the data
- Step 3: Code the data

The coding of the data was conducted according to the eight steps of the open coding process of Tesch, as discussed by Creswell (2009:186). To get a sense of the whole, the researcher read all the transcriptions carefully, listed the topics as codes and turned them into categories, and where necessary, recoded the existing data. Coding was done in several ways, such as using colour-coding schemes, cutting and pasting text segments into note cards.

- Step 4: Description and themes
- Step 5: Representation

An independent co-coder also analysed the data. A full set of the data, working protocol, including the purpose of the study, as well as the steps of data analysis was given to the independent co-coder. After coding by the independent co-coder, consensus conversations took place to come to an agreement about the coding and categorising of the data and the final themes.

#### **4.4 Ethical aspects**

Ethical approval was obtained from the Ethics Committee of the North-West University with number: NWU-00011-09-A1 for the period from 30 March 2009 -29 March 2014. Ethical aspects were observed throughout this study according to Burns *et al.* (2009:189-201) and the following aspects were taken into consideration: After informing prospective participants about the proposed study, they were allowed to voluntarily choose to participate or not, without the risk of penalty or prejudicial treatment, to withdraw from the study at any time, or to refuse to give information (Brink, 2007:32). They were informed about the use of digital-tapes during interviews and that confidentiality, anonymity and privacy would be maintained throughout the process.

To ensure *confidentiality*, precautions would be taken during this data collection to ensure that the participant's name would not be mentioned on the test batteries or the tape. The researcher would protect the anonymity of the participants by giving each a code number, to ensure that their identity could not be linked, even by the researcher, with his or her individual response. A master list of the subjects' names, addresses, and their code numbers would be locked in a safe place, for 5 years.

The researcher selected with fairness the study population, and the participants for reasons directly related to the study problem, and not because they were readily available or could be easily manipulated (Brink, 2007:33). The researcher was on time for each appointment with the participants and terminated the data-collection process at the agreed-on time. The activities and procedures were not changed, unless the researcher had obtained the participant's consent.

The researcher ensured the well-being of the participants, be it physical, emotional, spiritual, economic, social, or legal (Brink, 2007:32-33). The researcher used good clinical judgment to manage each interview and tried to avoid harming participants. This was achieved by carefully structuring the questions and monitoring the participants for any signs of distress. Support was available should they feel the need for further discussions.

#### **4.5 Trustworthiness**

To ensure trustworthiness in this study, the researcher refers to Lincoln and Guba's proposal (cited by Krefting, 1991:215 & 222; Polit & Beck, 2008:539 & 540; Klopper, 2008:70) and tabulated by Botma *et al.* (2010:234-235).

**Table 1:** Trustworthiness of the study

EPISTEMOLOGICAL STANDARDS	STRATEGIES	CRITERIA
<b>Truth value</b>	<b>Credibility</b>	<p>Prolonged engagement: the researcher will form part of the intervention, and project for a period of one month, as well as conduct the in-depth-interviews.</p> <p>Reflexivity: will be ensured by the researcher through field notes written from time to time, reflecting on the naïve sketches and discussions with study leaders.</p> <p>Triangulation:</p> <p>Methods: the researcher made use of a case study method, and interpretive description through in-depth interviews</p> <p>The researcher made use of different sources of information such as: literature review, intervention documentation, naïve sketches, field notes, project reports and in-depth-interviews</p> <p>Investigator: The researcher is part of a trans-disciplinary research team, acting as researchers and co-facilitators during the intervention. The researcher was guided by two experienced supervisors who form part of the bigger project, and had regular group discussions with the supervisors.</p> <p>The authority of the research is reinforced by the fact that the researcher is an experienced professional nurse within a research team of expertise, under the supervision of supervisors.</p>

(Table 1 Continued)

EPISTEMOLOGICAL STANDARDS	STRATEGIES	CRITERIA
<b>Applicability</b>	<b>Transferability</b>	The researcher made use of purposive and snowball sampling. Dense description of the research methodology and literature control of the findings.
<b>Consistency</b>	<b>Dependability</b>	An audit trail, intervention documentation, naïve sketches, field notes, project reports and transcribed interviews, were possible for evaluation. The dense description of study ensures that the study can be replicated. An independent co-coder involved in the data analysis.
<b>Neutrality</b>	<b>Conformability</b>	Conformability audit was done by the supervisors. All documents required for auditing, including the raw data, field notes, and data analysis documents will be made available if necessary. Reflexivity as mentioned under truth value.

## 5 SUMMARY

The overview of the study presented provides a brief literature review, the paradigmatic perspective, and detailed description of the planned study. This is followed by an extensive literature review focusing on previous research on stigma, the AIDS epidemic, the understanding of HIV stigma, stigma experiences of and by CFM, urban and rural differences on HIV stigma, and interventions for HIV-related stigma reduction interventions specific with CFM.

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**LITERATURE REVIEW:**  
**HIV STIGMA AND COMMUNITY-BASED INTERVENTIONS FOR PEOPLE LIVING  
WITH HIV AND CLOSE FAMILY MEMBERS**

“AIDS is probably the most stigmatized disease in history.... If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful.”

– Edward Cameron, Constitutional Court Justice in South Africa

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**1 INTRODUCTION**

The extensive literature review presents a critical synthesis of the existing literature available and will be discussed as: The AIDS Epidemic; Understanding HIV stigma; Stigma experiences of and by CFM; Urban and rural differences on HIV stigma; interventions for HIV-related stigma reduction are the key notions explored.

Stigma is a historical concept that, in health, has been attributed to diseases such as leprosy, tuberculosis, mental illness, mental and physical disability, to mention but a few common conditions (Brown, *et al.*, 2003:64), the classic example being the extreme stigma experienced by persons with leprosy that persisted long after the discovery of a cure. Gilmore and Somerville (1994, cited by Uys, *et al.*, 2005:12) found that stigma occurs when a disease is incurable or deadly and therefore seen as a threat to society. Nyblade *et al.* (2003:9) argued that stigma related to medical conditions is greatest when the condition is viewed as the responsibility of the individual, as is the case with HIV. Jonathan Mann (1987)(cited by Skinner, *et al.*, 2004:158) spoke of a third epidemic of discrimination that would follow the HIV and then AIDS epidemics. He asserted that this third phase would be as central to the global AIDS challenge as the disease itself. The stigma of HIV and AIDS nullifies efforts of preventing and treating the infected or to deal confidently with the pandemic (Ogden & Nyblade, 2005:34).

The concept of stigma has received significant attention in recent years in the HIV and AIDS literature (Greeff, *et al.*, 2008:79). Being diagnosed with HIV or AIDS is a life-changing event where PLHA must deal with the disease as well as its associated stigma and isolation (Abel, *et al.*, 2003:510). Palattiyil *et al.* (2008:881) supported Annan (2006) that on one hand there is a global scaling up of efforts to contain the epidemic and, on the other, are the hardly noticeable struggles borne on a day-to-day basis by families who support their members living with HIV and AIDS.

Greeff *et al.* (2007:12) found that the extent of the impact of HIV and AIDS-related stigma, turned out to be far worse than ever and supported the prediction by Abdool *et al.* (2005), and

Connolly *et al.* (2004) who found that 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.

## 2 THE AIDS EPIDEMIC

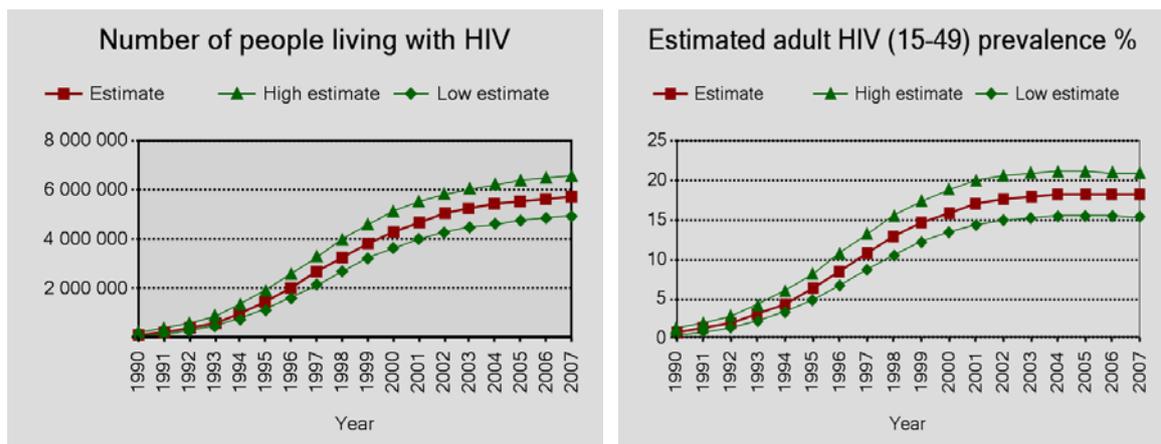
The global AIDS epidemic remains one of the greatest challenges in the field of global health, affecting people's quality of life and the costs of care. Stigma and discrimination continue to affect those living with and affected by HIV disease as well as their health care providers, particularly in Southern Africa, where so many people are infected and the burden of the disease is so significant (Greeff, *et al.*, 2010:476).

According to Tarantola *et al.* (1999)(cited by Wingood, *et al.*, 2008:237) epidemiological surveillance studies continue to document the high prevalence of HIV infection in developing countries. In those poor countries most severely affected by the HIV epidemic, there are widespread misconceptions regarding HIV transmission. Ignorance about HIV transmission, fear of those living with HIV, and lack of access to and understanding of treatment is at the very core of HIV stigma.

In 2008, among the 33.4 million people living with HIV worldwide, 2.1 million were children under 15 years of age and 31.3 million were persons aged 15 years or over. The latest epidemiological data indicate that globally the spread of HIV appears to have peaked in 1996, when 3.5 million new HIV infections occurred. In 2008, the estimated number of new HIV infections was approximately 30% lower than at the epidemic's peak 12 years earlier. Although the annual number of newly-infected people has fallen from an estimated 3.5 million in 1996 to 2.7 million in 2008, the total number of people living with HIV worldwide is still increasing rapidly because of both the large number of newly-infected persons and the increasing longevity of the growing number of persons receiving antiretroviral therapy (UNAIDS, AIDS Epidemic Update, 2009:7). HIV is a leading cause of death worldwide and the number one cause of death in Africa (Asiedu, 2007:5). It is estimated that 2 million deaths due to AIDS-related illnesses occurred worldwide in 2008 (UNAIDS, AIDS Epidemic Update, 2009:7). The nature of HIV and AIDS is yet another area requiring contextual understanding. In western nations, AIDS is now seen as a chronic disease that can be managed with proper medication and care. However, in most African contexts, AIDS remains a cause of premature death and an HIV positive status is taken as a death sentence by some. As a result the roots of stigmatization are different in these public health contexts (Ndiaye, 2008:26).

South Africa is experiencing the largest HIV and AIDS epidemic in the world (Nicolay, 2008:1). Forsyth *et al.* (2008:75) support this and found in their study that in the South African context, addressing AIDS-related stigma has become all the more urgent given the almost unmanageable scale of the epidemic. Gilbert *et al.* (2009:1123) supported this and agreed with Marks's (2008) argument that AIDS was an epidemic waiting to happen; South Africa's complex social history has compounded the way in which the epidemic has unfolded over the past three decades. At the end of 2007, South Africa was home to the largest number of people living with HIV: 5.6 million people (Figure 1). It was followed by Nigeria, with 2.6 million people living with HIV, and India, with 2.4 million (UNAIDS/WHO, 2008).

Different provinces in South Africa, however, experience different levels of HIV infections and AIDS-related deaths (Nicolay, 2008:1). The North West Province has nearly half a million HIV positive people, the fourth largest in SA. Around 13% of the population in this province, and one in every 5 adults were estimated to be HIV positive in 2008. The epidemic in the North West Province has not reached a mature phase yet and is still growing with new infections higher than the number of AIDS related deaths (Nicolay, 2008:5).



(UNAIDS/WHO, 2008).

**Figure 1:** Epidemiological profile on HIV and AIDS in South Africa

Furthermore, the ongoing epidemic of tuberculosis (TB) in South Africa has been directly implicated in the AIDS epidemic in a number of ways, with TB substantially increasing the number of AIDS-related deaths (Walker, *et al.* 2004) (cited by Gilbert, *et al.*, 2009:1124).

### 3 UNDERSTANDING HIV STIGMA

For persons living with HIV or AIDS, stigma is one of the most insidious barriers affecting access to and provision of health services, particularly in Southern Africa and also in India (AIDS Alert, 2002:1). Wingood *et al.* (2008:237), supported this and stated that ignorance about

HIV transmission, fear of those living with HIV, and lack of access to and understanding of treatment is at the very core of HIV stigma. Studies by Phaladze *et al.*(2005)(cited by Aggleton, *et al.*, 2005:7; Adewuya, *et al.*, 2009:761) found that AIDS stigma and discrimination have considerable influence on people living with the HIV infection, particularly in sub-Saharan Africa, where the burden of AIDS is so significant. Stigma is deeply rooted, operating within the values of everyday life and intense stigma may be traumatic.

Studying HIV and AIDS-related stigma in different settings may not only provide an in-depth understanding of the phenomenon, but it also may highlight a focus for developing culturally sensitive programs for HIV and AIDS education (Asiedu, 2007:1). There is a perception that rural and urban communities differ in their social structure and the experiences of individuals living in those settings. In their study in five African countries on urban and rural differences on HIV and AIDS stigma, Naidoo *et al.* (2007:22) explore possible urban-rural differences in HIV-related stigma. The results suggest that stigma in all forms is received more often in urban areas than in rural areas, and that PLHA in urban areas as compared to rural areas are more active in self-stigmatisation. They argued that there is a clear difference in character and intensity of stigma between an urban and rural setting. Although their findings contradict the results of some other research (such as the Rural Center for AIDS/STD Prevention, 1994; Sliep, Poggenpoel & Gmeiner, 2001; Duffy, 2005)(cited by Naidoo, *et al.*, 2007:22) and Campbell, *et al.*, 2008:510), who stated that issues of anonymity and confidentiality are major difficulties in rural areas, they recommend further research on HIV-related stigma in specific settings and that the HIV and AIDS treatment programs, and support structures be appropriately designed to suit the two settings (Naidoo, *et al.*, 2007:22).

Holzemer *et al.* (2009:77) have argued that it is important to describe the prevalence of HIV stigma in the lives of PLHA in specific settings. Gilbert *et al.* (2009:1128) support this and stated that in Southern Africa the virus has long been regarded as enigmatic, difficult to explain and imbued with cultural meaning. It is therefore important to acknowledge that stigma exists, and to describe the prevalence of HIV stigma in the lives of PLHA in specific settings (Holzemer, *et al.*, 2009:77).

The rest of the discussion on understanding HIV stigma focuses on defining HIV stigma, models or frameworks of HIV stigma, aspects of the HIV stigma process, stigma experiences of and by CFM, urban and rural differences, and interventions for HIV-related stigma reduction.

### 3.1 Defining HIV Stigma

The concept stigma originated from Greek. Harvey (2001) (cited by Holzemer, *et al.*, 2004:166) noted that ‘Stigma’ denotes a mark that, in ancient times, was burned or cut into the flesh of an unsavoury character — a traitor, criminal, or slave, and referred to marks exposing the unusual or the bad about the moral status of an individual. In her study Manyedi (2007:54) referred to Nord (1997), who in his writings on stigma also referred to this mark as that of shame and disgrace, but added that an individual was also socially discredited because of that mark. The concept evolved from being bodily signs of physical disorder until the present meaning, which is back to the original meaning of the concept, which is that of being a dreadful or disgraceful sign (Manyedi, 2007:54). Very broadly speaking, it is a term that marks and then excludes a person as being tainted or alien, of less value, blameworthy or to be feared as undesirably different. It leads to the rejection and exclusion of people on grounds for which they often bear no responsibility (Herek, 2002:595; Ackermann, 2005:388). Stigma is thus a complex, multi-layered and dangerous reality that demands our attention (Ackerman, 2005:386).

According to Stafford and Scott (1986)(cited by Cao, *et al.*, 2010:445) one of the curious features of literature concerning stigma is the variability that exists in the definition of the concept. Link *et al.* (2001:365) came to the conclusion that of the many reasons that definitions of stigma vary, two seem particularly prominent. First, that the stigma concept has been applied to an enormous array of circumstances of which each one is unique, and which led investigators to conceptualise stigma in different ways. Second, research on stigma is clearly multidisciplinary, and although there is a great deal of overlap in interests across these disciplines, there are nevertheless some differences in emphasis. They stated that because of the complexity of the stigma phenomenon, it seems wise to continue to allow variation in definition so long as investigators are clear as to what is meant by stigma when the term is used.

Although there are different definitions of stigma, discussion of stigma often begins with Goffman’s definition which is one of the oldest definitions of stigma. Goffman (1963), (cited by Uys, *et al.*, 2009:150) defines stigma as an “undesirable or discrediting “attribute that an individual possesses, which affects the person’s status in society. Stafford *et al.* (1986), (cited by Link, *et al.*, 2001:364) propose that stigma “is a characteristic of persons that is contrary to a norm of a “social unit” where a “norm” is defined as a “shared belief that a person ought to behave in a certain way at a certain time”. An especially influential definition (cited by Crocker, *et al.*, 1998:505) is that of Jones *et al.* (1984), who use Goffman’s (1963) observation that stigma can be seen as a relationship between an “attribute and a stereotype” to produce a definition of stigma as a “mark” (attribute) that links a person to undesirable characteristics

(stereotypes). Link *et al.* (2001:365) used the same definition as Jones *et al.* (1984), but added the component of discrimination, and define that stigma exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them.

Based on Goffman's work, Alonzo and Reynolds (1995)(cited by Greeff, *et al.*, 2008:312), expanded the definition of stigma and defined the same concept as "a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people". Crocker *et al.* (1998:505) supported Alonzo and Reynolds (1995)(cited by Greeff, *et al.*, 2008:312), and defined stigma as "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context". Herek and Capitanio (1998)(cited by Cao, *et al.*, 2010:445) refer to HIV-related stigma as "prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV and AIDS, but included individuals, groups, and communities with which they are associated.

While Goffman focuses on the individual aspects of stigma, Parker and Aggleton (2003) (cited by Ogden, *et al.*, 2005:8) offer a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control. Parker and Aggleton (2002) (cited by UNAIDS, 2000a), suggest that the dominant definition of stigma as an 'undesirable difference' ignores the fact that stigma is socially constructed. They oppose the idea that stigma is a static individual characteristic, and argue in favor of stigma as a social process. Ultimately, stigma creates and is reinforced by social inequality. Deacon *et al.* (2005:10) support the argument that stigma consists of beliefs that are part of a social process of stigmatisation, and defined stigma as negative social 'baggage' associated with a disease and differentiating those with a disease in negative social as well as biological terms, and projecting risk of contracting the disease onto other groups.

Stigma has thus been identified as a complex, diverse and deeply rooted phenomenon that is dynamic in different cultural settings, as a collective social process rather than a mere reflection of an individual's subjective behaviour. As Herek and Glunt (1988)(cited by the Population Council, 1999:2) point out, '... the stigma attached to AIDS as an illness is layered upon pre-existing stigma'. In her study Ackerman (2005:386) warned that focusing on stigma alone can undermine productive debate on how to deal with HIV and AIDS. Speaking only about stigma can shift the focus from the reality that infection is the result of certain types of behaviour in often complex situations. Discussions on stigma can, moreover, be undermined if they do not acknowledge people's legitimate fear of infection from a disease for which there is neither cure nor, for most, available treatment. Greeff *et al.* (2008:312) support this by quoting Herek *et al.*

(2002) that stigma is different when viewed from the inside, by those who are stigmatized, than from the outside, by those who stigmatize. Wingood *et al.* (2008:237) supported this view in their study and stated that ignorance about HIV transmission, fear of those living with HIV, and lack of access to and understanding of treatment is at the very core of HIV stigma.

After a careful review of all the discussions around stigma definitions, the researcher came to the conclusion that all the researchers define stigma as discrediting and undesirable, and which are most easily understood as social processes which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality (cited by the Siyam'kela project in their literature review on HIV and AIDS, 2003:2). Thus, the essential meaning of stigma is that the stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise detrimentally affected in their chances in life and in accessing the humanizing benefit of free and unfettered social intercourse (Alonzo & Reynolds, 1995)(cited by Greeff, *et al.*, 2008:312). For the purpose of this study, the researcher supports the definition by Alonzo and Reynolds (1995)(cited by Greeff, *et al.* 2008:312).

### **3.2 Models or Frameworks of HIV Stigma**

Several conceptual frameworks for understanding HIV stigma and its effects have been proposed. These frameworks pose that the fear of being identified with HIV prevents people from learning their serostatus, changing unsafe behaviours, and caring for people living with HIV (Wingood, *et al.*, 2008:237).

Parker and Aggleton (2003:15-16) offered a *theoretical framework for understanding HIV and AIDS stigma*. They suggested that most research on stigma has focused on how others view the stigmatized person and propose a framework of social inequality as a strategy to understand stigma. In order to understand stigmatization as a process of social structures, they urged the recognition of other contextual factors, such as culture and its impact on power relationships.

The study of Deacon *et al.* (2005:10) focused on *social theories of stigma*, and suggests that stigma should be understood as a problem of fear and blame, rather than as a problem of ignorance or a mechanism of social control, this helps to understand the stigmatization process without resorting to individualism or functionalism. They argued that theoretical models that take into account the interplay of individual and environmental factors are therefore considered since the study of HIV and AIDS-related stigma is a social phenomenon, but postulated that theoretical approaches to stigma remain problematic.

Campbell *et al.* (2005:810) studied AIDS-related stigma in a South African community using interviews, focus groups and fieldworker diaries. Their findings suggest that stigma serves as a form of 'social psychological policing', indicating a close relationship between stigma and power dynamics in social groups. They proposed a framework of the contexts in which stigma occurs: the economic, political, and local community contexts, and the organizational context of institutions working to address HIV and AIDS. Campbell *et al.* (2007:406) supported the view of Campbell and Deacon (2005), and came to the conclusion that there is an urgent need for more nuanced models of stigma which take greater account of its complex and multi-level nature. There is also a need for actionable models, which define stigma in ways that point to possible strategies for stigma reduction.

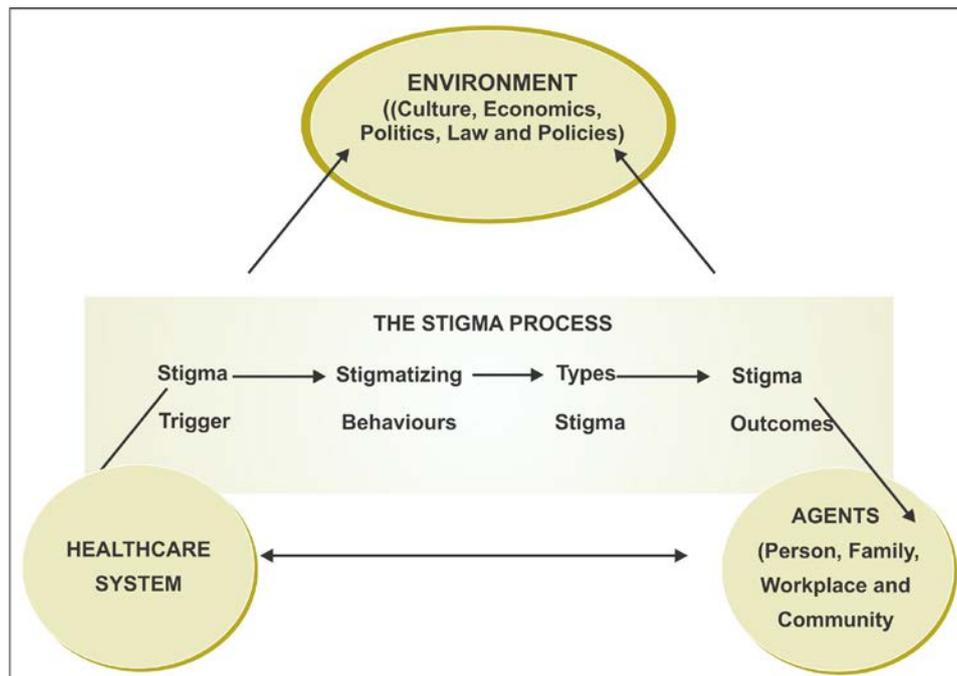
Bronfenbrenner's ecological model of human development (cited by Asiedu, 2007:40) provides a useful framework for examining HIV-related stigma. The model acknowledges that human development involves transactions between human beings and the characteristics of the environmental system within which they interact (Bronfenbrenner, 1979; Bronfenbrenner, 1986). Bronfenbrenner's model is important in looking at the impacts of HIV and its related stigma on family members of PLHA. It emphasizes that the individual does not grow/develop in isolation. It gives an insight to what is known that the individual does not grow/develop in isolation, in other words what befalls a person is also felt and experienced by the people/settings around him. It gives insight to how HIV and AIDS and its related stigma and discrimination are not an individual problem, but a familial and societal one.

Mak *et al.* (2007:1555) proposed a social cognitive framework to study the effect of self-stigma on psychological distress, and demonstrated the impact of stigma on psychological adjustment. The researchers found that self-stigma of PLHA negatively impacts their psychological well-being and by reducing the extent of self-stigmatization, PLHA's social relationships and long-term adjustment can be sustained (Mak, *et al.*, 2007:1557).

Many researchers have proposed definitions of stigma, investigated its impact and correlates, and proposed frameworks for thinking about stigma. None, however, have used a data-based approach to integrate theories on the context and process of stigma. None have focused on Africa, an area where stigma continues as a major challenge in addressing the HIV and AIDS epidemic. In order to fill this gap, Holzemer *et al.* (2007:545) proposed a conceptual model of HIV and AIDS stigma, to understand the stigma process that is specific to HIV and AIDS in Africa. It describes HIV and AIDS-related stigma as a cyclical process within a specific context. They identified three components in the data: contextual factors - environment, health care systems, and agents – that influence and affect stigma and the stigma process itself. The

stigma process included four dimensions: triggers of stigma, stigmatizing behaviours, types of stigma and the outcomes of stigma. They combined the stigma process with the context of stigma and created a Conceptual Model of HIV and AIDS in Stigma (see Figure 2).

The process begins with a trigger, for example a positive HIV test or getting an ARV pharmacy refill; and progresses to stigmatizing behaviour such as avoiding; which leads to three (3) types of stigma; which have specific outcomes (see figure 2). The Conceptual Model of HIV and AIDS Stigma by Holzemer *et al.* (2007:545) will form the theoretical grounding of the present study.



(Holzemer, *et al.*, 2007:546)

**Figure 2:** Model of the dynamics of HIV/AIDS stigma

### 3.3 Aspects of the HIV Stigma Process

For the purpose of this study, the Conceptual Model of HIV or AIDS Stigma by Holzemer *et al.* (2007:545) will be used. This framework will provide a structure for the rest of the discussion on stigma as this model grounds this research. Various authors' work will be integrated within the discussion.

#### 3.3.1 The context of stigma.

The Conceptual Model of HIV or AIDS Stigma by Holzemer *et al.* (2007:545) conceptualized stigma as a very specific process occurring within a context of three contextual factors: environment, healthcare systems and different agents. Aggleton *et al.* (2005:9) differ in how

they outlined stigma within the three contextual factors, and this will be discussed under each contextual factors:

### **3.3.1.1 Environment.**

Holzemer *et al.* (2007:545) cited Castro and Farmer (2005) and described a third context as “*environment*” but added culture and economy to the context of political, legal and policy environment. Politics, in the sense of power relationships, may play a role in the approach taken towards PLHA in the cultural, economic, and legal and policy environments. Aggleton *et al.* (2005:9) used similar context to environment, but refers to it as a national level and included aspects as discrimination which can reflect stigma that has been officially sanctioned or legitimized through existing laws and policies, and enacted in practices and procedures. These may result in the further stigmatization of people living with HIV and, in turn, legitimate discrimination. According to Aggleton and Parker (2002) (cited by Holzemer, *et al.*, 2004:169) the real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends.

### **3.3.1.2 Health-care systems.**

Holzemer *et al.* (2007:546) and Chirwa *et al.* (2009:16) supported the context of *healthcare systems* by Aujoulat *et al.* (2002) which includes settings such as hospitals, clinics and home-based care settings, and healthcare workers such as physicians, nurses and others. Health service delivery settings, as a context for stigma, are primary settings in which stigma can be triggered and stigma can be manifest. Holzemer *et al.* (2007:546) support this argument as informants in their study reported healthcare workers as a source of stigmatization. In research done in Natal, youth stated that they did not want to know whether they were infected. This was felt so strongly that medical personnel were seen as the worst culprits in the HIV epidemic, as they gave out the diagnoses (Skinner *et al.*, 2004:162). Aggleton *et al.* (2005:9) takes it a level higher to institutional settings, including health care services, school, prison and workplaces.

### **3.3.1.3 Agents.**

*Different agents or people*, identified in the study done by Holzemer *et al.* (2007:546) include the individual who may self-stigmatize, family members, work colleagues, and community members. Aggleton, *et al.* (2005:9) supported this context but referred to it as family and community setting. The context of “*different agents or people*” as outlined by Holzemer *et al.* (2007:546) also refer to the social context of the Ghanaian society which give some kind of understanding into the expectations of individuals and family members as well as women in the Ghanaian society. Hopefully this will help to understand the expectations of both PLHA and their

family members with issues of care and support as well as the impact of HIV- related stigma (Asiedu, 2007:34).

What we understand by stigma will vary, given our historical and cultural contexts. A key finding is that HIV or AIDS-related stigma is remarkably consistent across contexts (Holzemer, *et al.*, 2009:77). Referring back to the context of “*family and community settings*” as outlined by Aggleton *et al.* (2005:9) and “*different agents or people*” as outlined by Holzemer *et al.* (2007:545), Gilbert *et al.* (2009:1127) supported their view. They found that popular perceptions of AIDS are undoubtedly shaped by a wide variety of factors including the contextual nature of AIDS-related stigma in different communities, people’s understanding of the source of illness and misfortune, the availability of life-prolonging ARVs and people’s exposure to ‘treatment literacy’ initiatives.

Referring back to the context of environment, Holzemer *et al.* (2007:545) supported Ackerman (2005:38) who stated that stigma never arises in a social vacuum, but always has a history that influences the form it takes. Stigma functions particularly effectively at the point where *culture*, *power* and *difference* meet, and is not an isolated phenomenon. Pescosolido *et al.* (2008:431) supported this view by quoting Coleman (1990) and Pescosolido (1992) stating that individuals do not come to social interaction devoid of affect, values and motivation; and, they exist in larger political, cultural and social contexts which shape their expectations on all of these issues. This supported the view of Herek *et al.* (1998:1) who argued that AIDS stigma represents a set of shared attitudes, and beliefs that can be conceptualized at both cultural and individual levels. At the cultural level, AIDS stigma manifested in laws, policies, popular discourse, and the social conditions of PLHA and those at risk of infection. At the individual level, it takes the form of behaviours, thoughts, and feeling that express prejudices against persons infected with HIV, this prejudices can be found among PLHA as well as those who are uninfected. Further, supporting the context of Holzemer *et al.* (2007:545), social interactions take place in a context where organizations and institutions structure norms that create the possibility of marking and sharing notions of “difference.”

The way in which individuals discover and disclose their HIV status to others as well as how they cope with their infection is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic context, and social norms (Brown, *et al.*, 2001)(cited by Makoae, *et al.*, 2008:138). Cultural taboos have characterized the entire history of the epidemic and continue to function today as the most deeply rooted aspect of HIV and AIDS-related stigma. When cultural, gender, racial

and sexual stigmas work together with stigmas engendered by HIV and AIDS, the effects are complex and often devastating.

Research studies from Uganda and India supported the study by Aggleton (2005:9) and argued that AIDS-related discrimination may occur at various levels, namely family and community settings, as well as institutional settings (UNIADS /09.36E / JC1700, 2005:9). The stigma process described by Holzemer *et al.* (2007: 546) takes place within these contexts and is proposed to include four elements: stigma triggers, stigmatizing behaviours, types of stigma and stigma outcomes.

### **3.3.2 The HIV Stigma Process.**

Various scientists have defined stigma, explored its correlates, and tried to measure it, but often have not clearly distinguished between the causes of stigma, the stigma behaviours themselves, and the outcomes of stigma (Greeff, et al., 2010:476). In order to fill this gap, Holzeme et al. (2007: 546) developed a Conceptual Model of HIV and AIDS Stigma, conceptualizing the stigma process as being triggered by certain factors that activate stigmatizing behaviours of different kinds, that can be categorized as types of stigma, which ultimately lead to a variety of outcomes. These various aspects are discussed in more detail, adding the views of various authors.

Holzemer *et al.* (2009:77) support this notion of a process in their further study *Measuring HIV stigma for PLHAs and nurses over time in five African countries*, and stated that, although there is some prominent variation in stigma that stem from differences in language, culture, and epidemic history, these differences are largely of fine distinction and degree rather than substance. Instead commonalities were found in what *causes* stigma, the *forms* in which stigma is expressed, and the *consequences* of stigma. Aggleton *et al.* (2005:8) also describes HIV-related stigmatization, as a process by which people living with HIV are discredited. It may affect both those infected or suspected of being infected by HIV and those affected by AIDS by association, such as orphans or the children and families of people living with HIV. Kheswa *et al.* (2011:39) supported the view of Swaans (2008) that the processes of stigmatization, may have a strong 'policing' function, in the sense that they appear to play a powerful role in regulating the behaviour of citizens; for it is through these processes that people 'instructed' about, not only **what** behaviour is appropriate but also **what** would happen to those who breach the accepted behavioural codes established by their context

As mentioned, Holzemer *et al.* (2007:547) includes four elements in the Stigma Process.

### **3.3.2.1 Triggers of stigma**

The triggers mentioned by Holzemer *et al.* (2007:546) such as HIV testing, diagnosis, HIV disease, disclosure, suspicion and rumour, set off the process. Participants of the study indicated that the suspicion of being HIV-positive is enough to trigger stigma. Such suspicions can be created by a person's behaviour, such as attending a particular clinic, or a symptom, such as losing weight, and can lead to stigmatizing behaviour, this would include receiving an HIV diagnosis or disclosure of HIV status or any action that allows people to label themselves or others as HIV-positive is seen as a trigger (Holzemer, *et al.*, 2007:546; Raymond, 2009:15). Asiedu (2007:128) argued that HIV-related stigma has been known to be triggered by many factors, including insufficient knowledge about the transmission of the disease as well as the misconceptions and fear associated with a disease that is life threatening. In addition, irresponsible media reporting, as well as poverty are other factors that trigger HIV-related stigma. Nachegea *et al.* (2006) (cited by Dlamini, *et al.*, 2009:278) documented a strong relationship between failure to refill ARV medication prescriptions and survival in a large sample of patients in South Africa. It is possible that refilling a prescription is a trigger that results in increased stigma. Taking medications may indicate that someone is HIV-positive, so someone who does not wish to disclose his/her status may avoid taking medications (Makoae, *et al.*, 2009:1357). PLHA tend to avoid stigma triggers, if at all possible (Holzemer, *et al.*, 2007:546).

### **3.3.2.2 Stigmatizing behaviours**

Holzemer *et al.* (2006:547) argue that triggers lead to stigmatizing behaviours like blame, insult, avoidance and accusation, other authors added harm, isolation, abuse and excluding or identifying the person in a negative way (Deacon, 2006:385; Raymond, 2009:15; Sullivan, *et al.*, 2010:108; Sohn, *et al.*, 2012:26). The level of stigmatizing behaviour varies from very limited, such as asking a person to use special eating utensils, to extremely serious, such as chasing such a person out of their home (Holzemer, *et al.*, 2006:547). Gossip and rumours were also believed to be the most common way that people learned about another's sero-status. Other common ways included: a person's frequent visits to a particular health-care centre to collect antiretroviral therapy, a health-care worker told other people, the infected person told people, a health-care worker frequently visited a person's home, friends or neighbours of a PLHA told others members of the family (Sullivan, *et al.*, 2010:107).

Studies done by Shisana and Simbayi (2002) (cited by Hutchinson, *et al.*, 2007:490; Ndiaye, 2008:32) found that a significant proportion of people hold various stigmatizing attitudes, including that they would not share a meal or sleep in the same room with a person infected with HIV and AIDS. The common thoughts that HIV and AIDS is a disease resulting from

“immoral behaviour,” are intricately tied to cultural values and laws in the broader society. These behaviours have been associated with HIV and AIDS transmission, and therefore a person who contracts HIV is seen as immoral and irresponsible (Asiedu, 2007:41). Both the stigmatizers and the stigmatized are engaged in a similar process of gripping and being gripped by life, holding onto something, preserving what matters, and warding off danger. This is what makes stigma so dangerous, durable, and difficult to curb (Yang, *et al.*, 2007:1528). Stigmatizing behaviours ultimately lead to a variety of outcomes, which can in themselves become new stigma triggers (Dlamini, *et al.*, 2009:378).

### **3.3.2.3 Types of stigma**

Various behaviours then lead to specific types of HIV stigma (Holzemer, *et al.*, 2007:547).

According to Ndiaye (2008:20) HIV and AIDS stigma is unique because it provides a particular set of complex characteristics that combines all three types of stigma.

Various authors described different types of stigma but for the purposes of this study the three types of stigma described by Holzemer *et al.* (2007:547) will be used to structure the discussion, and descriptions by various authors will be discussed under the different types of stigma. Holzemer *et al.* (2007:547) differentiate between received stigma, internal stigma and associated stigma.

#### *Received stigma*

Holzemer *et al.* (2007:547) described received stigma as all types of stigmatizing behaviour towards PLHA as experienced or described by themselves or others. Nine dimensions of received stigma were identified by Greeff *et al.* (2007:15) in the same study namely neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping. It is similar to external or enacted stigma described by the Siyam'kela research project (2003:14) and refers to the etic or outsiders' view of Weiss *et al.* (1992)(cited by Greeff, *et al.*, 2008:313). Muhomba (2007:21) cited the definition of Pequegnat *et al.* (2001), and supported this but referred to received stigma as *perceived stigma*, and define it as what an individual believes others think and how that individual believes others will react upon disclosure and can be more psychologically damaging. Berger *et al.* (2001) (cited by Greeff, *et al.*, 2008:313) referred to perceived stigma and defined it as an individual's perceptions of societal attitudes towards people with HIV, and his or her personal knowledge of being infected with HIV.

Indicators described by the Social and Scientific Systems Inc. (2004)(cited by Muhomba, 2007:20) as external stigma differ from Holzemer *et al.* (2007:548) and Greeff *et al.* (2007:15) and include cruelty, isolation, discrimination, harassment, categorizing, accusation, punishment,

blame, exclusion, ridicule, or resentment. This type of stigma may sometimes lead to violence towards people living with HIV or AIDS.

Although different researchers have used different words to describe *received stigma*, like *external, etic view, enacted or perceived*, they all concluded that *received stigma* is experienced by the HIV-positive individual from the outside world.

### *Internal stigma*

The second type of HIV stigma namely *internal stigma* refers to stigma as thoughts and behaviours stemming from the person's own negative perception about them based on their HIV status, (Holzemer, *et al.*, 2007:547). Greeff *et al.* (2007:15) in this same study gave a finer description of internal stigma, identifying four dimensions of internal stigma, namely perception of self, social withdrawal, self-exclusion and fear of disclosure. According to Uys *et al.* (2005)(cited by Dlamini, *et al.*, 2007:395) examples of *internal stigma*, in which PLHA internalize their devaluation by others, include avoiding utilizing services due to fear of being abused. The Siyam'kela study (2003:19) identified indicators for personal stigma as *internal or felt stigma* which might lead to an unwillingness to seek help and access resources and refers to the emic or insider's perspective of Weiss *et al.* (1992)(cited by Greeff, *et al.*, 2008:317). According to AIDS Care Watch ([www.aidscareswatch](http://www.aidscareswatch) 2006:23), *self-stigma* can be defined as an individual's internalization of the public attitudes they experiences, or anticipates, in society and have an impact on people's psycho-emotional and physical health. High levels of stress and anxiety are the result of feelings of shame, depression, self-doubt, guilt, self-blame and inferiority and contributes to denial. PLHA may experience a lowered self-esteem and sense of self-worth and then they withdraw from society and stop participating in social activities.

In extreme cases, self-stigma leads to self-harm. It prevents individuals seeking health treatment and care. This shame is associated with HIV or AIDS and the fear of being discriminated against ([www.aidscareswatch](http://www.aidscareswatch) 2006:23). Muhomba (2007:20) supported this view and referred to the view of some scholars involved with the Policy Project/South Africa during 2003, who argued that *internal stigma* is a powerful defence mechanism to protect oneself from further stigmatization and may result in individuals feeling discouraged about seeking help, accessing resources or disclosing their status. Link and Phelan (2006)(cited by Dlamini, *et al.*, 2007:396) state that a subtle form of discrimination occurs when stigmatized individuals realize that a negative label has been attached to them. These authors came to the same conclusion that internal stigma, also defined as felt, emic or self-stigma refers to stigma that the HIV positive individual imposes on the self.

### *Associated stigma*

The last type of stigma identified by the Holzemer group (2007:547) defined *associated stigma* as incidents that describe stigma against people who work with (health care workers) or associate with HIV and AIDS-affected people (e.g. spouse/partner, children, family, and friends) (Greeff, *et al.*, 2007:15). Stigma by association involves people living and working close to PLHA (Greeff, *et al.*, 2008:318; Chirwa, *et al.*, 2008:20; Kohi, *et al.*, 2010:140-141; Uys, *et al.*, 2009:157). Ogden *et al.* (2005:31) support the view of stigma by association but refer to it as secondary stigma.

The Siyam'kela research project (2003:17) also described *associated stigma* but categorized it as a theme under external stigma in their research and not as a third type as did the Holzemer group. Studies done by the latter group came to the conclusion that people living and working close to PLHA experience levels of stigma by association that may lead to low levels of job satisfaction and migration by nurses caring for PLHA. Results showed that nurses experienced associated stigma, as the community may label and gossip that something must be wrong with the nurses who work with PLHA, or else they would not be prepared to work and care for them (Holzemer, *et al.*, 2007:547).

#### **3.3.2.4 Consequences or outcomes of stigma**

The last aspect of the process of HIV stigma in the Conceptual Model of HIV or AIDS Stigma by Holzemer *et al.* (2007:54) and Chirwa *et al.* (2009:16) outlines the consequences or outcomes of stigma under categories of general health, violence, poor quality of life and reduced access to care. Stigma and discrimination increase people's vulnerability, isolate them, deprive them of their basic human rights, care and support, and worsen the impact of the infection. Dlamini *et al.* (2008:393) mentioned that PLHA focus group participants expressed a range of negative feelings as a result of abuse, including feelings of hurt, despair, sadness, and shock. Self-pity was also expressed by some PLHA. In many instances HIV/AIDS places a person in a position where he or she has nothing to offer and nothing to gain: PLHA are not allowed to participate in community activities, they are marginalized and not regarded in the society, and they are given no position or authority in their community. As a result of this, they begin to internalize the negative attitudes of others (Asiedu, 2007:24).

The discussion that follows expands beyond the outcomes mentioned by Holzemer *et al.* (2007:547).

### *Poor physical and mental health*

Holzemer *et al.* (2007:547) outlined the idea that social exclusion, rejection, high stress due to stigma and economic pressures may lead to stress-related mental illness. Poor health thus

includes both physical and mental health. PLHA experience stigma and discrimination very strongly and it has enormously negative effects on the psychological wellbeing and social relationships of PLHA (Bos, *et al.* 2008:450). According to Gallant *et al.* (1996)(cited by Abel, *et al.* 2003:511) the diagnosis of HIV or AIDS carries an intense physical, psychological and social burden which has an effect on both physical and emotional health of people with HIV or AIDS. Because of signs and symptoms of the disease, side effects of anti-retroviral therapy and altered immune responses, PLHA frequently feel stigmatized and physically unwell. The study found that HIV-related stigma begins with sero-status disclosure. Stigma is manifested in a myriad contexts including the family, community, health-care institutions and gender. Extreme impacts such as suicidal thoughts were also experienced by PLHA (Asiedu, 2010: IV, Lichtenstein, *et al.*, 2010:143).

In a study done by Feng *et al.* (2009:486) in Taiwan, their findings demonstrated that family members of PLHA also suffered from high degree of stress and had many needs to be met. Smith *et al.* (2009:148) supported this argument by quoting Stein *et al.* (2007) to the effect that significant stressors encountered by HIV-affected families have been associated with poor mental health outcomes. The main findings in the study done by Lichtenstein *et al.* (2010:145) were that such families experienced multiple stressors and mental health conditions. The knowledge that a loved one's anticipated death as well as caring for such a person becomes increasingly distressing for the family. Depression among caregivers is common, and has been described as "a function of social constriction and AIDS-related bereavement."

#### *Violence/abuse*

In the conceptual framework of Holzemer *et al.* (2007:547), the HIV and AIDS stigma process shows a variety of possible outcomes, including verbal abuse, physical abuse, and neglect of PLHA. CFM of PLHA are in a unique position as they are often responsible for providing care to PLHA, however, not all families are supportive and caring (Dlamini, *et al.*, 2007:396). The important role of the extended family in African culture can put PLHA at a great risk of experiencing abuse within the family setting which may influence decisions regarding testing and disclosure (Dlamini, *et al.*, 2007:391). Dlamini *et al.* (2008:398) came to the conclusion that abuse is manifested not only by family members and colleagues but also in some cases by the health-care workers to whom PLHA looked for assistance. Wingood *et al.* (2008:237) found that stigma may at its most extreme manifest itself as violence perpetrated against PLHA.

Some **verbal abuse** may take the form of name calling, with the purpose of emphasizing that the PLHA are different or should be avoided, or separated from, others in the community or the immediate family (Dlamini, *et al.*, 2008:394). Siyam'kela Project report (2003b)(cited by

Dlamini, *et al.*, 2007:290) discusses a variety 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.

Like verbal abuse, **physical abuse** is often aimed at rejecting, dehumanizing, and isolating PLHA, to physical abuse against women and even abandonment by their intimate partners (Rothenberg & Paskey 1995; Maman, *et al.*, 2001)(cited by Hutchinson, *et al.*, 2007:491). Physical violence against PLHA, though occurring less frequently than other kinds of violence, also has been expressed as a form of stigma that has a deep impact and generates much fear (Brimlow, Cook & Seaton, 2003; Ogden & Nyblade, 2005; Piot, 1999; WHO, 2001)(cited by Asiedu, 2007:13).

In a study by Dlamini *et al.* (2008:395), results showed that physical abuse was sometimes not focused directly at the PLHA, but was instead aimed at causing inconvenience and loss, by the destruction of their personal possessions. HIV-positive participants in this study had experienced physical abuse on a daily basis, often from family and friends.

Poor quality of life

Stigma and discrimination increase people’s vulnerability, isolate them, deprive them of their basic human rights, care and support, and worsen the impact of the infection (Holzemer, *et al.*, 2007:547; Dlamini, *et al.*, 2007:396). Various authors found that HIV stigma has been linked with quality of life for PLHA (Chen, Han & Holzemer, 2004; Khakha, 2003; Surlis & Hyde, 2001 cited by Chirwa, *et al.*, 2009:15). PLHA reported being unable to access services, including life insurance and funeral insurance, medical schemes, and so forth or experiencing poor quality of care solely because of their HIV status (MANET, 2003; Petrak, *et al.*, 2001; POLICY Project, *et al.*, 2003)(cited by Greeff, *et al.*, 2008:316).

The specific aim of the study done by Chirwa *et al.* (2009:15) was to explore the relationship between perceived stigma and the job satisfaction among nurses in five African countries. They found that low levels of job satisfaction also relate to perceived HIV stigma that surrounds nurses working with PLHA, including both the stigma that nurses enact and the stigma that they experience as a result of their work. The result of this perceived stigma leads to poor quality of patient care and ultimately to poor general health of PLHA, who then refuse to visit health care facilities for treatment.

Family members experienced similar stigma as PLHA, such as loss of jobs, loss of social network, loss of identity and self stigma. Greeff *et al.* (2008:316) supported this in their statement that PLHA are in denial of employment and access to financial resources.

Reduced access to care

In 2005 UNAIDS (2005:4) stated that HIV-related stigma and discrimination continue to be evident in every country and region of the world, creating major barriers to the prevention of further infection, alleviating impact and providing adequate care, support and treatment. Duffy (2005:18) supports this and states that stigmatization resulting in silence, secrecy and denial not only affects care and treatment, it has serious implications prevention, which is critical in a disease with such a long subclinical phase.

The fear of being judged also escalates in other problem areas, e.g. access to HIV testing, treatment, care or counselling (Bell, *et al.*, 2007:114; Benotsch, *et al.*, 2008:34). In the African setting, HIV stigma remains a powerful barrier for PLHA as this inhibits testing, disclosure of HIV status, access to anti-retroviral medication, access to care services and also limits the availability of support for them (UNAIDS, 2006) (cited by Greeff, *et al.*, 2008:311-324). Dlamini *et al.* (2008:394) support this, but add that community members may blame HIV-positive people for getting infected or infecting others, and may even seek revenge against them by withholding assistance or access to treatment. The stigma of HIV and AIDS nullifies efforts of preventing and treating the infected or to deal confidently with the pandemic (Ogden & Nyblade, 2005:34).

### *Discrimination*

Discrimination occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of their belongings, or being perceived to belong to a particular group (Aggleton, *et al.*, 2002, cited by Rui, 2005:9). According to Rui (2005:9) discrimination is simply the practice of treating somebody or specific group in society less fairly than others. Discrimination is intensely personal and it takes many forms. From the start of the AIDS epidemic, stigma and discrimination have fuelled the transmission of HIV and have greatly increased the negative impact associated with the epidemic, and reinforced other stereotypes, prejudices and social inequalities relating to gender, nationality, ethnicity, and sexuality (UNAIDS, 2002:67). At a national level discrimination can reflect stigma that has been officially sanctioned or legitimized through existing laws and policies, and enacted in practices and procedures (UNADS /09.36E / JC1700, 2009:9). In a study done by Skinner *et al.* (2004:162) at the University of Cape Town, they cited Leclerc-Madlala (1997) to the effect that many infected teenagers were stating that they were scared that they would be facing rejection and social exclusion and therefore did not disclose their status. This was supported by Tshabalala (2008:3) by stating that earlier in the epidemic it was found that in some African communities people were more fearful of the social consequences of AIDS than of the disease itself.

AIDS stigma has historically been enacted in the forms of discrimination (e.g. being fired from a job, denial of services), compulsory testing without consent or protection of confidentiality, public violence, and advocacy for quarantining or tattooing positive individuals Herek *et al.* (1998)(cited by Clayton, 2009:2). Stigma stimulates people to act in ways that directly harm others, for example discrimination and isolation (Muhomba, 2007:16). The press and anecdotal reports from the early 1980s told the stories of PLHA, and those simply suspected of having the disease, being evicted from their homes, fired from their jobs, and shunned by family and friends (Herek, 1999:1106). Asiedu (2007:14) supported this idea in her study in Ghana where she found that PLHA often find that they are no longer welcome at important family and community events, such as parties, weddings, etc. In the realm of daily life, they often find that neighbours, friends and relatives are reluctant to visit or be close to them. Phaladze *et al.* (2005)(cited by Makoe, *et al.*, 2009:1357) argued that in sub-Saharan Africa stigma and discrimination have a considerable influence on PLHA.

#### *Limited Disclosure*

Previous research (Brown, *et al.*, 2003; Buwalda, Kruijthoff, de Bruyn, & Hogewoming, 1994; Parker & Aggleton, 2003; UNAIDS, 2003).(cited by Hutchinson *et al.* 2007:491) indicated that people are reluctant both to be tested for HIV and to disclose results because they fear the potential consequences of a positive test: loss of social status, discrimination Dlamini *et al.* (2008:396) supported this and cited Nyblade *et al.* (2002) to the effect that PLHA are ambivalent about disclosing their status. On the one hand, disclosure is seen as being a positive and necessary step; on the other, PLHA are aware of the stigma and abuse directed against persons identified as HIV-positive, and thus find disclosure to be difficult. HIV stigma in Africa has been accepted to be a stumbling block to disclosure of HIV status and this included fear of accusations of unfaithfulness, rejection, discrimination, and violence (Dlamini, *et al.*, 2009:378; Greeff, *et al.*, 2008:316).

The reaction from family and community members following disclosure is mostly **negative**, denying those who disclose parental and family care, believing they are promiscuous, chasing them away from their homes and calling them names, rejecting them, discriminating against them, and being violent towards them (Greeff, *et al.*, 2008:316).

Disclosure can also be **positive**. Family support can help PLHA to develop a sense of responsibility, and therefore changed their thoughts about HIV and their future (Li, *et al.*, 2006:515) and can lead to important social support, that participation in support groups will encourage people to disclose their status because of the sharing of experiences and psychological support they give each other during group therapy meetings (Greeff, *et al.*, 2008:316).

Stigmatisation impacts on various facets of the stigmatized person's life. A major role that stigma plays at a societal level is that it separates people, creating a feeling of superiority in those who are not affected by the stigmatising trait and establishing feeling of shame in or towards the group who is stigmatised (Skinner & Mfecane, 2004)(cited by Naidoo, *et al.*, 2007:18). Disclosure impacts on intimate relationships, leading to separation and divorce, and blaming by the partner (Greeff, *et al.*, 2008:316; Benotsch, *et al.*, 2008:342).

#### **4 STIGMA EXPERIENCES OF AND BY CLOSE FAMILY MEMBERS**

The focus of this study, as mentioned earlier, is on PLHA and specifically their close family members (excluding the partners and children), who are both *stigmatized* due to their association with the PLHA but who might also find themselves in a position of *stigmatizing* the PLHA. HIV- related stigma has an impact on PLHA who suffer from both internal and received stigma, as well as their close family members who suffer from associate stigma.

##### **4.1 Stigma Experiences of PLHA by CFM**

For the stigmatizer, stigma seems to be an effective and natural response, emergent not only as an act of selfpreservation or psychological defence, but also in the existential and moral experience that one is being threatened (Yang, *et al.*, 2007:1528).

Stigmatization by one's family members, at the very time one most needs their support, is often cited as the most hurtful and damaging form of stigma and the form that has the most negative effects on the HIV prevention struggle (Campbell, *et al.*, 2005:810). Judgment from family members can be one of the worst personal struggles for PLHA (Muhomba, 2007:16). Stigmatizing from family members often leaves the infected individuals with existential questions about the meaning of their infection, their behaviour, as it relates to their family relationships (Muhomba, 2007:12). For the *stigmatized*, stigma compounds suffering (Yang, *et al.*, 2007:1528). Feng *et al.* (2009:482) stated that in a Chinese culture the disease is often regarded as punishment of misbehaviour and is a shame to the family, making it extremely difficult to disclose this secret of carrying HIV or AIDS, resulting in feelings of stigmatization, discrimination and isolation of the family (Feng, *et al.*, 2009:487).

##### **4.2 Stigma Experiences of the CFM**

Ogden *et al.* (2005:31) argue that the consequences of HIV and AIDS-related stigma do not begin and end with PLHA, but extend to include families, children, and even friends and caregivers. Family members of PLHA experience many of the same expressions of stigma as

PLHA, including being the subject of gossip, being socially ostracized and isolated, and even losing income, employment, or housing even though they do not have HIV or AIDS (Ogden, *et al.*, 2005:33; Asiedu, 2007:118; Feng, *et al.*, 2009:487). Barnett and Whiteside (2003) (cited by Rotheram-Borus, *et al.*, 2005:979) support this and state that HIV impacts families “first and worst”, and it influences the family’s structure, economic resources, migration patterns and developmental life cycles. Krishna *et al.* (2005:484) found that the family and the community in India are vital aspects of the social structure. Nuclear families continue to maintain links with the extended family and that the extended family in particular is being counted upon as a “national strength” in developing countries. However, as stated by Krishna *et al.* (2005:485) most often the family’s response to the infected individual was heavily influenced by the community perception of the disease and they feared isolation within the community due to their HIV positive member.

Kaleeba *et al.* (2000), Zimmer and Kwong (2003)(cited by Rotheram-Borus, *et al.*, 2005:979) argued that although HIV is found in large cities, many countries, (e.g. Uganda and China) have more HIV-infected persons living in family clusters, within extended family networks, in small rural villages with few formal organizational entry points for interventions. Caring for a family member with HIV and AIDS presents multiple challenges that strain a family’s physical, economic and emotional resources. Results of the above-mentioned studies also imply that as soon as the diagnosis becomes known, spouses, children and family become targets of stigmatization.

As in India, Li *et al.* (2006) (cited by Feng, *et al.*, 2009:482) found that the primary source of support for PLHA in China is their families. However, the honour and dignity of the family are more important than the individual. Effects on the *family* may result in shock, anger and disappointment. Chirwa (2002)(cited by Mathambo, *et al.*, 2009:22) suggests that the extended family network is collapsing under the strain of AIDS. Little is known about how family carers cope with these challenges or about the ways that development impacts on the process of coping (Palattiyil, *et al.*, 2008:881).

#### **4.3 The Impact of HIV Stigma on Family Relationships**

In a qualitative study from China by Li Li (2006) (cited by Mohanan, *et al.*, 2009:7) it was found that support provided by families had multiple levels of **positive impact** on participants. As a result of family support, PLHA made important decisions, such as being tested for HIV and taking medication regularly. The positive impact on PLHA also benefited the family relationship; PLHA regained hopes for their future and valued their families more and had a positive attitude towards life in general. The strength of families and family networks is instrumental in

determining how well individuals and communities are able to cope with the disease and its consequences (Mohanani, 2009:2). Family caregivers perceived that information on the HIV infection and caring for PLHA helped to improve their interpersonal relationships with the PLHA (Feng, *et al.*, 2009:484). Little Family carers provide physical care and financial support and deal with changes in family relationships and roles, often with little support from outside of the family (Palattiyil, *et al.*, 2008:881).

Even though the extended family has traditionally been the "social security system" in Africa, and it is commonly understood that members are responsible for protecting each other, the challenges of the AIDS pandemic have a **negative impact** on relationships and are threatening to "wear down extended families (Foster, 2000:23). The important role of the extended family in African culture can put HIV-positive people at a great risk of experiencing abuse within the family setting, which may influence decisions regarding testing and disclosure (Dlamini, *et al.*, 2008:391).

HIV-positive persons and their families should have the right to competent, compassionate, quality health-care and social services. Article 19 of the UN Declaration of Commitment on HIV/AIDS (UNAIDS, 2001) recognizes this and reiterates that care, support and treatment can contribute to effective prevention through increased acceptance of voluntary and confidential counselling and testing, and by keeping people living with HIV and AIDS and vulnerable groups in close contact with healthcare systems and facilitating their access to information, counselling and preventive supplies (Palattiyil, *et al.*, 2008:885).

## **5 URBAN AND RURAL DIFFERENCES ON HIV STIGMA**

Results of a study done by Naidoo *et al.* (2007:22) on *Urban and rural differences in HIV and AIDS stigma in five African countries*, presented the conclusion that in general, the urban groups described more incidents of stigmatization and discrimination than did the rural groups. It might be argued that urban discussion groups express themselves more fluently and are more confident with researchers; however, the groups in rural areas were as keen to discuss their experiences and seemed as forthcoming in describing incidents. Although their findings contradict the results of some other research (such as the Rural Centre for AIDS/STD Prevention, 1994; Sliep, Poggenpoel & Gmeiner, 2001; Duffy, 2005)(cited by Naidoo, *et al.*, 2007:22); Campbell, *et al.*, 2008:510), who stated that issues of anonymity and confidentiality are major difficulties in rural areas, and that many people avoid seeking help out of fear that they will be suspected of having HIV and so will be stigmatised and ostracized, they argued that such an exploration is important for planning interventions for prevention, treatment and care,

since such programs might need to be specifically structured for an urban or rural population should stigma significantly differ between the two settings.

Campbell *et al.* (2008:510) added that PLHA and care workers, in isolated rural areas in South Africa felt isolated in a community where stigma made people reluctant to disclose their HIV status, often even to the people who care for them, and that both patients and care workers often battle on without emotional support. The report by the Rural Centre for AIDS/STD Prevention (1994)(cited by Naidoo, *et al.*, 2007:20) stated there was a significant difference between the urban and rural groups of PLHA concerning the expressed or reported dimensions of **received stigma**, and is similar to the findings of Duffy (2005) (cited by Naidoo, *et al.*, 2007:22), who reported fear of contagion, isolation and self-stigma in study participants. PLHA in three countries described more incidents of received stigma in rural than in urban settings in the category 'avoiding'.

In South Africa, the PLHA in rural settings more often described incidents fitting the category 'pestering' while PLHA in urban areas more often described incidents of stigma fitting the category 'abusing', and the highest expressed category of received stigma was 'fear of contagion' and stigma category 'abuse' ranked the lowest among both the urban and rural cohorts of nurses and PLHA.

The PLHA in urban settings described much higher levels of received stigma in five categories (i.e. neglecting, fear of contagion, labelling, pestering, and gossiping) than those in rural settings. In general the urban groups described more incidents of stigmatisation and discrimination than did the rural groups. That PLHA in urban areas as compared to rural areas are more active in **self-stigmatization**. Rost *et al.* (1993) found that rural residents labelled people (in this case, with depressive symptoms) more harshly than their urban counterparts, and this was significantly associated with lower utilization of healthcare services.

Based on the results of Naidoo *et al.* (2007:23) they recommend conducting of further research on HIV-related stigma in specific settings, as the data presented here indicate clear differences in character and intensity of stigma between an urban and rural setting.

## 6 INTERVENTIONS FOR HIV-RELATED STIGMA REDUCTION

Research in the field of HIV-related stigma reduction interventions did bring about certain results that can be used in future studies, but was mainly focusing on interventions done with nurses, PLHA, and service providers involving information-based approaches, skills building, counselling approaches and contact with affected groups, intervention of emotional disclosure

information, contact and empowerment behavioural intervention that included role-plays, group discussions, games, HIV advocacy testimony and presentations from a physician specialist in the field of AIDS care. Thus there is an urgent need for the development of an understanding of the causes of stigma to inform stigma reduction interventions (Brown, *et al.*, 2003:53). According to Brown *et al.* (2003:52) only a few stigma-reducing interventions have been done, but most of these interventions are not based on scientific insights on social stigma and stigma reduction, despite the big need to reduce AIDS-related stigma. To date, the majority of stigma-reduction interventions in sub-Saharan Africa have taken the form of information-based awareness programs designed to reduce ignorance about people living with HIV or AIDS (Campbell, *et al.*, 2007:403).

### **6.1 An Overview of Broader HIV Reduction Interventions**

In an earlier study by Brown *et al.* (2003:63) they stated that an information-based programme alone, aimed at increasing tolerance for people living with HIV and AIDS, could not change negative attitudes of people towards HIV or AIDS. This information-based approach was used as a basis for most interventions because in most communities, knowledge about HIV and AIDS issues might still be lacking (Yang, *et al.*, 2006:722). Most stigma intervention programmes utilise the skills acquisition approach to empower people with skills to train PLHA on coping strategies (Ogden & Nyblade, 2005:10). Levels of AIDS-related knowledge are often inversely correlated with stigma (Kalichman, Simbayi, & Cain, *et al.*, 2006) (cited by Campbell, *et al.*, 2007:405) however, providing people with factual information about stigmatised health conditions, does not lead to widespread stigma reduction (Hayes & Vaughan, 2002; Deacon, Stephney & Prosalendis, 2005)(cited by Campbell, *et al.*, 2007:405). Holzemer and Uys (2004:170) have discussed the challenge of developing strategies for healthcare workers to assist in managing HIV-related stigma. They argued that part of the challenge of AIDS stigma is to identify its impact on patients and caregivers alike and to develop strategies for justifying its effects. The investigation of the different cultural meanings of HIV or AIDS and attempts to understand the importance and manifestation of different determinants of HIV or AIDS-related stigma for each context will produce essential information of where the focus of an AIDS stigma intervention lie.

According to Campbell *et al.* (2007:405), psychological studies of stigma have tended to focus on cognitive properties of the conscious rational individual, with little attention to the way in which cognitions are shaped by factors at the unconscious, community and macro-social levels of analysis. Campbell *et al.* (2007:405) presented a six-factor model to address this gap. They provided abstract guidelines that they believe should inform stigma-reduction interventions. Facilitating awareness of the causes and consequences of stigma could serve as one useful

stepping stone for empowering individuals and local communities to start thinking of ways in which they can contribute towards the challenge of creating nurturing social environments.

Brown *et al.* (2003:52-53) reviewed 22 published studies that tested a variety of interventions to decrease AIDS stigma in developed and developing countries and the aim of many of the reviewed interventions was not exclusively aimed at reducing AIDS stigma, but many other components (i.e., increasing awareness and knowledge of HIV/AIDS, promoting behaviour change, etc.) were involved. The studies reviewed were classified into three categories based on the study goals and target population: (a) increased tolerance of PLHA among segments of the general population, (b) increased willingness to treat PLHA among health care providers, and (c) improved coping strategies for dealing with AIDS stigma among those at-risk or already infected with HIV. The study focused on the stigma component within these comprehensive interventions. Results suggest some stigma reduction interventions appear to work, at least on a small scale and in the short term, but many gaps remain especially in relation to scale and duration in impact and in terms of gendered impact of stigma reduction interventions. A follow-up study was done by Uys *et al.* (2009:1059) to explore the results of an HIV stigma intervention in five African health care settings. This group studied a further 15 intervention articles that included articles earlier than 2001 including illnesses such as leprosy and cancer. The intervention of Uys *et al.* (2009:1060) supported the results found by Brown *et al.* (2003) but added two extra categories: increasing contact with the affected group and improving coping through empowerment, leaving out the skills building component that Brown *et al.* (2003) used. The study focused on a two-day project initiation workshop with a group of PLHA and nurses. They were given the task of designing, implementing, and evaluating a project to reduce stigma in their health-care setting within a month, with the support of the facilitators. Most of the participants evaluated the intervention positively and agreed that the intervention increased their understanding and knowledge of HIV stigma and discrimination. There was a significant increase in voluntary testing and it is encouraging that these nurses, who carry a double risk for HIV due to occupational exposure, are taking steps to know their own status (Uys, *et al.*, 2009:1064).

In reviewing the literature on HIV stigma reduction programmes or interventions (Abel, *et al.*, 2003:510-525; Heijnders, *et al.*, 2006:353-363; Bos, *et al.*, 2008:450-460; Sheng, *et al.*, 2008:513-518) it was found that a few HIV stigma-reduction programmes have been developed and implemented, but not one rigorously evaluated. However, several researchers (Mahendra, *et al.*, 2007:616-625; Murphy, *et al.*, 2000:73-88; Pisal, *et al.*, 2007:32-43; Chirwa, *et al.*, 2008:20; Uys, *et al.*, 2009:1065) supported the argument that HIV-related stigma-reduction interventions can be effective. They reiterated that a combination of counselling, education and contact is very important as affected persons must not be expected to carry the burden of

stigmatization alone or that education of the general public and tolerance increasing is enough. Holzemer and Uys (2004)(cited by Holzemer, *et al.*, 2006:543) came to the conclusion that developing strategies is important to help health-care workers to assist in managing HIV-related stigma. In their study in 29 African countries, Benotsch *et al.* (2008:330) argued that given the myths surrounding HIV transmission, especially among rural populations and individuals with poor educational attainment, additional education about AIDS is clearly needed. Although it was not a primary objective of the present investigation, many NGO directors reported taking steps to reduce AIDS-related stigma in their communities, including efforts to make HIV-positive persons more visible and to portray them in a positive light in films and other media presentations. Making HIV-positive persons more visible and inducing sympathy for their plight may be one way to reduce stigma in Africa (Benotsch, *et al.*, 2008:343-344).

## **6.2 HIV-Related Stigma Reduction Interventions Focused on the Family**

In reviewing the literature on HIV-stigma related interventions, little research material was found that included information on interventions with families living with PLHA. Krishna *et al.* (2005:483) aimed to understand the impact of HIV on the family system in an Indian context. Indian families have strong emotional ties and sentiments that connect them together, that include links with the extended family.

In a study done in the Ghanaian context by Asiedu (2007:3), the author found that many intervention programmes and programme content do not consider the stigma family members experience and the influence it has on their relationships with PLHA. Many policy-makers, educators and the members of the society at large are either unaware of or feel helpless in dealing with HIV-related stigma. This is evidenced in the absence of a focused and culturally sensitive plan to fight HIV stigma. It is therefore imperative that HIV and AIDS- related stigma be studied in the context which it is manifested.

A study done by Mohanan *et al.* (2009) on the effect of family support on morbidity, mortality, quality of life, and economics in families with at least one HIV-infected member, in developing countries, came to the conclusion, from this review, that more rigorous studies are required in developing countries before substantive conclusions can be drawn about the effects of family support in reducing morbidity and mortality in HIV-infected persons. A qualitative study by Gaudine *et al.* (2010:1) on HIV-related stigma in Vietnam, including PLHA, family members, and community members and leaders came to the conclusion that HIV-related stigma is experienced in a different manner by each of these groups. No interventions to reduce stigma was done and they stated that this findings should help in developing culturally sensitive strategies to reduce HIV-related stigma.

Reviewing the above mentioned literature the researcher can argue that CFM also experience stigma like the PLHA and that the impact of the process of HIV-related stigma for both the PLHA and close family members could severely influence the relationship between them. The literature review showed no evidence of HIV-related stigma reduction interventions for specifically CFM, therefore the aim of this study is on a HIV-stigma reduction and wellness enhancement intervention focusing on PLHA and their close family members, as they play an important role in the lives of PLHA.

## 7 CONCLUSION

AIDS continues to be a major global health priority. Although important progress has been achieved in preventing new HIV infections and in lowering the annual number of AIDS-related deaths, the number of people living with HIV continues to increase (AIDS Epidemic Update, December 2009:8). PLHA experience stigma and discrimination very strongly and it has enormous negative effects on the psychological well being and social relationships of PLHA (Bos, *et al.*, 2008:450). The impact of HIV-related stigma can influence the relationship that exists within a family and can influence the support and understanding experienced by PLHA from their close family members. The family members might find themselves in a position of being stigmatized due to their association with the PLHA or stigmatizing the PLHA themselves.

Interventions to reduce AIDS-related stigma need a good theoretical understanding of the *change processes* that may lead to stigma reduction, thus not only to change individual behaviour, but to facilitate programme flow (Arjan, *et al.*, 2008:452). It is now generally accepted that efforts to reduce stigma should be an integrated part of all HIV and AIDS programming (Campbell, *et al.*, 2005:808). Consideration of the practical engagements of preserving what matters most can greatly enliven our understanding of how stigma pervades the life worlds of the stigmatized (Yang, *et al.*, 2007:1534).

Based on such results, Naidoo *et al.* (2007:23) recommended conducting further research on HIV-related stigma in specific settings, as the data presented here indicate clear differences in character and intensity of stigma between an urban and rural setting. A community-based HIV-stigma reduction and wellness enhancement intervention in urban and rural settings could contribute to a process that enhances an understanding of the stigma process by PLHA and CFM, enhance their wellness and empower them to become leaders in stigma reduction on a community level. Based on an intensive and comprehensive literature study the following article is presented: A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and a close family member

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**ARTICLE:**  
**A COMMUNITY-BASED HIV STIGMA REDUCTION AND WELLNESS  
ENHANCEMENT INTERVENTION FOR PEOPLE LIVING WITH HIV AND A CLOSE  
FAMILY MEMBER**

Submitted to: The Journal of the Association of Nurses in AIDS Care

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## **A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and a close family member**

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### **Declaration of Conflicting Interests**

The author(s) report(s) 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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**Key words:** AIDS; Close family member; Community-based; HIV; Intervention; Stigma

## **ABSTRACT**

People living with HIV or AIDS (PLHA) as well as their close family members (CFM) are stigmatized. CFM, however, also stigmatizes. The aim of this study was to evaluate the effect of a comprehensive community-based HIV stigma reduction intervention on PLHA and their CFM as well as to explore and describe their experiences during and after the intervention. A holistic multiple case study design, as well as a qualitative interpretive description approach through in-depth interviewing, was used in both an urban and a rural setting. Purposive sampling was used for the PLHA and snowball sampling for the CFM. Data was analysed using open coding and text document analysis. Both groups gained a richer understanding of HIV stigma and coping with it, and relationships were enriched. Leadership was activated through the project. Recommendations focused on the inclusion of HIV stigma reduction interventions in the educational programs of nurses and traditional healers, presenting these programmes and support groups at the health clinic and community levels, as well as possibilities for further research.

## 1 INTRODUCTION AND PROBLEM STATEMENT

This study was part of a bigger comprehensive community-based HIV stigma reduction and wellness enhancement intervention study. The focus of this study was on people living with HIV or AIDS (PLHA) and their close family members (CFM). CFM refers to a member who is part of the biological family but the concept excludes the husband/wife or children of the PLHA.

To focus on a better understanding of HIV stigma, definitions by several authors were studied. One of the oldest definitions of stigma is that of Goffman (1963)(cited by Greeff, *et al.*, 2008) who defined stigma as an attribute that is deeply discrediting within a particular social interaction. Alonzo and Reynolds (1995:310) adapted the definition of Goffman (1963), and expanded the definition as “a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people”. Other authors refer to additional aspects of stigma: “stigma attached to AIDS as an illness, is layered upon preexisting stigma” (Herek & Glunt (1988) (cited by the Population Council, 1999:2); “a social identity that is devalued in a particular social context”(Crocker, *et al.*, 1998:505); “attribute and a stereotype” (Jones, *et al.*, (1984)(cited by Crocker, *et al.*, 1998:505); “a collective social process rather than a mere reflection of an individual’s subjective behavior” (ICRW, 2001; Population Council, 2002; UNAIDS, 2002a). Parker and Aggleton (2003) oppose the idea that stigma is a static individual characteristic, and argue in favour of stigma as a social process. Deacon *et al.* (2005) refer to stigma as a “mark” and negative social ‘baggage’. After a careful review of all the discussions around stigma definitions, the researcher came to the conclusion that stigma is more easily understood as a social process (ICRW 2001; Population Council, 2002; UNAIDS, 2002a) which plays a key role in producing and reproducing relations of power and control in social systems.

Being diagnosed with HIV or AIDS remains a life-changing event that requires people to deal with the disease and its associated stigma and isolation (Abel, *et al.*, 2004). In the African setting, HIV stigma remains a powerful barrier to people living with HIV or AIDS as it inhibits testing and disclosure of HIV status, which would in most cases be accompanied by fear, *i.e.* fear of accusations of unfaithfulness, rejection, discrimination, and violence (Dlamini, *et al.*, 2009). Uys *et al.* (2009) found that HIV stigma is a problem for Africa and that it was more intense and more frequent in certain countries and settings than in others and that it remained a serious problem to PLHA and people associated with them. Phaladze *et al.* ( 2005)(cited by Makoe, *et al.*, 2009) found that in sub-Saharan Africa, stigma and discrimination have had a considerable influence on PLHA. However, according to Aggleton and Parker (2002) (cited by Holzemer, *et al.*, 2004), the real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends. Judgment from family members can be one of the worst personal struggles to PLHA (Muhomba, 2007), and often leaves the infected individuals with existential questions about the meaning of their infection,

their behaviour, as well as their HIV-positive status as it relates to their family relationships (Muhomba, 2007). Results of the studies by Ogden *et al.* (2005) and Holzemer *et al.* (2007), however, imply that as soon as the diagnosis becomes known, spouses, children and family also become targets of stigmatization. Ming-Chu *et al.* (2009) mention that family members of PLHA experience many of the same expressions of stigma as PLHA. The mentioned problematic intervention becomes even more problematic if the importance of the role of the family in support within the African context is compromised (Greeff, *et al.*, 2008). Greeff *et al.* (2008) reported that the family is the first the PLHA discloses to.

Rural and urban communities differ in their social structure and the experiences of individuals living in those settings. If urban and rural societies differ, Naidoo *et al.* (2007) question whether or not HIV stigma manifests differently between the two settings. In a study done in five African countries on urban and rural differences on HIV and AIDS stigma, Naidoo *et al.* (2007), suggest that stigma in all forms is applied more often in urban areas than in rural areas. They argue that there is a clear difference in character and intensity of stigma. Their findings contradict the results of some other authors (the Rural Center for AIDS/STD Prevention, 1994; Sliep, Poggenpoel & Gmeiner, 2001; Duffy, 2005) (cited by Naidoo, *et al.*, 2007), which found HIV-related stigma to occur more frequently in rural areas.

The literature on interventions to reduce HIV stigma related to family showed no evidence of HIV-related stigma reduction interventions for specifically CFM. Krishna *et al.* (2005), focused on the impact of HIV on the family system in an Indian context. Asiedu (2007) found that many intervention programmes in the Ghanaian context did not consider the stigma family members experience and the influence it has on their relationships with PLHA. Mohanan *et al.* (2009) looked at the effect of family support, and concluded that more rigorous studies are required in developing countries before substantive conclusions can be drawn about the effects of family support in reducing morbidity and mortality in HIV-infected persons. Gaudine *et al.* (2010) focused on HIV-related stigma in Vietnam, including PLHA, family members, and community members and leaders, and came to the conclusion that HIV-related stigma is experienced in a different way by each of these groups. No interventions to reduce stigma were found in the literature.

Reviewing the above-mentioned literature the researcher argues that both PLHA and CFM experience stigma, and that the CFM stigmatizes PLHA. This severely influences the relationship between them. This disturbed relationship is problematic within the African context, where the CFM plays an important role. It was also not clear whether stigma is highest in urban or rural communities. The literature review showed no evidence of available HIV-related stigma reduction interventions with PLHA and CFM. The researcher questioned whether a community-based HIV stigma-reduction and wellness enhancement intervention would reduce stigma in PLHA and CFM and whether it differs between an urban and a rural setting.

## 2 RESEARCH OBJECTIVES

- To evaluate the effect of a community-based HIV-stigma reduction and wellness enhancement intervention on PLHA and a CFM through a case study method in both an urban and a rural setting in the North West Province.
- To explore and describe the experiences of PLHA and a CFM during and after a community-based HIV stigma reduction and wellness enhancement intervention through a qualitative interpretive description approach in both an urban and a rural setting in the North West Province.

## 3 LITERATURE REVIEW OF INTERVENTIONS OF PEOPLE LIVING WITH HIV AND A CLOSE FAMILY MEMBER

HIV is a leading cause of death worldwide and the number one cause of death in Africa (Asiedu, 2007). South Africa is experiencing the largest HIV and AIDS epidemic in the world (Forsyth, *et al.*, 2008; Nicolay, 2008; UNAIDS/WHO, 2008). Forsyth *et al.* (2008) found in their study that in the South African context, addressing AIDS-related stigma has become all the more urgent given the almost unmanageable scale of the epidemic. Abdool *et al.* (2005), and Connolly *et al.* (2004) found that 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. For persons living with HIV or AIDS, stigma is one of the most insidious barriers affecting access to and provision of health services, particularly in Southern Africa and also in India (AIDS Alert, 2002). Greeff *et al.* (2007) found that the extent of the impact of HIV and AIDS-related stigma turned out to be far worse than ever and supported the prediction. Wingood *et al.* (2008) state that ignorance about HIV transmission, fear of those living with HIV, and lack of access to and understanding of treatment are at the very core of HIV stigma. Studies by Phaladze *et al.* (2005)(cited by Aggleton, *et al.*, 2005; Adewuye, *et al.*, 2009) found that AIDS stigma and discrimination have considerable influence in terms of PLHA, particularly in sub-Saharan Africa, where the burden of AIDS is so significant. Stigma is deeply rooted, operating within the values of everyday life and intense stigma may be traumatic.

The concept of stigma has received significant attention in recent years in the HIV and AIDS literature (Greeff, *et al.*, 2008). Several conceptual frameworks for understanding HIV stigma and its effects have been proposed. These frameworks pose the idea that the fear of being identified with HIV prevents people from learning their serostatus, changing unsafe behaviours, and caring for people living with HIV (Wingood, *et al.*, 2008). Parker and Aggleton (2003) offered a theoretical framework for understanding HIV and AIDS stigma, and propose a framework of social inequality as a strategy to understand stigma, taking contextual factors, such as culture and its impact on power relationships, into consideration. The study of Deacon *et al.* (2005) focuses on social theories of stigma as a problem of fear and blame rather than as a problem of ignorance or a mechanism of social control. Campbell *et al.* (2005) proposed a

framework of the contexts in which stigma occurs: the economic, political, and local community contexts, and the organizational context of institutions working to address HIV and AIDS. Campbell *et al.* (2007) supported this view and came to the conclusion that there is an urgent need for more nuanced models of stigma which take greater account of its complex and multi-level nature. The ecological model of human development by Bronfenbrenner (2007)(cited by Asiedu, 2007) is important in looking at the impacts of HIV and its related stigma on family members of PLHA. It emphasizes that HIV and AIDS stigma and discrimination are not an individual problem, but a familial and societal one. Mak *et al.* (2007) proposed a social cognitive framework to study the effect of self-stigma on psychological distress. The researchers found that the self-stigma of PLHA negatively impacts on their psychological well-being and by reducing the extent of self-stigmatization, PLHA's social relationships and long-term adjustment can be sustained (Mak, *et al.*, 2007).

Holzemer *et al.* (2007) proposed a conceptual model of HIV and AIDS stigma, taking the African context into consideration. This model forms the theoretical grounding of the present study. The model conceptualized stigma as a very specific process occurring within a context of three contextual factors: environment, health-care systems and different agents. The process begins with a trigger, for example a positive HIV test; and progresses to stigmatizing behaviour such as avoiding and labelling, that leads to three types of stigma (received, internal and associated) leading in turn to outcomes such as violence and abuse of poor quality of life.

Various authors have described different types of stigma but for the purpose of this study the three types of stigma described by Holzemer *et al.* (2007) will be used to structure the discussion, and descriptions by various authors included. Received stigma, according to Holzemer *et al.* (2007) is a type of stigmatizing behaviour towards PLHA as experienced or described by themselves or others. Received stigma is similar to external or enacted stigma described by the Siyam'kela research project (2003) or to etic or outsiders' view of Weiss *et al.* (1992)(cited by Greeff, *et al.*, 2008). The second type of HIV stigma namely internal stigma refers to stigma as thoughts and behaviours stemming from the person's own negative perception about them based on their HIV status (Holzemer, *et al.*, 2007). The Siyam'kela study (2003) identified indicators for personal stigma as internal or felt stigma which might lead to unwillingness to seek help and access resources. The last type of stigma identified by the Holzemer group (2007) defined associated stigma as incidents that describe stigma against people who work with (health care workers) or associate with HIV and AIDS-affected people (e.g. spouse/partner, children, family, and friends) (Greeff, *et al.*, 2007). Ogden *et al.* (2005) support the view of stigma by association but refer to it as secondary stigma.

In reviewing the literature on HIV stigma reduction programmes or interventions (Abel, *et al.*, 2003; Brown, *et al.*, 2003; Ogden & Nyblade, 2005; Heijnders, *et al.*, 2006; Campbell, *et al.*, 2007; Hayes and Vaughan, 2002; Deacon, Stephney & Prosalendis, 2005, cited by Campbell,

*et al.*, 2007; Bos, *et al.*, 2007; Sheng, *et al.*, 2008), it was found that few HIV stigma-reduction programmes have been developed and implemented, and that most of these stigma interventions are not based upon scientific insights on social stigma and stigma reduction, despite the big need to reduce AIDS-related stigma. However, several researchers (Mahendra, *et al.*, 2007; Murphy, *et al.*, 2000; Pisal, *et al.*, 2007; Chirwa, *et al.*, 2008) support the argument that HIV-related stigma reduction interventions can be effective. Brown *et al.* (2003) reviewed 22 published studies that tested a variety of interventions to decrease AIDS stigma in developed and developing countries. Studies reviewed were classified into three categories based on the study goals and target population: (a) increased tolerance of PLHA, (b) increase willingness to treat PLHA among health care providers, and (c) improved coping strategies for dealing with AIDS stigma among those at-risk or already infected with HIV. A further study was done by Uys *et al.* (2009) to explore the possibility of an HIV stigma intervention in health-care settings. Their finding about interventions was similar to the study of Brown *et al.* (2003) but added extra categories: increasing contact with the affected group sharing information on HIV stigma and improving coping through empowerment. As indicated earlier, the review of literature on HIV-stigma related interventions with CFM, shows limited evidence.

## 4 RESEARCH METHODOLOGY

### 4.1 Research Design

The design of the study was qualitative in nature using both the holistic multiple case study design (Yin, 2009:59) and interpretive description approach (Thorne, 2009).

### 4.2 Research Method

This research was conducted in two phases.

**4.2.1 PHASE 1: A holistic multiple case study of the community-based HIV stigma reduction and wellness enhancement intervention. *Sample.*** The researcher appointed a research assistant who acted as a mediator to identify potential PLHA who would attend the intervention. The population consisted of two groups namely PLHA and CFM in both the greater Potchefstroom urban and Ganyesa rural districts of the North West Province, South Africa. For PLHA purposive voluntary sampling (Burns, *et al.*, 2009) was used. Inclusion criteria were: participants had to be older than 25 years and could be male or female; diagnosed with HIV for at least six months; able to communicate freely; be prepared to disclose his/her HIV status; and willing to be interviewed and recorded. The final sample size was 10 (1 male, 9 females) for the urban group, and 8 (3 males, 5 females) for the rural group (n=18).

The CFM was identified through snowball sampling (Burns, *et al.*, 2009:356; Rossouw, 2005). Each of the mentioned PLHA, was requested to bring one CFM, should they feel comfortable to do so. The following inclusion criteria were used: had to be part of the extended family; older than 18 years; able to communicate freely and express himself/herself; and willing

to be interviewed and recorded. Not all PLHA brought a CFM. Two (2) females were included from the urban group, and 5 (1 male, 4 females) from the rural group (n=7).

**Data collection.** The researcher had entry into the community through previous studies, as well as through other Non-Governmental Organisations (NGOs). Ethical approval for this study was gained from the research committee of the School of Nursing Science, and the Ethics Committee of the North-West University. The case study method was used to record the community-based HIV stigma reduction and wellness enhancement intervention with both PLHA and their CFM. A three-day community-based HIV stigma reduction and wellness enhancement intervention was presented to a group of urban and rural PLHA and CFM. The underlying tenets of the intervention were to increase knowledge about HIV stigma and coping; to equalize the relationship between PLHA and CFM; and to empower both groups to become leaders in HIV stigma reduction. Two (2) facilitators, a non-infected person and an infected person, were trained to present the workshop. The workshop was presented by means of focused presentations, followed by activity-based group discussions. The focus on the first day was on understanding HIV stigma and coping with it. The second day focused on building a bridge between the knowledge and understanding they have gained and how to use this constructively in a visible HIV stigma reduction and wellness enhancement community project with others in the community, after being trained in project planning. The project was executed over a one-month period, and followed up by a third day, where the participants had the opportunity to give feedback of their community project and be evaluated on the success of their project.

Various sources of evidence were included in the case record: manuals and presentations, naïve sketches of participants that were gathered at the end of each day of the intervention (included two sentences: “*I experienced this first/ second/ third day of the workshop as ....*” and “*I feel ....*”), field notes done by the researcher, as well as a detailed description of the two projects and evaluation of those project.

**Data analysis.** Data analysis was done through open coding (Tesch, 1990), as discussed by Creswell (2009), as well as text document analysis for pattern-matching, logical models, time-series analysis and cross-case synthesis (Yin, 2009).

**4.2.2 Phase 2: A qualitative interpretive description of the experiences of PLHA and their CFM during and after the community-based HIV stigma reduction and wellness enhancement intervention.** This phase was conducted during and after the community-based HIV stigma reduction and wellness enhancement intervention in both the selected urban and a rural setting in the North West Province by means of in-depth interviews.

**Sample.** The sample in this phase consisted of the same two groups described in phase one.

**Data collection.** Open-ended questions were formulated and reviewed beforehand with experts in the field as well as pilot-tested. The PLHA were asked: How did you experience the workshop and project with CFM and others in the group? The CFM were asked: How did you experience the workshop and project with the PLHA and others in the group? Privacy and safety were ensured during interviews. They were informed that the researcher would make use of digital tape recordings. Communication techniques as described by Okun (1992:70-71) were utilized, and field notes recorded, focusing on methodological, theoretical and personal notes (Polit, *et al.*, 2008:406-7).

**Data analysis.** The open coding process of Tesch (1990), as discussed by Creswell, (2009) was followed. The researcher got a sense of the whole, listed the topics as codes and turned them into categories and themes. An independent co-coder was used. Consensus conversations took place about the analysed data.

#### **4.3 Ethical aspects**

Ethical aspects were observed throughout this study (Burns, *et al.*, 2009). Participants gave informed consent after being given background information about the study, and told they could withdraw at any time (Brink, 2007). They were informed about the use of digital tapes and that confidentiality, anonymity and privacy would be maintained throughout the process. The participants were each given a code and the data stored in a safe place, to keep for five years.

#### **4.4 Trustworthiness**

To ensure trustworthiness in this study, the researcher used Lincoln and Guba's model, (cited by Botma, *et al.*, 2010). Truth value was ensured through prolonged engagement, during in-depth-interviews, regularly using reflectivity and discussions with study leaders. Triangulation of methods, resources and investigations was done. Purposive and snowball sampling and a dense description of the research methodology made applicability possible. Consistency was ensured through an audit trail and using an independent co-coder during data analysis. The audit trail and reflexivity led to neutrality.

## **5 RESULTS OF THE STUDY**

The results of the study focus on the case study of the intervention and the findings of the in-depth-interviews. Although no significant differences were found among the rural and urban settings, special mention is made in the discussion where it differs. Findings are enriched by quotes, and reference made to applicable literature.

### **Results of Phase 1: The Holistic Multiple Case Study**

The intervention is presented in a rich description of the analysed case record of the various sources.

**Day one of the intervention.** The purpose of the first day was to get PLHA and CFM to understand HIV stigma and how to cope with it, as well as building on and improving the relationship by equalizing this relationship. Participants shared stigmatizing experiences, or what they have seen happening to others. Time was spent teaching them various ways to respond to HIV stigma.

From the naïve sketches of the PLHA it was found that they now had a much better understanding of HIV stigma: “Now I am in the lightness, before I was in the darkness.” The PLHA also came to understand that not only they, but CFM also experience the pain of stigma and realized how difficult it is for a family when someone is HIV positive: “I am sad that my mother can’t be here to learn about stigma...” and “.. how difficult it is in the family when someone has HIV”. It was such a relief for PLHA that they could experience sharing their pain within the group and got support from both other PLHA and CFM that were in the group: “We didn’t judge each other, and there was openness”; “I feel happy and like the way my people are supporting me”. They were very happy and grateful to be in the workshop, sharing emotions and experiences: “ .. was grateful to be part of this workshop and thank God who gave me the strength to talk about my status”. They felt empowered to cope with stigmatization and felt stronger to disclose in future: “... how to deal with stigma and how to talk about it.” and “ It opened my mind”.

The CFM similarly verbalized a better understanding of HIV stigma and how to cope with it: “I learned about how to change from where I was, to love each other”. Participants of the rural group experienced fear and shock during the first day of the workshop but at the end of the day became confident and happy: “During the first day I was shocked and afraid ... for the second day I talked to myself and became free and open”. The experiences of the workshop changed their minds and they realized how painful stigmatization is to PLHA, and wanted to be more supportive: “Stop undermining PLHA”; “We should be loving and caring toward them”.

**Day two of the intervention.** The second day of the intervention focused on building a bridge between the knowledge and understanding they had gained about HIV stigma and coping and how to use this constructively in a visible HIV stigma reduction and wellness enhancement community project with other CFM through activating their own leadership in social change.

PLHA experienced the planning of the project during day two as difficult but challenging and exciting: “It is difficult to plan a project and to be committed to something, but I think I am going to do it”. They felt proud of their ability to plan a project in the community: “It lifted the spirit of commitment and participation ... as a team we can plan to act for change in our environment, not to be afraid of the challenges”. They felt motivated and empowered to go out in the community and be leaders within the community they live in: “I learned how to be a leader, feel happy and educated”. They also mentioned feeling brave and strong and able to

stand up and go and teach the community how to reduce stigma and challenge them to make the change: “I can stand up and disclose ...” and “... encourage the people to go to the family living with PLHA and talk to them, don’t stigmatize ... we need our family to take care of us ..”. Sadly one of the PLHA from the rural group experienced so much pain that she felt out of place and decided to leave the workshop and not to be part of the project anymore “.. I experienced nothing because my heart was broken and felt out of place, I don’t believe I will come back again”.

During day two of the workshop, CFM also experienced difficulty in understanding what the project was about at first: “ ... at first I was a little bit confused but at last I have a green light”. They got excited about the project as the day progressed and felt motivated and committed: “... it gives us the responsibility to be a leader in the community”. In planning the project CFM experienced the importance of teamwork “... now as a team we can plan to act for a change in our environment..”. They felt less paralysed and wanted to make a change: “... I can do everything without fear ... not to sit around doing nothing but to go out and truly help people in need and support”. The rural group experienced feelings of power and success in the planning of the project, and the knowledge gained from the workshop made them excited to share this information with the community: “I have power and knowledge to form a project and I can teach people about stigma ... I’m so excited and happy”. CFM verbalized that while planning the project they were again reminded about the pain PLHA experience when stigmatized, and that they now feel happy to know now how to support PLHA and their family members: “... it makes me see the light about other people’s feelings when being called names, I did not know how it feels to be stigmatized ..”

***The two projects done by the urban and rural groups.*** The project of the urban group involved an afternoon event in one of the CFM’s house, targeting CFM in a close intimate context. The afternoon involved a discussion on HIV stigma and coping with stigma as well as serving tea and cake. 13 People attended, and it allowed for intimate discussions.

The project of the rural group was aimed at creating a psycho-drama about HIV stigma and how to cope with it, and then to perform this to community members. They arranged two events that reached 127 people. The events took place at the tribal hall and the Methodist church. The psycho-drama caught the interest of the community and escalated through invitation to several other community activities as well as the health care centre.

**Day three of the intervention.** The focus of day three was a report back on the execution of the project and for the project to be evaluated by the facilitators of the study and important stakeholders from the community. The process in the urban setting was only partly successful as there was no commitment from the CFM. The PLHA had to take over and ensure that the project took place. PLHA thus described the project as difficult and there was disappointment that the CFM did not do what they initially planned: “... the project broke into

two pieces”; “The people that we invited disappoint us”. The PLHA realized that for a project to be successful people had to be honest, truthful and committed: “The difficulties that we had before the project made me realize that you must be honest, truthful and don’t let go”. The PLHA driving the project felt happy, strong and motivated to do the project and felt proud that they could educate those that were present. “ ... educated and to be more strong .. to teach people and to make them aware about the disease and to learn how to disclose”. The workshop has empowered them to be leaders in the community: “I feel that I am a leader and wish that people can realize how dangerous it is to be in darkness not knowing your status”. There were good communication and teamwork between the three PLHA and CFM that were involved in the project. PLHA from the rural group felt excited, proud and happy about the project: “I didn’t realize I can be a leader for change, but here I am”. They felt strong and that they would be successful in the future as well: “I feel happy and strong ... we are going forward now ... we are going to be the light of the community“. They felt honored to be part of the project: “I’m so honoured and excited ...”. The group worked hard, performed well and the attendance was very good. People of the community that attended the play encouraged them to continue with it. This experience made one of the PLHA strong to stand up and disclose: “I can stand up and disclose ...”.

The two remaining CFM from the urban group felt: “Proud of the project we are doing ... to know about stigma, to love one another not, to discriminate other people”. The CFM from the rural group were also proud to be part of the project and experienced a positive outcome of the project as it helped them to come closer to the people and to teach them about HIV and stigma: “ ... presenting the show to the people so that they have learned more about stigmatizing people ..”. They experienced the project as something that changed and enriched their lives, to be able to educate: “ ... It has educated me. I can share in front of people tell them about stigma ...”. The whole experience gave them courage to go for testing: “I feel comfortable and I feel that I can volunteer to get a test now”. One of the CFM in the rural group felt proud of himself as he realized that he could be a leader: “I didn’t realize I can be a leader for change, but here I am. The support he received lifted his spirit, and he promised to continue with the play to the best of his ability: “When you stand up and decide to do something there is support out there which lifts you up to the sky”. The rural group was awarded the prize for the best rural project and successfully initiated an HIV stigma reduction Non-Governmental Organization (NGO) plan.

## **Results of Phase 2**

The in-depth-interviews with PLHA and CFM after the intervention were intended to obtain a deeper understanding of their experiences during the workshop and while conducting the project. Findings from the in-depth-interviews identified four main themes for PLHA: Initial fear to attend the workshop changed to support in the group; Gained knowledge about HIV stigma and how to cope with it; became aware of the painful experiences of HIV stigma; and

being part of the project was meaningful yet difficult. Five themes were identified for CFM: Initial reluctance to join the group turned meaningful; The workshop changed the attitudes of CFM; Awareness of the painful experiences created by health care services; The knowledge gained empowered CFM as leaders; and conducting the project was meaningful yet difficult. The experiences of the urban and rural group showed no real differences. Where differences were noted special mention will be made of it.

**Findings for the PLHA . Theme one: Initial fear to attend the workshop changed to support in the group.** The PLHA from the urban group verbalized feelings of loneliness and were initially scared to attend the workshop: ‘I was so scared ... felt lonely’. The PLHA from the rural group realized the importance of disclosure and what big role stigma played preventing them from disclosure: “... it was due to the fact that I realized that stigma was denying us the ability to disclose and then I understood that stigma must be reduced and that is where I gained my freedom”. Both urban and rural PLHA realized that non-disclosure could lead to isolation and stress: “... stress will catch up with you and you get sick ..”. Holzemer *et al.* (2007) confirmed this by outlining that social exclusion, rejection, high stress due to stigma and economic pressures may lead to stress-related mental illness.

They experienced the workshop as a safe and supportive environment for disclosure, without discrimination, rejection and value judgments: ‘We didn’t judge each other, and there was openness ... it felt like a blanket that keeps you warm ... sharing the same problem ...’. Leaving this safe environment to go back home was experienced as stressful: “I felt there was no pain, and if I go home I feel the pain again”. Both groups felt the initial feelings of fear changed to pride and happiness to be part of the group “... made me feel comfortable and strong to tell them..”. PLHA felt part of the group as they met new friends and learned that people are brave and are coping with stigma: “... people are brave ... can fight the stigma ... they don’t give up ...”.

The workshop encouraged a positive self-image among the PLHA: “I’m still strong to do more things ... it helped me to accept myself and understand myself better”. Uys *et al.* (2009) confirmed this in their study, stating that PLHA involved in their intervention reported an increased self-esteem. During the workshop PLHA from both groups learned that although they are HIV positive they are not different or less important than others: “HIV, they are still a person like anybody”, and that there are also others that are HIV positive: “I tell myself it isn’t only me that is HIV positive”. PLHA received a message of hope that made them feel strong and accepting themselves when they realized that they can still have a long and meaningful live: “... got hope in that sense you feel you accepted yourself and you can live long with this disease“. Greeff *et al.* (2008) confirmed that interaction in a group of other infected people or when another infected person disclosed his or her status tended to give PLHA more courage to disclose their status than when alone in this situation and Tshabalala (2008) confirmed that in

some African communities people were more fearful of the social consequences of AIDS than of the disease itself.

**Theme 2: Knowledge gained about HIV stigma and how to cope with it.** Both urban and rural groups verbalized similar experiences and indicated that they were not familiar with the word “stigma”: “It was my first time I hear the word stigma... I knew nothing about it, I was clueless . until the workshop”. During the workshop they became familiar with what stigma is. “They explained what HIV was and I got to understand ... I was stigmatized”; “Before the workshop people in families were dying because they did not know what HIV and AIDS were”. Uys *et al.* (2009) confirmed that an intervention increased the understanding and knowledge of HIV stigma and discrimination. Asiedu (2007) confirmed that insufficient knowledge about HIV-related stigma has been known to trigger stigma. Ogden *et al.* (2005) and Holzemer *et al.* (2007) confirmed that as soon as the diagnosis becomes known, PLHA and their family also become targets of stigmatization.

This was a learning experience for PLHA as they learned that stigma happens in different contexts: “ ... at the clinic, hospital and the community ...”, that stigma is discriminating against PLHA and that it is used as a social weapon: “Stigma is a powerful weapon ... a social weapon to hurt others ..”, and that stigma comes in different ways: “ ... a sign, gossiping or labelling other persons”. Aggleton *et al.* (2005) and Holzemer *et al.* (2007) confirmed that AIDS-related discrimination may occur at various levels, namely family and community settings, as well as institutional settings.

Both groups experienced the workshop as positive as it helped PLHA to understand and cope with stigma, and empowered them to talk with confidence to the community and share the information on HIV stigma: “... feel that what I learned here, give us power to share with other people in the community”. Greeff *et al.* (2008) confirmed in their study that knowledge of HIV made the PLHA feel more worthwhile because disclosing had some meaning.

**Theme three: Became aware of the painful experiences of HIV stigma.** PLHA from both the urban and rural groups verbalized severe experiences of stigmatization, trauma and neglect by family: “I was feeling very, very sad and lonely, my family doesn’t accept me because I’m HIV positive ... I was very ill and my family didn’t take care of me ... my sister used to beat me ..”. Before the workshop one participant was afraid to communicate with anybody and was staying in the room: “I was afraid of people knowing ... I was afraid to talk to them outside and sitting with them”.

Sharing stigma experiences during the interventions confirmed findings in the literature of severe stigmatization, trauma and neglect by family (Herek, 1999; Greeff, *et al.*, 2007; Holzemer, *et al.*, 2007) especially in the African culture where PLHA are at a great risk of experiencing abuse within the family setting and specific the extended family (Dlamini, *et al.*, 2007).

The workshop, however, gave them hope and helped them to accept and understand their illness: “It has helped me to accept myself and understand myself better ... after the workshop I feel so strong and happy and I know HIV is not the sickness of my body so I learnt how to know myself and how to cope with me”. Mohanan, (2009) confirmed that family support has a positive impact on PLHA and also benefited family relationships. PLHA regained hope for their future and valued their families more and had a positive attitude towards life in general. Bell *et al.* (2007) confirmed that knowledge about their health problems and rights can put PLHA in a much stronger position for accessing needed health care.

**Theme four: Being part of the project was meaningful yet difficult.** PLHA from both groups, experienced pride to be part of the project and a group that supported each other :..”... felt proud to be part of the project ... I felt so proud”. They were happy to talk to the community about HIV and stigma: “... talking freely with people about the sickness, I've been happy”. PLHA from the rural group, expressed hope and strength while doing the project: “I have hope ... I was able to teach people and I gained strength to disclose in front of people”.

They were excited to see change in the way people see HIV and stigma and PLHA accepting themselves as HIV positive: “We are bringing change, change in the way people see those with HIV, as well as change in people accepting themselves”. However, during the project, the rural group experienced that people still stigmatize, but that people from the community came forward to join them in the project: “Here in our village there's a lot of stigma ... but after this project they have become less ... people are willing to join us on our project”. They also verbalized feelings of disappointment when people in the community showed their willingness to come, but did not attend in the end: “ ... another one didn't want to hear about HIV”. PLHA from the urban group enjoyed the project, although it was at times very painful remembering those who were lost without this knowledge: “... enjoyable, was very painful, thinking about all those God had called back to Him ... they also be able to get help just like us”.

**Findings for the CFM. Theme one: Initial reluctance to join the group turned meaningful.** CFM from the rural group indicated that they were nervous and did not understand why they were grouped together with PLHA: “I was very nervous and I didn't understand why I as a person without HIV had to be grouped together with people who were”. It was painful for both urban and rural CFM to realize that they were stigmatizing PLHA because of a lack of knowledge: “... lack of information actually leads people to stigmatize other people. ... it was painful to realize that I was stigmatizing ... and what stigmatizing did to other people .. I have hurt people with my words”. Campbell *et al.* (2005) confirmed that stigmatization by one's family members, at the very time one most needs their support, is often cited as the most hurtful and damaging form of stigma.

Being HIV negative, one of the participants was very disturbed hearing about stigma and the pain it causes: “I'm very disturbed ... because I don't know maybe someday I will be one of

those people and that is why some people refuse to go get treatment". The group in general identified the notion that being in this workshop and project was a positive experience: "I have confidence of standing in front of people teaching, we got information from the workshop and deliver it to the community ... ". They experienced it as a new learning experience: "I learnt so many things and it made me feel good". The exposure to other people, helped them to feel good and part of the lives of PLHA: "... so fortunate to be in such a project ... coming together and forming a group with people who were HIV positive and those who were negative giving each other ideas and going to tell others about stigma ..".

**Theme two: The workshop changed the attitudes of CFM.** The workshop helped CFM to understand that PLHA are afraid to disclose because of the pain it can cause. A CFM in the urban group discovered that although her child was HIV positive she should support her: "I discovered also myself that I can stay with my child even if she has the HIV ... I shouldn't stigmatize her". The experience of the workshop opened the eyes of CFM, and changed their attitude towards PLHA: "I am no longer going to stigmatize people ... in the past I did not have the knowledge but now I have it". They also expressed the idea that the workshop and the project changed their own lives: "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".

**Theme three: Awareness of the painful experiences of HIV stigma created by health care services.** This is a unique experience mentioned only by the rural group. The CFM became aware of the HIV stigma caused by health-care services. They mentioned how PLHA are stigmatized by giving them files in the health clinics that have a different colour: "Their files are separate, the colour is not the same as others ...". The colour coded files lead to gossiping and discrimination, with PLHA refusing to go to the clinics: "People refuse to go get treatment because of this discrimination ... look at her she is here for her treatment she has a black file". Muhomba, (2007) confirmed that stigma stimulates people to act in ways that directly harm others, for example discrimination and isolation.

The break in confidentiality and privacy by health-care workers, was also an issue in the rural group, and they argued that this made people afraid to go to the clinics to test: "In the government department you cannot see anyone there but the community people and I'm not 100 percent sure about the privacy at the hospital there ..". They mentioned that also the counsellors could not be trusted: "People giving counselling talk behind our backs". People are thus afraid to test: "... because they know that as soon as they get tested someone will be talking about them". Holzemer *et al.* (2007) confirm this as informants in their study reported health-care workers as a source of stigmatization. Bell *et al.* (2007), and Greeff *et al.*(2008) confirmed that stigma and discrimination by health care providers are still widespread and can be life-threatening for PLHA.

**Theme four: The knowledge gained empowered CFM as leaders.** Both the urban and rural CFM indicated that they were not familiar with the word “stigma”: “I didn’t know about this stigma before, until I heard all this people...”. The workshop helped CFM to understand what stigma is and they felt good and empowered by the knowledge they received: “Stigma is when people go around gossiping about you and then your spirit becomes low....” and “. .I have learned how to reduce stigma”. CFM from the rural group, learned that PLHA can live longer with treatment and that it is a chronic disease: “Before the workshop people in families were dying because they did not know what HIV and AIDS were”. The group reflected on what they have learned and indicated that a lack of information actually leads people to stigmatize: “You must have knowledge ... if you have full information you can’t do the wrong thing”. Murphy *et al.* (2000), Mahendra *et al.* (2007), Pisal *et al.* (2007), Chirwa *et al.* (2008), Uys, *et al.* (2009) confirmed that a combination of counselling, education and contact is very important to reduce HIV stigma. As CFM, they felt empowered as leaders to talk to the community about stigma, and it gave them confidence to stand up in public and teach the community about what they have learned at the workshop: “It made me feel good because I was a leader in the group and people were listening to me”.

**Theme five: Conducting the project was meaningful yet difficult.** The rural group experienced a positive response after the psycho-drama. CFM experienced a change in the way people saw HIV and stigma as they could identify with the drama “... said that they were living with people with HIV at home ... we are bringing change, change in the way people see those with HIV, as well as change in people accepting themselves ... people are willing to join us on our project”. The rural group also experienced negative responses to the invitation to the psycho-drama. They indicated that the people of Ganyesa had not accepted that HIV is present in their community: “Some of them haven’t accepted that HIV can be talked about publicly. People don’t like it when we speak about HIV and take it as an insult to talk about it .“ People however were more willing to attend their show if food and drinks were provided: “People don’t like it when we speak about HIV, it’s better to provide something to eat”. The urban group experienced disappointment that people did not turn up as promised: “ ... say yes to me ... they didn’t come”.

## 6 CONCLUSION

The intervention was not only implemented successfully but also showed positive intervention outcomes. No big differences were found between rural and urban communities except the colour-coded files for PLHA mentioned by the rural group. Bringing PLHA and CFM together during an intervention, proved to be affective. All indicated a better understanding of HIV stigma and how to cope with it. The relationships enriched by PLHA, feeling more supported and CFM realizing how they stigmatized and that they should be more supportive. Leadership was activated through the project, as the project targeted other CFM showed

initiative and reached a bigger number of people in the community through their own initiatives. They were proud to act as leaders in educating others.

Conclusions drawn from the in-depth experiences of PLHA and CFM of the intervention and the project showed that both PLHA and CFM gained confidence during the intervention as they experienced the support and trust from the group. This changed the initial fear of the PLHA and reluctance of CFM to join the group to a joyful and informative experience. PLHA and CFM experienced the planning of the project as very difficult at first, but the new and close relationships in the group empowered them to plan a project and gave them the confidence to share it with the community. A positive outcome of planning a project for other CFM in the community was that they learned to work together as a group, to trust and support each other and that together they had a better chance of silencing the voice of HIV stigma. The implementation of the project led to activating leadership in both the PLHA and CFM, as they felt proud and confident to make the community aware about HIV stigma and how to cope with it. Unique to this study, and mentioned only by the rural group, is the fact that stigma in health clinics is evident through colour-coding of files and gossiping leading to PLHA refusing to go to the clinics for treatment.

The goals set for this study were successfully reached. The relationship between PLHA and CFM was equalized with the PLHA feeling more supported and CFM showing much more compassion towards PLHA. The intervention helped people to understand HIV stigma-reduction in the context of both PLHA and CFM experiences and empowered them to share this information with pride and confidence with other CFM. Thus the effect of the intervention was successfully evaluated as well as an in-depth understanding was gained of both PLHA and CFM experiences thereof.

## **7                    LIMITATIONS**

A possible limitation of the study is that the sample size for CFM could have been bigger, but not all of the PLHA were comfortable to invite a CFM to attend the intervention. The project in the urban setting initially had difficulties as it was not as successful as the one in the rural setting.

## **8                    RECOMMENDATIONS**

The inclusion of HIV stigma reduction interventions in the curriculum of student nurses and the implementation thereof in the community, through community-based nursing, could be meaningful. Nurses in clinics working with PLHA should be trained to handle stigma reduction programs through in-service education. It would be of benefit if the program could also be offered as a workshop to traditional healers in the community. HIV stigma reduction interventions should be included in educational programmes offered at health clinics to PLHA and CFM. Both PLHA and their CFM could be invited to participate in support groups to support each other in reducing HIV-related stigma and share problem-solving coping strategies. Follow-

up interventions with various community groups could ensure sustainability. The results of the current study have important implications for further research in HIV-related stigma reduction interventions of PLHA and CFM in other countries and demographic groups. It has the potential to be used for long-term monitoring studies of HIV stigma reduction interventions and the change over time of PLHA and CFM.

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## **CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

### **1 Conclusions**

#### **1.1 Conclusions on the effect of a three-day community-based HIV-stigma reduction and wellness enhancement intervention on PLHA AND CFM.**

The intervention was not only implemented successfully but also showed positive intervention outcomes. No big differences were found between rural and urban communities except for the colour-coded files for PLHA mentioned by the rural group. Bringing PLHA and CFM together during an intervention proved to be affective. All indicated a better understanding of HIV stigma and how to cope with it. The relationships enriched by PLHA feeling more supported and CFM realizing how they stigmatized and that they should be more supportive. Leadership was activated through the project, as the project targeting other CFM showed initiative and reached a bigger number of people in the community through their own efforts. They were proud to act as leaders in educating others.

#### **1.2 Conclusions of experiences of PLHA and CFM during and after the intervention and the project.**

Conclusions drawn from the in-depth experiences of PLHA and CFM of the intervention and the project showed that both PLHA and CFM gained confidence during the intervention as they experienced support and trust from the group. This changed the initial fear of the PLHA and reluctance of CFM to join the group to a happy and informative experience. PLHA and CFM experienced the planning of the project as very difficult at first, but the new and close relationships in the group empowered them to plan a project and gave them the confidence to share it with the community. A positive outcome of planning a project for other CFM in the community was that they learned to work together as a group, to trust and support each other and that together they had a better chance of silencing the voice of HIV stigma. The implementation of the project led to activating leadership in both the PLHA and CFM, as they felt proud and confident to make the community aware about HIV stigma and how to cope with it.

Unique to this study and mentioned only by the rural group was that stigma in health clinics is evident through colour-coding of files and gossiping by health workers and others attending the clinics, leading to PLHA refusing to go to the clinics for treatment. The goals set for this study were reached. The relationship between PLHA and CFM was equalized with the PLHA feeling more supported and CFM shown much more compassion towards PLHA. The intervention helped people to understand HIV stigma reduction in the context of both PLHA and CFM

experiences and empowered them to share this information with proud and confidence with other CFM. Thus the effect of the intervention was successfully evaluated as well as the in-depth understanding of the participant's experiences thereof.

## **2 LIMITATIONS OF THE STUDY**

A possible limitation of the study is that the sample size for CFM could have been bigger, but not all of the PLHA were comfortable about inviting a CFM to attend the intervention. The project in the urban setting initially had difficulties as it was not as successful as the one in the rural setting.

## **3 RECOMMENDATIONS**

### **3.1 Recommendations for Education**

Inclusion of HIV-related stigma reduction interventions in the curriculum of student nurses and the implementation thereof in the community, through community-based nursing, could be beneficial. Nurses in clinics working with PLHA should be trained to handle stigma reduction programmes through in-service education. It would be of benefit if the programme could also be offered as a workshop to traditional healers in the community, and effective communication should be facilitated to understand each other's world.

### **3.2 Recommendations for Nursing Practice**

As soon as HIV has been diagnosed, nurses could involve PLHA as well as their CFM, in stigma reduction programmes to increase their understanding of HIV stigma, to ensure better relationships, and to empower them to share this knowledge with other PLHA and CFM in the community. Both PLHA and their CFM could be invited to participate in support groups to reduce the effects of HIV-related stigma and share problem-solving coping strategies. Follow up interventions should be conducted with groups of PLHA and CFM in both the urban and rural settings to ensure continuation and sustainability of community based projects or programs to reduce HIV-related stigma in the communities, involving churches, schools, health clinics and hospitals, and to support NGO's in the communities.

### **3.3 Recommendations for Further Research**

Results of the current study have important implications for further research in HIV-related stigma reduction interventions for PLHA and their CFM in other countries and demographic groups. More community-health based projects with PLHA and CFM through group research within a multidisciplinary team to ensure that understanding of stigma, coping and support to

continue is gained. The outcome of the study has the potential to be used for long-term monitoring studies of HIV stigma reduction interventions and the change over time with PLHA and CFM.

# APPENDIX A: ETHIC APPROVAL OF PROJECT



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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.

<b>Project title:</b> A Comprehensive Community-Based HIV Stigma Reduction and Wellness Enhancement Intervention																
<b>Ethics number:</b>	<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></table>	N	W	U	-	0	0	0	1	1	-	0	9	-	A	1
N	W	U	-	0	0	0	1	1	-	0	9	-	A	1		
<small>Status: S = Submission, R = Re-Submission, P = Provisional Authorisation, A = Authorisation</small>																
<b>Approval date:</b> 30 March 2009	<b>Expiry date:</b> 29 March 2014															

Special conditions of the approval (if any): None

<p>General conditions:</p> <p>While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:</p> <ul style="list-style-type: none"><li>The project leader (principle investigator) must report in the prescribed format to the NWU-EC:<ul style="list-style-type: none"><li>annually (or as otherwise requested) on the progress of the project,</li><li>without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.</li></ul></li><li>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 deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.</li><li>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.</li><li>In the interest of ethical responsibility the NWU-EC retains the right to:<ul style="list-style-type: none"><li>request access to any information or data at any time during the course or after completion of the project;</li><li>withdraw or postpone approval if:<ul style="list-style-type: none"><li>any unethical principles or practices of the project are revealed or suspected,</li><li>it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,</li><li>the required annual report and reporting of adverse events was not done timely and accurately,</li><li>new institutional rules, national legislation or international conventions deem it necessary.</li></ul></li></ul></li></ul>
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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 SUBJECT**

**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 you 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 status of the person will be made known to all the people in the various groups. In workshops you will be joined by other people similar to yours. Sharing experience could be painful and uncomfortable. Some of your privacy might be lost during 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 result 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 stigma reduction. Your participation will help the researchers to develop 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 refreshment 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**

SANPAD informed consent 4 June 2010.doc

**APPENDIX C:**  
**SECTION OF FIELD NOTES**

**Example field note during the intervention / workshop**

***FIELD NOTES FOR STIGMA INTERVENTION RURAL FAMILY MEMBERS DAY-1***

*Theoretical notes:*

Prof Kruger started the workshop by welcoming everyone and explaining what the workshop was about. Everyone was given the opportunity to introduce themselves and explain why they were here. One of the family members said that she did not know why she was there. 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 would 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 wanting to learn about stigma, to 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 who disappeared, people not wanting to share food, cups etc. and refusing 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 them during activities. At 12H00 we all enjoyed lunch. After lunch the groups worked together and participation was more relaxed and spontaneous. Although a lot of information had to be translated into Tswana during the workshop, it did not have an effect on the time set aside for this 1<sup>st</sup> day of the workshop and one of the participants thanked the facilitators that the workshop was not so long. The participant, who mentioned in her introduction that she did not know why she had to attend, reported that she was glad that she had come and that she understood HIV/AIDS and the stigma the people experienced and that she would support any person who disclosed to her with love, care and understanding.

*Personal Notes:*

Although the participants were experienced as non-interested and not very observant early in the workshop it did get better as the day went on. Other observations made during the workshop were that PLHA and family members did not sit together, no relationship or bonding were was experienced between them, it seemed as if they did not know each other well and I wondered if the family members who had been 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 would lower his standing within the hierarchy and would bring back the stigma mentality. The person who had asked him to attend the workshop is normally a very outgoing person, but within the workshop she was very quiet and when asked what was wrong she just pointed in his direction and said it is because he was there, she had to 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 comment made by one of the family members about her feelings around stigma after day 1, that she would support and care for any of her children, or any family member who is HIV+, left the feeling that maybe she probably was not aware that her daughter who had asked her to attend the workshop, was actually HIV+.

*Methodological notes:*

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, the 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 was going to be done.

## APPENDIX D:

### SECTION OF A TRANSCRIPT OF AN INTERVIEW

**Moderator** XXX code 204-3, family member Ganyesa. XXX like I already told you my name is XXX; we are doing research on HIV stigma. I am part of the group that is looking at HIV stigma in the community, and you were part of the research last year when you took part in the workshops and projects. Am I right? So you know about that. Thank you for coming today to talk to me. The reason why I'm doing this interview is to get an understanding of your experience of the workshops and projects that were done last year as part of the stigma reduction program. I'll be conducting several interviews with people who took part in this study last year. It is going to take us plus/minus an hour to do the interview and everything you say will be kept confidential and your name never made known. It might be that I will be writing some notes in between, but it's just to follow you and if I need to go back and ask you a question on something you said, that's why I'm going to write. You gave us permission last year when you signed to participate, so today again we are going to use the voice recorder to tape what we are saying here is that okay?

**Respondent** Yes.

**Moderator** Okay. You also know that you are welcome to withdraw at any stage. If you feel uncomfortable afterwards and you need to talk or counseling then I will make some arrangements for you. Are there any questions from your side?

**Respondent** No, I don't.

**Moderator** Nothing? So we can start with the interview? The first question is how did you experience the HIV stigma reduction workshop and projects with the people living with HIV and other friends, like you are the friend of Doreen like how did you experience this workshop?

**Respondent** I've experienced a lot of things; they teach me how to treat people living with HIV stigma and living close to them.

**Moderator** You were taught how to treat people living with HIV and people living close to them. Tell me more about what you learned? You said that you learnt many things; you experienced many things, things with this workshop. What do you mean when you say you experienced many things? You said you learnt about HIV stigma? It's okay any answer; everything is correct nothing is wrong. What have you experienced when you were there at the workshops?

**Respondent** I've experienced that we are the same as that people living with HIV. We don't have to stigmatize.

**Moderator** So you've learnt that everyone is the same even if you're HIVpositive, you are just the same as anybody else and you must not stigmatize people with HIV?

And then if you can think about the projects, you were part of the friends group how did you experience the projects that were planned in your group?

**Respondent** We are working together preparing for the drama that we are going to participate at the tribal and there was so many people there.

**Moderator** So you prepared for the drama? Can you maybe tell me more about the drama what happened in the drama?

**Respondent** In the drama, we have school children and the mother, father and the mother got infected and the shop keeper they chase them out for buying food.

**Moderator** Why were they chased out of the shop?

**Respondent** Because they were HIV infected.

**Moderator** So they were.

**Respondent** They didn't want the money they say that it can also infect them.

**Moderator** So they were stigmatizing? What have you learnt out of this experience of being part of this group, what have you learnt from it? Like you said about the drama, what kind of effect did it have when the people watched the drama? You said that there were many people.

**Respondent** They were so interested and they were laughing.

**Moderator** Okay so they were interested in what was happening?

**Respondent** And the others, they said that they were living with people with HIV at home.

**Moderator** So they could learn from your drama? And how did you experience the drama? What did you think of the drama and about the whole workshops and about the stigma reduction? What did you think of it?

**Respondent** I have learnt that I can go and.

**Moderator** You can go and?

**Respondent** Talking to the community in the first place. I didn't know that.

**Moderator** So you learnt from the workshops and you've gained knowledge and now you can go out and use that knowledge and present it to people and share with other people about HIV stigma? And if you think about the project, what did you think of your project? You the people were interested and the people that attended said that they even learnt because they got people at home with HIV, is there anything more that you can tell me about this whole workshop and projects with HIV stigma? Anything that you feel, anything that you can think of when you think of this stigma reduction program, anything the way that you experienced it and what will you do with this knowledge that you got from the workshop? Anything is right there's no wrong answer. You said that you learned about stigma what have you learnt about stigma?

**Respondent** There are three different types of stigma; there's self stigma.

**Moderator** So there are different types of stigma?

**Respondent** Yes.

**Moderator** What was the most important lesson that you learnt from this workshop something that you took and you remember the lesson that you learned and you also done in your drama? You said that people with HIV are stigmatized, what have you learned in this workshop?

**Respondent** I have learned how to reduce stigma.

**Moderator** You've learned how to reduce stigma? And in the project what happened after the presentation of your drama? You said there were many people and they were interested what happened after wards?

**Respondent** Some want us to participate in the church we are going there so that many people can see.

**Moderator** So you got good feedback then they wanted it to be presented to other people also so that they can learn about HIV stigma? That's good and then did you present it at the church as well?

**Respondent** Yes.

**APPENDIX E**  
**SECTION OF A NAÏVE SKETCH**

**Family Urban Naive Sketches**

***Evaluation of day one***

Participant: Code: 105-3

I experienced this first day of the workshop as:

This workshop helps me to understand HIV, how to cope and to be strong.

I Feel:

Good, I understood about HIV and how to cope with difficulties and how to be strong to support my child.