

A mixed method study of a community-based HIV stigma reduction “hub” network

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Language Editor Declaration

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30 April 2015

Ms Rini Prinsloo

Dear Ms Prinsloo

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SECTION B AN OVERVIEW OF LITERATURE ON HIV STIGMA, PSYCHOSOCIAL WELL-BEING, OUTCOMES OF STIGMA ON INDIVIDUALS AND THE COMMUNITY AND HIV STIGMA REDUCTION INTERVENTIONS "Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviances, properly so-called, will there be unknown; but faults, which appear venial to the layman, will there create the same scandal that the ordinary offense does in ordinary consciousness. If then, this society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such" (Durkheim, 1895). An overview of literature to contextualise...

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List of Abbreviations

AIDS = Acquired Immune Deficiency Syndrome

ART = Antiretroviral Treatment

ARV = Antiretroviral

HCT = HIV counselling and testing

HIV = Human immunodeficiency virus

PLC = People living close to PLWH

PLWH = People living with HIV

PMTCT = Prevention of mother to child transmission.

Research Outline

The research in this study is presented in an article format with inclusion of the following:

Section A: An overview of the research and appendices

The overview entails a brief reference to the literature and paradigmatic context relevant to the research. It also gives an overview of the planning and methodology of the whole study. This is comprehensively described in the three articles.

Section B: A Literature Review

The literature review combines a critical synthesis of the existing body of research knowledge and possible gaps in such knowledge with a critical reflection on the literature as context for the research, previous findings as well as on the more recent relevant work.

Section C: Articles

The research findings will be reported in the following three separate articles and send to the mentioned journals for publication.

ARTICLE TITLE	JOURNAL FOR SUBMISSION
Article 1: HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention	Social Science & Medicine Journal
Article 2: A Community Hub Network for HIV Stigma Reduction: A Case Study.	The Journal of the Association of Nurses in AIDS Care (JANAC)
Article 3: Psychosocial Well-Being Of People Living with HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.	Journal of Psychology in Africa

Section D: Conclusions, limitations and recommendations

An overall set of conclusions will be drawn for the study which will include the results offered in the articles. Similarly will limitations be discussed and recommendations presented with regards to the findings of this study.

Authors' Contributions and Declarations

This research was planned and effected by four researchers at the North-West University, Potchefstroom and Vaal Triangle Campus. The contributions of each researcher to this study, is indicated in the table below.

Ms C. D. Prinsloo	Ph.D. Psychology student; liable for the review of literature, conducting the research process, interpretation of qualitative and quantitative data and writing of the text.
Prof. Dr M. Greeff	Promoter, project leader and critical reviewer of the total study.
Prof. Dr A. Kruger	Co-promoter and critical reviewer of the literature review, article one and article three.
Prof. Dr I.P. Khumalo	Co-promoter and critical reviewer of the literature review and article one.

The following is a declaration by the author and co-authors. It confirms their role in the study and their agreement that the article format is appropriate and acceptable for submission as a thesis entitled: A mixed-method study of a community-based HIV stigma reduction "hub" network.

A Declaration:

I hereby declare that I have approved the inclusion of the articles as mentioned above in this thesis and that my contribution to this study is indeed as stated above. I hereby grant permission that these articles may be published as part of the Ph.D. thesis of Ms C. D. Prinsloo.



Prof Dr. M. Greeff



Prof Dr. A. Kruger



Prof Dr. I.P. Khumalo



Ms. C.D. Prinsloo

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Prof. Minrie Greeff was the lead-promoter who facilitated the whole programme with all its different elements and people. There were some extremely challenging circumstances that included loss and grief, serious illness of senior colleges, career changes and long periods of managing more than one person's work. Prof Minrie has made an extraordinary effort and many sacrifices to support my study.

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My friends and family for ongoing support and encouragement. Especially my parents and grandparents who encouraged me to read since I was four years old. My 88 year old mother who became part of my study hours and stood by me in every possible way. I also honour my late father who would have truly enjoyed this achievement.

A special thank you to Christa and Bernard for their help, support and generosity during the time of study.

Summary

Over the years, growing concerns were raised about the serious effect that HIV stigma has on the global HIV and AIDS-prevention response, with appeals to regard HIV stigma reduction as one of the most important factors that need to be addressed in any HIV-prevention strategy. Studies have found scant evidence of comprehensive community-based approaches to reduce stigma, as few of the existing strategies address the community, but maintain the focus mainly on behaviour change in the individual. This research study is a follow-up study to two other studies. The first study focused on people living with HIV (PLWH) and nurses in health care settings; and the second was a trans-disciplinary, comprehensive, community-based HIV stigma reduction and wellness-enhancement intervention that involved PLWH and people living close to them (PLC). This HIV stigma-reduction community “hub” network intervention was specifically planned as an intervention for the community, targeting PLWH and their community members who live in the same ward in the Tlokwe municipality in the North West Province of South Africa.

The objectives of the study were to explore, describe and determine whether an HIV stigma-reduction community “hub” network intervention in a South African urban area will make a difference in the HIV stigma experiences of PLWH, as well as related stigmatisation by their community; to describe the implementation of this intervention; and to determine the change in depression and psychosocial well-being of PLWH and their community before and after the intervention.

The HIV stigma-reduction community “hub” network intervention defines a “hub” as a two-person mobiliser team consisting of a PLWH and a non-infected PLC who are inhabitants of the same community and functions from a “hub” in the community. The strategy is based upon the involvement of PLWH and PLC, as community mobilisers, who share their knowledge and who mobilise and empower their own community to reduce HIV stigma.

A convergent parallel mixed-method design with a single case pre-test post-test design for the quantitative data, and an interpretive description approach for the qualitative data were utilised. The sample for this study included PLWH recruited through accessibility sampling as well

as community members living in the same municipal ward through random voluntary sampling. Valid measures were used to determine and describe whether the HIV stigma-reduction community “hub” network intervention will affect change in the HIV stigma experiences of PLWH, the perceived stigmatisation by their community, as well as the depression and psychosocial well-being of both PLWH and the community. A sub-sample of both groups was selected by means of purposive voluntary sampling for the qualitative part of the study, consisting of in-depth interviews about stigma experiences of PLWH, as well as stigmatisation of the community toward PLWH. For the description of the HIV stigma-reduction community “hub” network intervention, a holistic single-case study design was used. Participants were recruited according to accessibility, during the various community activities, with no differentiation between PLWH and people of unknown HIV status residing in that community.

Findings indicate that the HIV stigma-reduction community “hub” network intervention, as planned and implemented, was successful in initiating the onset of changes in a community through the PLWH and PLC, as community mobilisers were active in the community “hub” network to mobilise their own communities towards HIV stigma reduction, sharing their knowledge and mobilising and empowering their own community. Changes were observed on an individual and social level. Recommendations focus on using and strengthening the present community intervention, adjusting some of the scales used in this study and ensuring stronger collaboration between health and social disciplines to address the various manifestations and to change the contexts of HIV stigma. It is furthermore recommended that future HIV stigma-reduction interventions give special attention to addressing aspects of psychosocial well-being.

Keywords: HIV stigma, HIV stigma reduction, stigmatisation, South Africa

Opsomming

Met verloop van tyd is groeiende kommer uitgespreek oor die ernstige gevolge van stigma op globale MIV- en VIGS-voorkomingsreaksies, met pleidooie dat MIV-stigmavermindering beskou moet word as een van die belangrikste faktore waarop enige MIV-voorkomingstrategie moet fokus. Studies het bevind dat daar min bewyse is van omvattende gemeenskapsgebaseerde benaderings om MIV stigma te verminder. 'n Beperkte hoeveelheid van die bestaande strategieë is op die gemeenskap gerig, en die fokus is hoofsaaklik op gedragsverandering in die individu. Hierdie navorsingstudie is voorafgegaan deur twee MIV stigmaverminderingintervensiestudies. Die eerste studie was gefokus op mense wat lewe met MIV en verpleegpersoneel in die gesondheidssektor. Die volgende studie was 'n transdissiplinêre, omvattende gemeenskapsgebaseerde MIV-stigmavermindering- en welstandsbevorderingintervensie gerig op mense wat lewe met MIV, sowel as mense wat naby aan hulle leef. Die huidige stelsel van gemeenskapsintervensie deur middel van "hub"-netwerke vir MIV-stigmavermindering is spesifiek beplan as 'n gemeenskapsintervensie wat gerig is op mense wat met MIV leef en hulle gemeenskapslede, in 'n spesifieke wyk van die Tlokwe-munisipaliteit in die Noordwes Provinsie van Suid-Afrika.

Die doelwitte was om te verken, te beskryf en te bepaal hoe en tot watter mate die gemeenskapsintervensie deur middel van "hub"-netwerke vir MIV-stigmavermindering lei tot 'n vermindering van die stigmabelewenisse van mense wat lewe met MIV sowel as die meegaande stigmatisering deur hulle gemeenskap; om die implementering van die intervensie te beskryf; en om die verskil in depressie en die psigososiale welstand van beide groepe voor en na die intervensie te bepaal.

Die beplande gemeenskapsintervensie deur middel van "hub"-netwerke vir MIV-stigmavermindering definieer 'n "hub" as 'n tweepersoon-mobiliseerdersspan bestaande uit 'n persoon wat lewe met MIV en 'n nie-geïnfekteerde persoon, wat albei in dieselfde wyk woon, en wat beskryf word as "mobiliseerders". Hierdie spanne funksioneer dan vanuit 'n "hub" in die gemeenskap. Die strategie is gebaseer op die betrokkenheid van mense wat lewe met MIV en

mense wat naby aan hulle leef, as gemeenskapsmobiliseerders wat hulle kennis en ervaringe deel en wat hul gemeenskap mobiliseer en bemagtig ten opsigte van MIV-stigmavermindering.

'n Konvergente parallelle gemengdemetode-ontwerp met 'n enkelgeval-voortoets-natoetsontwerp vir die kwantitatiewe data en 'n interpreterende beskrywende benadering vir die kwalitatiewe data is gebruik. Die steekproef vir hierdie studie het 'n groep mense ingesluit wat lewe met MIV (wat gewerf is op grond van toeganklikheid) en ook 'n groep lede van die gemeenskap wat in dieselfde munisipale wyk woon (wat gewerf is deur ewekansige vrywillige steekproeftrekking). Geldige meetinstrumente is gebruik om te bepaal of daar verandering bewerkstellig is in die MIV-stigmabelewenisse van mense wat lewe met MIV, asook in die waargenome stigmatisering deur die gemeenskap. Die depressie en psigososiale welstand van die mense wat lewe met MIV sowel as lede van die gemeenskap is ook in ag geneem. 'n Subgroep van beide groepe is deur middel van doelgerigte vrywillige steekproefneming vir die kwalitatiewe deel van die studie getrek. Die kwalitatiewe deel van die studie het bestaan uit indiepte-onderhoude oor stigmabelewenisse van mense wat lewe met MIV, sowel as die stigmatisering van die gemeenskap teenoor mense wat lewe met MIV. Vir die beskrywing van die gemeenskapsintervensie deur middel van "hub"-netwerke vir MIV-stigmavermindering is 'n holistiese enkelgeval-gevalstudie gebruik. Deelnemers is tydens die verskillende gemeenskapsaktiwiteite gewerf op grond van toeganklikheid. Daar was geen differensiasie ten opsigte van MIV-status nie.

Die bevindinge dui daarop dat die gemeenskapsintervensie deur middel van "hub"-netwerke vir MIV-stigmavermindering, soos beplan en geïmplementeer, suksesvol was wat betref die inisiëring van verandering in die gemeenskap deur die mobiliseerders (bestaande uit mense wat met MIV leef en die mense na aan hulle). Hulle mobilisering, deel van kennis en bemagtiging van hulle eie gemeenskap het gelei tot verandering op individuele en sosiale vlak. Aanbevelings fokus op die herhaling en versterking van die huidige gemeenskapsintervensie, aanpassing van sommige van die skale en sterker samewerking tussen gesondheids- en sosiale wetenskappe om die verskillende manifestasies en veranderende konteks van MIV-stigma te hanteer. Dit word

verder aanbeveel dat toekomstige intervensies ook spesiale aandag gee daaraan om te fokus op die psigososiale welstand van die gemeenskap.

Kernbegrippe: MIV-stigma, MIV-stigmavermindering, stigmatisering, Suid-Afrika

Section A: Overview of the Research

The following overview presents the introduction and problem statement, research questions, research objectives, central theoretical argument and the selected research methodology for this study. The research findings will be presented in three articles in Section C.

Introduction and Problem Statement

The HIV stigma reduction “hub” network intervention utilised in this study was specifically planned as an intervention for the community, targeting people living with HIV (PLWH) and community members that all live in the same municipal ward. This study was preceded by two other HIV stigma reduction intervention research studies. The first study focused on PLWH and nurses in health care settings (Uys et al., 2009a). Holzemer and a team of researchers (2004-2008) explored the experiences of HIV stigma (Greeff et al., 2008) and developed culturally appropriate scales to measure HIV stigma among PLWH and nurses (Holzemer et al., 2007 b; Uys et al., 2009b), conceptualise a model for the HIV stigma process, as well as plan and implement an intervention focusing on PLWH and nurses in healthcare settings (Holzemer et al., 2007a; Uys et al., 2009a). The second study was a trans-disciplinary, comprehensive, community-based HIV stigma reduction and wellness enhancement intervention that involved PLWH and people living close to them (PLC) whether partner, child, family member, friend, community member or spiritual leader (Chidrawi, Greeff, & Temane, 2014; French, Greeff, Watson, & Doak, 2015).

The conceptualisation of stigma and specifically HIV related stigma has been described over many years and a clear picture of the developments in thinking about HIV stigma and HIV stigma reduction interventions emerge in the literature. Goffman (1963, p13) defined stigma as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society”. By Goffman’s definition, stigmatisation is the societal labelling of an individual or group as different or deviant. Stigma can result from a particular characteristic, such as a physical deformity, or it can stem from negative attitudes

toward the behaviour of marginalised groups such as homosexuals or prostitutes. Alonzo and Reynolds (1995) describe people being stigmatised as a category of people who are negatively and even derogatorily regarded by the broader society and who are devalued, shunned and have less chance for life rewards or access to life chances and the benefit of free and unfettered social intercourse. What these definitions emphasise is the effect of stigmatisation on the individual in both the personal and the societal aspects of their lives. More recently the view of stigma has shifted from a specific emphasis on the devaluation of an individual's identity, to a view of stigma as a dynamic social process characterised by exclusion, rejection, blame or devaluation of people with an identifiable difference that results in the experience, perception or anticipation of an harmful or unfavourable social judgment about them (Golden & Earp, 2012; Weiss, Ramakrishna, & Somma, 2006). This social process of stigmatisation causes the effects of HIV stigma to reach deeply into the functioning of society as a whole as HIV stigma comprises various contextual elements that include shared values, attitudes and beliefs which are interpreted as perceived threats to physical or social health and welfare (Doná, 2010).

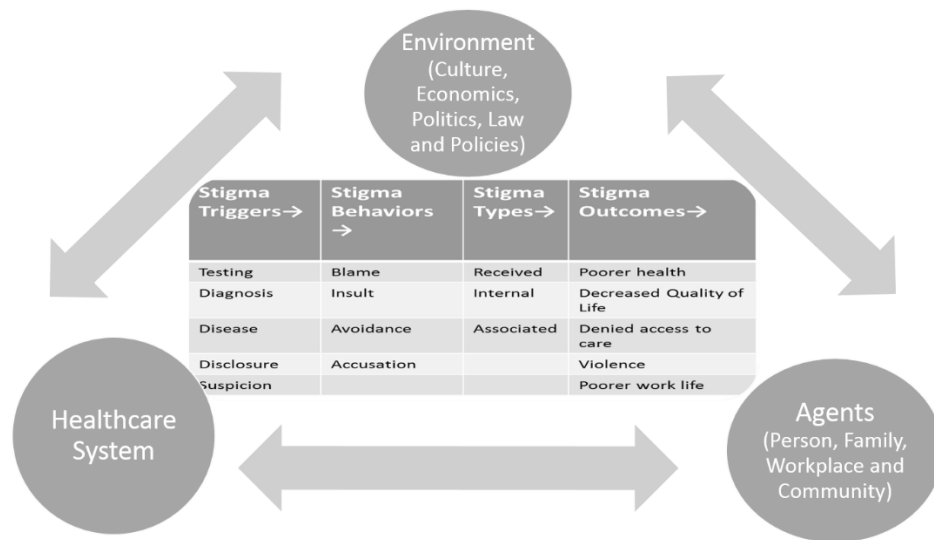
Concern about HIV-related stigma and discrimination is not new. Aggleton Parker, and Joint United Nations Programme on HIV/AIDS (2003) describe three widely recognised phases of the AIDS epidemic in any society: the first is the epidemic of HIV infection, the second is the epidemic of AIDS, and the third is the epidemic of stigma, discrimination, blame and collective denial. Various authors point out that the third phase makes it difficult to effectively tackle the first two phases, because HIV-related stigmatisation and discrimination make prevention difficult by forcing the epidemic underground and out of sight (Oanh, Ashburn, Pulerwitz, Ogden, & Nyblade, 2008; UNAIDS, 2010). Piot (2006) described the challenge of stigma as perhaps the greatest of all those facing the AIDS response. Edward Cameron (1993, p3) declared that "AIDS is probably the most stigmatised disease in history ... If we do not appreciate the nature and impact of [the] stigma, none of our interventions can begin to be successful." This means that a new and focused look needs to be taken at the reduction of HIV stigma and the resultant effect on the prevention of the disease. The

vision of UNAIDS (2010), which is “Zero infections, Zero discrimination, Zero AIDS related deaths” underlined the importance of increasing the response to HIV and AIDS at all levels. Clark (2011) mentions the need to get rid of stigma and discrimination, as it stands in the way of effective prevention and treatment, and prevents people from living their lives with dignity. She introduces the point that successful prevention needs strong leadership at all levels to bring HIV out of the shadows, to encourage people to make responsible choices, and to drive interventions which will meet the needs of vulnerable groups. The imperative of responding to HIV stigma is supported by Nyblade, Singh, Ashburn, Brady, and Olenja (2011) and Carr et al., (2010), who underline the need to upscale the response to stigma.

An extensive survey by the non-governmental organisational representatives of the UNAIDS Programme Coordinating Board in 2010 showed that PLWH and key populations at higher risk continue to experience high levels of HIV-related stigma and discrimination (UNAIDS 2010). Krajewski, Burazeri and Brand (2013) point out national disparities in stigma in six European countries and claim that there are differences between countries in terms of stigma, and possibly within countries, too. They suggest that the manifestation of stigma varies from country to country and from culture to culture. These and authors from The National Association of People Living with HIV in South Africa (NAPWA-SA) (2012) report that HIV-related stigma has an enormous negative impact on people’s social relationships, access to resources, and psychological well-being. Moreover, HIV stigma hampers HIV-related health promotion and various authors have found that HIV-related stigma and behaviour resulting from stigmatisation is a key barrier to all HIV activities, from prevention to care and treatment (Nyblade et al., 2011; Nyblade, Stangl, Weiss, & Ashburn, 2009).

The model of the dynamics of HIV and AIDS Stigma (see figure 1) formed the grounding for this research. Holzemer et al. (2007a) describe the interaction between elements involved in the process of stigmatising and postulate that addressing these variants would probably also play a role in stigma reduction (Figure 1). They define three types of stigma (received stigma, internal stigma and associated stigma) and, more importantly, they point out that stigmatisation is a process that happens within a described context. The context of HIV

stigma is created by the environment, the health care system and certain agents, including PLWH. Certain triggers like the disease itself, the diagnoses of being HIV positive, testing, disclosure and even suspicion cause stigmatising behaviour, resulting in three types of stigma, which is each identified with a specific set of outcomes (see Figure 1). This model places HIV stigma and stigmatising behaviour in a broader social context with multiple outcomes and serves as the underpinning for this study.



Adapted from Holzemer et al (2007)

Figure 1. Model of the Dynamics of HIV and AIDS Stigma

As the main objective of this study was to investigate a HIV stigma-reduction community “hub” network as a stigma reduction intervention, it proved necessary to look deeper into stigma reduction interventions and the key elements, strategies and people that would be involved in successful interventions. Barr, Amon, and Clayton (2011) observed that since the beginning of the epidemic, the protection of human rights has been an integral component in the response to HIV. They felt that the high degree of stigma and discrimination associated with AIDS has made human rights protection not only a priority to ensure the rights of people living with and at-risk for HIV, but to address public health goals as well. The Report Card on HIV Prevention for Girls and Young Women in Swaziland (2007) produced by the United Nations Global Coalition on Women and AIDS (GCWA) placed the emphasis on the violation

of human rights and voiced the concern that attention to this is vital in stigma reduction interventions. Under Prevention Component 5: Participation and Rights, the report expressed the need to ensure that the national response to HIV becomes more rights-based. Research found that the human rights of PLWH in different African countries are not adequately protected, and that many HIV-positive people are living in situations where their rights are actively denied (Turan & Nyblade, 2013). They pointed out that the two prevailing factors leading to this state of affairs are the lack of a human rights culture at grassroots level, and the fear of contagion. Both these factors could seriously effect community-based intervention strategies and should therefore be adequately addressed.

Historically The Paris Declaration (1994) pledged the participating governments' full involvement in the common response to HIV and AIDS at all levels (national, regional and global), believing that it will stimulate the creation of supportive political, legal and social environments. Many researchers and programme implementers have since increasingly turned to broader interventions that address the physical, social, and political contexts in which individual behaviour takes place. A community-led structural intervention in India contended that structural interventions represent a potentially powerful approach to HIV prevention among female sex workers, which focuses on changing the social context of risk rather than individual behaviour (Blankenship, Biradavolu, Jena, & George, 2010). Community-led structural interventions represent a particular form of structural interventions through which the collective energy of communities is directed toward action to address the contextual factors that promote their risk. Structural interventions that focus on three areas of change, namely social change, change within specific groups and harm reduction or health seeking behaviour change are categorised by Auerbach, Parkhurst, Cáceres, and Keller (2009). Engaging in a comprehensive process of making people more aware of HIV stigma could bring about broader social change, resulting in an enabling environment where individuals and communities are positively motivated to play an active role in HIV prevention initiatives (Greeff et al., 2008). This represents a shift from focus on the individual to the

individual in his/her social context, which implies a shift towards a community context. This, in turn, influences the way researchers are looking at interventions.

Heijnders and Van Der Meij (2011) believe that community-based stigma reduction strategies and interventions should aim to increase knowledge regarding specific health conditions and regarding stigma within specific community groups; as well as to increase community development skills, to develop support networks, and through these provide better access to services for people who are affected. Programmes promoting a combination of social mobilisation, human rights and legal activism turn people who would otherwise have been victims of stigma and discrimination into empowered groups engaged in self-determination and social change (Campbell, Skovdal, & Gibbs, 2011). Hence, interventions should firstly be aimed at empowering affected persons, always taking note of the context in which they find themselves. Persons who are empowered, aware of the barriers to active community participation and aware of their human rights, can actively participate in setting the priorities regarding the need for institutional and national change.

Brown, Trujillo, and Macintyre (2011) commented on their earlier review (2003) which reviewed 21 published and reported intervention studies that had explicitly attempted to decrease AIDS-related stigma both in developed and developing countries. The interventions tested in the 21 studies are grouped into four categories: information-based approaches, acquisition of coping skills, counselling approaches, and contact with affected groups. These categories show that stigma can be reduced through a variety of intervention strategies, including the provision of information and counselling, fostering of PLWH's coping skills to deal with stigmatising attitudes, and increasing individual contact with PLWH. The majority (14) of the studies aimed to increase tolerance of PLWH among different segments of the general population. The remaining studies tested interventions to increase willingness to treat PLWH among health care providers or improve coping strategies for dealing with AIDS stigma among PLWH or at-risk groups. Some of the studies helped those at risk or already infected deal with felt stigma. In the research update it was found that PLWH involvement in community-based organisations reduces felt stigma and social isolation (Brown, Trujillo, &

Macintyre, 2011). Uys et al. (2009), using the model of the dynamics of HIV and AIDS stigma (Figure 1), chose an intervention that combined three strategies: sharing information, increasing contact with the affected group, and improving coping through empowerment. These authors saw empowerment as attempting to equalise the relationship between health service providers and service users. This promoted empathy, changed roles, and facilitated the development of new perspectives on the issues. Empowerment involved engaging PLWH in an activity that saw them addressing stigma directly, and not accepting it or living with it.

The Paris Declaration (1994) resolved to facilitate this greater involvement of PLWH. It states that the success of national, regional and global programmes to confront HIV and AIDS effectively requires greater involvement of PLWH. It mentions an initiative to strengthen the capacity and coordination of networks of people living with HIV and AIDS. This was confirmed by The Good Practice Guide (McClelland & De Pauw, 2010) on involvement of PLWH and strategies for involvement of PLWH in stigma and other HIV interventions. The essential link between protecting human rights and promoting public health suggests that a greater pool of positive activists must be encouraged (Barr et al., 2011). Other authors introduced a broader context that involves people like peers and volunteers (Sanjuán, Molero, Fuster, & Nouvilas, 2013). Kurth, Celum, Baeten, Vermund, and Wasserheit (2011) favoured a start-at-home approach, involving frontline workers and PLWH and key people in the community. Champions for stigma reduction reach a wider community. Heijnders and Van Der Meij (2011) describe stigma as a social construct and not an attribute of individuals. They feel that it must not be expected of affected people alone to carry the burden of activism against stigma, and that educating the general public and increasing their tolerance are not enough. Several studies found that PLWH can take an active role in this process. Literature and studies show that stigmatisation have a serious effect on the global response to HIV and AIDS and that multiple elements are involved in implementing a successful stigma reduction programme. These studies found very little evidence of a comprehensive community-based approach to reduce stigma (Greeff, 2010).

There are existing models that theoretically underpin some of the above-mentioned approaches. Engel (1992), for example, postulated a bio-psycho-social model to offer a philosophic understanding of how suffering, disease and illness are affected by multiple levels of organisation, from the societal to the molecular level. Borrell-Carrió, Suchman, and Epstein (2004) review the 25 years that have elapsed since Engel's proposition and identify two new intellectual trends that have emerged. They move past the issue of mind-body duality by recognising that knowledge is socially constructed and consider complexity theory as a more adequate model for understanding causality, dualism and participation in care.

Lang (2002) postulated that both the medical model and the social model of approach to people have certain weaknesses in their explanation of how marginalised and often oppressed groups are able to recognise their potential to change their present situation, thereby becoming full and active citizens in the contemporary societies in which they live. The community-based rehabilitation model which Lang (2002) proposed, is underpinned by the theories of Social Transformation of Paulo Freire and is seen as an alternative model to both the medical model and the social model of approach. Freire's thesis of social transformation (Freire 1973), as adopted by Lang (2002), is to ensure that all individuals, particularly those who are subject to oppression, are treated more fully human. Freire (1973) maintained that all individuals, irrespective of the degree of oppression they have been subjected to, potentially have the innate ability to transform their political, social and economic situation. However, effective social transformation will only occur when marginalised groups meet collectively, critically analyse the constraints placed upon them by their social, economic and political environment within a historical framework, and devise strategies for their subsequent alleviation (Hope & Timmel, 1984). The theory is premised upon the assumption that all individuals, notwithstanding their class or social position, are innately self-conscious and creative, and able to change their present (and often very oppressive) environment. The most important ideas underlying Freire's work, simply put, is that we are all called upon to transform our own personal lives, our community, our environment, and ultimately our society.

Kiragu and McLaughlin (2011) described the participatory approach based on the early work of Freire. They accept the idea that people should be self-reliant and their own problem-solvers: people must engage with their environment and act upon their reality, as this is the only way to critical intervention and transformation. Kiragu and McLaughlin (2011) discussed this as part of their health promotion guidelines that recommend involving the community in health endeavours. The concept of participatory community involvement inevitably leads to the possibility of a new form of leadership in communities to empower people towards the efficacy of community-based endeavours. Leadership is seen as a process through which groups of committed people with a common purpose seek to create change. The goal is to facilitate positive social change in the community; that is, to undertake actions which will help the community to function more effectively and humanely (Campbell & Cornish, 2010).

A common definition of community is a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQueen et al., 2001). Bessette (2004) points out that a local community is not a unified group of people, but rather a grouping of individuals and groups with their own characteristics and their own interests. This could mean that ownership and leadership are of primary importance, that there is no one community and that separate groups have separate agendas and can be an influencing factor in community-based interventions. This strengthens the idea of a stigma reduction intervention as a community based effort. Establishing a network of “hubs” in the community could greatly enhance the taking of ownership and the new leadership in the community. The debate on community involvement in health care has been going on for many years and continues to capture the attention of international health policy makers. Morgan (2010) felt that communities need encouragement to participate outside, because a number of factors like poverty, disempowerment etc. prevent people from participation and argues that participation can be sustainable only as long as the relevant actors remain committed and the socio-political and economic environments remain conducive to the process.

As a result, community participation is not merely an input to the research but becomes the basis upon which it will operate. This process is explained by positive psychology, which is the scientific study of optimal human functioning and which aims to discover and promote the factors that allow individuals and communities to thrive (Seligman & Csikszentmihalyi, 2000). At the subject level, positive psychology is concerned with valued subjective experiences: well-being, contentment and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present). At the individual level, it is concerned with positive individual traits: the capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future-mindedness, spirituality, high talent, and wisdom. At the group level, it is concerned with the civic virtues and the institutions that move individuals toward better citizenship: responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic (Seligman & Csikszentmihalyi, 2000; Linley, Joseph, Harrington, & Wood, 2006). At this level, it is about the civic virtues and the institutions that move individuals toward better citizenship. This notion seems to fit well with the goal of a community-based stigma reduction “hub” network as an intervention to reduce HIV stigma, because it places the emphasis on the individual in his community and enhances the idea of a new kind of leadership amongst ordinary citizens.

The introduction has thus far focused on HIV stigma and its impact on individuals and communities as well as stigma reduction within similar contexts. The relationship between an individual and his/her society is inter-dependent and dynamic because human nature and the dynamics of social change are the product of the continuous interactive relationship between an individual’s naturally endowed characteristics and the social environment in which he lives, which is itself shaped by social, political and economic factors (Cardey 2006). This points towards a link between the individual’s well-being and the individual’s participation in processes of social change. A relationship has been found in regard to depression and HIV. HIV stigma is described as one of the key factors in the development of psychological distress, depression and anxiety as well as affecting mental health and well-being of PLWH (Breet, Kagee, & Seedat, 2014). Individuals with depression tend to adopt riskier sexual

behaviours, heightening the danger of contracting HIV. Also the infection increases the risk of depressive symptoms (Schadé, Van Grootheest, & Smit, 2013).

The concept *well-being* has reference to both the individual and a community as it describes the social, cultural and psychological needs of people, their family, institutions and communities. The concept of well-being for the *individual* has traditionally been viewed from two differing points of view, firstly a clinical orientation, measuring well-being through absence or presence of pathology like depression, distress, anxiety, or substance abuse (Els & De La Rey, 2006). Recent descriptions emphasise states of satisfaction with life, personal meaningful pursuit of goals, and descriptions of well-being such as good health, a sustainable environment, high levels of civic participation and intra- and interpersonal relationships and satisfactory relationships with the community and environment (Brown & Alcoe, 2010). In terms of the well-being of a *community* the report on community well-being and community process from the Institute of Medicine (IOM, 2012) describes community well-being as inclusive of the physical as well as the social and economic environments that affect the health of individuals and populations and refers to psychosocial well-being. It is also conceptualised as social capital, involving processes and systems like networks, norms, trust and relationships that open up opportunities for participation and collective action that allow communities to address issues of common concern (Gibbs, Campbell, Akintola, & Colvin, 2014). Elements of community well-being include employment, food, social support and social networks, and health care, among others. It includes social norms, how people relate to each other and to their surroundings, and how much investment they are willing to make in themselves and in the people around them (Kim, Kalibala, Neema, Lukwago, & Weiss, 2012). In the literature psychological and psychosocial well-being are used interchangeably.

A number of models and theories endeavoured to describe psychosocial well-being. Well known, is the Salutogenic model (Antonovsky, 1996) with its health-oriented sense of coherence in social support, coping and relational stability. Newer models followed like the Wheel of Wellness (Sweeney & Witmer, 1991) with its focus on the maintained balance

between different aspects of 'the self' or subtasks of self-direction. Further development led to The Indivisible Self model (Myers, & Sweeney, 2004) that emphasises holism as the foundation of human wellness as well as the Dynamic Equilibrium (DE) theory of well-being that accounts for a baseline interrelation between personality, life events, well-being and ill-being (Fujita & Diener, 2005). In this study the exploration of HIV-related psychosocial well-being was grounded by The Mental Health Continuum Model of Keyes (2002). The dynamic two continua model separates the mental illness and mental health states as two different dimensions. The model further suggests that subjective well-being is a person's own perceptions and evaluations of his/her own life in terms of personal emotion, affect and own psychological and social functioning. Such subjective well-being, also known as hedonic well-being, is defined as a mental state of being happy or experiencing pleasure as well as positive and negative affect (Tov & Diener, 2013). Three components of wellbeing are identified: Psychological well-being, Emotional well-being and Social well-being (Keyes, 2007). Psychological well-being, also known as eudemonic well-being, is described as a mental state of self-realisation in which self-development, personal growth and purposeful engagement plays a role. Psychological well-being components are levels of self-actualisation, locus of control and emotional intelligence (Fave, Brdar, Freire, Vella-Brodrick, & Wissing, 2011; Ryff, 2014). Emotional well-being is a sense of well-being which makes it possible for an individual to function in society and everyday life and recover effectively from illness, change or misfortune. Social well-being, according to Keyes (2007) is how people see their relations to others and the wider community. Social well-being has several components e.g. social acceptance, social actualisation, social contribution and social coherence. A combination of emotional well-being, psychological well-being and social well-being is seen as *mental health* or *psychosocial well-being* (Westerhof & Keyes, 2010).

The term *psychosocial* reflects the dynamic relationship between internal psychological processes like thoughts, feelings, emotions, understanding and perception and external social processes that is comprised of social networks, community, family and environment. Positive mental health is then described as having purpose in life, good social relationships,

feelings of efficacy, and optimism (Son & Wilson, 2012). Two other terms are also used in the Mental Health Continuum model, *flourishing* and *languishing*. Flourishing refers to the experience of life going well. It is a combination of feeling good and functioning effectively (psychological and social functioning). Flourishing is very strongly associated with a high level of mental well-being, and is a perfect representation of mental health. Languishing mental health is when an individual is not feeling good about life and not functioning well. Moderate mental health reflects a person being neither languishing nor flourishing (Keyes, Dhingra, & Simoes, 2010; Westerhof & Keyes, 2010).

The above mentioned literature indicate that HIV stigma is still a major factor influencing the success of the prevention of HIV worldwide. According to the literature, stigma reduction is one of the most important factors that need be addressed in any HIV-prevention strategy. Studies found very little evidence of comprehensive community approaches to reduce stigma. The challenge then is to find ways of stigma reduction interventions that would address the HIV and AIDS pandemic in a positive way, so as to reduce infections and to improve the lives of PLWH and people affected by HIV or AIDS. There seem to be a variety of suggestions and interventions for addressing this but very few of the strategies address the community at large. Instead, interventions are mostly focused on the individual and on individual responses to HIV stigma. This keeps the focus on behaviour change in the individual, without addressing the broader aspects of social change that is necessary for changes in the community itself. Literature identifies a variety of factors in the ongoing stigmatisation of people affected and infected by HIV. It appears that attempts to reduce HIV stigma often fail because in these interventions, the community does not assume responsibility for its own health and does not assume leadership towards its own well-being.

Based on the above description of the problem, this research attempted to answer the following questions:

1) Will the *HIV stigma-reduction community “hub” network intervention* result in a decrease in HIV stigma experiences of PLWH as determined and as verbalised by PLWH?

2) Will the *HIV stigma-reduction community “hub” network intervention* reduce the stigmatisation of PLWH by their community members as determined and as verbalised by the community?

3) Will the *HIV stigma-reduction community “hub” network intervention* result in a decrease in depression and an increase in psychosocial well-being in PLWH and the community in which they live?

Research Objectives

With the aim of answering the above questions, the objectives of this research were as follows:

- To explore, describe and determine whether a HIV stigma-reduction community “hub” network intervention in a South African urban area will make a difference in the HIV stigma experiences of PLWH, as well as related stigmatisation by their community.
- To describe the implementation of a HIV stigma-reduction community “hub” network intervention in an urban setting involving both PLWH and PLC as community mobilisers.
- To determine the change in depression and psychosocial well-being of PLWH and their community before and after a HIV stigma-reduction community “hub” network intervention.

Central Theoretical Argument

Literature demonstrates that the most promising approaches to HIV stigma reduction feature a combination of strategies, namely empowerment of PLWH, updated education about HIV, and activities that foster direct or indirect interaction between PLWH and key audiences. Interactive strategies like these are considered particularly useful in dispelling harmful myths and changing attitudes and even in bringing about social change on a broader scale. The above strengthens the novelty of an approach that would see PLWH and PLC from a specific community take the lead in reducing stigma in their community through a HIV stigma-reduction community “hub” network intervention in such a community. HIV stigma

reduction interventions are also important steps in a process that can lead to prevention of HIV. HIV stigma reduction interventions can be seen as a process of social change that is more likely to succeed if the individuals and communities most affected by HIV own the process and content of communication. This can present a strong element of sustainability because the approach requires communities to be the agents of their own change. The process should be empowering, horizontal (instead of top-down), giving a voice to previously unheard members of the community, and be biased towards local content and ownership. Outcomes should go beyond individual behaviour to social norms, policies, culture and the supporting environment. Therefore this study addresses the challenge of effectively building upon this existing body of knowledge. It aims to initiate strategies that mobilise HIV stigma reduction and social change in PLWH and their communities through the development, implementation and evaluation of an HIV stigma-reduction community “hub” network intervention. The strategy is based upon the involvement of PLWH and PLC, sharing their knowledge as community mobilisers and the mobilisation and empowerment of their own community.

Research Design

Bothma, Greeff, Mulaudzi, and Wright (2010) define mixed-methods as a class of research where the researcher mixes or combines quantitative and qualitative research approaches, techniques, methods, concepts or language in a single study. For this study, a convergent parallel mixed-method design was used as it is time efficient and lends itself to team research to understand the total content of a HIV stigma-reduction community “hub” network intervention. The flow of the convergent parallel design typically involves designing both the quantitative and qualitative strands in terms of collecting and analysing data separately and then using strategies to merge the two sets of results. These strategies included, inter alia, identifying content areas present in both data sets and comparing, contrasting or synthesising the results. The data was compared, related and interpretations drawn (Creswell & Plano Clark, 2011). The quantitative part entailed a single case pre-test post-test, while the qualitative part entailed a holistic single case design (Yin, 2011) as well

as the interpretive description approach (Thorne, 2008) was utilised in this study as it was the most suitable method to describe the various aspects of the intervention.

The study takes a dialectic stance, which assumes that all paradigms offer something and that multiple paradigms in a single study contribute to a richer understanding of the HIV stigma phenomenon being studied. Pragmatism in its simplest sense as a practical approach to a problem is in essence the core of this study. The pragmatic approach to science involves using the method which appears best suited to the research problem. It has strong associations with mixed-methods research. Pragmatism offers a bridge between paradigm, methodology and a practical and outcome-orientated method of inquiry (Feilzer, 2010). The fact that it is based on action and leads to further action and the elimination of doubt, offers a method for selecting methodological mixes that helps researchers to better answer their research questions (Cameron, 2011; Teddlie & Tashakkori, 2010).

Research Setting

Data was collected in a ward of Tlokwe, in the North West Province of South Africa that was known by the Department of Health to have high numbers of HIV infection. This province, according to the South African National HIV Prevalence, Incidence and Behaviour Survey, 2012 (Shishana et al., 2014), is one of the four provinces with the highest HIV prevalence in the country. According to Census 2011 (SA Statistics, 2014), Tlokwe Local Municipality has a total population of 162 762 people, of whom 71.3% are black African, and 20.6% are white. The other population groups make up the remaining 8.1%. In the study, the population of a specific ward of an urban area in the North West Province of South Africa was targeted for the HIV stigma-reduction community “hub” network intervention. This ward consisted of 784 houses with an estimated three to four people per house; thus an estimated total of 3 200 people.

Research Method

This project ran over an estimated five month period, as illustrated in Table 1. The three different phases of the project will be discussed below.

Table 1

Summary of the research process

PRE TEST (Time Line: One Month)		INTERVENTION (Time Line: Five Months)	POST TEST (Time Line: One Month)	
PLWH	PLWH		PLWH	PLWH
Quantitative Stigma Experiences N = 62 Test Battery: <ul style="list-style-type: none"> • Demographic Survey • HIV/AIDS stigma instrument – PLWH (Hasi-P)(Holzemer <i>et al.</i>, 2007b) • Patient Health Questionnaire (PHQ-9) (Kroenke <i>et al.</i>, 2001) • Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002) 	Qualitative N=10 In-depth interviews	Hub activities Two “hubs” Four mobilisers One mobiliser-coordinator Activities 3 hour workshops: <ul style="list-style-type: none"> • Understanding stigma • Coping with stigma Door-to-door education Support group Psychodrama groups Community Project: <ul style="list-style-type: none"> • Home visits to PLWH • Fruit at clinics to PLWH • Stigma campaigns 	Quantitative Stigma Experiences N = 57 Test Battery: <ul style="list-style-type: none"> • HIV/AIDS stigma instrument – PLWH (Hasi-P)(Holzemer <i>et al.</i>, 2007b) • Patient Health Questionnaire (PHQ-9) (Kroenke <i>et al.</i>, 2001) • Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002) 	Qualitative N=10 In-depth interviews
Community AIDS-related Perceptions of HIV Stigma N= 570 Test Battery <ul style="list-style-type: none"> • Demographic Survey • AIDS related stigma measure (Maughan-Brown, 2004) • Patient Health Questionnaire (PHQ-9) (Kroenke <i>et al.</i>, 2001) • Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002) 	Community N=10 In-depth interviews		Community N=469 Test Battery <ul style="list-style-type: none"> • AIDS related stigma measure (Maughan-Brown, 2004) • Patient Health Questionnaire (PHQ-9) (Kroenke <i>et al.</i>, 2001) • Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002) 	Community N=10 In-depth interviews

Phase one: Pre-test quantitative measures and qualitative in-depth interviews.

Phase one involved a quantitative and qualitative inquiry into the experiences of HIV stigma

of a group of PLWH living in a particular urban community and the related stigmatisation by their community (see Table 1).

Sample for the study. The sample for this study was made up of two groups: PLWH and community members residing in the same municipal ward. For the PLWH an accessibility sample was used. The two clinics of the Department of Health identified 1400 PLWH who were known to the clinics. A mediator at the clinics put the PLWH that were willing to participate in contact with the mobiliser-coordinator of the study. The inclusion criteria were HIV- positive status; being 18 years or older; having resided in the identified ward for at least 3 months; being conversant in Afrikaans or English or Setswana; and being prepared to be part of the quantitative study as well as to be interviewed if selected for the in-depth interviews. Care was taken that the ward was equally represented and that both males and females were included, even though the percentage of males was lower than the percentage of females. A final sample size of 62 (48 females and 14 males) were willing to participate in the quantitative part of the study. A sub-sample from these 62 PLWH was selected for the qualitative in-depth interviews. This was done by means of purposive voluntary sampling. A total of 10 in-depth interviews were conducted prior to the intervention. Data saturation (the point at which no new information is being obtained) was achieved after eight in-depth interviews, and a further two interviews were conducted to obtain a total of 10 in-depth interviews.

For the second group – the community members – random voluntary sampling was used and a member of each of the 784 households willing to participate, was included. The sampling strategy and size were determined beforehand by consultation with statistical support services. Inclusion criteria for the community members were: being 18 years or older; having resided in the identified ward for at least 3 months; being conversant in Afrikaans, English or Setswana; and being willing to be part of the quantitative study, as well as to be interviewed later if selected for the in-depth interviews. The ward was divided into six equal parts, as six trained fieldworkers went from door-to-door to collect the data. Care was taken to take age and gender into account with regard to the differentiation to the results. In this

way, 570 willing community members were included for the quantitative part of the study. A sub-sample of community members was selected for the pre-intervention in-depth interviews by means of purposive voluntary sampling. Data saturation was achieved after seven in-depth interviews and a further three in-depth interviews were conducted to bring it to a total of 10 in-depth interviews. Table 1 provides an overview of the research process that was followed in this study. Both the quantitative and qualitative aspects are indicated.

Data collection. The community was made aware of the research through several gatekeepers, e.g. ward counsellors and church leaders. A group of six trained field workers informed the participants about the purpose of the study, the reasons for their selection, the procedure and expected duration. They were informed that participation was voluntary and that they could withdraw from the study at any stage (adapted from Bothma, Greeff, Mulaudzi, & Wright, 2010). They could ask questions, had time to decide about their participation, and then signed informed consent forms. Potential availability was requested for further in-depth interviews that would be digitally recorded. Participants were assured that they would remain anonymous and that records would be kept safe.

The ward, consisting of 784 houses, was divided into six manageable areas, with a trained fieldworker allocated to each area (about 95 houses) for data gathering. The six field workers were trained in a two-day workshop to conduct the structured interviews to obtain the pre-test quantitative data. Different test batteries were used for the PLWH and the community.

Quantitative data collection. The test battery used for the PLWH consisted of a demographic survey and three measures (see Table 2).

The Demographic Survey. This survey was used in the Africa HIV stigma study (Holzemer et al., 2007b) and elicited data on demographics and illness. Participants are required to answer an 11 item survey. It covers questions on age, gender, literacy and education, income and state of household well-being.

Table 2

Test battery used for PLWH

Measures	Items
Demographic survey	11
HIV/AIDS Stigma Instrument – PLWA (HASI-P) © Holzemer et al. (2007b)	33
Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001)	9
Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002)	14

The Perceived AIDS stigma - PLWH's stigma instrument – Patient (HASI-P) © (Holzemer et al., 2007b). This instrument was designed to measure perceived HIV stigma, create a baseline from which to measure changes in stigma over time, and track potential progress towards reducing stigma. It was developed in three phases from 2003-2006: generating items based on results of focus group discussions; pilot testing and reducing the original list of items; and validating the instrument (Holzemer et al., 2007b). The Perceived AIDS stigma - PLWH's stigma instrument – Patient (HASI-P) is a 33-item measure that is read out and scored by the interviewer on a four-point scale from “Never” to “Most of the time”. It covers a list of events that may have happened to the respondent during the past three months. They need to indicate the frequency of the event that occurred because of their HIV status. The next set of questions is about their experiences in the hospital or clinic; and the last is about their feelings and thoughts. This 33-item instrument measures six dimensions of HIV-related stigma: verbal abuse (defined as behaviour or actions intended to harm the PLWH, such as being insulted or ridiculed); negative self-perception (a negative view of oneself based on HIV status, including feeling worthless or ashamed); health care neglect (patients being offered less care than expected, or being denied care or treatment); social isolation (being intentionally excluded from social events); fear of contagion (people avoiding a PLWH for fear of contracting HIV, e.g. being made to eat alone); workplace stigma (being denied opportunities due to HIV status); and total perceived stigma. The Cronbach

alpha reliability coefficients for the scale scores range from 0.76 to 0.90 (Holzemer et al., 2007b).

Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer & Williams, 2001). The PHQ-9 is the depression module of the PRIME-MD diagnostic instrument for common mental disorders, which scores each of the 9 DSM-IV criteria on a scale of 4 from 0 (“not at all”) to 3 (“nearly every day”). The PHQ-9 is a self-administered version. The respondent is asked to indicate these aspects as over the last two weeks. It comprises nine diagnostic symptom criteria upon which the diagnosis of Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) major depressive disorder (MDD) is based. The PHQ-9 has demonstrated good sensitivity and specificity for depressive disorder, addresses both depression severity and diagnosis, and facilitates communication among primary care clinicians, care managers, and mental health specialists (Monahan et al, 2009 & Chen et al., 2010). The PHQ-9 was completed by 6 000 patients in 8 primary care clinics and 7 obstetrics-gynaecology clinics. Construct validity was assessed using the 20-item Short-Form General Health Survey, self-reported sick days and clinic visits, and symptom-related difficulty. Criterion validity was assessed against an independent structured mental health professional (MHP) interview in a sample of 580 patients. In addition to making criteria-based diagnoses of depressive disorders, the PHQ-9 is also a reliable and valid measure of depression severity. These characteristics plus the brevity of the survey make the PHQ-9 a useful clinical and research tool (Kroenke, Spitzer, & Williams, 2001). According to Monahan et al. (2009) the validity and reliability of the PHQ-9 for assessing DSM-IV depressive disorders and depression severity showed a significant relationship between the PHQ-9 and general health rating or functional impairment scales. This supports construct validity, because depression is known to negatively impact upon perceived health. The internal reliability of the PHQ-9 was excellent, with a Cronbach alpha of 0.89 in the PHQ Primary Care Study and 0.86 in the PHQ Ob-Gyn Study (Kroenke et al., 2001).

The Mental Health Continuum Short Form (MHC-SF) (Keyes, 2006). The MHC-SF is an assessment and a categorical diagnosis of the presence of mental health, described as

flourishing; and of the absence of mental health, characterised as languishing. Positive functioning consists of six dimensions of psychological well-being: self-acceptance, positive relations with others, personal growth, purpose in life, environmental mastery, and autonomy (Keyes, 2006). This is a 14-point scale that focuses only on aspects of well-being (Lamers, Westerhof, & Bohlmeijer, 2011). The participant is required to answer a question on the preponderance of certain feelings, on a scale of “never” to “every day”. The MHC-SF contains three items of emotional well-being, six items of psychological well-being, and five items of social well-being, with each psychological and social well-being item representing one dimension. The MHC-SF was applied to a random sample of 1050 Setswana-speaking adults in the North West Province of South Africa. Factor analysis revealed that the mental health continuum short form (MHC-SF) replicated the three-factor structure of emotional, psychological and social well-being found in US samples. The internal reliability of the overall MHC-SF Scale was 0.74 (Keyes et al., 2008). The test battery used for the community consisted of a demographic survey and three measures (see Table 3).

Table 3

Test Battery used for the community

Measure	Items
Demographic survey	11
AIDS-related stigma measure (Maughan-Brown, 2004)	39
Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001)	9
Mental Health Continuum Short Form (MHC-SF) (Keyes, 2002)	14

The Demographic Survey. This is the same instrument described previously under the test battery for PLWH. This focus on data on demographics and illness.

AIDS-related stigma measure (Maughan-Brown, 2004). This is a 39 item measure answered on a five point scale ranging from “definitely yes” to “don’t know”. The scales measure HIV and AIDS stigma and explore potential determinants of stigma. Indices are

designed to measure the different dimensions of HIV/AIDS stigma (Maughan-Brown, 2004). The community members are tested on their perceptions of HIV stigma. The first index covers the behaviour intentions of the respondents in situations regarding PLWH. The following three indices capture different kinds of stigmatising attitudes towards PLWH: symbolic stigma (i.e. negative assessment of character); instrumental stigma (i.e. fear of infection) and resource-based stigma (i.e. opinions that PLWH should not gain preferential access to scarce social resources). Finally, all four indices are combined into a fifth index which is used as an indication of stigma in general (Maughan-Brown, 2004). Factor analysis was used to check the coherence of the indices formed, and three different factors were identified in this way, namely the behaviour index, symbolic stigma and instrumental stigma. Internal consistency was (alpha) 0.70-0.95 and the test-retest reproducibility was >0.70 (ICC or weighted kappa) (Maughan-Brown, 2004).

Patient Health Questionnaire (PHQ-9) (Kroenke et al, 2001). This is the same instrument described previously under the test battery for PLWH. The PHQ-9 is the depression module of the PRIME-MD diagnostic instrument for common mental disorders.

MHC-SF (Keyes, 2002). This is the same instrument described previously under the test battery for PLWH. This is an assessment and categorical diagnoses of the presence of mental health.

Qualitative data collection. This consisted of In-depth interviews with PLWH and community members prior to the intervention. In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, programme or situation (Boyce, Neale, & Pathfinder International, 2006). In this study the focus was on the experiences that PLWH have of HIV stigma before a HIV stigma-reduction community “hub” network intervention as well as the related stigmatisation by their community.

The in-depth interviews were conducted by the mobiliser-coordinator employed by the North-West University (NWU). She is trained and experienced in in-depth interviewing. She contacted the PLWH and community members that were purposively selected according to

the inclusion criteria from the initial quantitative sample, made appointments, reconfirmed consent and the use of digital recorders. These appointments were either at participants' homes or a place they found convenient and private. Their anonymity and the confidentiality of information that was shared, were confirmed and they were assured that their identity would never be linked to any transcriptions or recordings of the in-depth interviews due to the data being coded. The open-ended questions to be used during the in-depth interviews were given to experts, prior to the interviews, to evaluate their applicability and to adapt them accordingly. For PLWH the focus was on their experiences of HIV stigma and for community members the focus was on their perceptions of and attitudes towards PLWH. Questions to PLWH were: "Tell me about your experience with HIV stigma in ward X? What behaviour have you experienced against you by the community because you are HIV positive?" Questions to the community members were: "Tell me about your views of the PLWH that live in ward X. What behaviour have you shown towards PLWH here in ward X?" The in-depth interviews were digitally recorded. Field notes were written after each interview focussing on personal, methodological and observational notes.

Trustworthiness refers to the extent to which the researcher and the reader of the research report or article are convinced that the research process, findings and conclusions are credible (Botha, 2010). The model of Lincoln and Guba (Polit & Beck, 2008) was used for this study. Credibility was ensured by the prolonged engagement during interviewing. Reflexivity was based on the writing of field notes during the intervention and discussions with promoters. The use of both qualitative and quantitative methods and a trans-disciplinary research team ensured method and investigator triangulation. A dense description of the methodology and informed choice of sampling ensured applicability whilst consistency was ensured by the possibility of an audit trail and potential stepwise replicability due to a dense description of method and data. A co-coder was also used to enhance consistency. Neutrality was achieved through a combination of creating a possibility of an audit trail, the triangulation of investigators and methods as well as reflexivity. The authenticity of the research is beyond

reproach as the research team personally engaged with PLWH and community members during the five months of the intervention.

Phase two: A holistic single case study. The objective of the study was to describe the implementation of the HIV stigma-reduction community “hub” network intervention in an urban setting involving both PLWH and community members as mobilisers. The case study methodology provides tools for the researchers to study the complex phenomena within this context. Thus it becomes a valuable method to develop theory, to evaluate the intervention, and to develop further interventions (adapted from Baxter & Jack, 2008). The case study design followed in this research was a holistic single case study.

Setting. The HIV stigma-reduction community “hub” network intervention took place in the same ward of the municipality of Tlokwe, in the North West Province of South Africa as described in phase one. The selected ward for this study consisted of 784 houses with an estimated three to four people per house, thus an estimated average of 3200 people. According to the numbers available to the two clinics of the Department of Health there are approximately 1,400 of the people residing in this ward are HIV positive.

Participants. The participants in this study were PLWH and community members residing in the ward in question. Participants were recruited according to accessibility, during the various community activities, with no differentiation between PLWH and people of unknown HIV status residing in that community. A demographic survey indicated that the gender spread for PLWH was 77.4% female and 22.6% male, while for the community it was 60.5% female and 39.5% male. The inhabitants were mostly black: for PLWH 98.4% and for the community 97.9%. The participants were for a large part from the low socio-economic group and living in houses provided by the SA government’s reconstruction and development (RDP) programme.

The Intervention. The intervention took place over a five-month period. Two HIV stigma-reduction community “hubs” were created in the ward in question to establish a network. These “hubs” consisted of a two-person mobiliser team of one PLWH and one non-

infected person living close to a PLWH – they were referred to as *mobilisers* and functioned from a church and an informal housing setting (shack) in the community. The four mobilisers were inhabitants of the ward and were involved in a previous HIV stigma-reduction research project with PLWH and PLC as participants (French, Greeff, & Watson, 2014). In the previous study the mobilisers gained knowledge regarding the understanding of and coping with HIV stigma, as well as the planning and implementation of their own HIV stigma-reduction community project. In the present study they underwent further training in a four-day workshop, presented by the project leader, to become community mobilisers skilled to present workshops to their own community on *Understanding HIV stigma*, and *Coping with stigma*, as well as to lead a support group. They were introduced to the planned community “hub” network intervention for HIV stigma reduction. They were made familiar with the planned community “hub” network intervention for HIV stigma reduction. The mobilisers were trained to ensure effective record keeping of their community activities that took place during the intervention. A *mobiliser-coordinator* employed by the North-West University (NWU) and trained by the project leader supervised and oversaw all activities of the mobilisers in the hubs.

The planned intervention activities for the community consisted of the following:

Three-hour *Understanding HIV stigma* workshops ran twice a week. The rationale of the workshop was that by understanding stigma and the process of stigmatisation and by identifying personal strengths, participants would be empowered to take the lead in reducing HIV stigma. These workshops involved a flip chart presentation and activities that developed knowledge and skills with regard to understanding HIV stigma.

The *Coping with stigma* workshops followed the *Understanding HIV stigma* workshops with the aim to heighten awareness and broaden the positive coping skills, mechanisms and resources to meet the demands that HIV stigma place on people. These were also three-hour workshops running twice a week, for people who were interested after they attended the *Understanding HIV stigma* workshop.

Door-to-door teaching in the community was presented as an extension of the *Understanding HIV stigma* workshops by means of specially designed pamphlets. The mobilisers approached people in their own homes, mainly after hours.

A *weekly support group* of six sessions for community members and/or PLWH was led by the mobilisers as part of the intervention. The support group was presented with the aim of providing emotional support and coping mechanisms to those people who were willing to be part of a support group. It was presented after the workshops. The aim was to draw strength from other members' experiences, and to provide information for group members so that they could understand the disease and could educate their family members, friends, colleagues, and neighbours about the disease. The aim of the support group was also to demystify the disease and to promote stigma reduction and community acceptance of PLWH and their families, encouraging the community to have contact with PLWH. The support group was initially facilitated by the project leader, and the role was then taken over by the mobiliser-coordinator.

A *weekly psychodrama session* on the theme of HIV stigma reduction was planned by the mobilisers themselves and presented at various venues in the ward, such as churches and public gatherings like clinics, as well as private venues. The storyline of the drama, conceived by the mobilisers, was about a nurse and friend of an HIV-positive lady. One of the men played the boyfriend of the HIV-positive lady, who loved and supported her, while the other mobiliser played a bad guy who stigmatised the lady.

The four mobilisers further conducted their own community-based HIV stigma-reduction project with activities of their own choice. These involved mainly three activities:

- House visits to PLWH to support and encourage fellow PLWHs.
- Feeding project at clinics for PLWH. Mobilisers provided fruit and education, and used the opportunity to invite the PLWH to the workshops.
- HIV stigma campaign at the taxi rank, using the pamphlet to provide knowledge and understanding of HIV stigma.

- HIV stigma campaign in the main street, using the pamphlet to provide knowledge and understanding of HIV stigma.

Data collection. This was dependent on a case record consisting of reports on activities, field notes, naïve sketches, and a weekly report on events in the community. Reports and field notes on observational and personal impressions were kept by the mobilisers. These included the times of the workshops, door-to-door teaching on HIV stigma, the support groups and the psychodrama performances as well as the number and gender of participants and the methods that were used. They also reported on their own experiences of various activities in the intervention. The mobilisers kept similar reports and field notes on the community project with its various activities. The participants contributed by writing naïve sketches of their experiences of the workshops. They gave a written commentary on two questions “My experience...” and “I feel...” in the language of their choice after every workshop. This was translated into English where necessary.

Mobilisers kept a *weekly report of events* in the community relating to any HIV education, news or other activities during this period, to ascertain possible outside influences on stigma reduction. The mobilisers were tasked to complete a tick list on whether an HIV awareness campaign took place; whether a prominent leader disclosed his/her HIV status; whether a religious leader talked about acceptance of PLWH; whether a community leader/chief talked about acceptance of PLWH; whether a religious leader condemned PLWH; whether a political leader spoke up for PLWH; and whether positive media coverage was given about PLWH. The mobiliser-coordinator collected the reports on a weekly basis.

Data analysis of the case record. A systematic text analysis of the content of the various documents was done to identify and categorise specific observable actions or characteristics. The analysis of the HIV stigma reduction “hub” network intervention was based on the logic model technique of Yin (2011). Logic models support design, planning, communication, evaluation, and learning. It describes planned action and its expected results, enhancing understanding the relationship between activities and results (Yin, 2011).

The findings will reveal how the identified community has behaved and responded to new challenges and inputs and analyse what the case study has accomplished (Cooper, 2009).

Data analysis was further conducted by means of open coding by using the technique of Tesch (1990) as discussed in Creswell and Plano Clark (2011). This technique entails reading through all the data carefully, looking for the underlying meaning in several documents, making a list of all topics, clustering similar topics, and forming them into columns that might be grouped as major topics, unique topics, and leftovers, coding the topics and checking for emerging categories /domains and themes. A co-coder was used and discussions were held to reach consensus.

The mobilisers spent a prolonged, five-month engagement in the research field during the implementation of the community intervention, which ensured confidence in the truth of findings. The writing of field notes during and after the intervention activities, discussions amongst mobilisers, and discussions with study leaders ensured reflexivity. Applicability, consistency and potential stepwise replicability was ensured by a dense description of the method and data, which made an audit trail possible. A co-coder was also used to enhance consistency. Neutrality was achieved through this combination of a means for an audit trail, the triangulation of researchers and methods, as well as reflexivity. The personal engagement with PLWH and community members during the five months of the intervention by the research team ensured the authenticity of the research. There was ongoing supervision of the project leaders and promoters.

Phase three: Post-test quantitative measures and qualitative in-depth interviews. The post-test phase was a repeat of the quantitative measures and the qualitative inquiry into the experiences of HIV stigma of PLWH and related stigmatisation by community members. The same groups (PLWH and community) involved in the pre-test were also used in the post-test. The test battery, excluding the demographic survey, as well as the in-depth interviews, were repeated. In the post-test battery, five PLWH were lost to the study either through withdrawal, death or not being located again. The same 10 people

participated in the post-intervention in-depth interviews. In the post-test battery for the community 58 people were lost to the study and one person did not participate in the in-depth interviews.

Data analysis. The quantitative data analysis was conducted with the IBM Statistical Package for the Social Sciences (SPSS) version 22 software (Pallant, 2011). Descriptive statistics (mean and standard deviation, kurtosis and skewness values) of all study measures were calculated. A dependant t-test statistic was used to assess HIV stigma and stigmatisation differences as in the pre- and post-test phases. The probability values (statistical significance) and effect sizes (practical significance) were examined to determine the difference in construct levels between the different times of evaluation (Field, 2013).

The in-depth interviews that were digitally recorded were translated and transcribed verbatim. A second listener ensured the quality and validity of the translations. The computer software Atlas Ti. Version 6 was used during data analysis. Data analysis was conducted by means of open coding and by using the technique of Tesch as discussed in Creswell and Plano Clark (2011). This technique entails reading through all the data carefully, looking for the underlying meaning in several documents, making a list of all topics, clustering similar topics, and forming them into columns that might be grouped as major topics, unique topics, and leftovers, coding the topics and checking for emerging categories /domains and themes. A co-coder was used and discussions were held to reach consensus.

Ethical Considerations

Ethical permission was obtained from the ethics committee of the North-West University (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014). A high standard of research was a priority. Bothma, et al. (2010) strongly advocate this high standard and it complies with Coolican's (2009) requirement that strict ethical principles need to be followed. There was continued supervision by the researcher and mobiliser-coordinator. Respect for the participants was demonstrated through the provision of enough information to make participants feel comfortable in the situation and to provide voluntary written informed

consent. No form of identity was linked to collected data that was made available for analysis. Participants were informed that the research team could not safeguard information that was shared in groups but that participants could request that it be treated confidentially. This included situations where group members were known to each other, or shared their HIV status or feelings of discomfort, or experienced embarrassment. Debriefing by an independent counsellor was available to those who showed distress during any aspects of the intervention.

The direct benefits for the mobilisers were that they gained knowledge and skills to become community mobilisers and to reduce stigma in their own communities. The direct benefits for participants were that PLWH as well as the community gained knowledge about HIV stigma and coping, experienced enhanced personal growth and relationships and experienced a reduction of HIV stigma in the community. An indirect benefit for the researchers was the knowledge that they gained regarding the effective use of a HIV stigma-reduction community intervention.

Summary

In this section a short overview presented the introduction and problem statement, research questions, research objectives, central theoretical argument and the selected research methodology for this study. A narrative synthesis of the reviewed literature will follow in section B. The focus will be on: context of HIV stigma; psychosocial well-being; the causes and outcomes of stigma on PLWH, PLC as well as on the community at large; and lastly HIV stigma reduction in a community.

The findings of the research will be presented in Section C in an article format and will include three articles:

Article 1: HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention. This article deals with the HIV stigma quantitative measured and qualitative verbalised experiences of PLWH, as well as related stigmatisation by their community before and after the intervention.

Article 2: A Community “Hub” Network Intervention for HIV Stigma Reduction: A Case Study. This article focusses on a rich description of the intervention and all its various activities.

Article 3: Psychosocial Well-Being of People Living with HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention. This article deals with the psychosocial wellbeing of PLWH and the community before and after the intervention.

In section D the focus will be on summative conclusions, limitations and recommendations for the total study.

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Section B:

An Overview of Literature on HIV Stigma, Psychosocial Well-being, Outcomes of Stigma on Individuals and the Community and HIV Stigma- Reduction Interventions

“Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviances, properly so-called, will there be unknown; but faults, which appear venial to the layman, will there create the same scandal that the ordinary offense does in ordinary consciousness. If then, this society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such” (Durkheim, 1895).

An overview of literature to contextualise the research is presented. The following databases were used: Google Scholar, Ferdikat-Library Catalogue, Eric, NEXUS (NRF), SAePublications (Sabinet), PsycINFO, Science Direct, ProQuest and EbscoHost: Academic Search Premier, Cinahl, Health Source: Nursing Academic Edition, Medline, PsycArticles, PsycInfo and SocIndex.

In this literature review developments in how stigma was viewed through the years will be described. The concept of HIV stigma will be conceptualise by exploring various definitions, models and theories that deal with such concept and the types of HIV stigma. Psychosocial well-being and HIV stigma will be explored. The causes and outcomes of stigma on people living with HIV (PLWH), and people living close to them (PLC) with specific focus on the community at large will be dealt with. Developments in interventions to reduce HIV stigma within a community-based context will furthermore be described.

Introduction

The literature shows that stigmatisation has a serious effect on the global response to HIV and AIDS (Auerbach, Parkhurst, & Cáceres, 2011; Nyblade, Stangl, Weiss, & Ashburn, 2009; Pharris, et al., 2011). It seems that over the years growing concerns about HIV stigma were raised with serious calls to action. As early as 1996 a meta-analysis of 21 studies demonstrated the degree of HIV associated stigma to be higher than stigma associated with conditions like hepatitis, drug addiction, diabetes, and cancer (Crawford, 1996). Aggleton and

Parker (2002) made stigma part of the AIDS epidemic by describing three widely recognised phases of the epidemic in any society: namely the epidemic of HIV infection as the first phase, the epidemic of AIDS as the second phase, and the third phase is the epidemic of stigma, discrimination, blame and collective denial. Piot (2006) described the challenging stigma epidemic as possibly the greater challenge within the AIDS response and stigma reduction. In 2010 stigma was still a global target when UNAIDS in their vision indicated “Zero infections, Zero discrimination, Zero AIDS related deaths” (UNAIDS, 2010). It underlines the importance of deepening the response to HIV and AIDS on all levels. Clark (2011) yet again mentions the need to get rid of stigma and discrimination. Many other authors in looking at the serious effect of stigma and discrimination on the epidemic have found that HIV stigma and behaviour resulting from stigmatisation is an significant barrier to HIV activities like prevention, care and treatment (Deacon, Uys, & Mohlahlane, 2009; Mahajan et al., 2008; Nyblade, Singh, Ashburn, Brady, & Olenja, 2011; Salter et al., 2010; USAID, 2005).

In terms of goals and commitment maybe the most gripping is the statement of solidarity with Greater Involvement of People with HIV/AIDS (GIPA) made in the Ontario Accord (2011). PLWH and allies in the community pledged to greater involvement and meaningful engagement of PLWH. Important for this study is the commitment to personal and social transformation, placing great value on community expertise and inclusion over exclusion (Ontario AIDS Network, 2011).

Context of HIV Stigma

The conceptualisation of stigma, models and theories of stigma in general, as well as HIV stigma specifically will be explored.

Conceptualisation of stigma. Historically the definitions of stigma grew mostly out of the world of physical and mental illness (Arthur, Hickling, Robertson-Hickling, Haynes-Robinson, Abel, & Whitley, 2010). Stigma and discrimination can be experienced by people with mental health problems and other chronic diseases such as obesity, lifestyle choices like

alcoholism and smoking (Kleinman & Hall-Clifford, 2009; Sikorski et al., 2012) and even giftedness (Coleman & Cross, 2001).

Thoughts about the stigma concept, definition and character have shifted since the articulation of the theory of social stigma by Erving Goffman in the 1960s. He described a stigma as a given attribute, behaviour or reputation with the potential to socially discredit the individual in a particular way and caused the individual or group to be seen as undesirable by others (Goffman, 1963). Similarly, Jones, Farina, Hastorf, Markus, Miller, and Scott, (1984) focused on stigma as an attribute, but added the term 'mark' to emphasise how society identify a deviant condition and brand the individual as flawed or spoiled. Jones et al. (1984) further describe the stigmatising process as being influenced by the social environment in terms of what a particular social environment regards as deviant in the light of that environment's values and context. These authors furthermore refer to an internal psychological process within an individual, described as impression engulfment, which can be seen as the essence of stigma. Crocker, Major, and Steele (1998) for instance, understood stigma as an occurrence linked to an individual that display or expose an attribute, feature or characteristic that is devalued in the particular social context. Stigma, therefore, is not conceptualized as something located within the stigmatised person only, but also as an occurrence within a particular social context.

Falk (2001) is of the opinion that stigmatisation will always occur in society since it portrays a typical societal agreement about certain conditions and behaviour and thus provides societal solidarity by delineating "outsiders" from "insiders". In their early work Alonzo and Reynolds (1995) took the idea of stigma further by thinking of it as a social label that radically changes self-perception and perception coming from others because of power relations between them and the ability to discredit a person or their behaviour. As seen, different authors seem to concur that stigma can be defined as an attribute that marks certain individuals as different and leads to their devaluation. The conclusion is that stigmatisation is dependent on aspects of relationship and context and can be observed as a socially constructed phenomenon (Major & O'Brien, 2005). Kurzban and Leary (2001) present a

reconceptualisation of stigma. Their perspective is based on evolutionary psychology and these authors want to change the emphasis of stigma. They suggest that the emphasis of stigma is not on the devaluation of an individual's (spoiled) identity, but on the process by which individuals satisfy certain criteria. Individuals are, according to these authors, rather stigmatised because of characteristics that the particular society want to avoid or exclude from their midst. It is imperative though to realise that these conceptualisations are open to criticism if they do not take the stigmatised person's viewpoint into account, or conversely focus on forces within the individual rather than on the many societal forces that cause exclusion from social life (Parker & Aggleton, 2003). Manzo (2004) scathingly makes the claim that stigma has become under-defined and over-used. He feels that any condition, conduct or membership can be stigmatising - insofar as it can be discrediting, in some context. Krajewski, Burazeri, and Brand (2013) recognised national disparities in stigma in six European countries and claims differences, which exists between countries and possibly within them, too. They suggest that the concept of stigma, varies according to the country, or culture. Corrigan and Ben-Zeev (2012) ask the question: Is stigma a stigmatising word? They maintain that science and its methodology cannot be divorced from political agendas. Politics cover a diversity of perspectives; just not referring to stigma or replacing it with a different construct like social inclusion, may not be consented to by all parties.

In conceptualising HIV stigma several authors use more or less the base definition of spoiled identity but added important elements to this by adding structural and psychosocial elements to the definition (Holzemer et al., 2007; Link & Phelan, 2001; Petros, Airhibenbuwa, Simbayi, Ramlagan, & Brown, 2006; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009). Link and Phelan (2001) responded to criticisms that the stigma concept has not been vaguely defined precisely enough. It also often focuses on the individual. They define stigma as a more complex occurrence consisting of different elements like stereotyping, separation, labelling, loss of status, and discrimination. They further indicate that the processes of stigmatisation can only take place if certain measures of power exist and is exercised as such.

The Royal Tropical Institute (2004), in a research workshop on health-related stigma and discrimination focused on circumstances that defines stigma as existing where any two of the three following circumstances occur, namely that the person is regarded as of low value, is being excluded and/or placed at a disadvantage because of the stigmatised condition. This brings the political and community aspect of stigma into play. Aggleton and Parker (2002) interpreted stigma as being dynamic in its nature and constructed as a social process intertwined within a larger social context. These processes of interpretation and construction of stigma are linked with a micro (individual) as well as a macro (collective) level of society, as for example, HIV and AIDS related fear and shame are experienced on both a personal and a societal level (Daniel, Apila, Bjørgo, & Lie, 2007). Yang, Kleinman, Link, Phelan, Lee, and Good (2007) expand on the interpretation of stigma within a social and cultural process and introduce the aspect of stigma being an essentially moral issue. Kleinman and Hall-Clifford (2009) concur and explain that such moral experience would encompass a set of tailored social norms and obligations pertinent to any particular community. They make a further point that the term social death could replace the term stigma since it is more descriptive and offer clarity regarding societal responses to unacceptable occurrences or behaviour.

It is clear that HIV stigma, as a social construct, consists of various contextual elements that include shared values, attitudes and beliefs which are interpreted as perceived threats to physical or social health and welfare (Doná, 2010; Pulerwitz, Michaelis, Lippman, Chinaglia, & Diaz, 2008). Niehaus (2007) argues that due to their perceived status of eminent death PLWH may experience a so called social death. Steward et al. (2008) also refers to HIV stigma as a shared societal attitude of the devaluing and discrediting of PLWH. It becomes clear through attitudes of prejudice and discrimination towards PLWH and even individuals, groups, and communities close to them. Galindo (2013) in a study with a population of ethno racial and sexual minorities found HIV-related stigma threatened what really matters in a community, (moral experience), disrupted the accepted social connections

and in that way affected social structures. This impacted on the overall individual well-being as well as the social norms and cultural values of the community.

The term 'stigma', in academic literature, seems mainly to refer to a range of thoughts and attitudes within the social and psychological context of human functioning (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003) or obvious and dominant structural elements that start and maintain social bias, inequity and oppression (Blankenship, West, Kershaw, & Biradavolu, 2008; Chan & Reidpath, 2005; Golden & Earp, 2012; Link & Phelan, 2001). The formulation proposed by Weiss, Ramakrishna, and Somma (2006, p280) that "Stigma is typically a social process, experienced or anticipated, Characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group" seems to encompass most of all the recent thinking on a stigma definition.

A related concept in the stigma literature is that of discrimination. There have been suggestions to replace the term stigma with the term discrimination or even social oppression since the term stigma focusses too strongly on the attributes of the stigmatised instead of on social and structural mechanisms that institute and maintain discrimination (Everett, 2004; Manzo, 2004). Herek (2002) sees discrimination as behaviour or actions against a person that is reflected on their membership of a specific group, which becomes an outcome of stigma when defended or encouraged by society. In this light discrimination arises from prejudice towards the group. USAID (2005) link the terms discrimination and stigma by describing discrimination as the end result of the process of stigma consisting of negative behaviour that devalue the stigmatised. Petros et al. (2006) in a qualitative study that examined race and cultural behaviour relevant to HIV infection, explore the importance of social concepts like stigma and denial with regards to the transmission of HIV. They found that placing blame on the other for HIV and AIDS is central to these positions, with blame being magnified through the compounded perspectives of race, culture, homophobia and xenophobia. Rankin, Brennan, Schell, Laviwa, and Rankin (2005) suggest the limiting of the defining of stigma to describing the process of excluding the other (othering) through blaming

and shaming and say that stigma is a part of the attitudes and social structures that set people against each other. The separation of stigma from discrimination will facilitate the description and clarify the relationship between the two. Deacon (2006) who sought a common theoretical perspective on stigma agreed with the suggestion that it is vital to distinguish between what is known as HIV and AIDS stigma (negative things people believe about HIV and AIDS and PLWH), and what is discrimination (actions that unfairly disadvantage PLWH) (Deacon, 2006; Deacon, Stephney, & Prosalendis, 2005). In the view of these authors discrimination refers to behaviour that has the purpose of disadvantaging people. Deacon (2006) therefore advocate for a distinction between stigma and discrimination in order to emphasise the negative consequences of stigma as such and facilitate deeper conceptualising of responses to stigmatisation. They felt that a definition of stigma that combines both the individual and social dimensions of this complex phenomenon would reassess the existence of types of stigma. There is a growing understanding that stigmatisation and discrimination should not be seen as isolated phenomena that only express individual attitudes. They are social processes and are utilised to initiate and maintain social power that leads to social inequality. In this way discrimination is defined as a consequence of stigma (Cardey, 2006; Figueroa, Kincaid, Rani, & Lewis, 2002; Mahajan et al., 2008; Parker & Aggleton, 2003).

Models and Theories of Stigma and Discrimination. As previously stated, historically stigma and discrimination were experienced by people with mental health problems and other chronic disfiguring diseases such as leprosy. In this light the development of general stigma and discrimination models and theories will be covered leading to the more specific HIV stigma theories and models as portrayed in the literature.

General models and theories of stigma. Phelan, Link, and Dovidio (2008) examined 18 different models in a systematic literature review with a view of finding and understanding possible commonalities and distinctions between prejudice and stigma. Their conclusions were that most differences were a matter of focus and emphasis. One of the essential distinctions seem to be in the type of human attributes that forms the main focus of these

models relating to prejudice regarding race, and stigma regarding deviant behaviour, identity, disease and disabilities. Allport (1954) originally introduced the intergroup contact hypothesis for racial and ethnic encounters, and it resulted in the Intergroup Contact Theory. Allport (1954) described ethnic prejudice as an antagonism directed towards a group as a whole or towards an individual because he/she is a member of that group based on inaccurate and inflexible generalisation. It may be felt or expressed. A large number of influences affect the development of prejudice, including cognitive, social structural, cultural and psychodynamic factors. In criticisms of intergroup contact theory, Pettigrew (1998), referring to a heterosexual community and a sexual minority and transgender community, explained how contact between groups can improve intergroup relationships and facilitate processes of change. The heterosexual community is the designated in-group and the other as the out-group. This contact can challenge stereotypical beliefs and highlight stigmatised persons as individuals with common goals and desires. Pettigrew, Tropp, Wagner, and Christ (2011) found that Allport's original conditions of optimal contact, equal status, common goals, no intergroup competition, and authority help with change processes. The idea around the importance of groups was also brought in by the Realistic Group Conflict Model (Sherif, 1958). People with common goals form group structures expressed in statuses and roles. If two such groups are integrated under competitive conditions, it could lead to group frustration, hostility and social distance. Gaunt (2011) suggests that the desire to engage in intergroup contact can be strengthened by how strong the intergroup conflict is and by the individual's previous social contact with out-group members.

The Social Identity Theory of Tajfel and Turner (1979) also refers to groups. People have more than one social identity connected to their different group memberships. A positive social identity in a specific group leads to self-esteem associated with members of that group which forms an in-group for the individuals concerned. Ashburn-Nardo (2010) felt that an important contribution of the theory is its differentiation between how individuals view themselves (personal identity) and how individuals view their social group (social or collective identity). Ashburn-Nardo's (2010) definition describes personal identity as beliefs about

oneself and self-esteem. Social identity is the identification with and evaluation of a social group. On the theme of identity, the Identity Threat Model describe that being in possession of a stigmatised identity increases exposure to stressful situations that threaten identity (Bernstein & Claypool, 2012; Bernstein, Sacco, Young, Hugenberg, & Cook, 2010).

The Labelling Theory (Scheff, 1984) and the Modified Labelling Theory of mental disorders (Link, Struening, Cullen, Shrout, & Dohnrenwend, 1989) complements Goffman's (1963) work by formalizing a theory of mental illness as labelling. This approach emphasises the social construction of labels and stigma.

Equating moral experience and stigma brings in elements of self, others and standards. An early theory about self was the Objective Self-awareness Theory (OSA) (Duval & Wicklund, 1972). The OSA theory concerned itself with the ability of humans to reflect on the self. The theory tried to explain peoples' conforming to the behaviour, beliefs and appearances of others. It seems as if the human consciousness can focus on self-evaluation and compare the self to perceived standards set by a combination of self, others and the cause of experiences. Phemister and Crewe (2004) stated that individuals who perceive themselves as different may feel permanently stigmatised as stigma actually mirrors our social and cultural beliefs. Focusing attention on the self can lead to conscious awareness of the self which leads to a process of self-evaluation. There seems to be a growing body of knowledge clarifying the linkages between self-awareness and experiential attribution, the nature and discipline of self-standards and its discrepancies as well as the nature of standards (Silvia & Phillips, 2013; Yang et al., 2007). Moral experience, that which is most important for people in their local social world shapes the stigma process for stigmatisers and the stigmatised as stigma threatens the loss of what really matters (Yang et al., 2007).

The concept and impact of stigma on people, treatment and policies were the core emphasis of a sociological study of mental illness done by Pescosolido and Martin (2007). The social outcomes in the study were related to mental illness and demonstrated the power vested in common experiences. Occurrences like familiarity, interpersonal contact and

interaction played a vital role in the reduction of discrimination and prejudice. It also contributed to understanding the biological basis of many mental illnesses (Pescosolido & Martin, 2007). Pescosolido, Martin, Lang, and Olafsdottir (2008) propose a framework that uses insights from micro, meso- and macro levels. This framework, The Framework Integrating Normative Influence on Stigma (FINIS) explains that understanding stigma begins with understanding the individual's affect and motivation that manifests in social relationships. However, all social interactions play itself out in organizations and culture with its own normative expectations (Pescosolido, et al., 2008).

It seems from the literature that general theories and models of stigma and discrimination have importance for the understanding of HIV stigma in that they underline concepts like in and out group behaviour and even while focused heavily on the individual these theories and models link individual identity with group identity, eventually incorporating contexts like the social and political environment.

Models and Theories of HIV stigma. Probably the most relevant work on HIV stigma in the earlier years is by Link and Phelan (2001). Their perspective link individual and social stigma components and describe stigma as a constantly changing social process. Link and Phelan (2001) propose that stigma exists when four specific components converge. These components are that: individuals label what they perceive as differences (exercise of power, this include structural discrimination placed by institutions on stigmatised groups; stereotypes tie those labelled to adverse attributes (stereotyping); labelled individuals are separated into distinct groups that serve to establish a sense of disconnection between in-groups and out-groups; and labelled individuals lose status and experience discrimination that leads to disapproval, rejection and exclusion. Parker and Aggleton (2003) focused on how prejudice, stereotyping, and discrimination operate together within a broader social, cultural, political, and economic framework and not as individual processes to produce a society level outcome of the development and maintenance of stigma. Parker and Aggleton (2003) links stigma to the workings of social inequality which causes some groups to be devalued and others to feel they are superior. Their conclusion is that stigma plays a role in producing and reproducing

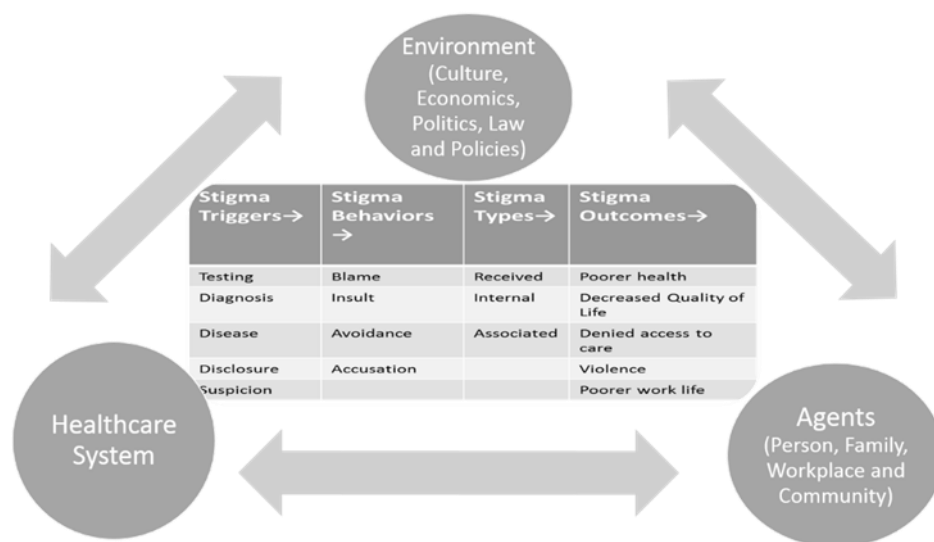
relations of power and control. Campbell, Foulis, Maimane, and Sibiya (2005) call stigma a form of psychosocial policing. They named the differing contexts in which stigma occurs as the symbolic, economic, political and local community contexts and add the organizational context of institutions that work to address HIV and AIDS. Visser et al. (2009) felt the nature of stigma in the specific cultural context merit understanding.

Through the years authors proposed models and frameworks for the understanding of stigma. Alonzo and Reynolds (1995) analysed HIV and AIDS in terms of a stigma trajectory. The trajectory is the course of the disease, tied to the responses of society. They suggest four phases of such a trajectory where stigmatisation can occur, namely the healthy people who might be worried and at risk when faced with the diagnosis; living between illness and health; the period the illness manifests; and the journey to social and physical death. Mahajan et al. (2008) offer a conceptual framework for HIV and AIDS related stigma derived from their review of the literature. They postulated that inequalities in power (social, political, and economic) are the basis on which stigma is founded and structural violence like racism, sexism inter alia and pre-existing stigmas like those against marginalized groups for example men having sex with men (MSM) are power based. This enables labeling, stereotyping, status loss, and discrimination in power settings. The HIV Stigma Framework of Earnshaw and ChauDoir (2009) make use of concepts and measurements of HIV stigma among individuals. Their HIV Stigma Framework points out that enacted stigma, anticipated stigma, and internalised stigma affects both HIV uninfected and infected people. The International Center for Research on Women (ICRW) (2013) in collaboration with UNAIDS published a global HIV stigma reduction framework adapted and implemented for India. The framework focuses on factors that cause HIV stigma that is termed 'actionable' because an intervention can effect change of these factors. These factors are aspects like knowledge of stigma and how harmful it is, social judgment and fears like fear of infection.

A conceptual model of HIV and AIDS stigma from five African countries by Holzemer et al. (2007) forms the theoretical framework of the research done for this study (Figure 1). The model refers to both context and process. The context of HIV stigma is created by (1)

the environment which is the cultural, economic, political, legal and policy environment; (2) the healthcare system which includes settings such as hospitals, clinics and home-based care settings and health service delivery settings, and (3) agents (people) like PLWH, family, workplace and community. The process of HIV stigma as conceptualized by Holzemer et al. (2007) shows the interlinking of the elements of the context that play a role in stigmatising. The process itself follows from certain triggers, namely the HIV disease, diagnosis, disclosure and the suspicion of having the disease to secondly stigmatising behaviour by other people like blame, insults avoidance and accusation. This then leads to certain types of stigma, (received, internal and associated) and finally certain stigma outcomes, e.g. poorer health, decreased quality of life, violence, poor quality of work life.

A trigger, as mentioned, is any action that allows people to label themselves or others as HIV-positive. It is important to note that HIV and AIDS stigma can be experienced not only by PLWH but also by people who are associated with PLWH, e.g. partners, children or healthcare workers.



(Adapted from Holzemer et al., 2007)

Figure 1: Model of the Dynamics of HIV and AIDS Stigma

Types of stigma. As mentioned the conceptual model of Holzemer et al. (2007) describe three types of stigma, namely received, internal and associated. This will be used as a framework to discuss similar or different views of other authors for understanding the experience of HIV stigma, Nyamathi et al. (2013) similarly emphasised the three ways in which individuals experience stigma, by the actions of others (received), or the subjective awareness of stigma (felt normative stigma), and internalised stigma, but does not mention associated stigma.

Received stigma. Received stigma is how respondents act toward PLWH (Holzemer et al., 2007; Steward et al., 2008; Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). This refers to all types of stigmatising behaviour towards a PLWH, as experienced or described by themselves or others (Holzemer et al., 2007). Greeff and Phetlhu (2007) identify nine dimensions of received stigma. These dimensions are neglect, fearing contagion, avoidance behaviour, rejecting, labelling, pestering, negating, abusing and gossiping. Stigma in the moral sense is a labelling of individuals and processes and negative or positive value assigned by individuals or groups to other people's behaviour, jobs, goals and more (Martinez, Piff, Mendoza-Denton, & Hinshaw, 2011; Quinn & Earnshaw, 2013). These and other authors examined how ascribing humanity to an individual labelled with illness may influence perceptions of dangerousness and be a motivation for social rejection (Haslam, Loughnan, Reynolds, & Wilson, 2007; Loughnan, Haslam, Murnane, Vaes, Reynold, & Suitner, 2010; Martinez et al., 2011).

A form of received stigma is violence and verbal abuse of PLWH. This could be words, phrases, shouting, and singing with the goal of insulting, blaming, or seeking revenge. PLWH could be called names referring to their being different or that they should be avoided and not be a part of the community or even their family (Dlamini et al., 2007). Uys et al. (2009) highlighted that the community view of HIV or AIDS and PLWH in African countries still seem to be mainly negative, derogatory and harmful and filled with name calling and blaming terminology. Uys et al. (2009) name a few "Eating plastic", "Winning the lotto" and "Joining

the www". Abrahams and Jewkes (2012) with a group of PLWH in Cape Town found that the most common stigma experiences of the participants were gossips and insults.

Received stigma relates to the etic perspective, which is the outsiders' view of the world as described by Pike (1954). This results in actual experiences of discrimination (enacted stigma). Enacted stigma could be experience of domination, oppression, harassment and the like. (Siyam'kela, 2003; UNAIDS, 2010). The etic view of the world, where others direct stigma-related remarks or actions to the person living with HIV and AIDS is related to received stigma (Carr & Nyblade, 2007).

Internal stigma. A person's own negative perceptions about themselves, leads to internal stigma (Holzemer et al., 2007). These perceptions are based on their HIV status. Types of internal stigma include reactions like social withdrawal, self-exclusion from activities, and fear of disclosure as well as negative perceptions of self (Greeff et al., 2010). Deep disgust can be felt against the self as an ill person and this can destroy the humane and humanizing self. It is upon this already serious oppression that illness-related stigma adds its heavy burden (Rankin et al., 2005; Verhaeghe, Bracke, & Bruynooghe, 2008; Verhaeghe, Bracke, & Christiaens, 2008). The individual's outward behaviours may project a debased inner frame of mind. A HIV-positive diagnosis and disclosure of HIV status can have a serious detrimental effect on PLWH's forming of new relationships or making life altering decisions about having children (Nattabi, Li, Thompson, Orach, & Earnest, 2011).

Internalised stigma among the general population of PLWH is described by Overstreet, Earnshaw, Kalichman, and Quinn (2013). They found that the magnitude to which PLWH support the negative beliefs associated with HIV, negatively direct interpersonal relations and have important implications for psychological and physical health. Results revealed a connection between internalised stigma and reduced HIV status disclosure to participants' last sexual partner and to family members. It is related to depressive symptomatology (Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007) and feelings of loneliness and social isolation (Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). This includes

feeling that one is unclean, a bad person, being punished, and being riddled with shame and guilt for being HIV positive. Feelings of hopelessness and increased symptom severity coupled with reduced treatment adherence, poor self-esteem and experiencing decreased empowerment, have been linked to self-stigma (Livingston & Boyd, 2010).

Internal stigma relates to the concept of the emic view of the world as opposed to the etic view of the world (Pike, 1954), or the person's perceived or self-interpreted view of stigma. The emic approach focuses on distinctions meaningful to the members of a given group. Internalised stigma or self-stigma is negative thoughts or feelings towards the self, based on the fact of having an illness and believing in negative stereotypes that have become linked to the experience of HIV (Nyamathi et al., 2013; Siyam'kela, 2003). There is a difference between self-stigma and self-discrimination which is behaviour that arises from this attitude, for example not applying for a job because of feelings of uselessness. For example a study by Schuster, Beckett, Corona, and Zhou (2005) found parents' fear of transmitting HIV to their children or fear of catching an illness or opportunistic infection from their children, led to avoiding physical interactions with the children because of these fears. Internal stigma (felt or imagined stigma) is the shame associated with HIV and AIDS and PLWHs' fear of being discriminated against. It can result in the refusal or reluctance to disclose HIV status or the denial of HIV and AIDS and avoidance of care settings. Internalised stigma occurs when an uninfected individual either stigmatises PLWH, or when PLWH believes that they deserve to be stigmatised (Thomas et al., 2005). Earnshaw, Quinn, and Park (2012) describe the belief and fear that prejudice, discrimination and stereotyping will be directed at the self from others as anticipated stigma.

Associated stigma. The conceptual model of HIV and AIDS stigma from five African countries (Holzemer et al., 2007) indicates associated stigma as the third type of stigma (see figure 1). It involves examples of stigma that result from a person's association with PLWH, through living or working with them for example a partner, child or healthcare worker.

The Siyam'kela (2003) indicators place stigma by association under external stigma and attribute it to a culture of suspicion. This type of stigma is also called secondary stigma (Holzemer et al., 2007; Hong, Anh, & Ogden, 2004). Busza (2001) refers to symbolic AIDS stigma which means a fear of being disgraced when associated with populations that seem more vulnerable to HIV and AIDS due to their association with behaviours considered deviant or immoral, like commercial sex workers or men who have sex with men, or healthcare workers delivering services. Verhaeghe and Bracke (2011) more recently strengthen these ideas. Their investigation into the stigma experiences of users in relation to trust in the caregivers found that service users with more stigma experiences display less trust and are generally less satisfied with the services. A study in Nigeria describes that social responses of fear, denial, stigma and discrimination has affected PLC as well as individuals infected and affected (Akpa, Adeolu-Olaiyaa, Olusegun-Odebirib, & Aganabac, 2011).

As the psychosocial well-being of the infected and affected by HIV plays a role in this study a view of psychosocial well-being is warranted.

Psychosocial Well-being

This section takes a closer look at the concept of well-being in general, leading to a specific look at psychosocial wellbeing as being one of the themes of this study. Certain models of psychosocial wellbeing are brought into clarity in terms of the study. Community well-being and psychosocial well-being and HIV stigma will be addressed.

Holistic and Multidimensional conception of well-being. The concept of well-being has traditionally been viewed from two differing points of view, a clinical orientation, measuring well-being through pathology like depression, distress, anxiety, or substance abuse and the psychological orientation which sees well-being in terms of an individual's personal evaluation of life satisfaction. These differing points of view lead to the search for a holistic model to provide an understanding of all the relevant factors that explain holistic well-being, mind, body and environment (Els & De La Rey, 2006).

Engel's (1977) proposition of a bio psychosocial model (BPS) model has become one of the main theoretical foundations in medical education and the development of integrated care models (Adler, 2009). This model is dynamic, interactional and has a dualistic (mind and body) view of human experience. It is based on systems theory and on the organization of organisms in hierarchical fashion. There is room within its framework for the social, psychological, and behavioural dimensions of illness (Engels, 1977). The model is extended by the introduction of semiotics, the signs which describe the relationships between the individual and his environment and constructivism which explains how an organism perceives his environment (Adler, 2009). The BPS model views illness as resulting from interactions at physical, intra- and interpersonal and environmental levels. The individual's physical, emotional and surrounding environment is essential components of the total human being and need be regarded in the illness. Psychosocial factors may facilitate, sustain or modify the course of illness. The relative weight of the factors might vary (Fava & Sonino, 2008). Positive health is seen as the most desirable functioning of manifold physiological systems plus functionality in daily life, productivity, social roles performance, intellectual capacity, emotional stability and well-being. BPS processes affect each other when they happen or exist together and can delay the onset of morbidity, help the individual function and thereby prolong periods of quality living (Ryff, Singer, & Dienberg Love, 2004).

The holistic anthropological eco-systemic approach represents a clear divergence from the established mechanistic medical-disease model. In this model health is an outcome of human-environment systems. In other words man, his environment and his community all play a role in determining health and disease, mental or physical (Williamson & Robinson, 2006). Reese and Myers (2012) present the concept of Eco Wellness as the missing connection in wellness models. Eco Wellness is not a single construct but rather consists of three separate dimensions. These include access to nature; environmental identity, found in environments that increase well-being and contribute to health, whereas negative environments, distract from health and contribute to sick responses to life; and transcendence

in nature, experiences of interconnectedness and unity with all things. Two elements of these experiences are spirituality and community connectedness.

The Wheel of Wellness is an early theoretical model (Sweeney & Witmer, 1991; Witmer & Sweeney, 1992) which proposes five life tasks. These are shown in a wheel which is interrelated and interconnected. These five spokes are spirituality, work and free time, friendship, love, and self-direction (Myers, Sweeney, & Witmer, 2000). The Wheel model led to the development of a new model, The Indivisible Self, consisting of the Creative Self, the Coping Self, Social Self, Essential Self, and Physical Self (Hattie, Myers, & Sweeney, 2004).

Recent definitions emphasise states of satisfaction with life, personal meaningful pursuit of goals, and descriptions of well-being such as robust health, a sustainable environment, high levels of civic participation and intra- and interpersonal relationships, understanding the self through the physical, mental, spiritual, and emotional levels, and relationships with the community and environment (Brown & Alcoe, 2010; Copestake, 2007; Foster & Keller, 2007). In most descriptions well-being are essentially six major dimensions namely the physical, emotional, mental, social, occupational and spiritual dimensions.

It seems that, well-being can be classified into objective and subjective measures. The objective factors are such as economic, social and environmental influences (social well-being). Factors for subjective wellness, (psychological well-being) relates to self-acceptance, positive relationships with others, personal growth, purpose in life, mastery over the environment and autonomy. The ability to bounce back from setbacks and failures, are often called resiliency (Conceição & Bandura, 2008; Cummins, Woerner, Gibson, Lai, Weinberg, & Collard, 2008). Resilience is a dynamic process in which individuals, family, and wider social contexts interact to make adaptation possible (Ruiz-Casares, Guzder, Rousseau, & Kirmayer, 2014). In defining well-being lie certain challenges as mostly descriptions using a range of theoretical perspectives and dimensions instead of precise definitions are found in the literature. Dodge, Daly, Huyton, and Sanders (2012) propose a new definition of stable well-being as the balance point between an individual's psychological, social and physical

resources needed to meet a particular psychological, social and/or physical challenge. When individuals have more challenges than resources, their well-being are negatively affected.

Models of psychosocial well-being. Traditionally two perspectives of well-being are found. One focuses on hedonic well-being, the other on eudemonic well-being (Ryff, Singer, & Dienberg Love, 2004). Hedonic well-being describes a mental state of being happy or experiencing pleasure and positive and negative affect (Son & Wilson, 2012). Eudemonic well-being is a mental state of self-realisation in which self-development, personal growth and purposeful engagement plays a role. Positive mental health is then described as purpose in life, good social relationships, feelings of efficacy, and optimism (Son & Wilson, 2012).

Antonovsky's salutogenic model focuses on origins of health. It concentrates on factors that support and increase well-being rather than on factors that merely prevent disease (Antonovsky, 1996). Salutogenesis looks at factors that enable health despite disease and illness. Salutogenesis are influenced in the first instance by factors such as social support, financial resources and culture as well as insight, experience and intellectual capacity. The belief is that if people have these kinds of resources available to them, there is a good chance they are better able to deal with the challenges of life. The second area of influence is a sense of coherence. The elements of a sense of coherence is understanding of life, being able to manage one's life, experiencing meaningfulness and emotional closeness to others and being a part of their community (Sagy & Antonovsky, 2000; Eriksson & Lindstrom, 2008; Lindstrom & Eriksson, 2009). Salutogenesis is accepted as an effective model for increasing health and well-being and addressing unfair health treatment (Billings & Hashem, 2010).

According to the dynamic equilibrium (DE) theory of well-being (Fujita & Diener, 2005), individuals have their own equilibrium level or set point of subjective well-being and revert to that equilibrium once the psychological impact of major life events has dissipated. DE theory and set point theory are taken to apply not just to *well-being* (life satisfaction and positive affects), but also to *ill-being* (anxiety states and related negative affects). The theory initially related to both well-being and ill-being (Headey & Wearing, 1992). In recent years the

inclination has been to refer solely to a well-being or happiness set point. However well-being and ill-being have been shown to be distinct dimensions, which are not just opposite ends of the same dimension (Cummins, Woerner, Gibson, Lai, Weinberg, & Collard, 2010; Headley, 2006).

In the Mental Health Continuum model, the two continua model states that mental illness and mental health are different dimensions. According to this model subjective well-being is the person's perceptions and evaluations of their own lives in terms of their emotion and affect and their psychological and social functioning. Subjective well-being is defined as the general evaluation of one's quality of life with three components, life satisfaction, positive levels of pleasant emotions, and low levels of negative moods (Tov & Diener, 2013). A sequential framework sees subjective well-being unfold over time, from causal events like life circumstances and events; emotional reactions to those events, recollection of one's reactions and a general evaluative judgment about one's life (Kim-Prieto, Diener, Tamir, Scollon, & Diener, 2005). Psychological well-being (PWB) components are level of self-actualisation, locus of control, sense of coherence and emotional intelligence (Keyes, Shmotkin, & Ryff, 2002). Emotional well-being (EWB) is a sense of wellbeing which makes it possible for an individual to function in society and everyday life and recover effectively from illness, change or misfortune (McLaughlin, 2008). Social well-being (SWB), according to Keyes (2007) is how people see their relations to others and the wider community. Social well-being has several components e.g. social acceptance, social actualisation social contribution and social coherence. A sense of belonging to a community, can help diminish social isolation, and increase self-esteem, thus enhance social integration into the community. A combination of emotional well-being, psychological well-being and social well-being is seen as mental health (Westerhof & Keyes, 2010). This combination is referred to as psychosocial well-being. Psychosocial well-being is often defined in terms of the quality of a person's psychological functioning with respect to an array of characteristics indicative of positive mental health (Keyes, 2002, 2006, 2007; Ryff & Singer, 2006). The terms psychological and psychosocial well-being seems to be used interchangeably in the literature

(Wissing & Van Eeden, 2002). The choice of the term psychosocial well-being acknowledges that social and psychological issues are closely related and dynamic (Williamson & Robinson, 2006).

Two other terms are also used in the latter model, *flourishing* and *languishing*. Flourishing refers to the experience of life going well. It is a combination of feeling good and functioning effectively (psychological and social functioning). Flourishing is very strongly associated with a high level of mental wellbeing, and is a perfect representation of mental health. Languishing mental health is when an individual is not feeling good about and not functioning well in life. Moderate mental health are used when a person are neither languishing nor flourishing (Huppert & So, 2013; Keyes, Dhingra, & Simoes, 2010; Westerhof & Keyes, 2010).

Community well-being. Community well-being includes social norms, how people relate to each other and to their surroundings, as well as how much investment they are willing to make in themselves and in the people around them. The report on community well-being and community process from the Institute of Medicine (IOM, 2012) describes community well-being as inclusive of the physical as well as the social and economic environments that affect the health of individuals and populations, directly and indirectly. Elements of community well-being are produced, reproduced, and transformed by the practice of individuals in the community and include wealth and income, crime, transportation, housing, education, employment, worksites, food, social support and social networks, and health care, among others.

Literature suggests that individual and collective well-being depends on what happens in a variety of areas (Kim, Kalibala, Neema, Lukwago, & Weiss, 2012; Mikkonen & Raphael, 2010). Place, neighbourhood, and community are important because of their assets in health promotion and wellness generation (Hayes, 2007). Going broader, it was found that being at ease in one's surrounding cultural context influences what constitutes well-being. Noticeably different cultural formulations have an effect on perceptions of well-being. In the West well-

being is viewed as personal and individual and thus is associated with self-esteem and the pursuit of one's own happiness. An Eastern conception of well-being is more relational, intersubjective and collective. (Ryff, et al. 2014) In a study on members of a community support and advocacy centre in Oregon, increased social and community supports was found to be of value to health management and recovery, as well as diminished the negative effects of perceived stigma and societal discrimination, and ultimately maximize said individuals overall well-being (Buck, 2013). Societal stigma associated with race and ethnicity contributes to general disparities in mental and physical health and health care (Earnshaw, Bogart, Dovidio, & Williams 2013).

Psychosocial well-being and HIV stigma. HIV as an illness first presents at the physical level of an individual as an aggressive virus that compromises immunity. From here follows a distinctive and sudden and extreme experience for the patient which greatly affect people's emotions, it is combined with a psychological emotional involvement or commitment of patients themselves and the significant people in their lives, needing in depth knowledge and understanding (Schweitzer, Mizwa, & Ross, 2010). Psychologists see the development of the disease based not only on the virulence of the virus but also on the psychological response, other pathologies and personality traits of the person, for example individuals diagnosed with a severe mental illness were found to be at higher risk for infection with HIV (Carey, Carey, & Kalichman, 1997).

Literature further suggests that being the target of prejudice and stigma is associated with reduced well-being (Major, Quinton, & McCoy, 2002). Emotional reactions like anxiety, depression, guilt, and isolation affect the PWHL's psychological well-being (Logie & Gadalla, 2009; Mak, Cheung, Law, Woo, Li, & Chung, 2007). Physical and emotional violence, grief, and lack or loss of social support, influence relationships which lead to social effects (Harapan, Feramuhawan, Kurniawan, Anwar, Andalas, & Hossain, 2013). In testing the HIV Stigma Framework it was found that internalised stigma equated significantly with affective and behavioural health and well-being indicators like helplessness and days in medical care gaps and antiretroviral medicine (ARV) non adherence. Enacted and anticipated stigma

linked with indicators of physical health and well-being like anticipated lower CD 4 counts (Earnshaw, Smith, ChauDoir, Rivet Amico, & Copenhaver, 2013).

Safren, Radomsky, Otto, and Salomon (2002) assessed the impact of depression, quality of life, and self-esteem among persons with HIV receiving highly active antiretroviral therapy (HAART). They found a significant relationship between negative life events and lower well-being among persons with HIV prescribed HAART. Findings suggest that well-being is associated with lack of self-care and adherence, and this is associated with a bad medical outcome (Safren, et al., 2002). Stigma has also been mentioned as associated with stress, depression and a lowered quality of life among PLWH (Simbayi et al., 2007; Venable, Carey, Blair, & Littlewood, 2006; Wingood et al., 2008). Teti, Bowleg, and Lloyd (2010) found that a group of women's experiences with discrimination also brought about psychological distress, which in turn, contributed to women's sense of sadness, helplessness, and desperation and made it difficult for the participants to believe their own importance in negotiating safer sex with a partner. Body image and HIV-associated body changes have been linked to inter alia worries about disclosure, social isolation, suboptimal adherence, low quality of life, and mental health problems (Brouwers, Van Brakel, & Cornielje, 2011; Martinez et al., 2011; Reynolds, Helgeson, Seltman, Janicki, Page-Gould, & Wardle, 2006; Mutimura, Crowther, Cade, Yarasheski, & Stewart, 2008). Livingston and Boyd's (2010) review found that internalised stigma affected hope, self-esteem and empowerment. When a person is targeted by stigma, perceives it, feels it, and finally internalizes it, negative self-perception and self-stigma is the result (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011).

The effects of community involvement like volunteerism and activism in organizations related to HIV on three psychological well-being indicators, self-esteem, depression, and loneliness, seemed to compensate for stigma, depression and loneliness, while buffering self-esteem (Ramirez-Valles, Stevenson, Reisen, Poppen, & Zea, 2005). In an environmental context, the existence of stigma is often associated with societal concerns about the ecological and human health risks of technologies. The negative economic effects of stigma, together with the social, psychological, and cultural impacts are significant. In resource-based

communities, residents may be shunned and their products may suffer a loss of markets, which in turn informs social and economic hardship for community residents (Gregory & Satterfield, 2002).

Causes and Outcomes of HIV Stigma

Root causes and outcomes of stigma as reflected in the literature are discussed.

The root causes of stigma. Lack of knowledge and moral judgment are considered to be the root causes of HIV and AIDS stigma (Nyblade et al., 2003; Siyam'kela, 2003), while fear, pity and anger are named as the emotional drivers of stigma and discrimination (Bos, Schaalma, & Pryor, 2008; Stutterheim, 2011). The role of lack of knowledge as well as values, norms and moral judgement is discussed as portrayed in the literature.

Role of lack of knowledge in HIV stigma. Lack of knowledge about the illness and the transmission thereof and the fear generated out of this lack of knowledge seem to be one of the root causes of stigma and discrimination (Stutterheim, 2011). A number of studies in Zimbabwe (Duffy, 2005; Tarwireyi, 2005); Thailand (Boer & Emons, 2004); South Africa (Campbell, Nair, Maimane, & Nicholson, 2007) and Tanzania (Nyblade, MacQuarrie, Phillip, Kwesigabo, Mbwambo, & Ndega, 2005), have raised concerns about inadequate knowledge of HIV transmission and poor education about HIV and AIDS as related to HIV stigma. Hamra, Ross, Orrs, and D'Agostino (2006) found that lower expressed stigma is positively associated with more extensive and more accurate knowledge about HIV and AIDS. A study that explored changes in stigma, and voluntary counselling and testing (VCT) access in a peri-urban South African community with high HIV prevalence, noted a reduction in levels of HIV and AIDS-associated stigma when knowledge increased (Mall, Middelkoop, Mark, Wood, & Bekker, 2013). Negative and restrictive attitudes towards PLWH were associated both with less knowledge regarding HIV transmission and fewer contacts with PLWH (Genberg et al., 2009; Searle & Antonio, 2007). Ugoji and Agokei (2012) in a study investigating the knowledge, beliefs of rural nursing students' and their attitudes towards PLWH, found a

significant negative relationship between the participants knowledge of HIV and AIDS and their beliefs and attitudes towards PLWH.

Transmission-related fears in families with an HIV-infected parent are found to be based on knowledge misconceptions about modes of HIV transmission (Cowgill, Bogart, Corona, Ryan, & Schuster, 2008). In comparing HIV stigma and discrimination in six international sites including South India, fear of transmission, fear of suffering and death became clear as factors affecting stigma (Charles, Jeyaseelan, Pandian, Sam, Thenmozhi, & Jeyaseelan, 2012; Maman et al., 2009). Deacon and Boule (2007) suggested that general medical education and specific education about HIV and AIDS will not necessarily reduce stigma and discrimination unless it reduces specific fears of infection in the workplace. Fear of infection in health care workers is probably related rather to what they know, how likely they are to be exposed to infection and their capacity to manage the risk of infection than to any general knowledge about transmission modes.

Values, norms and moral judgment. It is clear that stigmatisation is social and cultural phenomena linked to the actions of whole groups of people, and not simply the consequences of individual behaviour (Lifson et al., 2012; Mathangwane, 2011; Myer, Stein, Grimsrud, Seedat, & Williams, 2008). Nyblade and MacQuarrie (2006) refer to a moral- or value-driven stigma where assumptions and judgments are made about PLWH which manifest in stigmatising attitudes. The study of Pulerwitz et al. (2004) and the guidance document of Carr and Nyblade (2007) state that value-driven stigma link PLWH to behaviour considered improper and immoral, resulting in shame, blame and judgment. The Agency for co-operation and research in development (ACORD, 2010) reported from Uganda and Burundi that many people still associate HIV and AIDS with moral decadence and promiscuity, ultimately passing moral judgement on PLWH. PLWH can be blamed for what has happened to them because the infection was acquired by shameful or sinful actions. These actions are linked to sex, particularly extra-marital and pre-marital sex. Sexuality carries a taboo status in some communities and that could be a driver of stigma (Farris & Touray, 2005). PLWH are described as people who contracted HIV through sex or drug use and got what they deserve

or being weak willed and foolish (Herek, Gillis, & Cogan, 2009; Herek, Saha, & Burack, 2013; Kalichman, Simbayi, Cloete, Mthembu, Mkhonta, & Ginindza, 2009; Pulerwitz et al., 2004). Other studies confirm that at least three key dimensions are important in this domain: shame, blame and judgment (Malawi Network of People Living with HIV/AIDS (MANET), 2003; Ogden & Nyblade, 2005; Pulerwitz, Greene, Esu-Williams, & Stewart, 2004; USAID, 2005).

It seems that most populations have reacted with aversion to diseases that disfigure, debilitate and are fatal (Petros et al., 2006). Petros et al. (2006) found that the association of HIV with outsiders (“othering”) causes stigmatisation of particular groups on grounds of race, sexuality, or level of mental/physical health; especially when the outcomes of the disease is as fatal as HIV, and the fear of contagion is acute. Deacon’s (2006), definition of stigmatisation for example, includes blame, moralisation, and the association of HIV with outsiders (“othering”) as key components. This involves a process by which people distance themselves and their group from the risk of contracting a disease by describing it as preventable or controllable if it wasn’t for ‘immoral’ behaviours causing the disease and pointing to ‘carriers’ of the disease in other groups. In this way people are blamed for their own infection and they can be punished for it (Deacon et al., 2005). Duffy (2005) describes ‘blame and othering’ as an expression of stigma in communities with an overwhelming burden of care for PLWH. The association of HIV with outsiders (“othering”) and preoccupation with the circumstances of infection are more common in lower prevalence countries but vary substantially in tone depending on the sociocultural context (Winskell, Hill, & Obyerodhyambo, 2011).

Li, Liang, Lin, Wu, and Wen (2009) used the principles of Social Norms Theory to understand HIV-related stigma among service providers in China. The theory states that behaviour is influenced by perceptions of how other people in a social group behave and even how other social groups behave. There is then an assumption that this differs from the known group even if it is not the true case (Li, Lin, Wu, Comulada, & Ding, 2012). They found that the majority of providers in this study which compared service providers’ perception of social norms and their personal opinions regarding PLWH matched their reported personal

attitudes to what they thought the social norms were. Stein and Li (2008) found highly significant associations between attitudes such as discrimination intent against PLWH in their work settings and believing in weaker care for PLWH who contracted HIV through activities like drug abuse and other prejudiced attitudes of shame, fear, and blame. Li, Liang, Lin, Wu, and Rotheram-Borus (2010) strengthened this finding in their study which found that people generally aligned their individual attitudes with perceived social norms regarding PLWH.

Outcomes of HIV stigma. Crawford as early as 1996 published the results of 21 studies that compared the stigma associated with HIV and AIDS to the stigma associated with other comparable conditions. These studies pointed to a greater degree of stigma expressed toward PLWH than toward individuals with other illnesses. In a study in Vietnam HIV-related stigma was seen by all the participants as having a serious impact on PLWH and their family members (Gaudine, Gien, Thuan, & Dung, 2010). The outcomes of HIV stigma will be discussed as outcomes for PLWH, outcomes for people living close to PLWH (PLC) and outcomes for the larger community.

Outcomes of stigma for PLWH. A public and private partnership for funding AIDS research in Spain (FIPSE, 2005) showed in a study that although discrimination against PLWH is illegal, prejudice is deeply rooted, and PLWH face the outcomes of stigma in many aspects of their everyday lives. Other authors group outcomes of stigma under categories of general health, violence, poor quality of life, reduced access to care, poor physical health and psychological health and behavioural outcomes (Holzemer et al., 2007; Quinn & Earnshaw, 2011, 2013). For this study outcomes for PLWH will be discussed under the following headings: health care neglect, poor access to health care services, poor quality of work life, societal outcomes, reduced quality of life, reduced psychosocial well-being and social isolation by others,

Health care neglect. Literature suggests that PLWH are stigmatised and discriminated against by health care systems and by other people in charge of their care (Zamberia, 2011). In Nepal a study found that people believed health professionals lack knowledge and

sensitivity in providing health care to certain groups like injecting drug users, sex workers and PLWH. Withholding of treatment, neglecting patients, HIV testing without consent, breaching confidentiality and denial of hospital facilities and medicines are amongst the actions perpetrated (Jha & Madison, 2009). Participants in Indian studies claimed that they had poor support from clinics and that PLWH were not receiving appropriate assistance at home (Charles et al., 2012; Majumdar & Mazaleni, 2010). Oturo (2011) also found HIV stigma as a barrier to care of PLWH, reluctance of health care providers to treat PLWH and the further stigmatisation of providers of ancillary or support services to PLWH.

Haghdooost and Karamouzian (2012) reported that patients themselves report experiences of discrimination in clinics and hospitals. Von Hippel and Brener (2012) in their study revealed that people who experienced discrimination from healthcare workers had poorer physical health. Ahmedani (2011) found that reduced utilization of prevention services, as well as programmes to prevent mother to child transmission (PMTCT), HIV testing and counselling, and accessing care and treatment was blamed on HIV stigma and discrimination. Negative effects of stigmatisation span across the prevention to treatment continuum. Pregnant women avoid using PMTCT interventions and services (Rahangdale, Banandur, Sreenivas, Turan, Washington, & Cohen, 2010). PLWH avoid disclosure which worsens the psychosocial effects of HIV infection, and reduces the life prospects and quality of life of PLWH and their families (Deacon et al., 2009; Mahajan et al., 2008; Salter et al., 2010). Nyblade et al. (2009) felt that stigma and discrimination in the health care setting keep people, including health providers, from adopting sound HIV prevention behaviour and accessing needed care and treatment. This can have an outcome on care seeking and influences individual and public health. There is urgency for stigma reduction since stigma powerfully impedes the effective implementation of HIV prevention, testing, disclosure, care and support programmes (Campbell et al., 2005; Nyblade et al., 2003). Serious challenges to the global community goals of virtual elimination of new child HIV infections and 50 percent reduction in HIV-related maternal mortality by the year 2015 were found and the conclusion was that HIV related stigma play a significant role (Nyblade, 2013; Turan & Nyblade, 2013).

Poor access to healthcare services. High levels of stigma in a community can affect the willingness to disclose and the lack of disclosure can perpetuate internal and externalized forms of stigma (Donahue, Dube, Dow, Umar, & Van Rie, 2012; Greeff, 2013; Hult, Wrubel, Bränström, Acree, & Moskowitz, 2012). It was found that this affected uptake of services and enhanced poorer health and higher risk-taking behaviour (Castro & Farmer, 2005). Reidpath, Brijnath, and Chan (2005) found stigma aimed at HIV, homosexuality, commercial sex work and drug use impeded on HIV prevention services. King, Maman, Bowling, Moracco, and Dudina (2013) added to the growing body of evidence that vulnerable populations, may not feel comfortable accessing health services, discussing their social and behavioural risks for HIV with providers, or testing for HIV in settings where their identity is known. Reactions like voluntary excluding themselves from services and opportunities, self-esteem problems, social withdrawal and fear of disclosure weaken the social relationships of PLWH. It includes hiding their HIV status from others (Sikkema, Ranby, Meade, Hansen, Wilson, & Kochman, 2013; Siyam'kela, 2003; Swendeman, Ingram, & Rotheram-Borus, 2009). Many studies worldwide found that fears like a fear of infection, fear of disclosure, fear of partners' reactions were seen as barriers to seeking HIV counselling-and-testing services (Dlamini et al., 2009; Herek, Capitanio, & Widaman, 2003; Nyblade et al., 2011). A greater fear for social stigma in a low literate population seemed to be a significant independent predictor of adherence to HIV medication (Waite, Paasche-Orlow, Rintamaki, Davis, & Wolf, 2008).

Poor quality of work life. The quality of a person's work life is influenced by interactions in the workplace, including employee perceptions and whether the individual understands and experience workplace HIV and AIDS policies and programmes as positive. Employee interactions that relate to the physical job contacts and social interactions that take place at the workplace also play a role (Pulerwitz et al., 2004). Sprague, Simon, and Sprague (2011) found that employment discrimination based on HIV status happens in every region of the world. For example it was reported in all the African sub regions of the survey as well as in three major Chinese cities. Findings from 156 quantitative interviews with employers across Chicago, Beijing, and Hong Kong broadly argue that employers' fear of contagion and the

perception of incompetence are two characteristics that may negatively affect employers' decision to interview and hire PLWH (Liu, Canada, Shi, & Corrigan, 2012; Rao, Angell, Lam, & Corrigan, 2008). Once workers establish a wide social network in the workplace, fear of ostracism from the community, divorce and financial distress becomes clear (Meiberg, Bos, Onya, & Schaalma, 2009; Theilgaard et al., 2011). Pham, Protsiv, Larsson, Ho, De Vries, and Thorson (2012) hypothesized that experiencing stigma results in additional work related stress, low self-esteem, poor views of their profession, and lower income and their hypothesis proved to be true. The vulnerability of women in the sex trade to HIV is deeply shaped by structural gender relations which limit women's access to financially sustaining work, and their control over their sexuality and their living and working conditions (Ackerson, Ramanadhan, Arya, & Viswanath, 2012).

Societal outcomes. Societal stigma is observed in laws, regulations, and policies that single out PLWH. The National association of social workers (NASW), points out that PLWH continue to face discrimination in a variety of settings, even basic civil and human rights (NASW, 2013). The National Alliance of State and Territorial AIDS Directors (NASTAD) point out abuses like local school boards' refusal to enrol HIV-positive children and forcible segregation of HIV-positive prisoners (NASTAD, 2012). UNAIDS (2010) counted 44 countries, territories, and areas that impose restriction on the entry, stay and residence of PLWH based on their HIV status. There are five countries that completely ban the entry and stay of PLWH and five more countries deny visas to PLWH even for short-term stays. Nineteen countries deport individuals once their HIV-positive status is discovered. In 11 countries, PLWH applying for long-term stays will not be granted a visa. In 32% of the countries in the European Region there are some kind of HIV-related travel restrictions (Lazarus, Curth, Weait, & Matic, 2010). HIV-related restrictions exist in 45 out of 193 WHO countries (23%) in all regions of the world. The Eastern Mediterranean and Western Pacific Regions have the largest number of countries with these restrictions (Chang, Prytherch, Nesbitt, & Wilder-Smith, 2013).

Reduced Quality of life. The World Health Organization (WHO) (1995) defines quality of life (QoL) as a person's perception of their position in life in the context of the culture and value systems in which they live and that relate to their goals, expectations, standards and concerns. According to this definition QoL is a subjective element embedded in a cultural, social and environmental context. "The social determinants of health are the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics" (WHO, 2008, p. 6). Domains of QOL are seen as physical health, positive and negative feelings and intrapersonal relationships, social relationships including personal relationships, social support and sexual activities and environmental aspects like safety and security, finances, health and care, etc.(Liu, Xu, Lin, Shi, & Chen 2013). HIV Stigma negatively influences the quality of life (QoL) of PLWH. Quality of life studies demonstrate that a person's life satisfaction is sensitive to illness-related stigma (Holzemer et al., 2009; Greeff et al., 2010). Liu et al. (2013) found that PLWH's, compared to their caregivers, exhibited a higher level of perceived HIV stigma and lower level of quality of life. Rusch, Corrigan, Todd, and Bodenausen (2010) found that implicit and explicit self-stigma significantly influenced QoL. Studies also refer to health-related QoL, where outcome of medical care linked to issues of the impaired functional status, own perceptions, and social interactions of PLWH due to the influences of disease, treatment, and health care delivery (Phaladze et al., 2005).

Social isolation by others. Social isolation by others is an outcome of social stigma for PLWH. HIV-related stigma can influence social relationships, have a negative impact on access to resources, social support and the psychological well-being of PLWH (Nyblade et al., 2003; Bos et al., 2008). As far back as 1988 studies found social isolation a life threatening occurrence, inferring that mortality is higher among more socially isolated individuals (House, Landis, & Umberson, 1988). Stutterheim, Pryor, Bos, Hoogendijk, Muris and Schaalma (2009) found that increased physical distance, restrained social interaction, indifference

towards people, avoidance of PLWH, and more led to psychological distress that included depression, anxiety, disturbance of affect and behavioural control issues.

Outcomes of HIV stigma for people living close to PLWH. HIV stigma includes “prejudice, discounting, discrediting, and discrimination directed not only at people perceived to have HIV or AIDS, but also towards the individuals, groups, and communities with which they are associated” (Herek, 2002, p.595). Through association partners, children and extended family are often stigmatised, and even the caretakers like nurses involved in their care are targeted (Greeff & Phetlu, 2007). On social level stigma and discrimination brings distinction, exclusion and diminishing of equal enjoyment and human rights. Stigma seems powerful enough to set people up against each other and undermine social cohesion by dividing and breaking down different manifestations of community and society (Rankin et al., 2005). Families play central roles as they care for orphaned children and the ill, draining time and money, two family resources essential for supporting other children (Heymann & Kidman, 2009). Studies found that family members were shunned by neighbours, had their parenting skills questioned, was discriminated against by health professionals, was the subject of gossip, lived in secrecy about HIV, suffered financial hardship and feared contracting HIV (Hong et al., 2004). Asiedu (2010) in a Ghanaian study confirmed a further number of the vulnerabilities of PLC. The study suggests that the PLC could lose friends, potential partner relationships, changed social/sexual and spousal relationships, diminished social support and social standing or community respect because of the effects of associated HIV stigma manifesting all the same notions of various types of fear and discrimination like bullying or social isolation as the stigma directed at PLWH.

Stigma clings not only to PLWH, but sometimes to their families as well leading to the isolation and avoidance of PLWH and sometimes their close family members. In Vietnam, the families of drug users or sex workers who become HIV infected were accused of having neglected the education of their children, causing them to become “degraded” (Yang et al., 2007). Fear of being disgraced by association with certain populations because of behaviours considered deviant or immoral, like commercial sex workers or men who have sex with men.

More concerning is that healthcare workers delivering services or even truckers are seen as compromised groups (Verhaeghe & Bracke, 2011). Another seriously affected group is children. Not only are they left orphaned but experience being labelled as delinquents and criminals (Mueller, Alie, Jonas, Brown, & Sherr, 2011; Mueller, Fuermaier, Koerts, & Tucha, 2012). Family members of people living with HIV and AIDS are hurt by and abused about the blame their children receive for the increase in “social evils” (Yang et al., 2006).

A study by Li et al. (2009) found providers at both individual and institutional levels had negative experiences about caring for PLWH. They told of being stigmatised and discriminated against due to working with PLWH. Verhaeghe and Bracke (2012) found that health professionals and lay carers were affected by associated stigma, influencing their work experiences and the quality of the service they provide, leading to depersonalization and emotional exhaustion and eventually to a decrease in job satisfaction. In a survey of 358 home based caregivers from five hospices across KwaZulu-Natal, South Africa, it was found that 13.7% of caregivers personally experienced discrimination as a result of caring for PLWH (Singh, ChauDoir, Escobar, & Kalichman, 2011).

Outcomes of HIV stigma for the larger community. In describing the outcomes of HIV stigma for the larger community an anthropological approach gives a clearer view of how the so-called “others” constitute the world of stigma. This is because everybody is a member of some group, network, or even systems of care. The anthropological approach sees all of these people as being part of a shared social space carrying the burden of care, being part of getting things done together for the community in addressing illness and stigma. Social interactions take place at the individual level, but individuals do not come to social interaction without affect, values and motivation; and individuals exist in structured political, cultural and social contexts with defined social norms. Thus, social interactions take place in a structured context where the norms of that society create ideas of difference (Martin, Lang, & Olafsdottir, 2008; Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). There is togetherness in spite of possible positioning in societal structures of status, and prestige (Hong et al., 2004; Galindo, 2013; Kleinman et al., 2009; Rankin et al., 2005). A study done about the concerns

on hiring PLWH (Hong Kong and Beijing) relates to specific cultural dynamics related to losing face, the level of contact and knowledge about people with HIV as well as the psychological interconnectedness between people in society (Rao et al., 2008).

The disastrous effects of HIV-related stigma on PLWH and others and the penetrating effects of stigmatisation have created an environment in which public health itself is put at risk (Bayer, 2008), thus affecting the community at large. Stigma can reduce people's willingness to engage in HIV prevention, testing, and treatment, like attendance of HIV-related educational meetings, counselling sessions and participation in PMTCT (Young et al., 2010). Until at least part of the UNAIDS vision is reached (UNAIDS, 2010), it remains debatable that motivation of at-risk individuals to engage in appropriate health behaviours will change (Cross et al., 2012b; Smith & Morrison, 2006). Riley and Baah-Odoom (2010), using the social representation theory and the AIDS risk reduction model, felt that stigmatising, blaming and stereotyping attitudes tend to make people distance themselves and thus feel less at risk of infection and that this results in people taking fewer precautions in their sexual behaviour. Stigma creates inequality, undermines trust, and reduces opportunities for interpersonal interactions between community members. Social stigma interferes with bonding, bridging and linking people together and leads to negative health consequences (Chen et al., 2011).

Community and HIV Stigma

In the light of this study's stated objective to test a stigma intervention in a community, this part of the overview will deal with defining community and look at social and community change as driving forces in HIV stigma reduction.

Defining community. The definition of 'community' lacks consensus among researchers. The sociologist Hillery (1955) tried to pinpoint the components a community have in common. His research found that four components occurred in the majority (about 75%) of descriptions of community, these being 1) people, 2) common ties, 3) social interaction and 4) place. Subsequent researchers still apply these four components (Brown

Wilson, 2009; MacQueen et al., 2001). MacQueen et al. (2001) added a fifth component, namely diversity, as the core of a conceptual framework. This framework consists of a sense of place (geographic); interests and values held in common, activities such as sharing tasks and helping neighbours, relationships like social ties and diversity referring *inter alia* gender and age diversity. They came up with a common definition of community as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQueen et al., 2001). This description is accepted as applicable for this study. Wenger, McDermott and Snyder (2002) described communities of practice as groups of people with common concerns, similar problems, or a shared passion about a concept, which increase their knowledge and expertise by ongoing interaction. Murillo (2011) gives an in depth review of literature on community of practice. Interestingly he shows that community of practice does not last forever. Its lifespan is sometimes as long as people's interest in the subject lasts. In the light of these definitions of community it seems as if social and community change could play a defining role in HIV stigma reduction interventions.

Social and community change as driving forces in HIV stigma reduction.

Traditional thinking on community change are mostly based on the work of Rothman (1996) who described three important approaches to community interventions, namely social planning, community organizing and community development. An understanding of community-level models provides insight into how social systems function and can be changed and activated. Community-level models use strategies and actions that are planned and led by organizations and institutions that view their task as protecting and improving health (Rimer & Glanz, 2007; Sites, Chaskin, & Parks, 2012).

Social change to reduce HIV stigma. In classic views social change was mostly equated with negative outcomes for the community. The best known theory was proposed by Durkheim in his work between 1893 and 1917. He postulated that social changes result in anomie. Anomie is an absence of norms and social-cultural integration, and this absence of norms and social-cultural integration has negative effects on well-being (Durkheim, 1972).

Sztompka (2000) mentions that social change, brings cultural trauma and also have some negative effects in a process termed social becoming, like collective guilt, shame, identity crisis and cultural lag. On the other hand there are also significant arguments that social change positively influences well-being. Concepts like evolution, growth, and development has been equated with social change. This view proposes that social change may provide individuals with hope, excitement, and other positive opportunities to develop useful life skills and achieve self-actualisation (Wissing et al., 2011).

Person and Cotton (1996) introduced the idea that the reduction of HIV stigma – and in the end HIV prevention – will be achieved by processes of social change. Other authors, like Figueroa et al. (2002) and Cardey (2006) make a strong case for social change as a driver for HIV stigma reduction and HIV prevention in general. MANET (2003) motivates for an enabling environment where individuals and communities are positively motivated to play an active role in HIV prevention initiatives. This process of making people more aware could bring about broader social change. This represents a shift from focus on the individual to the individual in their social context, which implies a shift towards a community context. A key component of this shift is a change from biomedical and behavioural interventions aimed at individuals to comprehensive social programming (Coates, Richter, & Cáceres, 2008; Kurth, Celum, Baeten, Vermund, & Wasserheit, 2011). Social and structural approaches have as their aim the modification of social conditions and situations (Auerbach, Parkhurst, Cáceres, & Keller, 2009). When implemented, they can help people to act in their own and their community's best interests, as well as create and support AIDS-competent communities and build health-enabling environments (Campbell, 2014). A number of authors describe AIDS-resilient communities as having knowledge and skills for recognising and applying preventive behaviour for themselves and others. AIDS-resilient communities are described as safe social spaces where dialogue and debate can happen and where individual and social norms that might negatively influence the health and well-being of the community can be critically examined. These communities also recognise ownership and responsibility towards their

response to the epidemic (Campbell et al., 2007; Campbell, Skovdal, & Gibbs, 2011; Campbell et al., 2011)

Networks and social capital. Social capital is the total of resources, and shared network connections that brings power to a group. It utilizes shared assets to efficiently achieve group or community goals (Bourdieu, 1986; Chen et al., 2011). The French sociologist Bourdieu first systematically defined social capital as “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition” (Bourdieu, 1986, p.248). A network connection must have resources, bonding, and have a goal. (Chola & ALaba, 2013; Mohnen, Völker, Flap, & Groenewegen, 2012). The connected entities must have trust amongst themselves, share and work together (Bourdieu & Wacquant, 2013; Lindstrom, 2005). The aids2031 Initiative Report (Fisher & Thomas-Slayter, 2009) notes that understanding of health should include the understanding of social capital.

Cené, Akers, Lloyd, Albritton, Hammond, and Corbie-Smith (2011) suggest that social capital can help in understanding health disparities because it acknowledges the contribution of individual- and community-level factors that impact health care and outcomes. At the community level initiatives serving communities and populations, not just individuals, are at the heart of public health approaches to preventing and controlling disease. Authors sound a word of caution that mobilising social capital may disturb traditional sets. For example, in India the caste system is a strong bonding social capital system. There is exclusive support for its' recognised members, but hardly any contact and trust across groups (Cornish, Shukla, & Baneriji, 2010). People are empowered to connect with, and access resources; from outside support systems only is a spirit of solidarity and common purpose. New collectives need to be created that use the traditional spirit but are based fundamentally on empowerment and equity. There is limited empirical research concerning social capital building and its practice in improving people's health, especially in the context of developing countries (Muriisa & Ishtiaq, 2007).

Community change to reduce HIV stigma. Borrell-Carrió, Suchman, and Epstein (2004) reviewed the 25 years that have elapsed since Engel's (1992) proposition of a bio psychosocial model. They identify two new intellectual trends that have emerged. They refer to knowledge that is socially constructed and consider complexity theory as a model for understanding causality, dualism and participation in care. Complexity theory shows how, in open systems, it is often impossible to know all of the contributors to and influences on particular health outcomes. Lang (2002) postulates that both the medical model and the social model of approach to people have certain weaknesses. The community-based rehabilitation (CBR) model which Lang (2002) proposes is underpinned by the theories of Social Transformation of Paulo Freire (Freire, 1973) and seen as an alternative model to both the medical model and the social model of approach. The basis of the theory is that all individuals, including the oppressed, should be treated fully human. These groups can change their present situation, becoming full and active citizens in the societies in which they live. Freire (1973) maintained that all individuals, irrespective of the degree of oppression they have been subjected to, have the potential to transform their political, social and economic situation. He states nevertheless that effective social transformation will only occur when marginalised groups meet collectively, analyse their constraints and critically view their social, economic and political environment within its own history, and find their own strategies for remedy (Hope & Timmel, 1984).

Community Health Psychology (CHP) is grounded in respect for the communities believing they carry their own wisdom and that the foundation for human sociality, organisation and creativity lies in the everyday human relationships and practices in communities (Hadjez-Berrios, 2014). In this light Campbell (2014) suggests the need for a medley of approaches to accommodate health struggles in different times and places. She feels that Freire's understandings on social inequalities needs updating, but is still a powerful starting point for activism. One of the implications may be to recognise the need to develop and apply different theories of health-enhancing change to social contexts and to recognise multiple types of social struggle. She argues that to stick with simple binaries like individual–

society, or power vs powerless are problematic. In the same vein Cornish, Montenegro, Van Reisen, Zaka, and Sevitt (2014) feels that the model of community health mobilisation as used at present is a modernist model. They believe that contemporary conditions demands different analysis and initiation of community mobilisation which leads to Asset-Based Community Development (ABCD) which advocates changing the residents from clients to citizens. Local assets are the cornerstone of sustainable community development. The skills of residents, the power of local associations, and the support of local institutions, are the community strengths to build stronger, more sustainable communities for the future (Mathie & Cunningham, 2005).

Project Accept is a social movement for the infected and affected by HIV and STI's to empower the community to present a solid social front *inter alia* to combat stigma. The project utilizes an approach to community change based on the diffusion theory. The diffusion theory has been used as the base for community-level HIV prevention interventions. This model focuses on social networks, and uses popular opinion leaders (POL) as change agents (Kelly, 2004). Social networks affect health through a variety of mechanisms, including (a) the provision of social support (both perceived and actual), (b) social influence (e.g. norms, social control), (c) social engagement, (d) person to-person contacts e.g. viral exposure, and (e) access to resources e.g. money, jobs, information (Berkman & Glass, 2000). The convincing evidence of the relationship between social support, social networks, and health status has influenced the development of program strategies which are relevant to health education.

Psychosocial models where behavioural outcomes are determined by individuals as the driving force in their social networks, address the well-being of individuals in relation to their environments (Kiragua & McLaughlin, 2011; Sanjuán, Molero, Fuster, & Nouvilas, 2013). These authors accept the idea that people should be self-reliant and their own problem-solvers: people must engage with their environment and act upon their perceived reality, as this is the only way to critical intervention and transformation.

Ecological models suggest that there are multiple levels of interaction, including the interpersonal and community levels. As ecological thinking gained strength, intervention strategies have broadened to target factors at other levels by considering individuals in their immediate environment, and wider society (Glanz, Rimer, & Lewis, 2005). At the most basic level, an ecological perspective points to two approaches to addressing health problems: change people's behaviour or change the environment (Glanz et al., 2005). Community Organization and other participatory models like the Social Change Model (1994) advocate approaches driven by the community to assess and solve health and social problems. Community organizing is consistent with an ecological perspective in that it recognises multiple levels of a health problem (Kerrigan et al., 2004). Community organizing is democratic and driven by stated values that use the power of individuals to work together to change their communities (Foster & Louie, 2010). This viewpoint sees leadership as socially responsible, collaborative, a process, not a position, inclusive, accessible to all people and influence change on behalf of others (Astin & Astin, 1996).

Whitehead (2002, p.2) defined "community based interventions (CBIs) as "programs designed to address health or social problems within a community through the significant participation of members of that community in the planning, implementation, and evaluation of such efforts". A community-based approach is defined by the United Nations High Commissioner for Refugees (UNHCR, 2008) as a partnership of all persons concerned during all stages of a planning and execution cycle. The resilience, capacities, skills and resources of these people, provide protection and solutions to problems, and supports the community's own goals. The community-based approach reinforce the dignity and self-esteem of people of concern and empower everybody to work together to support the different members of the community in exercising and enjoying their human rights (Turan & Nyblade, 2013; UNHCR, 2008). Nyblade et al. (2008) reported on the community interventions and results from a project (2005-2007), which involved work with community leaders and members in two provinces in Vietnam to increase their understanding of stigma and build capacity to reduce

it. All activities used participatory methods, with community members leading their design and implementation.

There seems to be an urgency towards developing a conceptual framework based on the knowledge that stigma and discrimination are social processes and stigma and discrimination can be resisted and challenged by social action and community involvement (Bessette, 2004; Benotsch et al., 2008; Blankenship, Biradavolu, Jena, & George, 2010; Brown & DiClemente, 2011; Carr, Eckhaus, Brady, Watts, Zimmerman, & Nyblade, 2010; Flanagan & Bundick, 2011; Kegeles et al., 2012). The understanding that stigmatisation and discrimination are social processes rather than isolated phenomena or the expression of individual attitudes, are voiced by a number of researchers and leads to a new look at strategies for intervention (Cardey, 2006; Figueroa et al., 2002; HORIZONS, 2002; Holzemer et al., 2007; Link & Phelan, 2001).

HIV Stigma Reduction

An overview of approaches to HIV health behaviour, health behaviour change models and theories, stigma reduction models and HIV stigma reduction strategies as well as interventions focusing on the community is provided.

Approaches to HIV Health Behaviour. A variety of approaches towards health behaviour in general started appearing since the health-promotion approach formulated in the Ottawa Charter (1986), which was a response to the realisation that information and knowledge alone were not enough to facilitate behaviour change and is based on the idea that there are a multitude of factors that influence how people handle their health and that communities and their environments must be acknowledged for effective health promotion (WHO, 2002). Some researchers on HIV and AIDS have argued that the determinants of health have been ignored. An example is educational programmes. There is a need to adopt socio-cultural and participatory approaches (Coates et al., 2008; Kurth et al., 2011). There have however been intense disagreements among practitioners who advocate the different approaches. Williamson and Robinson (2006) emphasised that psychosocial programming

has tended to separate mental and emotional issues from physical and material issues. They feel that potential effectiveness of programmes depends significantly on whether biological and material needs are also being met. It must be recognised that HIV programmes must respond holistically to the needs and rights of PLWH.

Health behaviour change models and theories. It is not possible to fully discuss theories on stigma reduction without looking at health behaviour theories and their applicability in developing interventions (Fishbein, 2000). Using theory as a foundation for programme planning and development concurs with the practice of using evidence-based interventions. Theory is the map for researching problems, developing interventions that is appropriate, and evaluation of successes (Glanz, Rimer, & Lewis, 2005). HIV and AIDS reduction models are mostly theoretically underpinned by existing theories of behaviour and behaviour change and specifically health behaviour (Glanz, et al., 2005).

Four of the most commonly used models in HIV prevention literature is: The Health Belief Model (HBM); the AIDS Risk Reduction Model (ARRM); the Stages of Change (Trans theoretical model [TMM]); and the Theory of Reasoned Action (TRA). The HBM was a popular approach in the early years of behaviour change communication (Rosenstock, Strecher, & Becker, 1994). It is a framework for motivating people to prevent negative health outcomes by taking positive actions of avoidance. A review in 1984 on ten years of the use of the HBM showed that it was successfully used for health education strategies (Janz & Becker, 1984). On the strength of the evidence compiled, it was recommended that consideration of HBM dimensions be a part of education programming but not all programming (Kirby, Laris, & Rolleri, 2007).

The Social Learning Theory (SLT), later to be called Social Cognitive Theory (SCT) was successfully combined with the HBM. SLT postulates that people learn by observing the beneficial behaviour of others and their own experiences. Bandura, (1977) updated the SLT by adding the element of self-efficacy and renaming it Social Cognitive Theory (SCT). Bandura (1989) found that perceived self-efficacy played a role in the exercise of control over

risky behaviour. According to this thinking effective programmes of self-directed change require four major components: information, social and self-regulatory skills, enhancement and building resilient self-efficacy, and lastly enlisting social supports for desired personal change. Bandura's construct came under criticism. Biglan (1987) did a behaviour-analytic critique that did not deny self-efficacy theory, but pointed out environmental variables that could also affect behaviour and should be understood in developing more effective treatment procedures. Other authors criticized the theory in terms of work they did (Vancouver, More, & Yoder, 2008; Weinhardt & Vancouver, 2012; Vancouver et al., 2013). Bandura (2012) retained self-efficacy as one factor operating together with many others. All of the major theories of health behaviour tend to include self-efficacy as a key component (Maddux, 2000).

The AIDS Risk Reduction Model (ARRM), introduced in 1990, provides a framework for explaining and predicting the behaviour change efforts of individuals specifically in relationship to the sexual transmission of HIV and AIDS. The stages in the model are 1) identifying and labelling risk behaviour, 2) commit to making the change and 3) taking steps to change (Catania, Coates, & Kegeles, 1994; Riley & Baah-Odoom, 2010). The Trans Theoretical Model (TMM) was developed in 1982 and is a bio-psychosocial model to conceptualize the process of intentional behaviour change. Change is seen as a cyclical process of behaviour change progressing through a series of stages (Prochaska, Redding, Harlow, Rossi, & Velicer, 1994).

Other models are also used in HIV behaviour change research. Research using the Theory of Reasoned Action (TRA) are based on the premise that humans are rational and that the behaviours being explored are under the control of individual willpower (Fishbein et al., 2001). According to Fishbein (2000) HIV and AIDS infection is in the first place an outcome of behaviour. It is the individual's behaviour that will expose themselves or others to HIV. Fishbein (2000) argues that an integration of theories give a more culturally specific viewpoint. Fishbein (2000) demonstrates that these models require one to understand the behaviour from the perspective of the population being considered as each of the variables in the model can be found in almost any culture or population.

De Wit and Adam (2012) in the light of this perceived overlap between theories proposed integrated models to explain and address HIV-related behaviours. These include inter alia the Information–Motivation–Behavioural skills model (IMB) that sees HIV preventive behaviour as the behaviour of individuals with the necessary knowledge and the motivation to act, plus possessing the skills and confidence to take action. Rimer and Glanz (2007) proposed that the most powerful interventions integrate various approaches and treat them all as crucial. Individual-level theories contain strategies intended to change people's behaviour. Strategies aimed at changing the environment rely on community-level theories, while theories such as SCT lie in-between, exploring the exchanges between individuals and their environments.

A strong case is made for sensitivity to the underlying worldviews across different cultures, when developing interventions without imposing viewpoints of health and healing. Worldviews express how cultures interpret and explain their experience. Worldviews play a role in how illness should be addressed in interventions. Tilburt (2010) feels that a worldview is an important concept for health disparities education that might even transform the culture of health care professionals toward a more sensitive posture. Worldview constructs join with other social and psychological elements such as locus of control, determinism, collectivism, etc., each of which could influence health disparities. Worldviews may also be seen as collective positions in which the group is favoured over individual achievement and uniqueness (Ting, 2012). Collectivistic worldviews thus usually favour interdependence and family and other kinship ties and place social group goals over individual goals. This includes the worldviews on body and mind, on the self, on mental health, on healing, and on spirituality. Collectivistic worldviews have played a strong role in the survival and resilience of persons of African descent in the face of colonialism and racism (Kamwaria & Katola, 2012; Vilakati, Shcurink, & Viljoen, 2012; Stevenson, 2004). Conversely Lam et al. (2010) describe Chinese lay theories of mental illness in Chinese culture reflecting Chinese belief in values as found in Taoism, Confucianism Buddhism etc. These have guided Chinese social behaviour for unnumbered years and are worldviews and philosophies. They mention that many of these

beliefs severely stigmatise mental illness and as such will play a role in any programmes designed to address stigma.

Stigma reduction models. In the literature looking at stigma reduction models in a broader field, for example mental health, Rusch, Kanter, and Brondino (2009) found that stigma reduction programs are dominated by a biomedical approach that sees depression as a medical illness as opposed to social and environmental influences. Contextual factors like poverty, unemployment and trauma seems to be ignored in this biomedical model, as well as having no sensitivity to how individual people view their condition or treatment. They introduced a control model addressing stigma as a cause because of fear and found that the contextual and control programmes succeeded in reducing stigmatising attitudes. Thachuk (2011) in a critical analysis of the use of biomedical models of mental illness as a means of challenging stigma found these models fail to effectively address the real issue because emphasis remains on the individual, and not the relationships that make stigma possible and dangerous. Thachuk (2011) suggests that biomedical models themselves contribute to the very stigma they purport to undermine. There was a period of biomedical dominance in the HIV response with a tendency to neglect the social sciences in HIV prevention, treatment and care. This is a cause for concern as the social sciences are essential to complement, strengthen and situate biomedical research (Auerbach et al., 2009; Kippax, Holt, & Friedman, 2011). In reality biomedical approaches are placed within an interlocking construct of social, behavioural and ethical challenges. MacQueen (2011) places stigma at the heart of the interlock. A social marketing model to challenge stigma is described by Kirkwood and Stamm (2006) that incorporated methods to empower people, campaign design and distribution and evaluating effectiveness in the context of stigma.

Sengupta, Banks, Jonas, Miles, and Smith (2011) decries the fact that in spite of expanded scientific literature on stigma the number of intervention studies aimed at reducing HIV stigma seems few especially as HIV is seen as a more severely stigmatised illness in comparison with other stigmatised conditions, such as mental illness and other physical health problems (Simbayi et al., 2007; Venable et al., 2006; Wingood et al., 2008). Stigma

exists not simply within individual actions, but within broad social and cultural contexts that need to be addressed in stigma-reduction programmes (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013; Herek et al., 2009; Herek et al., 2013).

A number of authors stress that the many underlying factors at the community or social levels which produce stigma should be understood in developing HIV stigma reduction interventions. These factors are the causes of stigma as discussed like lack of knowledge, misconceptions on transmissions; a lack of access to treatment; the ways in which the media shapes the reporting on the epidemic; the incurability of AIDS; and prejudice and fear toward certain groups (Herek et al., 2003; Keusch, Willentz, & Kleinman, 2006).

HIV Stigma reduction strategies and interventions focusing on the community.

Strong voices speak for community-based interventions, looking at a community as a community of practice (Stephens, 2007). Kingori et al. (2012) report on the inclusion of HIV prevention strategies that focus on the emerging dimensions of felt stigma. Stigma and discrimination in health care settings leads to negative health outcomes making it necessary for HIV prevention and treatment programmes to focus greater efforts on reducing HIV and AIDS stigma. The International HIV/AIDS Alliance (2011) sets out ways of integrating stigma reduction strategies and activities into HIV programmes and policy work. The alliance issued a call for the integration of HIV stigma reduction activities into all HIV programmes.

Interventions and strategies implemented on different levels are identified in the literature. These are intrapersonal, involving counselling (Brown, Trujillo, & Macintyre, 2003; Family Health International (FHI), 2004; Seaton, 2003; WHO, 2002), support groups (Demissie, Getahun, & Lindtjorn, 2003; Lyon & Woodward, 2003) and interpersonal: social support and social networks (Busza, 2001; Gewirtz & Gossart-Walker, 2000). On organizational and institutional, community and governmental/structural level organisational change, training, policies and education, contact, advocacy are identified (Cross et al., 2012b). In Thailand a study evaluated the effect of project interventions on reducing community-level HIV stigma. The project address HIV stigma and discrimination within

communities with monthly banking days, HIV campaigns, information, education and communication (IEC) materials and even “Funfairs” (Jain et al., 2013). Also in Thailand an integrated socioeconomic and community participation intervention was used to reduce HIV and AIDS stigma. The authors felt that the intervention worked well, resulting in a significant improvement in HIV/AIDS knowledge and a significant reduction in HIV/AIDS stigma (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007).

Cross et al. (2012b) constructed an intervention matrix to help ensure that fundamental considerations are addressed in intervention reduction plans. They consider how interventions address the components of stigma at the level of targeted stigma. The components of stigma they mention are labelling, stereotyping, separation, status loss and discrimination and the levels are intrapersonal, interpersonal, organizational/institutional and community/government. Collins, Wong, Cerully, Schultz, and Eberhart (2012) produced a conceptual model for reducing stigma called stigma and discrimination (SDR) initiatives. SDR interventions clearly advocate that interventions should effect change at multiple levels, e.g. policy and practice change (laws, policies and behaviour), individual change (both the stigmatiser with negative attitudes, stereotypical beliefs and social distance and stigmatised with disclosure and treatment seeking) and social change (community dialogues, media portrayals and norms). An information-motivation-behavioural skills (IMB) model intervention addressed information about HIV and the importance of adherence, motivation to adhere to medications, and the skills needed to manage and maintain these healthy behaviours in a combination of face-to-face and telephone sessions. Sustaining retention to HIV care, proved moderately successful, but medication adherence showed little difference (Konkle-Parker, Amico, & McKinney, 2014).

Brown et al. (2003) reviewed 21 interventions that have explicitly attempted to decrease AIDS stigma and 9 studies that tried to decrease stigma related with other diseases. They found that through a variety of intervention strategies including information, counselling, gaining coping skills, and interpersonal contact, stigma can be addressed and reduced. Heijnders and Van Der Meij (2006) later conducted a further review of evaluated stigma

reduction interventions. They reported a general weakness in the evaluation of the reviewed interventions, and concluded that interventions that included cognitive therapy, counselling, home-based care, education and contact, appeared to be the most promising ones. Rimal and Creel (2008) tested a radio program campaign in Malawi aimed at reducing stigma against social marketing principles. They found that audience self-efficacy and education played a big role in the success of the intervention and its true impact could not be established.

Various studies suggest that educational strategies focussed on improving knowledge, when used on its own, have limited effectiveness on stigma reduction (Campbell et al., 2005; Chen et al., 2011; Kalichman et al., 2009; Nyblade et al., 2008). However, participatory education that encourages reflection on attitudes and actions seem more effective as change agent (Hong et al., 2004; Ogden & Nyblade, 2005). This is especially effective when people living with HIV are also included as participants or facilitators. Certain fundamental principles for all stigma reduction interventions are awareness raising, addressing transmission fears and misconceptions, and discussions and challenges on the underlying value and belief systems (Nyblade et al., 2011). The change agents should be affected groups to be sure of a meaningful role for PLWH. A 'buddy system' as well as integrating other organized activities with PLWH, like meetings with designated groups and assuming demonstration roles are possibilities to increase contact with PLWH.

Alinagi, Daraei, and Moraz (2012) created a systematic management procedure called the Stigma Reduction Management Model (SRMM) involving a council run by PLWH and committees with PLWH and other volunteers. This model involves PLWH in activities, including peer outreach, to indicate that PLWH can manage their condition while fully integrated with the community. Sensitization for family and community members living with PLWH, interventions based on community organizing and building among PLWH and community entities are important avenues for the root causes of HIV stigma and discrimination and bridge the social gap between PLWH and others. These principles are found to a more or lesser extent in different programmes. There are commonly programmes

run by external change agencies within a designated community where the participants are programme recipients and have no input like Project Explore. Project Explore was a large behavioural study with the purpose to ascertain if an intensified program of counseling helps to prevent men who have sex with men contracting HIV. The change agencies could be public or private organizations, universities, a corporation, a foundation or some other philanthropic group (Koblin, Chesney, Coates, & the EXPLORE study team, 2004). Further there are programmes where all initial planning and constructing are done by external change agencies. Community members participate by invitation on community advisory committees, or as community outreach workers, or as volunteers (AIDS Community Demonstration Projects, 1991, 1994). Fairly recent are equitable partnership programmes planned and implemented together by CBOs and an external change agent or technical organization (The Malawi BRIDGE Project, 2009/2013). This project was designed to intensify HIV prevention activities in Malawi by assisting individual action at the society level.

Cross, Heijnders, Dalal, Sermittirong, and Mak (2012a) conducted a systematic review which built on the earlier review of Heijnders and Van Der Meij (2006). They concluded that there was some evidence to support approaches that included various training programmes, contact and education. This corresponded to findings of Brown et al. (2003). They reported that some multi-method approaches seemed to work: information in combination with skill-building approaches, and information together with contact approaches. The Brown et al. (2003) review study showed that only two out of the twenty-two studies involved a sample of PLWHs. The research is mostly about behaviours that may suggest that an individual is stigmatising PLWH, not on the experience of the PLWH themselves. In other words, at that time there was a gap in the literature regarding the experience of PLWH that stigma is directed at. The AIDS Community Demonstration Projects (1992) described the implementation of volunteer networks for HIV-prevention programmes. Peer networks was implemented for a community-level HIV prevention programme for injecting drug users (IDU) that was useful in the dissemination of materials and that led to the empowerment of IDU as a community plus normalizing casual, close contact with PLWH (Simons, Rietmeijer, Kane,

Guenther-Grey, Higgins, & Cohn, 1996). Oyserman and Swim (2001) explains that without experiences of PLWHs, it is impossible to gain an understanding of stigma. Barr, Amon, and Clayton (2011) felt that a paradigm shift was necessary viewing the role of patients and communities in receiving health services. Instead of being the recipients of interventions, they should be chief collaborators and partners. By only measuring stigma from the standpoint of the stigmatisers, researchers are missing nuances in how stigma is experienced. Focusing on the perspective of the stigmatisers is problematic because it has potential of reinforcing unequal power structures (by only including the voice of stigmatisers who tend to be a more powerful group (Manzo, 2004). Pham, Pharris, Nguyen, Nguyen, Brugha, and Thorson (2010) advocates for a rights based policy approach in Vietnam.

Uys et al. (2009) chose a health setting based intervention targeting nurses and PLWH that combined three strategies: sharing knowledge, increasing contact with the affected group, and improving coping through empowerment by having PLWH addressing stigma directly in activities. As a result a measure of perceived HIV/AIDS stigma for nurses in five African countries which is suitable in the circumstances in terms of language and culture was developed and validated. Maynard, Gilson and Mathieu (2012) when reviewing the past two decades of research in this area likened empowerment to meaning, competence, self-determination, and choice. They concluded that there is abundant support in the literature (Corrigan, 2003; Corrigan, Kerr, & Knudsen, 2005) that empowerment initiatives are beneficial to individuals, teams, and organizations. Empowerment on community level is a social action process where members of communities participate in activities that lead to increased individual and community decision-making and control, in the interests of improving their quality of life.

Blankenship et al. (2010) describe a community-led structural intervention in India among female sex workers and conclude that structural interventions that focus on changing the social context of risk rather than individual behaviour are effective in prevention. Community-led structural interventions represent a form of structural interventions where the collective energy of communities is directed toward action to address the factors that promote

risk. Social and structural approaches become a core element (Auerbach & Coates, 2000; Coates et al., 2008; Kurth et al., 2011). Structural approaches address the key drivers of HIV vulnerability and attempt to change social conditions. These approaches can help to allow people to act in their own and their community's best interests and create and support AIDS-competent communities (Campbell & Cornish, 2010). Health enabling social environments or AIDS competent communities is ones where community members support each another in achieving goals like sexual behaviour change; the reduction of stigma; and other common interests of the community in providing better living conditions (Campbell & Murray, 2004; Campbell, Nair, & Maimane, 2007).

Michaels et al. (2014) assessed the Anti-Stigma Project (ASP) workshop, a consumer-based stigma reduction programme. This workshop was a contact and education intervention using existing as well as newly developed stigma change tools. The ASP educated participants in small group settings about stigma impact on participants, their families and health providers. Post-intervention, participants were more aware of stigma, had lower levels of prejudice, and increased concurrence in self-determination of people.

In conclusion, a systematic review of 48 interventions to reduce HIV-related stigma and discrimination from 2002 to 2013 revealed tremendous advancement in the stigma-reduction field over the last decade. It presented 14 different target populations in 28 countries. The majority of interventions included at least two strategies to reduce stigma and discrimination, and ten of these included structural or biomedical components. However, challenges and gaps remain as most interventions targeted a single socio-ecological level and a single domain of stigma, like the individual level (Stangl, Lloyd, Brady, Holland, & Baral, 2013).

Summary

The focus of this study is the use of a HIV stigma reduction intervention in the community, using PLWA as change agents in partnership with community members.

In this literature review developments in how stigma was viewed through the years were described. The concept of HIV stigma was conceptualise by exploring various definitions,

models and theories that deal with this concept. Psychosocial well-being and its role in HIV stigma were explored. The causes and outcomes of stigma on PLWH, PLC and the broader community were dealt with. As the specific focus of this study, developments in interventions to reduce HIV stigma within a community-based context were explored. From the literature it is clear that growing concerns about HIV stigma are raised with serious calls to action. The challenge of stigma was identified as perhaps the greatest of all the challenges facing the AIDS response and stigma reduction became a battle cry in deepening the response to HIV and AIDS on all levels. A review of definitions of stigma show a distinct development in thinking and shifts from individual processes to social processes and the influence of structural drivers in the stigma process. It is clear that there have been significant changes in this view developing from a strictly individual point of view to a broader societal linked view. This shift strongly influences the modern trend of thinking that the reduction of stigma, with an end goal of HIV prevention – will be achieved by processes of social change. HIV stigma is a pervasive problem that affects health globally and threatens both an individual's psychological, physical and social well-being. It prevents individuals from coming forward for diagnosis and impairs their ability to access care or participate in research studies designed to find solutions. HIV stigma hampers HIV-related health promotion HIV-related stigma and behaviour resulting from stigmatisation are a key barrier to all HIV activities, from prevention to care and treatment.

The concept of HIV stigma was conceptualise by exploring various definitions, models and theories that deal with such concept and the types of HIV stigma. General theories and models of stigma and discrimination have importance for the understanding of HIV stigma in that they underline concepts like in and out group behaviour and even while focused heavily on the individual these theories and models link individual identity with group identity, eventually incorporating contexts like the social and political environment. Most models and theories found in the literature explore various components and contexts of stigma leading to a growing realisation that the person and the disease cannot be viewed in isolation. As recent

as 2013 a global HIV stigma reduction framework was published that focuses on actionable factors that can be affected by interventions.

For the use of this study present day thinking is well captured by the conceptualisation by Holzemer et al. (2007) of the process of HIV stigma revolving around the interlinking of elements that play a role in stigmatising and would need to be considered in stigma reduction interventions. The process follows from certain triggers, namely the HIV disease, diagnosis, disclosure and the suspicion of having the disease to stigmatising behaviour like blame, insults avoidance and accusation. This leads to certain types of stigma, (received, internalised and associated) and finally certain stigma outcomes. It becomes clear that the individual is not affected on their own. HIV stigma equally affect people living close to PLWH and the larger community suffers as well, as this conceptualisation places HIV stigma and stigmatising behaviour in a broader social context with multiple variants. Thus stigma and discrimination become social processes that create and legitimize social hierarchies and inequalities. The role that lack of knowledge and enforced values, norms and moral judgement play in HIV stigma cannot be underestimated as the main causes of HIV stigma.

One of the themes of this study is the psychosocial wellbeing of people infected and affected by HIV stigma. General models of psychosocial wellbeing are brought into clarity in terms of the study. The Wheel of Wellness is an early theoretical model that led to the development of a new model, The Indivisible Self, consisting of the Creative Self, the Coping Self, Social Self, Essential Self, and Physical Self. Recent definitions of psychosocial wellbeing emphasise states of satisfaction with life, personal meaningful pursuit of goals, and descriptions of well-being such as robust health, a sustainable environment, high levels of civic participation and intra- and interpersonal relationships, understanding the self through the physical, mental, spiritual, and emotional levels, and relationships with the community and environment. Traditionally two perspectives of well-being are found. One focuses on hedonic well-being, a mental state of being happy or experiencing pleasure and positive and negative affect, the other on eudemonic well-being, a mental state of self-realisation in which self-development, personal growth and purposeful engagement. Some of the models that

have been overviewed are Salutogenesis, the Dynamic Equilibrium Theory and specific to the purpose of this study the Mental Health Continuum model.

Literature further suggests that being the target of prejudice and stigma is associated with reduced well-being. Emotional reactions like anxiety, depression, guilt, and isolation affect the PWHL's psychological well-being. Literature suggests that individual and collective well-being depends on what happens in a variety of areas. Place, neighbourhood, and community are important because of their assets in health promotion and wellness generation. Going broader, it was found that being at ease in one's surrounding cultural context influences what constitutes well-being. Noticeably, different cultural formulations have an effect on perceptions of well-being.

Most researchers seem to have consensus that lack of knowledge about the illness and the transmission thereof and the fear generated out of this lack of knowledge seem to be one of the root causes of stigma and discrimination plus they refer to a moral- or value-driven stigma where assumptions and judgments are made about PLWH which manifest in stigmatising attitudes. This leads to specific outcomes of stigma for PLWA, people affected by the illness and the broader community. A range of outcomes are covered.

In the light of this study's stated objective to test a stigma intervention in a community, the overview also dealt with defining community and taking a look at social and community change as driving forces in HIV stigma reduction. Once again definitions of community seem to lack consensus but a common definition of community as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings was accepted as applicable for this study. The idea that the reduction of HIV stigma – and in the end HIV prevention – will be achieved by processes of social change make a strong case for social change as a driver for HIV stigma reduction and HIV prevention in general and motivates for an enabling environment where individuals and communities are positively motivated to play an active role in HIV prevention initiatives. This process of making people more aware could bring about broader social

change. This represents a shift from focus on the individual to the individual in their social context, which implies a shift towards a community context. There seems to be an urgency towards developing a conceptual framework based on the knowledge that stigma and discrimination are social processes and stigma and discrimination can be resisted and challenged by social action and community involvement. A key component of this shift is a change from biomedical and behavioural interventions aimed at individuals to comprehensive social programming. The convincing evidence of the relationship between social support, social networks, and health status has influenced the development of program strategies which are relevant to health education.

An overview of approaches to HIV health behaviour, health behaviour change models and theories, stigma reduction models and HIV stigma reduction strategies as well as interventions focusing on the community is provided. In the literature there is a realisation that information and knowledge alone are not enough to facilitate behaviour change. There are a multitude of factors that influence how people handle their health and communities and their environments must be acknowledged for effective health promotion. A brief overview of the most used health behaviour change models and theories are given, leading to suggestions of integrated models to explain and address HIV-related behaviours. It is proposed that the most powerful interventions integrate various approaches and treat them all as crucial.

The development in thought from individual to society is also observed in the views and research on stigma reduction and specifically HIV stigma reduction interventions. The strict biomedical approach is slowly making way for an approach integrating the social sciences also incorporating the many underlying factors at the community or social levels which produce stigma in developing HIV stigma reduction interventions. Recent studies decry the fact that in spite of expanded scientific literature on stigma the number of intervention studies aimed at reducing HIV stigma seems few and speak strongly for interventions moving past being knowledge and individual counselling based to multi-method approaches: information in combination with skill-building approaches, and information together with contact

approaches. Participatory education that encourages reflection on attitudes and actions seem more effective as change agent, especially when people living with HIV are also included as participants or facilitators. Certain fundamental principles for all stigma reduction interventions are awareness raising, addressing transmission fears and misconceptions, and discussions and challenges on the underlying value and belief systems. The change agents should be affected groups to be sure of a meaningful role for PLWH. Community-led structural interventions represent a form of structural interventions where the collective energy of communities is directed toward action to address the factors that promote risk. Social and structural approaches become a core element. These approaches can help to allow people to act in their own and their community's best interests and create and support AIDS-competent communities.

In the development of the concept of stigma as applicable to HIV related stigma through at least the last twenty years it is clear that there are significant shifts from individual to societal processes and further to organizational processes. General consensus about the negative effects of stigma on individual and community alike underscore the necessity of reducing and eradicating HIV stigma. Drivers of HIV stigma that address these negative effects of stigma should underlie interventions for reducing HIV stigma. The development of interventions lean more and more towards deeper PLWH and community involvement. The importance of securing input from the civil society with many voices and many different perspectives, including people living with HIV, cannot be overstated. The literature show that stigmatisation have a serious effect on the global response to HIV and AIDS and that also that multiple elements are involved in implementing a successful stigma reduction programme.

In conclusion, tremendous advancement in the stigma-reduction field over the last decade is obvious but challenges and gaps remain as most interventions targeted a single socio-ecological level and a single domain of stigma, like the individual level.

In the next section findings of the research are presented in three articles:

Article 1: HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

Article 2: A Community “Hub” Network Intervention for HIV Stigma Reduction: A Case Study.

Article 3: Psychosocial Well-Being of People Living With HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

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doi:10.1080/0376835X.2011.623914

Section C: Articles

Article 1:

**HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction
Community “Hub” Network Intervention.**

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**HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction
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HIV Stigma Experiences and Stigmatisation Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

Abstract

This study intended to explore, describe and determine whether an HIV stigma-reduction community “hub” network intervention will change the HIV stigma experiences of people living with HIV (PLWH) and stigmatisation by the community in an urban municipal ward of Tlokwe in the North West Province of South Africa. A convergent parallel mixed-method design with a single case pre-test post-test design for the quantitative data and an interpretive description approach for the qualitative data were utilised. The *HIV/AIDS stigma instrument for PLWH* (Hasi-P) © was applied to measure stigma experiences of PLWH; and the *AIDS-related stigma measure* was applied to measure community stigmatisation. The sample for this study included 62 PLWH recruited through accessibility sampling and 570 community members recruited through random voluntary sampling. A sub-sample of both groups, selected by means of purposive voluntary sampling, was utilised for the qualitative part of the study consisting of in-depth interviews about stigma experiences of PLWH, as well as perceptions and attitudes of the community toward PLWH. The study stretched over a period of three years (2011-2013). Both quantitative and qualitative data showed that stigma is present. Although no statistically significant changes were found, small practically significant changes were demonstrated in the experiences of PLWH as well as the perceptions and attitudes of the community. The extent of changes was much more obvious in the responses of the PLWH and the community during their post-intervention interviews than the changes found with the quantitative measures. It can thus be concluded that the HIV stigma-reduction community “hub” network intervention was successful in initiating the onset of changes in a community through the PLWH and PLC as community mobilisers active in the community “hub” network to mobilise their own communities towards HIV stigma reduction through social change. It is recommended that the present community intervention is used and strengthened, that the two scales used in this study is amended and that stronger collaboration between health and

social disciplines is ensured to address the various manifestations and changing contexts of HIV stigma.

Keywords: stigma reduction, stigmatisation, community, “hub” network, South Africa

Background and Problem Statement

HIV stigma affects health globally, threatens the psychological, physical and social well-being of people living with HIV (PLWH) and often inhibits free access to diagnosis, healthcare and research participation (Auerbach, Parkhurst, & Cáceres, 2011; Pharris et al., 2011). HIV stigma furthermore hampers HIV-related health promotion and has become a key barrier to HIV prevention, care and treatment (Nyblade, Singh, Ashburn, Brady, & Olenja, 2011). HIV stigma reduction has become a battle cry for deepening the HIV and AIDS response on all levels (UNAIDS, 2010) and authors like Turan and Nyblade (2013) emphasised the need for appropriate action.

A search for a deeper understanding of HIV stigma based upon proposed models and frameworks are found in literature. Already in the 1990s, Alonzo and Reynolds (1995) analysed HIV in terms of a distinctive stigma trajectory involving the course of the disease and the responses of society. Mahajan et al. (2008) later postulated that HIV stigma is founded on inequalities of social, political and economic power of people and communities. For Weiss, Ramakrishna, and Somma (2006, p280) stigma is “typically a social process, experienced or anticipated, Characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group”. HIV stigma exist when individuals or groups label others or processes and assign negative values to other people, their behaviour, jobs, goals and circumstances (Quinn & Earnshaw, 2013).

The HIV stigma conceptual model of Holzemer et al. (2007a) was chosen as a grounding theory for this study, where HIV stigma is outlined firstly as a process within a specific context of the environment, including cultural, economic, political, legal and policy aspects; secondly in the context of the healthcare system, including settings such as

hospitals, clinics and home-based care settings and health service delivery settings; and thirdly in the context of certain agents, like PLWH themselves, their family, their colleagues in the workplace and their community. The stigma process is triggered by triggers like the disease itself, the HIV diagnosis, disclosure and the suspicion of having the disease. When the process is triggered, stigmatising behaviour like blame, insults, avoidance and accusation towards self and others occur. Such stigma processes gives rise to three types of HIV stigma. *Received stigma* is how people act towards PLWH and include all types of stigmatising behaviour towards PLWH, as experienced or described by themselves or others. *Internalised stigma* are thoughts and behaviours stemming from the affected persons' own negative perceptions about themselves, based on their HIV status. A third type of HIV stigma, known as *associated stigma* (Holzemer et al., 2007a), results from an individual's association with someone living with, working with or otherwise associated with PLWH, like health workers. HIV stigma then lead to specific HIV stigma outcomes for PLWH, people close to them and the community.

Various types of HIV stigma outcomes feature in the literature, these being healthcare neglect, poor access to healthcare services, poor quality of work life, a reduced quality of life (QoL), societal stigma, and social isolation. Healthcare neglect implies that PLWH are stigmatised and discriminated against by healthcare systems and people in charge of their care (Zamberia, 2011). This can affect the willingness of PLWH to disclose their HIV-positive status (Overstreet, Earnshaw, Kalichman, & Quinn, 2013). The lack of disclosure can perpetuate internal and external forms of stigma (Donahue, Dube, Dow, Umar, & Van Rie, 2012; Greeff, 2013), and lead to poor access to healthcare services. PLWH can also suffer a poor quality of work life (Sprague, Simon, & Sprague, 2011). HIV stigma also negatively influences the quality of life (QoL) of PLWH (Herek, Saha, & Burack, 2013; Liu, Xu, Lin, Shi, & Chen, 2013). The condition leads to social isolation and loneliness, with effects on PLWH, their illness, and their quality of life (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011).

As indicated, not only PLWH suffer the results of HIV stigma, but also the people associated with them. All suffer prejudice, discounting, discrediting and discrimination

(Verhaeghe & Bracke, 2012). Partners, children and extended family and even the caretakers like nurses involved in their care are often stigmatised through association (Greeff & Phetlu, 2007). People associated with PLWH could lose friends, potential partner relationships, changed social/sexual and spousal relationships, diminished social support and social standing or community respect (Asiedu, 2010).

Furthermore, as with PLWH and the people associated with them, the community also suffer. In the larger community everybody is a member of some group, network and systems of care or have identifiable bonds and allegiances to family, village, neighbourhood and community. This means that stigma and discrimination, when and where this occur, are social and cultural phenomena linked to the actions of whole groups of people, and not simply the consequence of individual behaviour (Akpa, Adeolu-Olaiyaa, Olusegun-Odebirib, & Aganabac, 2011; Mathangwane, 2011) and should be addressed by involving as many stakeholders as possible in HIV stigma reduction efforts. Abrahams and Jewkes (2012) found that stigma experiences tended to intermingle with other daily conflicts and created simultaneous tensions. They found however evidence of how structural interventions such as de-stigmatising policies impacted on experiences and transference into active resistance.

Sengupta, Banks, Jonas, Miles, and Smith (2011) found in their review that the number of HIV stigma reduction intervention studies seems few. This is critical for HIV as a severely stigmatised illness with broad social and cultural contexts that need to be addressed in stigma-reduction programmes (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013). Different interventions and strategies for different contexts are denoted in the literature. Brown, Trujillo, and Macintyre (2011) commented on their earlier review (2003) which reviewed 21 published and reported intervention studies that had explicitly attempted to decrease AIDS-related stigma both in developed and developing countries. They confirmed the intervention categories they articulated formerly which are based on psychosocial conceptualisations of the stigmatisation process, namely; information-based approaches (e.g. written information in a brochure), skills building (e.g., participatory learning sessions to reduce negative attitudes), counselling/support (e.g. support groups for PLWH), and contact with affected

groups (e.g. interactions between PLWH and the general public). Stangl, Loyd, Brady, and Baral, (2013) produced a systematic review of studies and reports that appraised the effectiveness of interventions to reduce HIV stigma and discrimination, minimise manifestations of stigma and/or bolster manifestations like resilience. These authors denote that critical challenges and gaps impeding the identification and implementation of effective stigma-reduction strategies still exist.

In developing the HIV stigma-reduction community “hub” network intervention the above-mentioned models and types of HIV stigma and other factors including the root causes of HIV stigma needed to be understood. Various authors (Carr & Nyblade, 2007; Stutterheim, 2011) concur that a lack of knowledge about the illness and the transmission thereof generates fear that seems to be one of the root causes of stigma and discrimination. Another root cause seems to be moral judgment delivered on PLWH (Hadjipateras, 2004) where people still associate HIV and AIDS with moral decadence and promiscuity leading to moral judgement on PLWH. It is believed that an intervention can effect change in factors that cause HIV stigma, like knowledge of stigma and its harmful effects or social judgment and fears (The International Center for Research on Women (ICRW), 2013).

In summary it can be said that certain fundamental principles for all stigma-reduction interventions that have been identified are awareness raising, addressing transmission fears and misconceptions, as well as discussions and challenges on the underlying value and belief systems (Sanjuán, Molero, Fuster, & Nouvilas, 2013). PLWH should be involved as change agents. PLWH can then act in their own and their community’s best interests and create and support AIDS-competent communities (Campbell, Skovdal, Madanhire, Mugurungi, Gregson, & Nyamukapa, 2011). The Stigma and Discrimination Reduction Initiative (SDR) clearly advocates that interventions should effect change at multiple levels, e.g. policy and practice change (laws, policies and behaviour), individual change (both the stigmatiser with negative attitudes, stereotypical beliefs and social distance and stigmatised with disclosure and treatment seeking) and social change (community dialogues, media portrayals and norms)

(Collins, Wong, Cerully, Schultz, & Eberhart, 2012; Konkle-Parker, Amico, & McKinney, 2014).

This study was built on, and followed two HIV stigma-reduction interventions: one conducted in several healthcare settings in Africa and one with PLWH and people living close to them in the North West Province of South Africa (Uys et al., 2009; French, Greeff, Watson, & Doak, 2015). The tenets for the previous studies were (a) the sharing of information on the nature of HIV stigma and coping with it; (b) equalising relationships between the PLWH and community members through increased interaction and contact and (c) empowering participants to become leaders in HIV stigma reduction through planning and implementing projects and campaigns in the community,

Therefore this study addresses the challenge of effectively building upon this existing body of knowledge. It aims to initiate strategies that mobilise HIV stigma reduction and social change in PLWH and their communities through the development, implementation and evaluation of an HIV stigma-reduction community “hub” network intervention. The strategy is based upon the involvement of PLWH and people living close to them (PLC) as community mobilisers, sharing their knowledge and the mobilisation and empowerment of their own community. This article focusses on changes in the HIV stigma experiences of PLWH and stigmatisation by the community due to the intervention.

The following research questions were considered:

- 1) Will the *HIV stigma-reduction community “hub” network intervention* result in a decrease in HIV stigma experiences of PLWH as determined and as verbalised by PLWH?
- 2) Will the *HIV stigma-reduction community “hub” network intervention* reduce the stigmatisation of PLWH by their community members as determined and as verbalised by the community?

Research Objectives

To explore, describe and determine whether a HIV stigma-reduction community “hub” network intervention in a South African urban area will make a difference in the HIV stigma experiences of PLWH, as well as related stigmatisation by their community.

Research Design

This study applied a convergent parallel mixed-method design as described by Creswell and Plano Clark (2011). The quantitative design comprised a single case pre-test post-test design, while the qualitative section followed an interpretive description approach (Thorne, Kirkham, & O’Flynn-Magee, 2004). The flow of the convergent design allowed for both the quantitative and qualitative strands in terms of collecting and analysing data separately and then using strategies to merge the two sets of results. The study takes a dialectic stance, which assumes that all paradigms offer something and that multiple paradigms in a single study contribute to a richer understanding of the HIV stigma phenomenon being studied. Pragmatism in its simplest sense as a practical approach to a problem is in essence the core of this study. The pragmatic approach to science involves using the method which appears best suited to the research problem. It has strong associations with mixed-methods research. Pragmatism offers a bridge between paradigm, methodology and a practical and outcome-orientated method of inquiry (Feilzer, 2010). The fact that it is based on action and leads to further action and the elimination of doubt, offers a method for selecting methodological mixes that helps researchers to better answer their research questions (Cameron, 2011; Teddlie & Tashakkori, 2011).

Research Setting

Data was collected in a ward of Tlokwe, in the North West Province of South Africa, known for high numbers of HIV infection according to the Department of Health. This province, according to the South African National HIV Prevalence, Incidence and Behaviour Survey, 2012 (Shisana et al., 2014), is among the four provinces with the highest HIV prevalence in the country. According to Census 2011 (SA Statistics, 2014), Tlokwe Local Municipality has a total population of 162 762 people, of whom 71.3% are black African, and

20.6% are white. The other population groups make up the remaining 8.1%. In the planned study, the population of a specific ward of an urban area in the North West Province of South Africa was targeted for the HIV stigma-reduction community “hub” network intervention. This ward consisted of 784 houses with an estimated three to four people per house, thus an estimated total of 3200 people.

Research Method

Table 1 provides an overview of the research process that was followed in this study. Both the quantitative and qualitative aspects are indicated.

Sample. The sample for this study was made up of two groups: PLWH and community members residing in the same municipal ward. For the PLWH an accessibility sample was used. 1400 PLWH known to the two clinics of the Department of Health were identified by the clinics. A mediator at the clinics put the PLWH that were willing to participate in contact with the mobiliser-coordinator of the study. The inclusion criteria were HIV positive adults; being 18 years or older; residing in the identified ward for at least 3 months; being conversant in Afrikaans or English or Setswana; and being prepared to be part of the quantitative study as well as to be interviewed if selected for the in-depth interviews. Care was taken that the ward was equally represented and that both males and females were included, even though the percentage of males was lower than the percentage of females. A final sample size of 62 (48 females and 14 males) were willing to participate in the quantitative part of the study. In the post-test battery, 5 PLWH were lost to the study either through refusal, death or not being located again. A *sub-sample* from these 62 PLWH was selected for the qualitative in-depth interviews. This was done by means of purposive voluntary sampling. A total of 10 in-depth interviews were conducted prior to the intervention. Data saturation (the point at which no new information is being obtained) was achieved at eight in-depth interviews, and a further two were done for a total of ten in-depth interviews. The same 10 people participated in the post intervention in-depth interviews.

Table 1

Summary of the research process

PRE TEST (Time Line: One Month)		INTERVENTION (Time Line: Five Months)	POST TEST (Time Line: One Month)	
<i>PLWH</i>	<i>PLWH</i>		<i>PLWH</i>	<i>PLWH</i>
Quantitative Stigma Experiences N = 62 Test Battery:	Qualitative N=10	Hub activities	Quantitative Stigma Experiences N = 57 Test Battery:	Qualitative N=10
<ul style="list-style-type: none"> Demographic Survey HIV/AIDS stigma instrument – PLWH (Hasi-P)(Holzemer <i>et al.</i>, 2007b) 	In-depth interviews	Two “hubs” Four mobilisers One mobiliser-coordinator Activities 3 hour workshops: <ul style="list-style-type: none"> Understanding stigma Coping with stigma Door-to-door education Support group Psychodrama groups Community Project: <ul style="list-style-type: none"> Home visits to PLWH Fruit at clinics to PLWH Stigma campaigns 	<ul style="list-style-type: none"> HIV/AIDS stigma instrument – PLWH (Hasi-P)(Holzemer <i>et al.</i>, 2007b) 	In-depth interviews
<i>Community</i>	<i>Community</i>		<i>Community</i>	<i>Community</i>
AIDS-related Perceptions of HIV Stigma N= 570 Test Battery	N=10		N=469 Test Battery	N=10
<ul style="list-style-type: none"> Demographic Survey AIDS related stigma measure (Maughan-Brown, 2004) 	In-depth interviews		<ul style="list-style-type: none"> AIDS related stigma measure (Maughan-Brown, 2004) 	In-depth interviews

For the second group, the community members, random voluntary sampling was used where a member of each of the 784 households willing to participate was included. The sampling strategy and size was determined beforehand by consultation with statistical support services. Inclusion criteria for the community members were adults of 18 years and older; having resided in the identified ward for at least 3 months; being conversant in

Afrikaans, English or Setswana; and being willing to be part of the quantitative study, as well as to be interviewed later if selected for the in-depth interviews.

The ward was divided into six equal parts, as six trained fieldworkers went from door-to-door to collect the data. Care was taken to take age and gender into account to bring differentiation to the results. In this way, 570 willing community members (345 female and 225 males, approximately 18% of the community) were included for the quantitative part of the study.

In the post-test battery 58 people were lost to the study, either through refusal, death or not being located again. A *sub-sample* of community members was selected for the pre-intervention in-depth interviews by means of purposive voluntary sampling. Data saturation was achieved after seven in-depth interviews and a further three in-depth interviews were conducted to bring it to a total of ten (10) in-depth interviews. The same participants were part of the post-intervention in-depth interviews, but one participant was lost to the study making it a total of nine in-depth interviews.

Demographic data. The outlay of the demographic data is provided to facilitate a better understanding of the population in this study. The gender spread for PLWH was 77.4% female and 22.6% male, while for the community it was 60.5% female and 39.5% male. The inhabitants were mostly black: for PLWH 98.4% and for the community 97.9%. The participants were for a large part from the low socio-economic group and living in houses provided by the SA government's reconstruction and development (RDP) programme. Marital status of both PLWH and community was that 46% never married. 14.5% of the PLWH and 20.7% of the community were married and 27.4% of the PLWH and 3.7% of the community were living together with their partners. 13% of the PLWH had no schooling, 51% had left school between grades 3 and 9: and 37% attended school up to grades 10 to 12. 6% had a post-school qualification. In the community group 11% had no schooling, 37% had grades 3 to 9, and 52% achieved grades 10-12. 15% had a post- school qualification. An estimated 79% of PLWH and 69% of the community were unemployed and utilizing income support from friends or family, civil pensions or governmental grants.

The intervention. The intervention that ran over a five-month period consisted of creating two HIV stigma-reduction community “hubs” in the specific ward. Each “hub” had a team that comprised two mobilisers, one PLWH, and one non-infected person who had a close relationship with a PLWH. The four mobilisers were inhabitants of the ward and were involved in a previous HIV stigma-reduction research project with PLWH and people living close to them. In the previous study (French, Greeff, & Watson, 2014) these mobilisers gained knowledge regarding the understanding and coping with HIV stigma, as well as the planning and implementation of their own HIV stigma people reduction community project. During the present study they underwent further training in a four-day workshop to become community mobilisers in their own community and were skilled to present workshops to the community on “Understanding HIV stigma”, “Coping with stigma” as well as how to lead a support group. They were also trained to ensure effective record keeping of their community activities that would take place during the intervention.

Table 2

Demographic data of PLWH and community members in the study

Demographic element		PLWH (n = 62)		Community (n=570)	
			%		%
Gender	Female	48	77.4	345	60.5
	Male	14	22.6	225	39.5
Ethnicity	Black	61	98.4	558	97.9
	Other	1	1.6	12	2.1
Marital status	Never married	29	46.8	267	46.8
	Married	9	14.5	118	20.7
	Living together	17	27.4	39	6.8
	Divorced	3	4.8	11	1.9
	Widowed	4	6.5	135	23.7
*School grade	No schooling	8	12.9	64	11.0
	Grades 1-9	31	51	210	37.2
	Grade 10	11	17	85	14.9
	Grade 11	7	11	83	14.8
	Grade 12	5	8	127	22.3
Highest post school education	None	57	92	473	83.0
	Certificate	5	8	86	15.1
	Diploma			4	0.7
	degree			4	0.7
Main source of income	Employed	13	22	178	31.2
	Social or HIV grant	16	26	53	9.3
	Pension	9	14	69	12.1
	Family/Friend support	10	16	137	24.0
	Other (odd jobs /part time)	9	22	133	23.2

*School grade -2 missing from community

The following intervention activities were conducted by the mobilisers over a five-month period of the intervention: 27 workshops of three hours each on “Understanding HIV stigma” for both PLWH and community members at least twice a week; 5 workshops on “Coping with HIV Stigma” for people from the first “Understanding HIV stigma” workshops and people who were interested to continue with the “Coping with HIV Stigma” workshops; additional activities included weekly door-to-door teaching of “Understanding HIV stigma” by means of a specially designed pamphlet on HIV stigma information. The door-to-door teaching activities reached 326 people. After the workshops a support group for community members and/or PLWH (6 sessions in total) was run. The mobilisers presented 8 psychodrama group performances on the theme of HIV stigma reduction at various venues in the ward (e.g. churches, gatherings and clinics). A HIV stigma-reduction community project planned and conducted together by the four mobilisers focussing on HIV stigma reduction and that entailed visiting the houses of PLWH, reached 117 people to give support and encouragement as well as to provide fruit and education to 160 PLWH at clinics. As part of this project two stigma campaigns were conducted at a taxi rank, as well as in the main street, reaching respectively 128 people and 46 people. Detailed records were kept of community activities referring to HIV stigma during this period, and weekly activity reports and field notes specifically related to the various activities. A mobiliser-coordinator employed by the North-West University and trained by the project leader supervised all activities of the mobilisers in the two “hubs”, gave support and collected the weekly activity reports.

Data Collection

The community was made aware of the research through several gatekeepers, e.g. ward counsellors and church leaders. A group of six trained field workers informed the participants about the purpose of the study, the reasons for their selection, the procedure and expected duration. They were informed that participation was voluntary and that they could withdraw from the study at any stage (adapted from Bothma, Greeff, Mulaudzi, & Wright, 2010). They could ask questions, had time to decide about their participation, and then signed informed consent forms. Potential availability was requested for further in-depth interviews

that would be digitally recorded. Participants were assured that they would remain anonymous and that records would be kept safe.

Quantitative data collection. Measures for PLWH and the community were implemented pre- and post-intervention. The ward, consisting of 784 houses, was divided into six manageable areas, with a trained fieldworker allocated to each area (about 95 houses) for data gathering. The six field workers were trained in a two-day workshop to conduct the structured interviews to obtain the pre-test and post-test quantitative data. These structured interviews consisted of the HIV/AIDS stigma instrument – PLWH (HASI-P) used for the identified PLWH, and the AIDS-related stigma measure used for the community members.

The HIV/AIDS Stigma Instrument – PLWH (HASI-P) © (Holzemer et al., 2007b). This instrument consists of 33 items scored on a four-point Likert scale ranging from “Never” to “Most of the time”. It measures six dimensions of HIV-related stigma: 8 items on verbal abuse (VA), 5 items on negative self-perception (NSP), 5 items on social isolation (SI), 7 items on healthcare neglect (HCN), 6 items on fear of contagion (FoC), 2 items on workplace stigma (WS); and the total perceived stigma score. Holzemer et al. (2007b) found Cronbach’s alpha reliability coefficients for the subscale scores ranging between 0.76 and 0.90 among 1477 respondents from five African countries.

The AIDS-related stigma measure (Maughan-Brown, 2004). This is a 39-item instrument answered on a five-point scale ranging from “definitely yes” to “don’t know”. Four dimensions are measured: behaviour index (BI), symbolic stigma (SS), instrumental stigma (IS), policy stigma (PS) as well as general stigma (GS). Internal consistency was $\alpha = 0.70 - 0.95$ and the test-retest reproducibility was >0.70 (ICC or weighted kappa) (Maughan-Brown, 2004).

Qualitative data collection. In-depth interviews with PLWH and community members were conducted prior and after the intervention. These in-depth interviews were conducted by the mobiliser-coordinator employed by the North-West University (NWU). She is trained

and experienced in in-depth interviewing. She contacted the PLWH and community members that were purposively selected from the initial quantitative sample, made appointments, reconfirmed consent and the use of digital recorders. These appointments were either at their homes or a place they found convenient and private. Their anonymity and the confidentiality of information that was shared, were confirmed and they were assured that their identity would never be linked to any transcriptions or recordings of the in-depth interviews due to the data being coded. For PLWH the focus was on their experiences of HIV stigma and for community members the focus was on their perceptions of and attitudes towards PLWH. The open-ended questions to be used during the in-depth interviews were given to experts, prior to the interviews, to evaluate its applicability and to adapt accordingly. Questions to PLWH were: "Tell me about your experience with HIV stigma in ward X? What behaviour have you experienced against you by the community because you are HIV positive?" Questions to the community members were: "Tell me about your views of the PLWH that live in ward X. What behaviour have you shown towards PLWH here in ward X?" The in-depth interviews were digitally recorded. Field notes were written after each interview focussing on personal, methodological and observational notes.

Data Analysis

Quantitative analysis. The data analysis was conducted with the IBM Statistical Package for the Social Sciences (SPSS) version 22 software (Pallant, 2011). Descriptive statistics (mean and standard deviation, kurtosis and skewness values) of all study measures were calculated. The t-test statistic was used to assess HIV stigma and stigmatisation differences as in the pre and post-test phases. The probability values (statistical significance) and effect sizes (practical significance) were examined to determine the difference in construct levels between the different times of evaluation (Field, 2013).

Qualitative analysis. The in-depth interviews that were digitally recorded were translated and transcribed verbatim. A second listener ensured the quality and validity of the translations. The computer software Atlas Ti version 6 was used during data analysis. Data analysis was conducted by means of open coding and by using the technique of Tesch as

discussed in Creswell and Plano Clark (2011). This technique entailed reading through all of the data carefully, looking for the underlying meaning in several documents, making a list of all topics, clustering similar topics, and forming them into columns that might be grouped as major topics, unique topics, and leftovers, coding the topics and then checking for emerging categories /domains and themes. A co-coder was used and discussions were held to reach consensus.

Trustworthiness

The model of Lincoln and Guba (Polit & Beck, 2008) was used to ensure trustworthiness in this study. Credibility was ensured by the prolonged five-month engagement of mobilisers in the research field during the implementation of the intervention. Reflexivity was based on the writing of field notes during and after the intervention activities, and discussions amongst mobilisers and discussions with study leaders. The use of both qualitative and quantitative methods and a trans-disciplinary research team ensured method and investigator triangulation. A dense description of the methodology and informed choice of sampling ensured applicability whilst consistency was ensured by the possibility of an audit trail and potential stepwise replicability due to a thick description of method and data. A co-coder was also used to enhance consistency. Neutrality was achieved through a combination of creating a possibility of an audit trail, the triangulation of investigators and methods as well as reflexivity. The authenticity of the research is beyond reproach as the research team personally engaged with PLWH and community members during the five months of the intervention.

Ethical Considerations

Ethical permission was obtained from the ethics committee of the North-West University (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014). A high standard of research was a priority and there was continued supervision by the researcher and mobiliser-coordinator. Respect for the participants was demonstrated through the provision of enough information to make participants feel comfortable in the situation and to give voluntary written informed consent. No form of identity was linked to collected data that was made available for analysis.

Participants were informed that the research team could not safeguard information that was shared in groups but that participants could request that it be treated confidentially. This included situations where group members were known to each other, or shared their HIV status or feelings of discomfort, or experienced embarrassment. Debriefing by an independent counsellor was available to those who showed distress during any aspects of the intervention.

The direct benefits for the mobilisers were that they gained knowledge and skills to become community mobilisers and to reduce stigma in their own communities. The direct benefits for participants were that PLWH as well as the community gained knowledge about HIV stigma and coping, experienced enhanced personal growth and relationships and experienced a reduction of HIV stigma in the community. An indirect benefit for the researchers was the knowledge gained regarding the effective use of a HIV stigma-reduction community intervention.

Results and Discussion

The mixed-method approach leads to an integrated reporting and discussion of the quantitative and qualitative results of the study. The quantitative data is expanded by using newly generated data from the qualitative in-depth interviews. The qualitative data is enriched by using direct quotes from the in-depth interviews with the participants.

Results and discussion on the HIV stigma experiences of PLWH. The pre- and post-test findings of the HIV/AIDS Stigma Instrument – PLWH (HASI-P) © (Holzemer et al., 2007b) are integrated with the findings from the in-depth interviews with the PLWH (See table 3). The subscales of the HASI-P and their itemised descriptors (column 1), comparative mean scores (\bar{x}) per subscale for the before and after groups, as well as the p-value ($p < 0.05$) and effect sizes [small ($d = 0.2$), medium ($d = 0.5$) and large ($d = 0.8$)] are displayed in table 3. Included alongside the itemised descriptors of the results of the HASI-P are descriptive quotes of these items as found during the in-depth interviews, as well as those itemised descriptors that were not found during the interviews. The subscales have been grouped

under Received Stigma: Verbal Abuse (VA), Healthcare Neglect (HCN), Social Isolation (SI) and Fear of Contagion (FoC) and Internal Stigma: negative self-perception (NSP). A scale on Total Stigma (TS) is included. The subscale for Workplace Stigma (WPS) was not used in this profile, as only 21% of the participants were employed.

Received stigma. This is a measure of the stigma PLWH received from others and comprises of 4 subscales:

Verbal abuse (VA). This is an 8-item subscale with itemised descriptors “Scolded”, “Insulted”, “Blamed”, “No future”, “and Gossip”, “Labelled”, “Name Calling and Mocked”. The mean scores for VA were 8.9 before and 8.4 after the intervention, showed no statistical ($p=0.36$) or practical ($d=0.14$) significance. However, the scores in both the pre- and post-test indicate the presence of verbal abuse. In the pre-intervention interviews, all eight items were mentioned. Participants mentioned that they were scolded for childish behaviour and a lack of common sense. PLWH are insulted by being called whores and blamed for contracting the illness and had to hear “you’re sick, you’re going to die”. People freely gossiped and spread rumours like ‘Hey did you hear? Your neighbour is sick.’ Being labelled on physical appearance was common and even being mocked for physical disabilities like having support when walking. In the post- intervention interviews the eight items reduced to four: “Scolded”, “Insulted”, “No future” and “Mocked” were not mentioned. The community even came up with new names for PLWH “There’s new names that they have come up with that they call us by. They call us ‘Hemela’”, referring to dying and going to heaven. Although neither statistically or practically significant differences were observed in VA there was a notable decrease on the verbalised items showing a subtle shift in perception.

However, in addition to the existing eight items of the VA subscale, one new possible item, “Pestering”, was mentioned. Quotes included statements like “*Why is it that you got HIV?*”; “*Why is she losing so much weight?*” and “*Hey you don’t look well. What’s wrong?*” Furthermore two new *additional* types of abuse were mentioned: physical abuse and emotional abuse. Physical abuse became obvious through statements like: “*Her son leaves us hungry in the house and goes to eat at his mother’s place*”; “*When we have been drinking,*

he takes my medication and spills them out in front of my kids". Emotional abuse was observed in remarks like: *"She turned and told me that she will not be reprimanded by people with Aids, who do I think I am?"* and *"She came to my house and threatened to talk about my illness to people."*

Healthcare neglect (HCN) is a seven-item subscale. A mean score of 7.4 before the intervention and 7.0 after the intervention showed no statistically ($p=0.05$) but a small practically significant difference ($d=0.27$) between the two measures. HCN was thus also present as a stigmatising experience in both the pre-and post-tests. Although participants were measured on the seven items of the subscale ("Being denied care", "Refused treatment", "Discharged when still needing care", "Shuttled around", "Waited till last to be helped", "Left in soiled bed" and "Pain ignored"), none of these items were specifically mentioned during the interviews. However, one possible new item, "Separation", was mentioned in both the pre- and post-intervention interviews by remarks like *"Yes the ones with TB and Aids go on the other side"; "like ours is hell, and the other one is made of gold"* and *"There's a side for those with TB and for withdrawing blood, and there's another side for all other illnesses"*. According to the scores on HCN it would seem that this kind of stigma is still present even though the participants did not express the specific items of the scale in the interviews. It would seem as though the context of health care neglect has changed since the development of the scale.

Social isolation (SI), a five (5) item subscale "Not visiting", "End relationships", "Not chatting", "Stopped being friends" and "Avoided", showed no statistical significance ($p=0.10$) but a small practical significant difference ($d=0.22$) between the before- and after intervention measures. The mean score before was 5.8 and 5.2 after. SI was present in both pre-and post- tests. Four of the five items were confirmed in both measures. "Not chatting" was never mentioned. The pre-intervention participants mentioned people avoiding visiting them and coming to their house and the end of intimate relationships. It is described that friendships change or end and people withdraw *"They start to pull away"*. Although a small practically significant difference is present it seems as if social isolation remains a problem for PLWH.

Fear of contagion (FoC) consist of six items “Eating utensils”, “Sharing cups”, “Not touch someone’s child”, “Stopped eating with others”, “Made to eat alone” and “Asked to leave due to coughing”. FoC was evident in both the pre-and post-test measures, with a mean score of 6.5 before and 6.2 after the intervention, with no statistically ($p=0.32$) or practically ($d = 0.14$) significant difference. Five of the six items were present in the pre-intervention interviews and four in the post-test interviews. “Asked to leave due to coughing” was not present in either the pre- or post-test interviews. Participants describe how their dishes were covered with a cloth or even marked with nail polish and people, even their children, refused to share a glass a cup or a meal with them. They were separated at mealtimes and made to eat in a different place. “Not touch someone’s child” was identified in the pre-test interview. The other items confirmed in the post-test interviews clearly stated separation of eating utensils, not sharing food and being isolated at mealtimes. A new item, “Not dealing with PLWH”, was mentioned in the pre-intervention interviews. It referred to not buying produce from PLWH: *“You know they said I should no longer buy your beer because I will get AIDS”*. This item was not in the post- intervention interviews as well as “Not touch someone’s child”. It would seem that FoC is deeply embedded and difficult to change as no true changes were observed.

Internal stigma. Negative self-perception (NSP) is the only type of internal stigma identified in the stigma scale. It is a 5-item subscale that showed no statistically ($p=0.14$) but a small practically ($d= 0.21$) significant difference between the mean score of 6.3 before the intervention and 5.6 afterwards. NSP is shown as being present among PLWH. The items are “Not deserve to live”, “Worthless”, “Feel ashamed”, “Trouble to family” and “Not a person”. Mention of all five items were found in the pre-intervention interviews, but only two of the items were found in the post-intervention interviews: “Feel ashamed” and “Trouble to family”. They mentioned that *“I think that I don't deserve to live because I don't live like other people”* and reported not meaning anything to others in the pre-intervention interviews. Participants indicated that they felt ashamed to share their status with others and that their own family hated them. They felt that people looked down on them, not treating them as a person. After

the intervention responses like “the *family they are staying with will complain about them*”; and “*They are always expecting food that they do not work for*” remained. The biggest change in stigma experiences occurred in internal stigma. It seems that PLWH have more control over changes in this area as they can exercise control over themselves if not others.

During the interviews four new additional items were found that could be included under internal stigma. These were “Lack of self-care”, “Suicidal thoughts”, “Lack of self-acceptance” and “Self-isolation”. All four these items were found in the pre-intervention interviews but only “Suicidal thoughts”, were still expressed in the post-intervention interviews. In the pre-intervention interviews it was described in references like “*the moment a person finds out that they have HIV they don’t take their treatment*”. Suicidal thoughts were expressed as “*The day they told me I was positive, I didn’t believe it. I even wanted to use my dad’s gun*”; Lack of self-acceptance became obvious in the pre-intervention interviews, with the PLWH saying “*and I saw that I wasn’t going to be accepted and I wasn’t going to accept myself*”. “Self-isolation” was mentioned with PLWH describing that they avoided being with people.

Total stigma (TS). On this scale, a mean score of 36.92 before the intervention and 34.35 after the intervention, shows no statistically ($p=0.09$) but a small practically ($d=0.25$) significant difference that indicate a small reduction in stigma experienced by PLWH after the intervention. The score of 36.92 indicates that a high incidence of HIV related stigma is experienced by PLWH. The interviews strengthened this finding by describing most of the items and even adding some new items. The results of the post-intervention measures display an encouraging notion of practically significant changes in the stigma experiences of PLWH in three of the subscales (HCN, SI and FoC) as well as the total score.

Additional changes observed during the post-intervention in-depth interviews. The post intervention interviews give a stronger picture of change that took place, highlighting self-acceptance and acceptance from others, changes in affect and a growing sense of trust and connection between PLWH and community members. It would seem as if the strongest influence of the HIV stigma reduction intervention was on personal and social changes. In

the post- intervention interviews the following changes in the experience of stigma by PLWH that were not measurable by the instrument were described:

The PLWH realised that with the support of people close to them and the community, they can live positively with the illness: *“The people I am living with have accepted my situation.”* This leads to enhanced feelings of being accepted as well as self-acceptance. They expressed feelings of freedom and strength that were noticeably absent in the pre-test interviews. One PLWH said about the intervention: *“Your treatment gives me strength. I feel human again”*.

Changes in affect took place, as a participant claimed that it *“changed a lot of emotions within me”*. Relationships were also strengthened. The participants referred to family: *“I feel good. The other day, my family came to see me”* and to friends *“My two friends are always asking me, ‘are you taking your medication?’* A new social freedom was expressed, even in terms of visits to the clinics: *“Yes, it’s actually very nice going to the clinic”*. Participants experienced a growing sense of trust and connection between community members and PLWH making statements like *“There are people within the community that go around and encourage us”*. The role that lack of knowledge play in HIV stigma was realised. More than one participant made observations such as *“Okay, I’ve experienced that people still don’t have enough knowledge about this thing”*. This led to a sense of empowerment, helping others with the new knowledge gained: *“You could clearly see that this person has HIV, and I told him to go see a doctor”*.

PLWH found a liberating effect in disclosure, and they also realised the importance of disclosure in the health and well-being of themselves and others: *“but I am open about my status to everyone, and I can talk to people about it”*. The socially isolating effect of not being able to talk about the illness was expressed with participants stating: *“It’s important to talk to someone about your status because you’re able to express yourself and it makes it easier for people to accept you”*.

Table 3

Combined results for the HASI-P and the in-depth interviews before and after the intervention.

HASI-P scale for PLWH (n = 62)	\bar{x}	Quotations Before Intervention (n=10)	\bar{x}	Quotations After Intervention (n=10)	p	d
Received Stigma						
Verbal Abuse (VA)	8.85		8.38		0.36	0.14
Scolded		"Would that I behave like a child if I had any sense then maybe I wouldn't have HIV."		Not found		
Insulted		"Say hurtful things like how I'm a whore."		Not found		
Blamed		"She was making it seem like it was my fault."		"They will remind you that you are sick and shouldn't have done all the bad things you were previously doing to end up with HIV."		
No future		"You're sick. You're going to die."		Not found		
Gossip		"I will hear, "Hey did you hear? Your neighbour is sick."		"They used to talk about the spots on her face and mouth, saying, "Something is wrong with her. She must have HIV."		
Labelled		"They see you and your thin they say you have Aids and they won't even ask you what the problem is."		"They will lie and say that they have seen HIV-like symptoms in you."		
Name-calling		"We know her she's leaving the hood."		"There's new names that they have come up with that they call us by. They call us 'Hemela'."		
Mocked		"I used to use the wall to walk. They would all laugh at me while sitting under a tree."		Not found		
Additional items found						
Pestering		They would say, "Why are you sitting alone? Come sit with us or are you stressed? What's stressing you?"		"Hey you don't look well. What's wrong?"		
Other forms of received stigma						
Physical abuse		"Her son leaves us hungry in the house and goes to eat at his mother's place."		"When we have been drinking, he takes my medication and spills them out in front of my kids".		
Emotional abuse		"She turned and told me that she will not be reprimanded by people with aids, who do I think I am?"		Not found		

HASI-P scale for PLWH (n = 62)	\bar{x}	Quotations Before Intervention (n=10)	\bar{x}	Quotations After Intervention (n=10)	p	d
Healthcare neglect (HCN)	7.40		7.00		0.05	0.27
Denied care		Not found		Not found		
Refused treatment		Not found		Not found		
Shuttled around		Not found		Not found		
Discharged, still needing care		Not found		Not found		
Waited till last to be helped		Not found		Not found		
Left in soiled bed		Not found		Not found		
Pain ignore		Not found		Not found		
Additional item						
Separation		"Yes the one's with TB and Aids go on the other side."		"There's a side for those with TB and for withdrawing blood, and there's another side for all other illnesses."		
Social Isolation (SI)	5.8		5.17		0.10	0.22
Not visiting		"Almost as if they thought they would be positive by just coming into our house."		"They started discriminating me. They still do and don't even come to visit me"		
End relationships		"I don't want us to be intimate anymore."		"Our friendship ends, but then they start talking about you."		
Not chatting		Not found		Not found		
Stopped being friends		"They start distancing themselves from you."		"They no longer act the same around you."		
Avoided		"They start to pull away from you and not live with you."		"When I enter a room, that person leaves and tells others not to socialise with me because I have AIDS and I will infect them."		
Fear of contagion (FOC)	6.5		6.2		0.32	0.14
Eating utensils		"The bowl she had covered in Cutex (nail polish) she was holding it with a cloth."		I see that my mug has been covered up."		
Sharing cups		"I don't use glasses because they won't drink from something that I've used."		"I won't share a drink with XX."		
Not touch someone's child		"Hear them say not hold someone's child because you will affect the child with your blood."		Not found		
Made to eat alone		"No that's yours and dads, that's where you guys will eat."		"Whenever we would sit down somewhere in a group, drinking, they would refuse to drink with her."		
Stopped eating with Others		No, don't dish for me. I already ate."		"It's almost as if they think I put this illness in the food."		

HASI-P scale for PLWH (n = 62)	\bar{x}	Quotations Before Intervention (n=10)	\bar{x}	Quotations After Intervention (n=10)	p	d
Asked to leave due to coughing		Not found		Not found		
Additional Item Not dealing with PLWH		"You know they said I should no longer buy your beer because I will get AIDS."		Not found		
Internal Stigma Negative self-Perception (NSP)	6.22		5.59		0.13	0,21
Not deserve to live		"I think that I don't deserve to live because I don't live like other people."		Not Found		
Worthless		"Maybe I don't mean anything to them."		Not Found		
Feel ashamed		"Like I have a sister and she likes visiting me so now maybe I'm ashamed to tell her that I have HIV."		"It's because they are ashamed of being HIV-positive."		
Trouble to family		"My own family hated me."		"The family will complain about them."		
Not a person		"People look down on you; they don't treat you like a person."		Not found		
Additional items found Lack of self-care		"The moment a person finds out that they have HIV they don't take their treatment and think that people don't like them anymore."		"Sometimes I think of taking all the pills I can find and killing myself."		
Suicidal thoughts		"The day they told me I was positive, I didn't believe it. I even wanted to use my dad's gun."		Not found		
Lack of self-acceptance		"And I saw that I wasn't going to be accepted and I wasn't going to accept myself."		Not found		
Total Stigma	36.92		34.35		0.09	0.25

Results and Discussion of AIDS-Related Perceptions of the Community. The pre- and post-test findings of the AIDS-related stigma measure for the community are integrated with the findings of the in-depth interviews with the community (see table 4). Itemised descriptors (column 1), comparative mean scores (\bar{x}) per subscale for the before- and after-intervention measures, as well as the p-value ($p < 0.05$) and d-value, [0.20 = small effect size,

0.50 = moderate effect size and ≥ 0.80 = large effect size] (Cohen, 1992), together with the findings of the in-depth interviews that describe the items, are displayed in table 4. Included alongside the itemised descriptors of the results of the AIDS-related stigma measure for the community are descriptive quotes of these items as found during the interviews, as well as those itemised descriptors that were not found during the interviews. The subscales are Behaviour Index (BI), Symbolic Stigma Index (SSI), Instrumental Stigma (IS) and General Stigma (GS). One subscale, Policy Index (PI), is excluded from the discussion because the independent factor analysis for items on this index did not prove reliable on the Cronbach alpha (0.421) for this study.

The Behaviour Index (BI). This is regarded as measuring the intended behaviour towards PLWH. BI had a mean score of 7.38 for the before-intervention measure and 6.97 for the after-measure, and shows no statistical ($p < .001$) or practical ($d = 0.18$) significance. It was expected that scores for the BI would decrease after the intervention. Intended stigmatising behaviour towards PLWH was present. The four items are “Care for family member”, “Not remain friends”, “Dealing with PLWH”, and “Relationship like dating”. In the pre-intervention interviews three of the four items were mentioned. “Dealing with PLWH” was not found. “Care for family member” was expressed as *“This person no longer has an appetite and they are always shouting at her so this person can’t do anything for themselves anymore”*. Breaking up of friendships are mentioned, with the participant referring to *“Like you have friends then they find out that you have HIV, your relationship with them changes completely”*. Participants also mentioned *“I don’t like people who are HIV positive and I feel guilty and I don’t like HIV”*. Only two of the items were verbalised during the post-intervention interviews, namely “Care for family member” and “Not remain friends”: *“Family speaks bad about her for living off the mother’s pension”* and *“it was difficult for me to be with her”*. The intervention did not really make a change in the behaviour towards PLWH.

Symbolic Stigma Index (SSI). This index refers to a moralistic, value-based or prejudice based position about what HIV stands for or symbolises for the community. The pre-intervention mean score is 7.90 and post-intervention 8.88. This is not statistically

($p < .001$) significant but shows a small practical ($d = 0.31$) significance. The score for SSI should show an increase as an indication of positive change. Symbolic stigma seems strong and the interviews concur well with the presence of SSI in the scale. The four items in this index are “Receiving of grants”, “Punishment for sexual behaviour”, “Blaming”, and “Evil Intent”. Three of the four items are present in both the pre- and post-intervention interviews. Only “Evil Intent” was not mentioned. Participants were clear that PLWH should not receive grants *“because they drink. There are people that need the help seriously”*. HIV as punishment for sexual behaviour was expressed by referring to *“they are people who didn’t look after themselves in terms of safe sex”*. PLWH were blamed *“If only you weren’t such a smarty-pant that time then you wouldn’t be in this situation now, look at you you’re dying.”* To change moral and value based positions towards PLWH proved difficult to do. Only a small practical significant change was observed. However people seemed less judgemental and punishing during the post-test interviews.

Instrumental Stigma Index (IS). This indicates actions, attitudes or beliefs based on a fear of contagion. IS had a mean score of 8.20 for the before-intervention measure and 9.44 for the after-intervention measure and were thus not statistically significant ($p < .001$). The score however shows a practically significant ($d = 0.40$) increase, as was expected, to indicate a positive change. The items in this index are “Share food and utensils”, “Disclosure so can avoid”, “Avoid physical interaction”, “HIV pupil allowed in school”. Three of the four items were mentioned in the pre-intervention interviews, and only “HIV pupil allowed in school” was not mentioned. Participants said *“Even if you’re wearing something of theirs they think that you’ll get infected”*. The item “Disclosure so can avoid” was only found in the pre-intervention interviews, where it was said *“You have to know where they stand”*. “Avoid physical contact” was indicated by *“You should have minimum contact with them”*. In the post-intervention interviews three of the items were found, but they were different from the ones in the pre-intervention interviews. “Disclosure so can avoid” was not found. “Share food and utensils” was present as participants noted *“I know what things I can share with them, but that I won’t be affected. I mean sharing a cup or a teaspoon”*. It is mentioned that people are ashamed

of the illness and therefore don't visit or allow people to visit, avoiding physical contact. The item "HIV Pupil" referring to whether there should be contact with HIV infected children at school was found in the after-intervention interviews as a participant mentioned "*Some parents like telling their kids that other kids within the community have HIV, so they mustn't play or socialise with them.*" On this subscale again only a small practically significant change was observed, reflecting the difficulty in changing peoples' fear of contagion. However this index shows the strongest change positive change indicating that the fear of contagion has decreased following the intervention. This could be ascribed to knowledge gained and the increased contact with PLWH.

The General Stigma Index (GS). This index had a mean score of 33.20 for the before measure and 34.89 for the after measure. This is not statistically significant ($p < 0.001$) but shows a small practical significance ($d = 0.26$). The GS score is expected to increase as indication of positive change. Some positive changes were observed throughout the intervention.

Additional changes observed during the post-intervention in-depth interviews. Post-intervention interview results display changes in the attitudes and behaviour towards PLWH that could not be observed in the instruments. There was a realisation that someone who has HIV is a person like everyone else, should be accepted and not criticised or spoken about badly. Statements such as "*I used to have that negative thinking that the person is sick and she is going to die ...*" were found. Some realised that their stigmatising behaviour compounds the effects of the illness. They would say "*Not to drop that person at the position they are at because that person will stop using their medication*" and "*will start not trusting themselves and in the end will give up on life*". Some were able to acknowledge the fear and, even more importantly, some acknowledged having a PLWH as a child or partner and that they were ashamed to mention initially, as they feared being blamed. They also do not want the child or loved one to be stigmatised. There was an increase in disclosure amongst some of the participants.

Table 4

Combined results of AIDS-related perceptions of stigma in the community

AIDS related perceptions of stigma in the community	\bar{x}	Quotations Before Intervention (n=496)	\bar{x}	Quotations after intervention (n=496)	p	d
Subscales						
Behaviour Index (BI)	7.38		6.69		<.001	0.18
Care for family member		"This person no longer has an appetite and they are always shouting at her so this person can't do anything for themselves anymore."		"Family speaks badly about her for living off the mother's pension."		
Remain friends		"Your relationship with them changes completely."		"After she told me about it, it was difficult for me to talk to her."		
Dealing with PLWH		Not found		Not found		
Relationship like dating		"HIV, I don't like people who have HIV positive and I feel guilty and I don't like HIV."		Not found		
Symbolic Stigma Index (SSI)						
Grants		"No they don't because they don't need help because they drink."		"But why must people with HIV get paid whereas we don't get paid."		
Punishment for sexual behaviour		"If only you weren't such a smarty-pant that time then you wouldn't be in this situation now, look at you you're dying."		"I think it is hard for them to stop their bad habits about being promiscuous, going to taverns for alcohol and so on."		
Blaming		"You then help me without taking precaution, so in those cases the blame is to the positive person."		"Since people talk about people and would blame the one who went to visit that person at their house."		
Evil intent		Not found		Not found		
Instrumental Stigma Index (IS)	8.20		9.44		<.001	0.40
Share food and utensils		"So people don't like people with AIDS, they don't want to touch them or even sit on the same chair as them. Even if you're wearing the something of theirs they think that you'll get infected."		"I know what things I can share with them, but that I won't be affected. I mean sharing a cup or a teaspoon."		
Disclosure so can avoid		"You have to know where they stand."		Not found		
Avoid physical interaction		"You should have minimum contact with them."		"People are ashamed of this illness and therefore don't visit or allow people to visit."		
HIV pupil		Not found		"Some parents like telling their kids that other kids within the community have HIV, so they mustn't play or socialise with them."		

General Stigma (GS)	33.20	34.89	<.001	0.26
	"HIV I don't like people who have HIV positive and I feel guilty and I don't like HIV."	"... I used to have that negative thinking that the person is sick and she is going to die ..."		
<i>Behaviour Index (BI), Symbolic Stigma Index (SSI), Instrumental Stigma (IS), General Stigma (GS)</i>				

Conclusions

It may be concluded that the intervention did make a difference in the experiences of stigma of PLWH as well as the stigmatisation by the community. Although the HIV stigma-reduction community "hub" network intervention could not make a statistically significant change in HIV stigma experiences of PLWH, it did bring about a practically significant change on three of the five subscales as well as on the total stigma score (HCN, SI, NSP and TS). The extent of these changes was much more obvious in the responses of PLWH during their post-intervention interviews than the changes found with the quantitative measures indicating that the changes were more clearly reflected in the verbalisation of their experiences reflected the changes more. The category "verbal abuse" proved resistant to change, leading to the conclusion that verbal abuse directed at PLWH is entrenched habitual behaviour and difficult to change in the three- months period that the intervention lasted. This conclusion is confirmed by the identification of two new categories of abuse that emerged namely *physical* and *emotional* abuse that were not reflected in the original stigma scale. With the category "fear of contagion" the least changes in both the post-test results and the interviews were observed which leads to the conclusion that despite claims of adequate knowledge, fear of contagion is still deeply embedded in the psyche of the population. The category "health care neglect", although present as a stigmatising experience in the pre-and post-test measures was hardly mentioned during the in-depth interviews. This leads one to believe that the context of stigma in health care facilities as it was reflected in the scale could have changed as people no longer verbalise the items. It was now verbalised in a different context as in terms of feelings of being separated or isolated. The positive intra-personal changes measured in the category "negative self-perception" emerged the strongest during the post-test interviews leading to the conclusion that PLWH have a stronger control over changing their personal perceptions but do not have that control over their community's actions. The

change in the “total stigma” score confirms the conclusion that the intervention showed some success in terms of the objectives set for this study of to reduce HIV stigma experiences of PLWH through a community intervention. Aspects of behaviour change - like heightened awareness, self-sufficiency and acceptance of reality, changed intentions of actions and strengthened trust and improved relationships between PLWH, their friends, family and the community - which were clearly expressed during the post-intervention interviews confirms the conclusion that the intervention was successful. The limited statistical improvement could possibly be ascribed to the short duration of the intervention of three months and the fact that two “hubs” were not sufficient to change the deep-seated perceptions and behaviour of a total community.

With regard to changes in the stigmatising behaviour of the community towards PLWH, the AIDS-related stigma measure in the community showed no statistically significant change but practically significant changes occurred in three of the four subscale (SSI, IS, GS) suggesting that some change was achieved in the stigmatising behaviour of the larger community. The changes expressed in the post-test interviews confirm the conclusion that the community’s understanding of the issue was enhanced through the intervention and that the prejudice of community members and their intention to stigmatise were reduced. The scores on the “behaviour index” lead to the conclusion that behaviour over the three month period of the intervention showed resistance to change. The change in terms of the SSI suggests that the community’s prejudicial or moralistic views could be altered as they were less judgemental after the intervention. The IS score showed the same embedded fear of contagion that was identified in the earlier discussion of PLWH’s experiences of people being fearful of becoming infected. However, the practically significant change on this score could also indicate that the added knowledge and the increased contact with PLWH had the beneficial effect of reducing the overall stigmatising behaviour of the community. The similar practical significant change in the “general stigma index” shows that the intervention had the ability to make a difference in the community’s stigmatising behaviour. The Information-Motivation-Behavioural skills model (Fisher, J., Fisher, W., Misovich, Kimble, & Malloy, 1996)

refers to three constructs that influence change: information and knowledge about the behaviour; the individual's motivation to perform the behaviour; and the behavioural skills necessary to perform the behaviour. These constructs formed part of the community intervention and could thus influence the community as a whole. Rongkavilit et al. (2010) further refers to the motivational construct, which includes both personal, social and cultural motivations. The former includes positive or negative attitudes, perceived benefits, and/or perceived negative effects, while the latter includes the individual's perceptions of social support by others and his/her desire to conform with others. For a collectivistic society it also carries a cultural component.

From the discussion it can thus be concluded that the HIV stigma-reduction community "hub" network intervention, which involved PLWH and PLC sharing their knowledge as community mobilisers and mobilising and empowerment of their own community to reduce HIV stigma, was successful. The intervention initiated the onset of changes in a community through the PLWH and PLC as community mobilisers who were active in the community "hub" network to mobilise their own communities towards HIV stigma reduction through social change. The involvement of PLWH and PLC as community mobilisers, who shared their knowledge and mobilised and empowered their own community brought about changes in the short term for a whole community. Addressing more than one level of change (individual change and social change) as well as involving a whole community regardless of the HIV status of individuals could be of use in future HIV stigma reduction interventions for communities. By involving the whole community, the possible negative effect of stigma on PLWH and PLC in the intervention is mitigated as the intervention is aimed at the entire community.

Limitations of the Study

Although the sample size for PLWH was small, the mixed-method study combined two measures in order to counteract this limitation. The true value of mixed-methodology in this study lies in the fact that the in-depth interviews shed new light on the experiences of PLWH and the community as it gave voice to the people, highlighting points of view not found in the

measures. Observation over a longer period could have broadened insight in terms of whether the raised awareness of stigma and stigmatisation will have an influence on subsequent stigma related experiences of PLWH and behaviour of their community.

Recommendations

It is recommended that the HIV stigma-reduction community “hub” intervention that involved PLWH and PLC sharing their knowledge as community mobilisers and mobilising and empowering their own community to reduce HIV stigma, be used again in future to address community HIV stigma reduction. It may be beneficial to research ways in which the elements that proved resistant to change - like verbal abuse and fears of contagion - could be addressed in more depth during the intervention. Further research is needed on if and how the context of stigma in health care facilities has changed. Follow-up workshops with other techniques like community conversations on the subject could increase community participation and mobilisation. Upskilling and implementing more mobiliser “hubs” could extend the reach of the intervention and broaden the potential of behaviour change and stronger ownership in the endeavour to reduce stigma and address HIV prevention. This should influence the sustainability of the project. Due to the difficulty of mobilising change in a limited time the intervention should become part of the everyday activities of the community to ensure lasting effects. Further research to evaluate how long the change in the community lasts would also be important to truly influence or reduce HIV stigma. In terms of sustainability of community mobilisation authors like Campbell and Cornish (2012) propagate enhanced transformative communication and strengthening of health enabling environments. This could be in the form of helpful networks with powerful groups, improved access to resources and services, and more democratic and cohesive relationships within local communities.

It could be beneficial to revise the *HIV/AIDS stigma instrument for PLWH* (Hasi-P) © on a continuous basis, to adapt to the changing context of HIV stigma. The subscales for received stigma namely VA, HCN, SI and FoC could be revised with items found during the in-depth interviews of this study. For the internal stigma section (NSP category), items like

lack of self-care, suicidal thoughts, lack of self-acceptance, fear of disclosure and self-isolation could enrich the measure.

The *AIDS-related stigma measure* for stigmatisation by the community intended to measure the stigmatising behaviour of individuals but in general this measure and the in-depth interviews did not correlate well. Hence, a different measure for stigmatisation by the community needs to be explored. Items found during the in-depth interviews with the community could form the basis of such a new scale.

It is evident from this research that the context of stigma changes over time. There is also a growing understanding in the literature that stigmatisation involves both automatic, implicit responses as well as controlled, deliberate responses (Bos, Pryor, Reeder, & Stutterheim 2013). Due to the interrelatedness of different manifestations of stigma and the changes in context over time the stigma research field would likely benefit from collaboration between different disciplines from health and social sciences to incorporate multiple measures allowing for comparison of their validity and reliability.

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**Article 2: A Community “Hub” Network Intervention for HIV Stigma Reduction: A
Case Study**

Journal: Journal of the Association of Nurses In Aids Care

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A Community “Hub” Network Intervention for HIV Stigma Reduction: A Case Study

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A Community “Hub” Network Intervention for HIV Stigma Reduction: A Case Study

Abstract

The purpose of this article is to describe the implementation of a community “hub” network intervention for the reduction of HIV stigma in a ward of the Tlokwe Municipality in the North West Province, South Africa. A holistic single case study design was used, focusing on members from the above-mentioned community, with no differentiation in HIV status. The participants were recruited through accessibility sampling. Data analysis was done by means of open coding and document text analysis. It is concluded that the HIV stigma-reduction community “hub” network intervention as it was implemented, was successful in activating mobilisers to initiate change in their community, to lessen the experience of stigma for PLWH and to lessen stigmatisation by the community. The intervention was successful in addressing HIV stigma reduction in a whole community by utilising a combination of strategies and by including individual and interpersonal levels as well as social networks and the public. It is recommended that the intervention is repeated and enhanced in future. In particular, the “hub” network system should be extended, the intervention period should be longer, there should be a stronger support system for the mobilisers, and the multiple strategy approach should be continued on both an individual and a social level.

Keywords: community, HIV stigma reduction, “hub” network intervention, South Africa.

Background and Problem Statement

The serious manner in which of HIV stigma and discrimination affect the global response to HIV and AIDS is well known (Turan & Nyblade, 2013) as HIV stigma and discrimination cause a significant barrier to HIV reduction activities like prevention, care and treatment. The International HIV and AIDS Alliance (2011) issued a call for the integration of HIV stigma reduction activities into all HIV programmes. This call underlines the importance of deepening the response to HIV and AIDS on all levels as the stigma attached to HIV leaves nobody untouched.

In the quest to understand stigma and its devastating effects various models and frameworks were proposed through the years. Alonzo and Reynolds (1995) pioneered an analysis of HIV stigma in terms of a trajectory spanning the course of the disease tied to the stigmatising responses of society. Over time researchers postulated that inequalities in power (social, political, and economic), structural violence like racism and sexism amongst others and pre-existing stigmas like those against marginalized groups result in labeling, stereotyping, status loss, and discrimination. They noted that these factors are the basis on which stigma is founded (Mahajan et al., 2008; Weiss, Ramakrishna, & Somma, 2006).

The conceptual model of HIV and AIDS stigma by Holzemer et al. (2007) forms the theoretical framework of the research done for this study. The model refers to both context and process. The context of HIV stigma is created by the environment, including the cultural, economic, political, legal and policy environment; the healthcare system which includes settings such as hospitals, clinics and home-based care settings and health service delivery settings, and agents (people) like people living with HIV (PLWH), family, colleagues and community. The process of HIV stigma as conceptualised by Holzemer et al. (2007) shows the interconnectedness of the elements in the context that play a role in stigmatisation. These elements are triggers, stigmatising behaviours, types of stigma and outcomes. Triggers; namely the HIV disease itself, diagnosis, disclosure and the suspicion of having the disease lead to a person's own negative perceptions about the self and to stigmatising behaviour by other people such as blame, insults avoidance and accusation. These in turn give rise to certain types of stigma, (received, internal and associated) and finally to certain stigma outcomes, such as poorer health and decreased quality of life, among others.

The focus for this study is the community as PLWH, people living close to them (PLC) and the community that they live in all face the outcomes of stigma in their lives (Earnshaw & Chaudoir, 2009). In a study with a population of ethno-racial and sexual minorities it was found that HIV-related stigma threatened and disrupted the accepted social connections and affected the social structures in the studied community (Galindo, 2013). This impacted on the overall individual well-being as well as the social norms and cultural values of the community.

Stigma creates inequality, undermines trust, and reduces opportunities for interpersonal interactions between community members. Social stigma interferes with bonding, bridging and linking people together, and has negative health consequences (Chen et al., 2011). Human beings are part of a shared social space carrying the burden of care, being part of getting things done together for the community in addressing illness and stigma. Social interactions take place at the individual level, but individuals do not come to social interaction without affect, values and motivation; and individuals exist in structured political, cultural and social contexts with defined social norms. Thus, social interactions take place in a structured context, where the norms of that society create ideas of difference (Pulerwitz, Michaelis, Weiss, Brown & Mahendra, 2010).

There is a growing interest in addressing the social drivers of HIV, using core social change communication principles of participation, which is mutual understanding, equal voices, local ownership, sustainability, collective learning and multiple accountabilities. In other words it involves a focus on social change (Byrne & Vincent, 2011). Social change is always a function of the collective actions and interactions of groups of people and always in the process of evolving (Kippax, Stephenson, Parker, & Aggleton, 2013). There are significant arguments that social change positively influences evolution, growth, and development. This view proposes that social change may provide individuals with hope, excitement and other positive opportunities to develop useful life skills and achieve self-actualisation (Wissing et al., 2011). Community Health Psychology (CHP), the theory and method of working with communities to combat disease and to promote health, is grounded in respect for communities believing that they carry their own wisdom and that the foundation for human sociality, organisation and creativity lies in the everyday human relationships and practices in communities and that community mobilisation changes the residents from clients to change agents (Hadjez-Berrios, 2014). A new way of conceptualising community health action, which is labelled 'trusting the process' introduces possibilities of an open-ended, anti-hierarchical and inclusive mode of community action (Cornish, Montenegro, Van Reisen, Zaka, & Sevitt, 2014).

If the perspective on how change in human behaviour occurs is in itself changing, a new look should be taken at interventions to reduce HIV-related stigma and the elements necessary for its success. A systematic review of 48 interventions to reduce HIV-related stigma and discrimination from 2002 to 2013, presenting 14 different target populations in 28 countries, revealed advancement in the stigma-reduction field over the last decade (Stangl, Lloyd, Brady, Holland, & Baral, 2013). It becomes clear that multi-tiered aspects need attention in HIV stigma reduction interventions, these being: drivers, agents, intersecting stigmas and manifestations of stigma; the levels of intervention including individual, interpersonal, social networks, organizational, community and public and lastly the strategies employed in the intervention. These strategies referred to are information-based approaches, skills building, counselling/support and contact with affected groups as was explored in the review of Brown Trujillo, and Macintyre (2011). The review of Stangl et al. (2013) found that the majority of interventions utilised two or more strategies to reduce stigma and discrimination, and ten included structural or biomedical components on a single social-ecological level. Single level behavioural interventions cannot alter social structures that generate patterning of risk over generations. Long-term, sustained alteration of these patterns requires a more comprehensive approach to structural change (Parkhurst, 2013). Campbell (2014) suggests the need for a medley of approaches to accommodate health struggles in different times and places.

A number of factors then should be addressed in successful HIV stigma reduction interventions. A global HIV stigma reduction framework developed by The International Center for Research on Women (ICRW) (2013), focused on causal factors, (factors which can be changed by interventions), like lack of knowledge of stigma and how harmful it is, moral judgment and fears like fear of infection. A study in Thailand evaluated the effect of project interventions on reducing community-level HIV stigma. The project addressed HIV stigma and discrimination within communities involving monthly banking days, HIV campaigns, information, education and communication (IEC) materials and even “Funfairs”

(Jain et al., 2013). The authors observed significant changes in HIV transmission knowledge, fear of HIV infection and the shame associated with having HIV.

There is a growing awareness that the success of national, regional and global programmes to effectively confront HIV and AIDS in general requires greater involvement of PLWH. The Good Practice Guide (McClelland & De Pauw, 2010) on involvement of PLWH and strategies for involvement of PLWH in stigma reduction and other HIV interventions mentions an initiative to strengthen the capacity and coordination of networks of PLWH. The Asia Pacific Network of People living with HIV and AIDS (2011) agrees that publicly acknowledged involvement empowers PLWH to help reduce stigma and discrimination. In review of the past two decades of research in this area empowerment was likened to meaning, competence, self-determination, and choice (Maynard, Gilson, & Mathieu, 2012). These authors concluded that there is abundant support in the literature for the view that empowerment initiatives are beneficial to individuals, teams, organizations and communities. Michaels et al. (2014) assessed the Anti-Stigma Project (ASP) workshop, a consumer-based stigma reduction programme. The ASP educated participants in small group settings about stigma impact on participants, their families and health providers. Post-intervention, participants were more aware of stigma, had lower levels of prejudice, and increased agreement in self-determination of people.

In terms of this study a group of researchers conducted intensive research on HIV stigma within the African setting over a five-year period. They aimed to understand HIV stigma in Africa, formulating the conceptual model for HIV stigma mentioned earlier and developed and validated two stigma scales for the African context for PLWH and nurses (Holzemer et al., 2007; Uys et al., 2009). One component of their study focused specifically on HIV related stigma in healthcare settings as perpetrated and experienced by nurses. They concluded that the instrument has the potential to be used not only to measure stigma, but also to develop stigma-reduction interventions. This was followed by research using a trans-disciplinary, comprehensive community-based HIV stigma reduction and wellness enhancement intervention that involved PLWH as well as people living close to them (PLC)

be it partner, child, family member, friend, community member or spiritual leader (French, Greeff, Watson, & Doak, 2015). The study found that the comprehensive nature of the intervention facilitated relationships in all groups and enhanced knowledge about stigma. PLWH felt less stigmatised and more willing to disclose and PLC became aware of their stigmatising behaviours and were empowered to lead stigma reduction in their communities. However, challenges and gaps remain as studies targeting communities to reduce HIV stigma remain limited. This study initiates strategies that mobilise PLWH and PLC in HIV stigma reduction in their communities through the implementation and evaluation of an HIV stigma-reduction community “hub” network intervention that assumes, and is based upon the involvement of PLWH and PLC as community mobilisers, sharing their knowledge and the mobilisation and empowerment of their own community.

Research Question

This study endeavours to answer following question: Will a HIV stigma-reduction community “hub” network intervention reduce stigmatisation by community members?

Research Objective

An objective was developed in response to the afore-mentioned problem statement and research question. The objective of the study was to describe the implementation of an HIV stigma-reduction community “hub” network intervention in an urban setting involving both PLWH and PLC as community mobilisers.

Research Design

A holistic single case design (Yin, 2011) was used in this study. It was the most suitable method to describe the various aspects of the intervention.

Setting. The HIV stigma-reduction community “hub” network intervention took place in a specific ward of the municipality of Tlokwe, in the North West Province of South Africa. The North West Province is one of the four provinces with the highest HIV prevalence, according to the South African National HIV Prevalence, Incidence and Behaviour Survey, 2012 (Shishana et al., 2014). Census 2011 (SA Statistics, 2014) found that the Tlokwe Local

Municipality has a total population of 162762 people, of whom 71.3% are black African, and 20.6% are white. There is a small population of other race groups. The selected ward for this study consisted of 784 houses with an estimated three to four people per house; thus an estimated number of 3 200 people. According to the numbers available to the two clinics of the Department of Health, approximately 1 400 of the people residing in this ward are HIV positive.

Participants. The participants in this study were PLWH and community members residing in the ward in question. Participants were recruited according to accessibility, during the various community activities, with no differentiation between PLWH and people of unknown HIV status residing in that community. A demographic survey indicated that the gender spread for PLWH was 77.4% female and 22.6% male, while for the community it was 60.5% female and 39.5% male. The inhabitants were mostly black: for PLWH 98.4% and for the community 97.9%. The participants were for a large part from the low socio-economic group and living in houses provided by the SA government's reconstruction and development (RDP) programme. 46% of both PLWH and the community had never been married. The married group made up 14.5% of the PLWH and 20.7% of the community. Amongst the PLWH, 27.4% participants were living together with a partner without being married, and amongst the community it was 3.7%. 13% of the PLWH group had no schooling, 53% passed grades 3 to 9 and 37% passed grades 10 to 12. 6% had a post-school certificate. In the community group 11% had no schooling, 37% passed grades 3 to 9, and 52% achieved grades 10-12. 15% had a post-school qualification. An estimated 79% of PLWH and 69% of the community were unemployed and depended on income support from friends or family, civil pensions or governmental grants.

The Intervention. The intervention took place over a five-month period. Two HIV stigma-reduction community "hubs" were created in the specific ward to establish a network. These "hubs" consisted of a two-person mobiliser team consisting of one PLWH and one non-infected person living close to a PLWH. These persons were referred to as *mobilisers* and functioned from a church and an informal housing setting (shack) in the community. The

four mobilisers were inhabitants of the ward and were involved in a previous HIV stigma-reduction research project with PLWH and PLC as participants (French, Greeff, & Watson, 2014). In the previous study the mobilisers gained knowledge regarding the understanding of and coping with HIV stigma, as well as the planning and implementation of their own HIV stigma-reduction community project. In the present study they underwent further training, presented by the project leader in a four-day workshop, to become community mobilisers skilled to present workshops to their own community on *Understanding HIV stigma*, *Coping with stigma* as well as how to lead a support group. They were introduced to the planned community “hub” network intervention for HIV stigma reduction.

The planned intervention activities for the community consisted of the following:

- Three-hour *Understanding HIV stigma* workshops to run twice a week. The rationale of the workshop was that by understanding stigma and the process of stigmatisation, and by identifying personal strengths, participants would be empowered to take the lead in reducing HIV stigma. These workshops included a flipchart presentation and activities that developed knowledge and skills towards understanding HIV stigma.
- The *Coping with stigma* workshops followed the *Understanding HIV stigma* workshops, with the aim to heighten awareness and broaden the positive coping skills, mechanisms and resources to meet the demands that HIV stigma places on people. These were also three-hour workshops planned to run twice a week, for people who were interested after they attended the *Understanding HIV stigma* workshop.
- Door-to-door teaching in the community was presented as an extension of the *Understanding HIV stigma* workshops, by means of specially designed pamphlets.
- A support group with the aim of providing emotional support and coping mechanisms to those people who were willing to join the support group. It was run after the workshops. The aim was to draw strength from other members’ experiences, provide information for its members so that they could understand the disease and could educate their family members, friends, colleagues and neighbours about the disease. Another aim with the

support group was to demystify the disease and promote stigma reduction and community acceptance of PLWH and their families, and encouraging the community to have contact with PLWH.

- A weekly psychodrama on the theme of HIV stigma reduction had to be planned and presented at various venues in the ward, e.g. churches and public places like clinics, as well as private venues.
- The four mobilisers furthermore had to conduct their own community HIV stigma-reduction project with activities of their own choice.

Data Collection

The mobilisers were trained to ensure effective record keeping of the community activities that would be presented during the intervention. A mobiliser-coordinator employed by the North-West University (NWU) and trained by the project leader supervised all activities of the mobilisers in the “hubs”.

Data collection was dependent on a **case record** comprising reports on activities, field notes, naïve sketches, and a weekly report on events in the community:

Reports and field notes on observational and personal impressions were kept by the mobilisers. These included the times of the workshops, door-to-door teaching on HIV stigma, the support groups and the psychodrama groups, as well as the number and gender of participants and methods used. Mobilisers also reported on their own experiences of various activities in the intervention. The mobilisers kept similar *reports and field notes on the community project* with its various activities.

The participants contributed by writing *naïve sketches* of their experiences of the workshops. They gave written comments on two topics, “My experience...” and “I feel...”, in the language of their choice after every workshop. This was translated into English where necessary.

Weekly reports of events in the community relating to any HIV education, news or other activities during this period were kept by the mobilisers to ascertain possible outside influences on stigma reduction. The mobilisers were asked to complete a tick list on whether an HIV awareness campaign took place; whether a prominent leader disclosed his/her HIV status; whether a religious leader talked about acceptance of PLWH; whether a community leader/chief talked about acceptance of PLWH; whether a religious leader condemned PLWH; whether a political leader spoke up for PLWH; and whether positive media coverage was given about PLWH. The mobiliser-coordinator collected the reports on a weekly basis.

Data Analysis

A systematic text analysis of the content of the various documents was done to identify and categorise specific observable actions or characteristics. This was based on the logic model technique of Yin (2009), according to which a research activity can cause a further stage in the research. Data analysis was also conducted by means of open coding and by using the technique of Tesch as discussed in Creswell and Plano Clark (2011). This technique entails reading through all the data carefully, looking for the underlying meaning in several documents, making a list of all topics, clustering similar topics, and forming them into columns that might be grouped as major topics, unique topics, and leftovers, coding the topics and checking for emerging categories/domains and themes. A co-coder was used and discussions were held to reach consensus.

Trustworthiness

The mobilisers had a prolonged five-month engagement in the research field during the implementation of the community intervention, which ensured that they had confidence in the reliability of the findings. Reflexivity was obtained through the writing of field notes during and after the intervention activities as well as discussions amongst mobilisers and discussions with study leaders. Applicability, consistency and potential stepwise replicability was ensured by a dense description of the method and data, which made an audit trail possible. A co-coder was also used to enhance consistency. Neutrality was achieved by this combination of the means for an audit trail, the triangulation of researchers and methods, and

reflexivity. The personal engagement with PLWH and community members during the five months of the intervention by the research team ensured the authenticity of the research. There was ongoing supervision of the project leaders and promoters.

Ethical Considerations

The Faculty of Health Sciences Ethics Research Committee of the NWU granted permission for this research (NWU-000 11-09-A1) (30/03/2009-29/03/2014).

To ensure ethical risk management, participants had to understand that the research team could not safeguard information shared in groups. This included aspects such as whether group members were known to each other, disclosure of HIV status or feelings of discomfort, embarrassment or violation by members of the groups. Debriefing was available during all stages of the intervention. The intervention activities were mostly conducted in the identified church and in the shacks or the homes of the participants. The participants were ensured of anonymity during the reporting of the study.

Built-in benefits for participants were mainly that they would gain knowledge about HIV stigma and on coping with HIV stigma, and that they would see stigma reduction in their community. The benefits for the mobilisers were that they would gain knowledge and skills to reduce stigma in their own communities. Enhanced knowledge of HIV stigma-reduction interventions was an indirect benefit for the researchers.

Results of the Intervention

The results of the intervention will be described under the categories of *Understanding HIV stigma* workshops, *Coping with stigma* workshops, door-to-door teaching in the community, the support group, and psychodrama performances. These results will be described in terms of the activities, goals, number of activities and participant involvement and the gender spread, where available (see Table 1), as well as the experiences of both participants and mobilisers. The results of the community project will be described in terms of the categories of house visits to PLWH, feeding project of PLWH at clinics and HIV stigma campaigns (see Table 1). The results will also be described in terms of the activities, number

of activities, participants and the gender spread, where available (see Table 1), as well as the experiences of both participants and mobilisers.

Understanding HIV stigma workshops. 28 workshops of three hours each were presented at least twice a week, involving 156 participants (57 male and 99 female). There was no differentiation between the number of PLWH and non-infected community members in the groups, as participants were not asked to disclose their status.

Table 4

Intervention and Community Project description

Activity	Goals	Number of activities and participant involvement	Male	Female
Understanding HIV stigma Workshop	Knowledge and skills in understanding HIV stigma	28 workshops with 156 participants	57	99
“Coping” with HIV stigma Workshop	Positive coping skills, mechanisms and resources to meet the demands that HIV stigma place on people	5 workshops with 27 participants	18	9
Door-to-door education on “Understanding HIV stigma”	Knowledge and skills in understanding HIV stigma	30 visits with 326 participants	134	192
Support groups	Support and encourage	1 group of six sessions- involving 29 participants	Not known	Not known
Psychodrama groups	Presentation of HIV stigma drama	8 groups with 100 participants	Not known	Not known
Community Project				
House visits to PLWH	Support and encourage PLWH	117 houses	Not known	Not known
Feeding project at clinics of PLWH	Providing fruit and education and invite to workshops	5 Clinics including 160 PLWH	Not known	Not known
HIV stigma campaign at the taxi rank	Knowledge and understanding of HIV stigma	1 with 128 beneficiaries	Not Known	Not Known
HIV stigma campaign in the main street	Knowledge and understanding of HIV stigma	1 with 46 beneficiaries	Not Known	Not Known

Experience of participants. The experiences of the participants are presented as seven recognisable themes: improved knowledge; attitude and behaviour towards PLWH; disclosure of HIV status; change in personal behaviour; the empowerment of participants;

bonding in the community and expression of positive feelings. Remarks by participants are quoted verbatim, to enrich the description.

Improved knowledge. The participants of all the groups indicated that they gained knowledge of both HIV and HIV stigma, for example “*I am happy for your effort I did not fully understand about stigma, now I understand. I am going to take forward the knowledge I have learnt.*” They confirmed that they realised the value of knowledge and what harm the lack of knowledge did to others.

Attitude and behaviour towards PLWH. Participants voiced an understanding of stigmatising attitudes, for example “*I thought that people that are HIV positive ... deserve to die.*” However, they could indicate that an understanding HIV stigma should cause a behaviour change in terms of respect and acceptance of others. Participants were able to recognise the various types of stigma, for example “*Stop bad words*” and “*don't gossip about people who have HIV and AIDS*”. They acknowledged the fear of contagion and the rejection that often goes along with it, such as when people refuse to share eating utensils with PLWH. It was clear that an awareness of their own behaviour brought about feelings of shock and pain: “*we destroy our friends*”. They realised the serious effects, like PLWH's unwillingness to take their medication, losing confidence in themselves and even death.

Disclosure of HIV status. There was an openness and a willingness among the participants in the groups to disclose their own HIV status if they were HIV positive, as well as an understanding of the role that stigma plays in nondisclosure. They made comments like “*I accept the disease that I have, not being knowing that this thing is stigma because I too have this disease and now I am going to speak.*” Participants learned that more people were infected than they were aware of, and this helped them to accept their status. They understood that non-disclosure is a form of abuse of partners and of others: “*the abuse of the people specially the women the man they don't test they status and take care of the family.*” They managed to face their own fear: “*The fear that I have is finished. I have changed my thoughts. The next day I am going to take my blood.*”

Change in personal behaviour. The participants described a change in their view of their *personal behaviour* in terms of the illness. They acknowledged the importance of self-care and the need for adherence to the medication regime. There was an understanding of safer sexual practises: “*I have been going around having sex sometimes not using condoms and today I realise that not using condoms is not good.*”

The empowerment of participants. The participants felt *empowered* and expressed the wish to *share the knowledge with others*. They commented: “*I am healed in my spirit. I will teach others where I am staying.*” A sense of community and ownership came through in the wish to encourage their community and spread knowledge by working with the community, as knowledge would “*control the figures of this disease*”. They contemplated projects: “*To go and teach other people in the community*” and even civic projects: “*That here at X what can we do. We can build police station and clinic.*”

Bonding in the community. The development of bonding in the community was confirmed by all participants, regardless of their HIV status, for example: “*We understand each other, we are all speaking. We will come again.*” The participants enjoyed the *increased positive contact* with the mobilisers and with each other in the groups: “*I found warmth in messages, we spoke about HIV and people do not love each other. They shun each other. Let us change be proper people to people.*” Participants reported that they found the contact with PLWH enriching; and that they found the caring and help of the mobilisers encouraging and strengthening.

Positive feelings of the participants. The participants expressed *satisfaction*: “*I feel happy, my eyes have opened, I have learned a lot of things.*” They expressed feelings of self-worth, freedom and acceptance: “*I have been built. I have strength*”; “*I feel free. I wish as if always I can be part of this workshop every time*”; and “*I enjoy the workshop and its rules of not laughing at others.*” Yet, they also acknowledged that this was not an easy process: “*Your education is painful and truthful.*” They also confirmed that the project made them feel special: “*I feel honoured to take part in this project and I want to learn more.*” Most importantly,

participants acknowledged the value of the workshop for the community: *“I am happy of what I am seeing in our community. It must remain there at all times”* and *“Together we can do it, to fight the HIV in our community.”* Appreciation was expressed: *“Thank you for teaching us. I love your manners – you have taught us nicely.”*

Experience of the mobilisers. The mobilisers gave their own comments on both their experience of the workshop and their personal views. They pointed out logistical difficulties with finding participants and retaining them all in the group, but they found the overall experience totally satisfying. They described most participants as positive and interested. Participants were generally in a happy mood and asked questions. The mobilisers found that they were accepted by the participants. They learned that people were unaware of stigma and the destruction it causes in human lives: *“You can see shame on their faces and pain as we explain. The message I think is going to spread because they wanted to come even if they are not the PLWH.”* The mobilisers voiced a strong sense of responsibility: *“We wish that people can understand and disclose. It will be easy for us to help them even if we are not counsellors.”*

The Coping with HIV Stigma workshops. Five workshops of three hours each on “Coping with HIV Stigma” followed the workshops on *Understanding HIV Stigma*, involving 27 participants (18 male and 9 females). Participants were invited to attend this workshop after the workshop on *Understanding HIV Stigma*. Fewer workshops were held because of time constraints for the community members.

Experience of the participants. Four themes emerged from the reports: acceptance of their own status and disclosure; understanding various means of coping with HIV stigma; acceptance of self and others; and acknowledgement of the role of PLWH.

Acceptance of their own status and disclosure. The participants mostly acknowledged that the workshop helped them to accept and disclose their own status: *“Cause I was in denial of going to test but now I feel to go there”* and *“it’s difficult to deal with HIV, it make things easily for me how to handle my status.”*

Understanding various means of coping with HIV stigma. The participants understood various means of coping with HIV stigma, for instance: “*You have to discipline yourself . You have to think, feel and do.*” They realised that denial was not an effective coping mechanism: “*Running away does not help. A person must problem solve in a right way*” and neither is substance abuse: “*You think smoking and drinking is problem solving but it is not a good idea of solving problems.*”

Acceptance of self and others. Participants described their acceptance of themselves and of others: “*We must accept who we are and treat other people with the same attitude*” and “*I have learnt that we must not judge people who are living with HIV and AIDS.*”

Acknowledgement of the role of PLWH. The role of PLWH was acknowledged with statements like “*People like XX, they are strong. They deal with problem of HIV stigma*” and “*I understood very well. I love to be taught by you.*”

Experience of Mobilisers. The mobilisers found the workshop difficult to handle. Participants became bored and complained that the lecture was too long, or they left early because of other obligations. Participants’ ability to understand the issues varied, and the mobilisers found it difficult to accommodate everyone’s needs. Time management also proved to be difficult. They felt that the workshops were better managed when all four mobilisers were present.

Even though the *Coping with HIV Stigma* workshop had fewer participants and experienced difficulties with attendance and the understanding of concepts, an important result was the strong acknowledgement of the role of the mobilisers. The involvement of mobilisers contributed towards participants’ acceptance of their HIV status and led to more effective coping mechanisms. Participants also came to self-acceptance as well as acceptance of others.

Door-to-door teaching in the community. The workshops were extended into the community by door-to door teaching of “Understanding HIV stigma” using specially designed pamphlets. They completed 30 visits and addressed 326 participants (134 male and 192

female). The mobilisers went from door-to-door requesting to speak to the inhabitants on HIV stigma.

Experience of participants. The four themes that emerged from the reports were: improved knowledge; change in personal behaviour; disclosure of HIV status and fears; and expression of positive feelings.

Improved knowledge. Participants indicated that they recognised stigma and its effects on people. The community members could describe what stigma is: “*HIV has a lot of problems due to the bad words said by people in our community*” and they could also describe its effect on PLWH and others: “*I can feel that if you stigmatise someone, it’s very painful.*” Some of the names that PLWH are called, were mentioned: “*They call the virus 8.ta, Hevbex, hlasela.*” Some of the myths surrounding HIV were also described: “*There was a boy who says that he doesn’t believe that big people are HIV positive*”, as well as tales that the government had a cure but that it was too expensive to give to poor people. Some of the men blamed HIV on women or on people from outside the community: “*They argue that this HIV comes with the truck drivers.*”

Change in personal behaviour. People learned the importance of *accepting themselves* and that it was the underpinning of self-care. With this comes the realisation that the HIV diagnosis is not a death sentence, but that the way people deal with PLWH, often is: “*It’s like you’re infecting them on top of infection.*”

Disclosure of HIV status and fears. Participants described the experience as enlightening and were grateful for the courage it gave them to *disclose*. They referred to the loss of children, family members and friends because of the fear of stigma. The discrimination that children experience when a parent is diagnosed with HIV, was also clearly illustrated: “*Just because you are HIV positive your children could be discriminated because of your status.*” They realised that just about everyone has suffered some loss due to the illness: “*Now I understand that each and every one suffer the pain of losing a loved one with HIV.*”

Expression of positive feelings. The participants were not very verbal in describing their feelings, but they mostly portrayed feelings of “*satisfaction*” and “*happiness*” in their naïve sketches.

Experience of the mobilisers. They found the door-to-door teaching much more difficult than the workshops. Unlike the participants in the workshops, the residents of the houses did not volunteer for the study, so the mobilisers first had to gain their trust and their permission to speak to them. An additional problem was that people’s attention was distracted and some were tired after a working day. Some residents were rude to the mobilisers and did not want to listen to what they had to say. People were also suspicious of them, thinking they were from the government or a housing agent, or wanted special treatment: “*They think we want to be treated special because we talk to them about our status.*” Because of time constraints, some residents were not available; and in December, with the holiday season at hand, this problem increased. Nevertheless, it is clear that the mobilisers persevered, and in most instances they found the experience very rewarding. They learned that most people were not at all aware of their own stigmatising behaviour; and they were truly sorry about it once they became aware of it. They realised that this behaviour occurred amongst all generations.

The support group. A weekly support group of six sessions for community members and/or PLWH were led by the mobilisers as part of the intervention. There were 29 participants. The support group was initially facilitated by the project leader and the role was then taken over by the mobiliser-coordinator.

Experience of the participants. The participants found that there were ways to help others, like home-based care and giving personal attention: “... *Seeing how we can help the people that are HIV positive*” and “*clean the houses for the people who cannot do that and even to help the people that are unable to take their medication.*” They realised that support is mutual and not just a matter of giving but also of receiving; and that there were others with the same problems: “*One also experienced that the problems that are affecting other people,*

as I thought that I was the only one.” They enjoyed meeting different people and gained a sense of freedom and understanding about how others live their lives. They felt that being together like a family and friends would bring about change in the community and for PLWH. All participants expressed a wish for the groups to continue.

Experience of the mobilisers. The mobilisers felt that people were supportive and interested in what the group was doing. According to the mobilisers, participants said that they felt a sense of togetherness and belonging: *“Others feel together they can make change in the community when we walk together”*; *“sharing ideas”* and *“doing something very important and knowledgeable”*. The results of the support groups demonstrated that participants realised that there were ways to help others in a mutually supportive relationship and felt a sense of belonging and sharing that – according to them – can make a change in a community and for PLWH.

Psychodrama performances. Eight psychodrama sessions were performed on a weekly basis for approximately 100 people at clinics and churches on the theme of HIV stigma reduction. The storyline of the drama, conceived by the mobilisers, was about a nurse and friend of an HIV-positive lady. One mobiliser played the boyfriend of the HIV-positive lady, who loved and supported her, while the other mobiliser played a bad guy who stigmatised her.

The audience enjoyed the drama, described it as educational and asked for repeats: *“They enjoy our drama. They were laughing and they want us to do more.”* All the mobilisers felt that the message of the psychodrama was clearer because *“We feel that some people understand actions more than teaching, that is why people enjoy the drama.”* The psychodrama provided enjoyment for the participants as well, in addition to enhancing people’s understanding of HIV stigma and of the stigmatisation message, since actions speak louder than words.

The community project presented by the mobilisers. The community project presented by the mobilisers aimed at supporting and encouraging other PLWH and at

mobilising people to attend HIV stigma-reduction workshops; and it also campaigned against HIV stigma in public places. The community project planned and presented by the mobilisers themselves consisted of house visits to PLWH; feeding projects for PLWH at clinics; and two HIV stigma campaigns. For the initial planning the mobilisers met on a regular basis with the mobiliser-coordinator, who facilitated the planned meetings.

House visits to PLWH. House visits entailed that the mobilisers visited the PLWH at their homes to offer support and encouragement. The PLWH they visited were people whose poor personal circumstances were known to them. They visited 117 houses. The teams experienced that they were welcomed at all the houses. The residents of the house were made informed of the mobiliser's HIV status. The four themes that emerged from the reports were disclosure of HIV status; non-adherence to medication; improved knowledge; and fears and losses.

Disclosure of HIV status. The mobilisers managed to gain sufficient trust so that some participants disclosed to them: *"She disclosed to us and told us we were the first people in the community to know because of our support and care."* One person even disclosed to her children.

Non-adherence to medication. The mobilisers found that people who defaulted on their medication, presented a variety of reasons: *"because she doesn't have any pain, but recently she sees a difference because she became thin"*; or because the medicine would disclose their status to others. Someone said that he did not believe in HIV and that he made his own medication: *"He said he did not agree and that they should only drink the traditional medication and they will be cured."*

Improved knowledge. The mobilisers shared knowledge on HIV with the PLWH and encouraged them to visit the clinics. Some showed interest in becoming part of the project or the support group: *"He is very supportive and curious about the project and wants to be involved in the support groups."*

Fears and losses. People voiced their fears concerning childbirth: “*She then said that because she was pregnant she always prayed that the baby would be healthy.*” Losses due to HIV were acknowledged: “*They are the orphans after they lost their mother because of HIV and AIDS.*” On the negative side, the mobilisers found people who were not willing to talk about HIV because of their fear of the disease: “*It was difficult on her side to talk and she changed the subject of HIV and told us about the church and other stuff of the church.*”

Experience of the mobilisers. The mobilisers got a strong impression that their visits of support were important. It gave people strength and courage, but it also provided useful knowledge to the PLWH. The mobilisers themselves reported that they felt honoured, but it was also clear that they felt a tremendous responsibility: “*We felt we should do more visiting in our community and talk to them about HIV stigma.*” Appreciation was expressed for the community members who understood and encouraged them in the work in which they were engaged: “*We felt so happy to be encouraged by other and to be care for what we are doing – it is good.*” Some of the older people were not PLWH but nevertheless enjoyed the visit: “*It was lovely to visit the old people and we gained more knowledge for the new world.*”

Feeding project for PLWH at clinics. The feeding project for PLWH at clinics involved that mobilisers would visit Department of Health primary health care clinics where they, with the permission of the nurse in charge, provided fruit purchased out of their own pockets and used it as an entry to educate and invite people to the workshops. They reached about 160 people. The mobilisers tremendously enjoyed providing the fruit and education at clinics. They reported that they felt appreciated and honoured because they helped their community and made a difference: “*... feel great because people appreciate what we are doing. It's very nice and would keep it up.*” They felt it demonstrated caring for the community and it gave people pleasure and encouragement: “*It shows that we care for our community while we educate them about stigma.*” They also mentioned that eating healthy is good for PLWH: “*They can't even buy some fruits for their bodies and the fruit are good for their bodies.*” People were interested and asked about the workshops, as mobilisers “*found people curious asking about workshops and times*”.

HIV stigma campaigns. The two HIV stigma campaigns entailed that the mobilisers handed out the pamphlets on HIV stigma at the taxi rank and in the main street after brief information sessions with the public. The mobiliser-coordinator reported that the mobilisers handed out 128 pamphlets on HIV stigma at the taxi rank and 46 in the main street.

Results of weekly reports of HIV stigma events in the community. The weekly tick-list report kept by the mobilisers reflected a serious lack of HIV stigma events in the community. Only one other HIV awareness campaign took place in the community for the duration of the HIV stigma reduction “hub” network intervention. There were 11 media events, mostly radio shows and an advertisement for TB testing. The weekly reports of events in the community relating to any HIV education, news or other activities during this period reflect limited outside influences on the community regarding HIV stigma reduction.

Conclusion

The detailed description of the case study on the implementation of the HIV stigma-reduction community “hub” network intervention leads to the conclusion that the intervention that involved PLWH and PLC, sharing their knowledge as community mobilisers who mobilised and empowered their own community to reduce HIV stigma, was successful in activating mobilisers to initiate change in their community, to lessen the experience of stigma for PLWH and to lessen stigmatisation by the community. The short-term intervention running over three months was not sufficient to ensure a sustainable change in stigmatisation over time, but it initiated the change. The establishment of two community “hubs” in the community created an opportunity for constant direct interaction with the community about HIV stigma. The “hubs” were operated by a two-person mobiliser team of one PLWH and one non-infected person living close to a PLWH from that specific community. This was effective, although difficult for the mobilisers. The use of two people in the “hub” was effective in terms of the mutual support it provided the mobilisers, the role modelling and the meaningful contact between an affected and a non-affected person. Familiarity with the community proved to be beneficial, as the mobilisers understood the community; but it was also challenging, because of the discomfort that both team members sometimes experienced because it was known in

their own community that they were a PLWH or a person living close to a PLWH. The strong acknowledgement of the role of the mobilisers was an important factor as it underpins the notion of utilising PLWH in stigma reduction.

Empowerment is based on the idea that by providing people with skills, resources, authority, opportunity and motivation, and by expecting them to be responsible and accountable for the outcomes of their actions, a contribution can be made towards their enhanced competence, satisfaction and self-actualization. The training provided to them on *Understanding stigma* and *Coping with stigma* during the training sessions to develop them as mobilisers and to improve their knowledge, gave them sufficient skills and knowledge to cope with the training during the intervention. However, it was apparently more difficult to convey knowledge on coping and the need for more support. Mobilisers' training on how to handle a support group gave them enough skills for their task as mobilisers and supporters during support groups. Their previous training and skills development to plan an HIV stigma-reduction project in their own community were essential for the success of the intervention and formed an important element of this intervention. In addition, it also formed an important part of the intervention, as the mobilisers planned and conducted their own HIV stigma-reduction project during the intervention. It can be concluded that the HIV stigma-reduction "hub" network intervention resulted in a generally satisfying experience for the mobilisers because they felt accepted and valued by participants in all the activities and they reported a heightened sense of responsibility towards the community.

The conclusion can be drawn that the HIV stigma-reduction "hub" network intervention activities (workshops on *Understanding stigma* and *Coping with stigma*; the door-to-door teaching on HIV stigma; the support group; the weekly psychodrama on a HIV stigma-reduction theme; and the HIV stigma-reduction project of their own choice) were successful in addressing stigma reduction in a whole community by utilising a combination of strategies that are regarded as being the most promising approaches to HIV stigma-reduction interventions. These strategies include information-sharing, skills building, support and contact with affected groups, as identified in the review of Brown et al. (2011). The levels of

intervention included individual and interpersonal levels as well as social networks and the public (Stangl et al., 2013). The intervention improved the knowledge and awareness of both the mobiliser teams and the community, as well as the attitudes and behaviour of the community towards PLWH. PLWH became more willing to disclose their HIV status and they gained an understanding of the destructive role stigma play in their lives.

It may also be concluded that social change communication principles of participation – which include mutual understanding, equal voices, local ownership, sustainability, collective learning and multiple accountabilities – managed to address social and cultural norms, values, networks and individual behaviours and practices. The HIV stigma-reduction “hub” network intervention acted with respect towards the community and their everyday human relationships and practices, which created possibilities of an open-ended, anti-hierarchical and inclusive mode of community action.

Limitations

It is known that behaviour is not easy to change, and the participants possibly had insufficient exposure time to bring about sustainable change. Nevertheless, there were clear indications of intent to change. More “hubs” in the network could also have improved sustainability.

Recommendations

Given the success of the HIV stigma-reduction community “hub” network intervention in terms of its stated aims, repeating and strengthening the intervention could be beneficial to communities, to reduce HIV stigma and to change a whole community’s stigmatisation practices. Given the large number of people who have been reached during the intervention, it could be beneficial to present follow-up workshops, to expand the “hub” network and to conduct the intervention over a longer period of time. This will improve the sustainability of the intervention and its effects on the community. The larger network system could increase the reach of the intervention as well as broaden the potential of social change and stronger ownership in the endeavour to reduce HIV stigma. The two-person mobiliser team should be

an essential component in any future interventions as it involves PLWH but also demonstrates the positive relationship between a PLWH and a non-infected person. Training is of the utmost importance. A stronger support system should also be available to the mobilisers, as they are often the lesser skilled people of the community. Training and support should focus on specific skills development as the needs arise as well as practical aspects like timekeeping and handling the distrust from the community. The fact that the mobilisers lived in the community was extremely helpful to the project, but it also gave mobilisers a bigger sense of purpose and pride, as they were doing something for their own community. This practice should continue in follow-up interventions. It could also possibly solve the problem of “communities of practise” being involved only as long as interest lasts. Mobilisers should form part of the sustained partnership with stakeholders in the community. Additional techniques, like community conversations, could open the door to extended community participation and mobilisation.

Future interventions should ensure the involvement of PLWH and PLC who share their knowledge as community mobilisers and who mobilise and empower their own community to reduce HIV stigma through a variety of activities to ensure a multiple-strategy approach; and who also work on individual and social levels. When interventions with communities are conducted, they should continue to follow the respectful, anti-hierarchical and inclusive approach, and they should continue to focus on the whole community and not only the PLWH.

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Article 3:

Psychosocial Well-being of People Living with HIV and the Community

Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention

Journal: Journal of Psychology in Africa

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Psychosocial Well-being of People Living with HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

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Psychosocial Well-being of People Living with HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

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Psychosocial Well-being of People Living with HIV and the Community Before and After a HIV Stigma-Reduction Community “Hub” Network Intervention.

Abstract

The purpose of the research was to determine whether an HIV stigma-reduction community “hub” network intervention in a South African urban area would bring about a difference in the psychosocial well-being of people living with HIV (PLWH), as well as their community (living in the same municipal ward). A single case pre-test post-test design was implemented. The sample for this study included 62 PLWH who were selected through accessibility sampling and 570 community members who were selected through random voluntary sampling. Participants completed the Patient Health Questionnaire (PHQ-9) and the Mental Health Continuum Short Form (MHC-SF) before and after the intervention. A dependent t-test as well as Cohen’s d-values was used to calculate the differences between the pre- and post-test results for depression and well-being. Levels of languishing, moderate mental health and flourishing before and after the intervention were determined. Although the focus of the HIV stigma-reduction community “hub” intervention that was followed in this study, was on the involvement of PLWH and PLC to share their knowledge as community mobilisers and to mobilise and empower their own community to reduce HIV stigma, it can be concluded that a secondary gain was the effect it had on both depression and mental health of the PLWH as well as the community. Of interest is how these effects differed for PLWH and the community. It is thus recommended that future interventions should give special attention to aspects of depression and well-being.

Keywords HIV stigma, psychosocial well-being, depression, stigma reduction intervention, South Africa.

Background and Problem Statement

Globally the existence of HIV stigma is not only a major barrier to prevention of HIV but it also has a significant impact on the health and well-being of the people living with HIV (PLWH). It also impacts negatively on family, friends and the broader community (Pharris et

al., 2011). As early as 1996 a meta-analysis of 21 studies demonstrated the devastating effect of HIV stigma specifically by mentioning that the degree of HIV-associated stigma is higher than stigma associated with conditions like hepatitis, drug addiction, diabetes and cancer (Crawford, 1996). HIV at first presents as an aggressive virus that compromises the immunity of an individual at a physical level. This is an extreme experience for the person that greatly affects his or her emotions and behaviour and of the significant people in their lives as well as the communities they live in (Lawler et al., 2011; Schweitzer, Mizwa, & Ross, 2010). In recent times the view of stigma has shifted from a specific emphasis on the devaluation of an individual's identity, to a broader view of stigma as a dynamic social process characterised by exclusion, rejection, blame or devaluation of people with an identifiable difference that results in the experience, perception or anticipation of an harmful or unfavourable social judgment about them (Weiss, Ramakrishna, & Somma, 2006). As a result of this social process of stigmatisation the effects of HIV stigma reaches deeply into the functioning of society as a whole, as HIV stigma comprises various contextual elements such as shared values, attitudes and beliefs which are perceived as threats to physical or social health and welfare (Doná, 2010). The current study subsequently portrays the effects of HIV stigma on the psychosocial well-being of both the individual PLWH and the communities they live in.

The concept well-being has reference to both the individual and a community as it describes the social, cultural and psychological needs of people, their family, institutions and communities. The concept of well-being for the *individual* has traditionally been regarded from two differing points of view. The first of these involves a clinical orientation, measuring well-being through absence or presence of pathology such as depression, distress, anxiety, or substance abuse (Els & De La Rey, 2006). Recent descriptions emphasise states of satisfaction with life, personal meaningful pursuit of goals, and descriptions of well-being such as good health, a sustainable environment, high levels of civic participation and intra- and interpersonal relationships and satisfactory relationships with the community and environment (Brown & Alcoe, 2010). The report on community well-being and community

process by the Institute of Medicine (IOM, 2012) describes *community* well-being as inclusive of the physical as well as the social and economic environments that affect the health of individuals and populations and refers to psychosocial well-being. It is also conceptualised as social capital, involving processes and systems like networks, norms, trust and relationships that open up opportunities for participation and collective action that allow communities to address issues of common concern (Gibbs, Campbell, Akintola, & Colvin, 2014). Elements of community well-being include employment, food, social support and social networks, and health care, among others. It includes social norms, how people relate to each other and to their surroundings, and how much investment they are willing to make in themselves and in the people around them (Kim, Kalibala, Neema, Lukwago, & Weiss, 2012). In the literature psychological and psychosocial well-being are used interchangeably.

A number of models and theories endeavoured to describe psychosocial well-being. The Salutogenic Model (Antonovsky, 1996) with its health-oriented sense of coherence in social support, coping and relational stability is well known.. Newer models followed like the Wheel of Wellness (Sweeney & Witmer, 1991) with its focus on the maintained balance between different aspects of 'the self' or subtasks of self-direction. Further development led to the Indivisible Self model (Myers, & Sweeney, 2004) that emphasises holism as the foundation of human wellness as well as the Dynamic Equilibrium (DE) theory of well-being that accounts for a baseline interrelation between personality, life events, well-being and ill-being (Fujita & Diener, 2005). In this study the exploration of HIV-related psychosocial well-being was grounded by The Mental Health Continuum Model of Keyes (2002). The dynamic two continua model separates the mental illness and mental health states as two different dimensions. The model further suggests that subjective well-being involves a person's own perceptions and evaluations of his/her own life in terms of personal emotion, affect and own psychological and social functioning. Such subjective well-being, also known as *hedonic well-being*, is defined as a mental state of being happy or experiencing pleasure as well as positive and negative affect (Tov & Diener, 2013). Three components of wellbeing are identified: Psychological well-being, Emotional well-being and Social well-being (Keyes, 2007).

Psychological well-being, also known as *eudemonic well-being*, is described as a mental state of self-realisation in which self-development, personal growth and purposeful engagement play a role. Psychological well-being components are levels of self-actualisation, locus of control and emotional intelligence (Fave, Brdar, Freire, Vella-Brodrick, & Wissing, 2011; Ryff, 2014). Emotional well-being is a sense of well-being which makes it possible for an individual to function in society and everyday life and recover effectively from illness, change or misfortune. Keyes (2007) describes social well-being as the way people see their relations to others and the wider community. Social well-being has several components, such as social acceptance, social actualisation, social contribution and social coherence. A combination of emotional well-being, psychological well-being and social well-being is seen as *mental health* or *psychosocial well-being* (Westerhof & Keyes, 2010).

The term *psychosocial* reflects the dynamic relationship between internal psychological processes like thoughts, feelings, emotions, understanding and perception and external social processes and comprises of social networks, community, family and environment. Positive mental health is then described as having purpose in life, good social relationships, feelings of efficacy, and optimism (Son & Wilson, 2012). Two other terms are also used in the Mental Health Continuum model, namely *flourishing* and *languishing*. Flourishing refers to the experience of life going well. It is a combination of feeling good and functioning effectively (psychological and social functioning). *Flourishing* is very strongly associated with a high level of mental well-being, and is a perfect representation of mental health. *Languishing* mental health is when an individual is not feeling good about life and not functioning well. *Moderate* mental health reflects a condition in which a person is neither languishing nor flourishing (Keyes, Dhingra, & Simoes, 2010; Westerhof & Keyes, 2010).

The focus of this research was on the resultant changes in psychosocial well-being after a community HIV stigma reduction intervention. The conceptual model of Holzemer et al. (2007a) for HIV stigma served as a grounding theory for understanding stigma in this research. This model outlines HIV stigma as a process within the specific context of the environment, which include cultural, economic, political, legal and policy aspects; the

healthcare system, including settings such as hospitals, clinics and home-based care settings and health service delivery settings and the agents of stigma, like PLWH themselves, people living close to them (family, friends, colleagues) and their community. Within this context the stigma process evolves. The disease itself, HIV testing, the HIV diagnosis, disclosure and the suspicion of having the disease, are factors that triggers the stigma process. These triggers then lead to stigmatising behaviour like blame, insult, avoidance and accusation. Three types of HIV stigma, namely received, internalised and associated stigma are identified. All these types of stigma result in specific HIV stigma outcomes for PLWH, people close to them (PLC) and the community. These outcomes are both psychological and social in nature.

Against the background the above mentioned concepts like psychosocial well-being and HIV stigma the impact of a devastating disease like HIV on the individual and the community is explored further. Breet, Kagee, and Seedat (2014) for example found a meaningful relationship between depression and HIV and describe HIV stigma as one of the key factors in the development of psychological distress like depression and anxiety and would thus affect the mental health and well-being of people living with HIV (PLWH). The authors also noted that individuals with depression could be more vulnerable to HIV as they tend to engage in risky sexual behaviour. On the other hand, HIV infection as such may increase the risk of depressive symptoms (Schadé, Van Grootheest, & Smit, 2013). The link between HIV stigma and the wellbeing of PLWH is indicated by Earnshaw, Smith, Chaudoir, Amico, and Copenhaver (2013). They found that internal stigma correlated significantly with indicators of affective (depression and helplessness) and behavioural (medication non-adherence) well-being. Received stigma and anticipated stigma were associated with indicators of physical health and well-being (low CD4 counts and chronic illness co-morbidity). The prevalence of depression among HIV-positive patients in Eastern Nigeria and its association with HIV-related stigma was explored (Onyebuchi-Iwudibia & Brown, 2014). In this study depression is positively associated with HIV-related stigma. Both stigma and depression have been shown to have a negative impact on quality of life for PLWH. The

authors concluded that screening for both HIV-related stigma and depression would be an important intervention to promote both physical and psychological well-being amongst HIV-positive patients.

The web of relationships among individuals, their social networks, and larger social structures and environmental relationships is dynamic and also impacted upon by HIV stigma (Nyblade, Singh, Ashburn, Brady, & Olenja, 2011). Physical and emotional violence, grief, and lack or loss of social support have a negative influence on relationships, which lead to social effects (Harapan, Feramuhawan, Kurniawan, Anwar, Andalas, & Hossain, 2013). Galindo (2013) found that HIV-related stigma disrupted the accepted social connections in a community, and in that way affected social structures. This impacted on the overall individual well-being as well as the social norms and cultural values of the community. Stigma creates inequality, undermines trust, and reduces opportunities for interpersonal interactions between community members. Social stigma interferes with bonding, bridging and linking people together, and has negative health consequences (Chen et al., 2011). The negative economic effects of stigma, together with its social, psychological, and cultural impacts are significant for the psychosocial well-being of a community (Ryff, et al. 2014). Persons living in settings of generalised poverty rely heavily on social capital and particularly on bonding to build relationships of trust and bridging to establish strong links to access material resources needed for survival. (Samuels & Rutenberg, 2011). There can thus be no doubt about the far reaching impact of HIV stigma and stigmatisation and the imperative quest for interventions that could best address these for PLWH and their communities.

In spite of expanded scientific literature on HIV stigma the number of interventions aimed at reducing HIV stigma seems few (Sengupta, Banks, Jonas, Miles, & Smith, 2011). Stangl, Loyd, Brady, and Baral, (2013) produced a systematic review of studies and reports that appraised the effectiveness of interventions to reduce HIV stigma and discrimination, minimise manifestations of stigma and/or bolster manifestations like resilience. These authors still denote critical challenges and gaps impeding the identification and implementation of effective stigma-reduction strategies. None of the interventions addressed

psychosocial well-being and another gap was a lack of interventions that supported PLWH to fulfill their human rights to care and dignity. The review has also however contributed to a more complete picture of the full range of intervention efforts and their effectiveness in reducing the stigmatisation process and building resilience. The majority of interventions utilised two or more strategies to reduce stigma and discrimination, and ten included structural or biomedical components. However, most interventions targeted a single socio-ecological level and a single domain of stigma.

Literature identifies certain fundamental principles for all stigma reduction interventions, like awareness raising, addressing transmission fears and misconceptions, as well as discussions and challenges on the underlying value and belief systems and increased contact with affected groups (Sanjuán, Molero, Fuster, & Nouvilas, 2013). There is concurrence that broad social and cultural contexts must be addressed in HIV stigma-reduction programmes, as HIV stigma does not simply exist within individual actions (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013). It calls for multilevel approaches functioning on the intrapersonal, interpersonal and structural levels of an ecological system to reduce HIV stigma and its consequences for population health (Cook, Purdie-Vaughns, Meyer, & Busch, 2014) as well as for multi-method approaches that combine various strategies like information sharing in combination with skill-building approaches, and information sharing together with contact approaches (Cross, Heijnders, Dalal, Sermittirong, & Mak, 2012). Active community involvement is mentioned increasingly as a pertinent component of “health-enabling” social environments and social contexts that enable members of that community to optimise opportunities for health and well-being (Campbell & Cornish, 2010). Proactive community level interventions could focus on communal driven coping skills, relationship building and the promotion of mental health through the experience of purpose in community engagement (Maré, Wissing, Watson, & Ellis, 2011). PLWH should be involved as change agents, to act in their own and their community’s best interests and to create and support AIDS-competent communities (Campbell, Skovdal, Madanhire, Mugurungi, Gregson, & Nyamukapa, 2011).

The HIV stigma-reduction community “hub” network intervention that was used in this study was specifically planned as an intervention for the community, run by a PLWH and a PLC as mobilisers living in that community, focusing on HIV stigma reduction. This study was preceded by two other HIV stigma reduction intervention research projects, one focusing on PLWH and nurses in healthcare settings (Uys et al., 2009) and the other on the HIV stigma and stigmatisation experiences of PLWH and PLC (; French, Greeff, Watson, & Doak, 2015). These interventions were constructed upon three tenets: the sharing of information on the nature of HIV stigma and coping with it; equalising relationships between the PLWH and PLC through increased interaction and contact; and the empowerment of participants to become leaders in HIV stigma reduction through HIV stigma reduction projects in the community developed by themselves.

The current HIV stigma-reduction community “hub” network intervention combines strategies of PLWH involvement through PLWH and PLC as community mobilisers, the sharing of their knowledge on HIV stigma reduction, and utilising them as community mobilisers to mobilise and empower their own community in HIV stigma reduction. This article reports on changes in depression and the psychosocial well-being of both PLWH and the community due to the HIV stigma-reduction community “hub” network intervention.

The study responds to the following research question:

Will the HIV stigma-reduction community “hub” network intervention result in a decrease in depression and an increase in psychosocial well-being in PLWH and the community in which they live?

Research Objectives

To determine the change in depression and psychosocial well-being of PLWH and their community before and after a HIV stigma-reduction community “hub” network intervention.

Research Method

A single case pre-test post-test design was followed. The research setting for the HIV stigma-reduction community “hub” network intervention was a specific urban ward of the

municipality of Tlokwe, in the North West Province of South Africa. According to Statistics SA, 2012 (2014) the municipality of Tlokwe has a population of 128,357. Of these, 69.6% are African, 27.0% are white, 3.0% are coloured (mixed race) and 0.4% are Asian. The selected ward for this study consisted of 784 households with an estimated three to four people per house, thus an estimated total of 3200 people.

The participants in this study consisted of two groups: one group of PLWHs and one group of community members who all lived in the same ward. In this ward 1 400 PLWH attended the two clinics of the Department of Health. Accessibility sampling was done from this group. A mediator at the clinics linked the PLWH that were willing to participate with the mobiliser-coordinator of the study. The inclusion criteria were: HIV-positive status; being 18 years or older; having resided in the identified ward for at least 3 months; and being conversant in Afrikaans or English or Setswana. Gender equity was sought but there were fewer males than females. The total PLWH sample for this study was 62 people (48 females and 14 males). In the post-test battery 5 PLWH (8.06%) was lost to the study either through withdrawal, death or not being located again.

For the second group, the community members, random voluntary sampling was used. One member of each of the 784 households was included if willing to participate in the study. The sampling strategy and sample size were determined beforehand by consultation with statistical support services. Inclusion criteria for the community members were: being 18 years or older; having resided in the identified ward for at least 3 months; being conversant in Afrikaans or English or Setswana; and willingness to be part of the quantitative study. The ward was divided into six equal parts as six trained fieldworkers went from door to door to collect the data from a certain point in each of the six areas. In this way, 570 community members (345 female and 225 males, approximately 18% of the community) who adhered to the inclusion criteria and were willing to participate in the study, were included. In the post-test battery 58 people (10.18%) were lost to the study either through withdrawal, death or not being located again.

Demographic data. The outlay of the demographic data is provided to provide a better understanding of the community that was involved in the research. See Table 1 for an outlay of the demographic data of participants in this study. The gender spread for PLWH was 77.4% female and 22.6% male, while for the community it was 60.5% female and 39.5% male. The inhabitants were mostly black: for PLWH 98.4% and for the community 97.9%. Most participants were living in brick houses provided by the SA government's reconstruction and development programme (RDP). 46% of the total group were never married; for the PLWH this figure was 14.5% and for the community it was 20.7%. 27.4% of the PLWH were living together without being married, and 3.7% of the community did so. 13% of the PLWH group had no schooling, 53% achieved grades 3 to 9 and 37% grades 10 to 12. 6% had a post-school certificate. In the community group 11% had no schooling, 37% achieved grades 3 to 9, and 52% achieved grades 10 to 12. 15% had a post-school qualification. An estimated 79% of PLWH and 69% of the community were unemployed and dependent on income support by friends or family, civil pensions or governmental grants.

Table 1

Demographic data of PLWH and community members in the study

Demographic element		PLWH (n = 62)		Community (n=570)	
			%		%
Gender	Female	48	77.4	345	60.5
	Male	14	22.6	225	39.5
Ethnicity	Black	61	98.4	558	97.9
	Other	1	1.6	12	2.1
Marital status	Never married	29	46.8	267	46.8
	Married	9	14.5	118	20.7
	Living together	17	27.4	39	6.8
	Divorced	3	4.8	11	1.9
	Widowed	4	6.5	135	23.7
School grade*	No schooling	8	12.9	64	11.0
	Grades 1-9	31	51	210	37.2
	Grade 10	11	17	85	14.9
	Grade 11	7	11	83	14.8
	Grade 12	5	8	127	22.3
Highest post school education	None	57	92	473	83.0
	Certificate	5	8	86	15.1
	Diploma			4	0.7
	degree			4	0.7
Main source of income	Employed	13	22	178	31.2
	Social or HIV grant	16	26	53	9.3
	Pension	9	14	69	12.1
	Family/Friend support	10	16	137	24.0
	Other (odd jobs /part time)	9	22	133	23.2

*School grade -2 missing from community

The community HIV stigma-reduction “hub” network intervention. The intervention that ran over a five-month period involved creating two HIV stigma-reduction community “hubs” in the specific ward. Each “hub” had a team that consisted of two mobilisers, one PLWH, and one non-infected person that had a close relationship with a PLWH. The four mobilisers were inhabitants of the ward and were involved in a previous HIV stigma-reduction research project with PLWH and people living close to them. In a previous study (French, Greeff, & Watson, 2014) the mobilisers gained knowledge regarding the understanding and coping with HIV stigma, as well as skills in the planning and implementation of their own HIV stigma-reduction community project. During the present study they underwent further training in a four-day workshop to become community mobilisers in their own community and to become skilled to present workshops to the community on *Understanding HIV stigma*, and on *Coping with stigma*; as well as to lead a support group. They were also trained to do effective record keeping of the community activities that would take place during the intervention.

The following intervention activities were conducted by the mobilisers over a five-month period of the intervention: 27 workshops of three hours each on *Understanding HIV stigma* for both PLWH and community members at least twice a week; 5 workshops on *Coping with HIV stigma* for people who attended the first *Understanding HIV stigma* workshops and who were interested to continue with the *Coping with HIV stigma* workshops; and additional activities such as weekly door-to-door education on *Understanding HIV stigma* by means of a specially designed pamphlet on HIV stigma information. The door-to-door teaching activities reached 326 people. After the workshops, support groups (six sessions in total) were presented for community members and/or PLWH. The mobilisers presented eight psychodrama group performances on the theme of HIV stigma reduction at various venues in the ward (e.g. churches, gatherings and clinics). An HIV stigma-reduction community project planned and conducted together by the four mobilisers focussing on HIV stigma reduction and that entailed visiting the houses of PLWH, reached 117 people, to provide support and encouragement to them. Fruit and education were also provided to 160 PLWH

at clinics. As part of this project, two stigma campaigns were conducted at a taxi rank, as well as in the main street, reaching respectively 128 people and 46 people. Detailed records were kept of community activities relating to HIV stigma during this period, and weekly activity reports and field notes specifically related to the various activities. A mobiliser-coordinator employed by the North-West University and trained by the project leader supervised all activities of the mobilisers in the two “hubs”, gave support and collected the weekly activity reports.

Data collection: Pre-test and Post-test.

Several gatekeepers, such as ward counsellors and church leaders, made the community aware of the research. The community was informed about the purpose and the expected duration of the study. The selected participants were informed of the reason for their selection, and how the information would be kept confidential and records safeguarded. They were informed that they could withdraw from the study at any time (Bothma, Greeff, Mulaudzi, & Wright, 2010). Informed consent was signed after questions were dealt with and participants had time to decide about their participation.

Six field workers were trained in a two-day workshop to obtain the pre-test and post-test quantitative data through two measures. The battery consisted of the Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) and the Mental Health Continuum Short Form (MHC-SF) (Keyes, 2006).

The Patient Health Questionnaire (PHQ-9). This is a 9- item measure that covers the individual’s broad world of emotions. It is based on an indication of degrees of disturbances during the two weeks prior to testing and can be used to determine the existence and severity of depression. It screens participants for a major depressive disorder (MDD) based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) criteria. It can be self-administered and is used to indicate the following levels of depression: minimal depression 0-4, mild depression 5-9, moderate depression 10-14, moderately severe depression 15-19 and severe depression 20-27. Its composition requires scores to decrease as a sign of

improved well-being. The PHQ-9 showed original internal reliability with a Cronbach alpha of 0.89. The test-retest reliability of the PHQ-9 as a short depression measure was excellent and the diagnosis of DSM-IV depressive disorders resembles the PHQ-9 criteria (Kroenke et al. 2001).

The Mental Health Continuum – Short form (MHC-SF) (Keyes, Wissing, Potgieter, Temane, Kruger, & Van Rooy, 2008). The subscale for MHC-E measures a hedonic subsystem concerning the maximisation and duration of positive feelings and the minimisation of negative or unpleasant feelings, like happiness, interest in and satisfaction with life. The MHC-S subscale indicates maximisation of social integration, social contribution, social coherence, social actualisation and social acceptance of an individual – thus addressing the five dimensions of social well-being. The MHC-P subscale measures the maximisation of eudemonia that relates to the full functioning capacity of an individual demonstrated in self-acceptance, personal growth, purpose in life, positive relations with others, autonomy and environmental mastery. A total score on well-being (MHC-T) is added. This scale offers a categorical diagnosis of the presence of mental health (flourishing) and the absence of mental health (languishing). A score of 70 on the MHC-SF scale indicates maximised subjective well-being and the absence of mental illness. The scale is further categorised as *flourishing*, *moderate mental health*, and *languishing* (Keyes et al., 2008). The Cronbach alpha for the total scale tested at 0.74 in terms of internal reliability. It also showed excellent internal consistency (>.80) and discriminant validity in adolescents (ages 12-18) and adults in the United States and the Netherlands.

Data Analysis

The data analysis was conducted by means of the IBM Statistical Package for the Social Sciences (SPSS) version 22 software (Pallant, 2011). Descriptive statistics (mean and standard deviation, kurtosis and skewness values) of all study measures were calculated. The probability values (statistical significance) and effect sizes (practical significance) were examined to determine the difference in construct levels between the different times of evaluation (Field, 2013). A dependent t-test as well as Cohen's d-values was used to

calculate the differences in the pre- and post- test results for depression and well-being. Cross-tabulations and Chi-square tests for levels of flourishing and languishing before and after interventions were calculated to determine the outcome of the intervention.

Ethical Considerations

Ethical permission was obtained from the Ethics committee of the North-West University (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014). Continued supervision by the researcher and mobiliser-coordinator ensured a high standard of research. By providing sufficient information to participants, it was ensured that the participants felt comfortable within the situation and were able to give voluntary written consent. Respect for the participants was demonstrated in this manner. Codes were used and no identifying practises were used to ensure anonymity. Collected data that was made available for analysis had no identity linked to it, which ensured anonymous reporting of data. Electronic data will be preserved for five years, protected by a password. Hard copies are locked away on the University premises.

Results

The results for the PLWH will be presented first followed by the results of the community. For both groups the PHQ-9 and the MHC-SF will be presented.

Results of psychosocial well-being of the PLWH. A combined view of the scores obtained from the PHQ-9 and MHC-SF measures, the comparative mean scores (\bar{x}) per subscale of the MHC-SF measure for before and after the intervention, as well as the statistical significance ($p < 0.05$) and practical significance (small [$d = 0.2$], medium [$d = 0.5$] and large [$d = 0.8$]) are displayed in Table 2.

The PHQ-9 measure. For the PLWH in the pre-test group an average score of 5.56 was observed for the PHQ-9 measure which indicated mild depression. Although not statistically ($p = 0.34$) or practically ($d = 0.14$) significant, this mild depression decreased after the intervention to an average score of 4.65. However it remained in the mild depression range.

The MHC-SF measure. Before the intervention the average score for the total well-being (MHC-T), was 56.47. This can be considered as moderate mental health. After the intervention this average score decreased to 51.4 which is statistically ($p = 0.04$) significant and had a small practical ($d = 0.30$) significance. The sub scales of the MHC-SF indicated the following:

- The average emotional well-being (MHC-E) before the intervention was 13.0 and decreased to a statistically ($p = 0.015$) and a medium practical ($d = 0.53$) significant average of 11.25.
- Social well-being (MHC-S) had an average of 18.98 and decreased to an average of 16.35 after the intervention. This decrease is statistically ($p = .019$) significant and had a small practical ($d = 0.38$) significance.
- Psychological well-being (MHC-P) had an average of 25.61, before the intervention and 25.01 after the intervention. This was neither a statistically ($p = 0.60$) nor a practically ($d = 0.08$) significant change.

Table 2

Descriptive statistics of PLWH on PHQ-9 and MHC-SF before and after the intervention

PLWA (n = 57)	BEFORE intervention		AFTER intervention		p-value	Cohen's d-value
	\bar{x}	SD Before	\bar{x}	SD After		
Measures						
PHQ-9	5.56	6.64	4.65	5.31	.349	0.14
MHC-SF						
MHC-T	56.47	16.68	51.4	13.29	.042	0.30
MHC-E	13.0	3.30	11.25	4.04	.015	0.53
MHC-S	18.98	7.01	16.35	6.19	.019	0.38
MHC-P	25.61	7.36	25.01	5.47	.601	0.08

Patient Health Questionnaire (PHQ-9); Mental Health Continuum Short Form (MHC-SF); Sub scales of the MHC-SF measure: MHC-T = Total Well-Being; MHC-E = Emotional Well-Being, MHC-S = Social Well-Being, MHC-P= Psychological Well-Being.

Additional calculations on the MHC-SF. The obvious decreases observed in two of the subscales gave the impression of a negative effect of the intervention and necessitated further investigation of the possible reasons. Therefore scores on languishing, moderate mental health and flourishing were calculated for the total group of PLWH (n = 57) before and after the intervention using the categorical calculation of Keyes et al. (2008). It was found that 45 (78 %) of the group were flourishing, 9 (15.8%) experienced moderate mental health and 3 (5.3%) were languishing before the intervention. After the intervention these scores shifted and it was found that 32 (56.14%) were flourishing, 22 (38.6%) experienced moderate mental health and 3 (5.26%) were languishing. These shifts were analysed more closely by cross-tabulation of the end scores with the baseline scores to explain these internal shifts (See Table 3).

Table 3

Cross-tabulation for measures of Languishing, Moderate Mental Health, and Flourishing for PLWH

PLWH (n=57)	Total group before the intervention	Shifts after the intervention		
		Languishing	Moderate Mental Health	Flourishing
Languishing	3 (5.26%)	0 (0%)	2 (66.67%)	1 (33.33%)
Moderate Mental Health	9 (15.79%)	1 (11.11%)	3 (33.33%)	5 (55.56%)
Flourishing	45 (78%)	2 (4.44%)	17 (37.78%)	26 (57.78%)
Total	57 (100%)	3 (5.26%)	22 (38.6%)	32 (56.14%)

Results from the cross-tabulation showed that 26 (57.8%) of the PLWH who were in the *flourishing* group before the intervention remained flourishing. In the rest of the flourishing group 17 (37.78%) shifted to the *moderate mental health* group and 2 (4.44%) shifted to the *languishing* group. 3 (33.33%) participants who were previously in the *moderate mental health* group, remained in this group. 5 participants (55.56%) shifted to the *flourishing* group

and 1 (11.11%) was *languishing* after the intervention. 2 (66.67%) participants who were previously in the *languishing* group shifted to the *moderate mental health* group and 1 (33.33%) shifted to the *flourishing* group.

For a further exploration of the results of the MHC-SF scores, the group was divided into only two groups, by merging the moderate mental health and languishing groups into one group (n = 12) while keeping the flourishing participants in the other group (n = 45). See Table 4.

These results indicate that in the languishing/moderate mental health group, MHC-E did not increase with statistical ($p = 0.34$) significance but had a medium practical ($d = 0.42$) significance.

Table 4

Descriptive statistics of PLWH scores with dependent t-test results of within the languishing/moderate mental health and flourishing groups

			\bar{x}	SD	t	p	Cohen's d-value
Combined languishing and moderate mental health (n=12)	MHC-E	Before	8.75	4.61	-1.00	0.34	0.42
		After	10.67	3.75			
	MHC-S	Before	9.50	5.46	-1.66	0.13	0.81
		After	13.92	7.96			
	MHC-P	Before	13.75	8.11	-3.28	0.01	1.24
		After	23.83	6.23			
	MHC-T	Before	30.83	16.12	-3.28	0.01	0.99
		After	46.83	15.75			
Flourishing (n=45)	MHC-E	Before	14.13	1.50	4.10	0.00	1.82
		After	11.40	4.14			
	MHC-S	Before	21.51	4.90	4.39	0.00	0.92
		After	17.00	5.56			
	MHC-P	Before	28.73	1.95	4.59	0.00	1.76
		After	25.33	5.27			
	MHC-T	Before	63.31	7.87	5.91	0.00	1.36
		After	52.62	12.46			

The Mental Health Continuum Short Form (MHC-SF); Sub scales of the MHC-SF measure; MHC-E = Emotional Well-Being, MHC-S = Social Well-Being, MHC-P= Psychological Well-Being. MHC-T= Total Well-Being

MHC-S did not show statistical significance ($p = 0.12$) and had a large practical ($d = 0.81$) significance, MHC-P increased statistically significantly ($p = 0.07$) with a large practical ($d = 1.24$) significance, and MHC-T increased statistically ($p = 0.35$) and practically ($d = 0.99$) significantly. The practical significance in both instances was in the large range.

In the flourishing group, MHC-E showed a statistically ($p < 0.01$) and practically ($d = 1.82$) significantly *decrease*, MHC-S showed a statistically ($p < 0.01$) and practically ($d = 0.92$) significant *increase*, MHC-P showed a statistically ($p < 0.01$) and practically ($d = 0.76$) significant *decrease* and MHC-T showed a statistically ($p < 0.01$) and practically significant ($d = 1.36$) *decrease*. All the effect sizes were in the large range. Due to the smaller sample sizes, these results were verified with the Wilcoxon rank sum test and similar results were found.

Results of psychosocial well-being of the community. A combined view of the scores obtained from the PHQ-9 and MHC-SF measures, the comparative mean scores (\bar{x}) per subscale of the MHC-SF measure before and after the intervention, as well as the statistical significance ($p < 0.05$) and practical significance (small [$d = 0.2$], medium [$d = 0.5$] and large [$d = 0.8$]) are displayed in Table 5.

Table 5

Descriptive statistics of the community on PHQ-9 and MHC-SF before and after the intervention with dependent t-test results

Community (n = 496)	BEFORE Intervention		AFTER intervention		p-value	Cohen's d-value
	\bar{x}	SD	\bar{x}	SD		
Measures and sub scales						
PHQ-9	5.84	3.1	5.85	4.18	<.001	.45
MHC-SF						
MHC-T	52.55	17.75	54.62	11.26	.032	.12
MHC-E	12.02	3.78	12.25	3.03	.312	.06
MHC-S	17.26	7.05	17.83	5.40	.156	.08
MHC-P	24.19	8.27	25.92	4.92	<.001	.21

Patient Health Questionnaire (PHQ-9); Mental Health Continuum Short Form (MHC-SF); Sub scales of MHC-SF measure: MHC-T = Total Well-Being; MHC-E = Emotional Well-Being, MHC-S = Social Well-Being, MHC-P= Psychological Well-Being.

The PHQ-9 Measure. Before the intervention, the community group (n = 496) scored an average of 5.84 on the PHQ-9 measure, which indicated mild depression. After the

intervention, this average was 3.19. This was statistically ($p < 0.01$) significant and had a medium practical ($d = 0.45$) significance. The average after the intervention indicated an absence of depression in the community.

The MHC-SF Measure. The average total well-being (MHC-T) before the intervention was 52.55 which can be considered as moderate. This scale showed a statistically ($p = 0.03$) significant but not practically ($d = 0.12$) significant increase after the intervention to an average of 54.62. The subscales of the MHC-SF indicated the following:

- Emotional well-being (MHC-E) before the intervention was 12.02. This average remained stable at 12.25 after the intervention, which was neither statistically ($p = 0.31$) nor practically ($d = 0.06$) significant.
- Social well-being (MHC-S) had an average of 17.26 and remained the same after the intervention with an average of 17.83. No statistical ($p = 0.15$) or practical ($d = 0.08$) significance was observed.
- Psychological well-being (MHC-P) had an average of 24.19, before the intervention and 25.92 after the intervention. This was statistically ($p < 0.001$) significant and had a small practical ($d = 0.21$) significance.

Additional calculations on the MHC-SF. Scores on flourishing, moderate mental health and languishing were calculated using the categorical calculation of Keyes et al. (2008) for the total community group ($n = 492$) before and after the intervention. This was done because no discernible changes could be observed in the MHC-SF scores and further investigation was therefore necessary. It was found that 347 (70.53%) of the group were flourishing, 96 (15.79%) experienced moderate mental health and 49 (9.96%) were languishing. These scores for the total group after the intervention showed shifts that indicated that now 317 (64.43%) were flourishing, 171 (34.76%) experienced moderate mental health and 4 (0.81%) were languishing. These scores were therefore analysed more

closely by cross-tabulation of the end score with the baseline scores of the group before and after the intervention. See Table 6 to explain these internal shifts.

Cross-tabulation showed that 229 (65.99%) of the community in the *flourishing* group before the intervention remained flourishing. Among the other participants, 115 (33.14%) shifted to the *moderate mental health* group and 3 (0.86%) shifted to the *languishing* group. Among the participants who were previously in the *moderate mental health* group, 47 (48.96%) remained in this group, but 48 (50%) participants shifted to the *flourishing* group and 1 (1.04%) was *languishing* after the intervention. Among the *languishing* group, 9 (18.37%) people shifted to *moderate mental health* and 40 (81.63%) shifted to *flourishing*.

Table 6

Cross-tabulation for measures of Languishing, Moderate Mental Health, and Flourishing in the community

Community N=492	Total group before the intervention	Shifts after intervention		
		Languishing	Moderate Mental Health	Flourishing
Languishing	49 (9.96%)	0 (0%)	9 (18.37%)	40 (81.63%)
Moderate Mental Health	96 (15.79%)	1 (1.04%)	47 (48.96%)	48 (50%)
Flourishing	347(70.53%)	3 (0.86%)	115(33.14%)	229 (65.99%)
Total	492 (100%)	4 (0.81%)	171 (34.76%)	317 (64.43%)

As in the case of the PLWH group, for purposes of further exploration of the results, the languishing and moderate mental health groups were combined ($n = 149$) as they were the smaller group. The larger, flourishing group ($n = 347$) remained the same, as shown in Table 7.

In the languishing/moderate mental health group, MHC-E, showed a statistically significant ($p < 0.001$) and a large practically ($d = 1.04$) significant increase. The same was found for the MHC-S, $p < 0.001$ and $d = 1.62$, MHC-P $p < 0.001$ and $d = 1.32$ and MHC-T ($p < 0.001$) and $d = 1.58$. In the flourishing group, MHC-E showed a statistically significant

($p < 0.001$) and a large practically ($d = 0.86$) significant *decrease*. For MHC-S, $p < 0.001$ and $d = 0.57$ showed a medium practically significant decrease and the MHC-P ($p < 0.001$) showed a large practically significant decrease ($d = 0.89$) whilst for MHC-T, $p < 0.001$ similarly showed a large practical decrease ($d = 0.95$).

Table 7

Descriptive statistics of community scores with dependent t-test results of the languishing/moderate mental health and flourishing group

			\bar{x}	SD	t	p	Cohen's d-value
Combined languishing and moderate mental health (n=149)	MHC-E	Before	7.97	4.12	-8.84	0.00	1.04
		After	12.26	3.24			
	MHC-S	Before	9.60	5.13	-11.88	0.00	1.62
		After	17.93	5.97			
	MHC-P	Before	14.13	8.29	-11.83	0.00	1.32
		After	25.06	5.78			
MHC-T	Before	30.53	14.96	-12.43	0.00	1.58	
	After	54.14	13.45				
Flourishing (n=347)	MHC-E	Before	13.77	1.75	8.60	0.00	0.86
		After	12.25	2.94			
	MHC-S	Before	20.56	4.87	7.52	0.00	0.57
		After	17.80	5.15			
	MHC-P	Before	28.52	2.48	8.56	0.00	0.89
		After	26.30	4.46			
MHC-T	Before	62.01	7.53	11.49	0.00	0.95	
	After	54.82	10.20				

The Mental Health Continuum Short Form (MHC-SF); Sub scales of the MHC-SF measure; MHC-E = Emotional Well-Being, MHC-S = Social Well-Being, MHC-P = Psychological Well-Being, MHC-T = Total Well-Being

Discussion of results

The discussion will firstly focus on depression and then on the psychosocial wellbeing of PLWH and the community.

The score on The Patient Health Questionnaire (PHQ-9) for the PLWH indicates the presence of mild depression. The intervention did not seem to have a marked effect on these mild levels of depression amongst the PLWH participants. According to the PHQ-9, depression is usually described as anhedonia with feelings of helplessness and hopelessness, loss of interest in daily activities, appetite or weight and sleep changes, a loss of energy, self-loathing and suicidal thoughts. In the community group the mild presence of depression that was observed with the PHQ-9 score decreased significantly to show an

absence of depression, indicating the effect the intervention had on the community as a whole.

The scores on The Mental Health Continuum – Short form (MHC-SF) seem to underline the findings of the PHQ-9 for the PLWH. Neither the three subscales nor the MHC-T showed any significant changes after the intervention. For PLWH their total well-being indicated a moderate mental health status before the intervention that decreased after the intervention yet still remained within the range of moderate mental health. This could be interpreted as that the intervention seemed to have had no effect. However, the further exploration into the categories of languishing, moderate mental health and flourishing after the intervention, changes the perception of the effect of the intervention. It would seem as if the intervention had significant effects on the psychosocial well-being of the group of PLWH that was languishing, moving from languishing towards moderate mental health and flourishing. The group of PLWH that was flourishing also showed telling post-test changes. This group showed decreases on all the scales shifting towards moderate mental health. This also indicated that PLWH in the languishing group might have improved due to the intervention whilst those who regarded themselves as flourishing might have gained insight into the devastating effect of stigmatisation during the intervention and moved more towards moderate mental health. The categorical calculations distinguishing between the groups that were languishing, in moderate mental health and flourishing found that most of the group were flourishing in the pre-test. After the intervention more of the PLWH moved to the moderate mental health category. Several of the people in either the moderate mental health or languishing groups shifted to a better category.

The total well-being of the community group also remained in the moderate well-being range even though there was a statistically significant increase shown in the MHC-T after the intervention. Decreases in some of the subscales of the MHC-SF were also observed for the community that gave the impression of no change or negative change. However, using the same further exploration into the categories of languishing, moderate mental health and flourishing it was found that their emotional and social well-being remained stable, with an

increase in their psychological well-being. The same categorical calculation was done to distinguish between what happened to their languishing, moderate mental health and flourishing statuses. In the pre-test most of them were flourishing. After the intervention a number of the previously flourishing group moved to the moderate mental health category. Interesting however, was that nobody remained in the languishing group but moved to either moderate mental health or flourishing. These results gave an indication that the total group shifted towards a more balanced mental health.

Conclusions

Although the focus of the HIV stigma-reduction community “hub” intervention that was followed in this study, was on the involvement of PLWH and PLC to share their knowledge as community mobilisers and to mobilise and empower their own community to reduce HIV stigma, it can be concluded that a secondary gain was the effect it had on both depression and psychosocial well-being of both the PLWH and the community. Of interest is how these effects differed in PLWH and in the community. The findings of the The Patient Health Questionnaire (PHQ-9) for measuring depression indicated the presence of mild depression for PLWH in the pre-test that remained unchanged in the post-test. The intervention did not succeed in making a difference on this aspect. It could be because their status as PLWH remained the same and could be a factor in depression. The community similarly scored mild depression on the pre-test but changed to the absence of depression after the intervention. It could be concluded that in the community’s case the intervention did alleviate their depression which could possibly be from relief that they now had a better understanding of their own actions in stigmatising PLWH in their community and could constructively handle it.

The Mental Health Continuum – Short form (MHC-SF) measures on the various subscales of well-being also showed differences between the effect of the intervention on PLWH and the community. Looking closer at the three subscales for the PLWH their emotional and social well-being decreased and there was no change in the psychological well-being. It could have been concluded that it seemed as though the intervention had a negative effect on PLWH. The further analysis distinguishing between the groups

languishing, in moderate mental health and flourishing found that most of the group were flourishing in the pre-test which seemed incongruent if taken their state of mild depression. After the intervention more of the PLWH moved to the moderate mental health category which would seem more realistic for what they are going through. It can be concluded that they were now much more realistic about their illness and understanding the effects that the stigma had on their lives and were probably less in denial and adapting to circumstances. For the community their total well-being showed a marked increase after the intervention. It could be concluded that they felt less incapacitated by the illness causing such devastation in their midst and have gained a better understanding of how to handle human issues of stigma. It can be concluded that as for the PLWH the community also became more realistic and less in denial.

Limitations

The single case pre-test, post-test design had a smaller sample for the PLWH, and this limits the internal validity of the findings about this group. However, it is clear that a high level of stigma is present and this made it very difficult to obtain a larger sample in this particular community. The inclusion of repetitive post-tests could have limited this factor and could have provided more insight into the perceived changes.

Recommendations

The findings of this study suggest that interventions aimed at HIV stigma reduction at community level may also be important to reduce the impact of HIV stigma on PLWH and the community's depression and total well-being. It is thus recommended that future interventions should pay special attention to aspects of depression and well-being. Such initiatives should foster a renewed dialogue about living with HIV and what it is like to be stigmatised by the community; it should create opportunities to share experience and foster understanding among PLWH and their communities; and it should aim to reunite communities by reducing HIV stigmatising behaviour and by providing meaningful community support. Interventions should continue to involve PLWH and PLC who share their knowledge as community mobilisers who mobilise and empower their own community to reduce HIV stigma.

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Section D: Conclusions, Limitations and Recommendations

Introduction

The conclusions, limitations and recommendations that follow are based on the findings of the three research articles in section C reporting on various aspects of the implementation of the HIV stigma-reduction community “hub” intervention as well as the literature review. The objectives of this study were *to explore, describe and determine* whether a HIV stigma-reduction community “hub” network intervention in a South African urban area will make a difference in the HIV stigma experiences of PLWH and the stigmatisation by their community; *to describe* the implementation of a HIV stigma-reduction community “hub” network intervention in an urban setting involving both PLWH and PLC as community mobilisers; and *to determine* the change in depression and psychosocial well-being of PLWH and their community before and after the HIV stigma-reduction community “hub” network intervention.

Conclusions

The study concludes that the intervention as planned did make a difference in the experiences of stigma of PLWH, as well as the stigmatisation by the community. Although the HIV stigma-reduction community “hub” network intervention could not make a statistically significant change in the HIV stigma experiences of PLWH, it did make a practically significant change on three of the five subscales as well as on the total stigma score (HCN, SI, NSP and TS) of the HASI-P. The extent of these changes were much more obvious in the responses of PLWH during their post-intervention interviews than the changes found with the quantitative measures, indicating that the changes were better reflected in the verbalisation of their experiences. The category “verbal abuse” proved resistant to change, leading to the conclusion that verbal abuse directed at PLWH relates to entrenched habitual behaviour and that it was difficult to change in a three-month period, such as the period that the intervention lasted. This conclusion is confirmed by the finding of two new categories of abuse that emerged, namely physical abuse and emotional abuse, which are not reflected in the original

stigma scale. The category “fear of contagion” showed the least changes in both the post-test results and the interviews, leading to the conclusion that despite the population’s claims that they have adequate knowledge about HIV and AIDS, fear of contagion is deeply embedded in the psyche of the population. The category “health care neglect”, although present as a stigmatising experience in the pre- and post-test measures, hardly featured at all during the in-depth interviews. This suggests that the context of stigma in health care facilities could have changed, as it was not verbalised by participants, as reflected in the scale. It was now verbalised in a different context, as conditions of being separated and isolated. The positive intrapersonal changes measured in the category “negative self-perception” came through the strongest during the post-test interviews, indicating that PLWH have stronger control over changing their personal perceptions than they have over their community’s actions. The change in the “total stigma” score confirms the conclusion that the intervention showed some success in terms of the objectives set for this study to decrease HIV stigma experiences of PLWH through a community intervention. Aspects of behaviour change – like heightened awareness, self-sufficiency and acceptance of reality – changed intentions of actions and strengthened trust and improved relationships between PLWH, their friends, family and the community. This was clearly stated during the post-intervention interviews, which confirmed the success of the intervention. The limited statistical success could possibly be ascribed to the short duration – three months – of the intervention and to the fact that only two “hubs” were not sufficient to change the deep-seated perceptions and behaviour of a total community.

With regard to changes in the stigmatising behaviour of the community towards PLWH, the AIDS-related stigma measure in the community showed no statistically significant change. Yet, practically significant changes occurred in three of the four subscales (SI, IS, GS), leading to the conclusion that some change was accomplished in the larger community’s stigmatising behaviour. The changes expressed in the post-test interviews confirm the conclusion that the community’s understanding of stigma was enhanced through the intervention and that the prejudice of community members and their intention to stigmatise

declined. The scores on the “behaviour index” suggest that behaviour showed resistance to change over the three-month period of the intervention. The change on the “symbolic stigma index” implies that the community’s prejudicial or moralistic views could have been altered, with them being less judgemental after the intervention. The “instrumental stigma” score showed the same embedded fear of contagion shown in the earlier discussion of PLWH’s experiences of people’s fear of becoming infected. However, the practically significant change on this score could lead to a conclusion that the new knowledge and the increased contact with PLWH had beneficial effects on reducing the overall stigmatising behaviour of the community. The similar practically significant change in the “general stigma index” shows that the intervention had the ability to make a difference in the community’s stigmatising behaviour.

From the discussion it can thus be concluded that the HIV stigma-reduction community “hub” network intervention, which involved PLWH and PLC sharing their knowledge as community mobilisers, and mobilising and empowering their own community to reduce HIV stigma, was successful in initiating the onset of changes in a community. This success was achieved through the PLWH and PLC as community mobilisers, who were active in the community “hub” network to mobilise their own communities towards HIV stigma reduction through social change. The involvement of PLWH and PLC as community mobilisers who shared their knowledge and who mobilised and empowered their own community, showed that changes in the short term could be achieved for a whole community. Addressing more than one level of change (individual change and social change) as well as involving a whole community, regardless of the HIV status of individuals, could be used fruitfully in future HIV stigma-reduction interventions for communities. By involving the whole community, the possible negative effect of stigma on PLWH and PLC in the intervention is mitigated, as the intervention is directed at all members of the community.

Based on the detailed description of the case study on the implementation of the HIV stigma-reduction community “hub” network intervention, further conclusions are possible. The intervention was successful in activating mobilisers to initiate change in their community,

reduce the experience of stigma for PLWH, and reducing the stigmatisation by the community. The short-term intervention, running over the three months, was not sufficient to ensure sustainability of the change in stigmatisation over time, but it did initiate change. The two community “hubs” in the community created an opportunity for constant direct interaction on HIV stigma with the community. The “hubs” were served by a two-person mobiliser team, consisting of one PLWH and one non-infected person living close to a PLWH from that specific community. Although the “hubs” were effective, the mobilisers found it difficult. The use of two people in the “hub” seemed beneficial in terms of the mutual support it provided the mobilisers, and the role modelling of meaningful contact between an affected and a non-affected person. The fact that they knew the community well, also proved to be beneficial as the mobilisers understood the community. However, their known status as PLWH in their own community, or as persons living close to a PLWH, sometimes caused hardship or discomfort for both team members when they had to face the community. The strong acknowledgement of the role of the mobilisers was important, as it underpins the notion of utilising PLWH in stigma reduction.

The training provided to the mobilisers on *Understanding stigma* and *Coping with stigma* during the training sessions to train them as mobilisers and to improve their knowledge, equipped them with sufficient skills and knowledge to cope with the presentation of training during the intervention. It seems, however, that it was more difficult for them to convey knowledge on coping and that they needed more support in this regard. The training on how to handle a support group gave them sufficient skills to act as mobilisers and supporters during support groups. Their previous training and skills development, to plan a HIV stigma reduction project in their own community, were essential for the success of the intervention and were an important element of this intervention. The importance is linked to the fact that this formed an important component of the intervention, with the mobilisers planning and conducting their own HIV stigma-reduction project during the intervention. With regard to the mobilisers, it can be concluded that the HIV stigma reduction “hub” network intervention resulted in a generally satisfying experience because the mobilisers felt accepted

and valued by participants in all the activities and voiced a heightened sense of responsibility towards the community.

It may be concluded that the HIV stigma reduction “hub” network intervention activities (workshops on *Understanding stigma* and *Coping with stigma*; the door-to-door teaching on HIV stigma; the support group; the weekly psychodrama on an HIV stigma-reduction theme; and the HIV stigma-reduction project of their own choice) were successful in addressing stigma reduction in a whole community by utilising a combination of strategies that are regarded as being the most promising approaches to HIV stigma-reduction interventions. The strategies that are referred to included information-sharing, skills building, support and contact with affected groups. The levels of intervention included individual and interpersonal levels as well as social networks and the public. The intervention improved the knowledge and awareness of both the mobiliser teams and the community, and it also improved the attitudes and behaviour of the community towards PLWH. For PLWH, there was a greater willingness to disclose their HIV status as well as an understanding of the destructive role stigma plays in their lives.

It may further be concluded that social-change communication principles of participation managed to address social and cultural norms, values, networks as well as individual behaviours and practices. The HIV stigma-reduction “hub” network intervention approached the community respectfully, and the everyday human relationships and practices introduced possibilities of an open-ended, anti-hierarchical and inclusive mode of community action.

Although the focus of the HIV stigma-reduction community “hub” intervention that was followed in this study, was on the involvement of PLWH and PLC to share their knowledge as community mobilisers and to mobilise and empower their own community to reduce HIV stigma, secondary gain was also derived from the effect it had on depression and mental health of the PLWH as well as the community. Of interest is how these effects differed for PLWH and in the community.

The intervention did not succeed in making a difference on the depression level of PLWH, possibly because they now had to cope more with the understanding and reality of stigma in their lives. The community also scored mild depression on the pre-test, but this changed to an absence of depression after the intervention. This indicates that in the community's case, the intervention did alleviate their depression – possibly because of the relief they experienced in now having a better understanding of their own actions regarding stigmatising PLWH in their community, and being able to manage it more constructively.

The Mental Health Continuum – Short form (MHC-SF) measures on the various subscales of well-being also showed differences between the effect of the intervention on PLWH and the community. For PLWH, their total well-being indicated a moderate mental health status before the intervention, which decreased after the intervention but still remained within the range of moderate mental health. The decrease in well-being could be because they became more realistic about what stigma truly involved, and that they were therefore less in denial. They could be in a phase of adaptation. The measures on the three subscales also suggest that the intervention had a negative effect on PLWH, which required further analysis. The categorical calculations distinguishing between *languishing*, *moderate* mental health and *flourishing* show that most members of the group were flourishing in the pre-test – this seemed incongruent, in the context of their state of mild depression. After the intervention, more of the PLWH moved to the moderate mental health category, which would seem more realistic for what they are going through. Several of the people in either the moderate mental health or languishing groups shifted to a better category. It can be concluded that they were now much more realistic about their illness, that they understood the effects that the stigma had on their lives and that they were probably less in denial and more adapting. For the community, their total well-being showed a marked increase after the intervention. It could be concluded that they felt less incapacitated by the illness that caused such devastation in their midst, and that they had obtained a better understanding of how to handle human issues of stigma. Their emotional and social well-being remained stable, with an increase in their psychological well-being, leading to the conclusion that they felt more

personal control. The same categorical calculation was done to distinguish between what happened to their flourishing, moderate mental health and languishing statuses. In the pre-test, most of them were flourishing. After the intervention, a large group remained in the flourishing category but a big group of the previously flourishing group moved to the moderate mental health category. Interesting however, was that fewer of them remained in the languishing group, but moved to a better category. Similar to the PLWH, the community therefore also became more realistic and less in denial.

Lastly, based on the discussion above it can be concluded that the multi-level community intervention utilised in this study successfully contributed to initiating a decrease in HIV stigma experiences of PLWH, as well as a decrease in stigmatisation by their community. It can thus be concluded that the objectives of the research were achieved.

Limitations of the Study

The single case pre-test, post-test design with the smaller sample for the PLWH, limits the internal validity of the findings about them. It is clear, however, that a high level of HIV stigma is present, and this made it very difficult to obtain a larger sample in the particular community. Including repetitive post-tests could have limited the effect of this aspect and could have provided more insight into the perceived changes.

Although the sample size for PLWH was small, the mixed-method study combined two measures in order to counteract this limitation. The true value of mixed methodology in this study lies in the fact that the in-depth interviews shed new light on the experiences of PLWH and the community, as it gave a voice to the people, and revealed points of view that were not detected in the measures. Observation over a longer period could have broadened insight in terms of whether the raised awareness of stigma and stigmatisation will have an influence on subsequent stigma-related experiences of PLWH and behaviour of their community.

As stigma and stigmatisation fall in the realm of behaviour, and as it is known that behaviour is not easy to change, the exposure time of participants was possibly insufficient

to sustain change, even though there were clear indications of intent to change. More “hubs” in the network could possibly have improved sustainability.

Recommendations

It is recommended that the HIV stigma-reduction community “hub” intervention that involved PLWH and PLC sharing their knowledge as community mobilisers, and mobilising and empowering their own community to reduce HIV stigma, should be used again in future to address community HIV stigma reduction; and that working on individual and social levels should continue, using a variety of activities. It may be beneficial to research ways in which the elements that proved resistant to change – like verbal abuse and fears of contagion – could be addressed in more depth during the intervention. Further research is needed on if and how the context of stigma in health care facilities has changed. Follow-up workshops, with additional activities like community conversations on the subject, could also increase community participation and mobilisation. Upskilling and implementing more mobiliser “hubs” could increase the reach of the intervention and could broaden the potential of behaviour change and stronger ownership in the endeavour to reduce stigma and to address HIV prevention. This should influence the sustainability of the project. Because it is so difficult to mobilise change in a limited period, the intervention should become part of the everyday activities of the community, to ensure lasting effects. Further research to evaluate how long the change in the community lasts, is also important to truly reduce HIV stigma. Sustainability could be achieved in the form of helpful networks with powerful groups, improved access to resources and services, and more democratic and cohesive relationships within local communities.

Given the success of the HIV stigma-reduction community “hub” network intervention in terms of its stated objectives, repeating and strengthening the intervention could prove beneficial to communities to reduce HIV stigma, and to change stigmatisation practices of a whole community. Using the two-person mobiliser team should be an essential principle in any future interventions, as it involves PLWH but also demonstrates the positive relationship between a PLWH and a non-infected person. Training is of the utmost importance and a

stronger support system should be available to the mobilisers, as they are often the lesser skilled people of the community. Training and support should focus on specific skills development as the needs arise, as well as practical aspects like timekeeping and dealing with the distrust from the community. Using mobilisers that live in the community was extremely helpful, but also gave mobilisers a bigger sense of purpose and pride because they were doing something for their own community. This practice should continue in follow-up interventions. It could also possibly solve the problem of “communities of practise” being involved only as long as interest lasts. Mobilisers should form part of the sustained partnership with stakeholders in the community. When interventions with communities are conducted, they should continue to follow the respectful, anti-hierarchical and inclusive approach, focusing on the whole community and not only the PLWH.

It could be beneficial to revise the *HIV/AIDS stigma instrument for PLWH* (Hasi-P) © on a continuous basis, to adapt to the changing context of HIV stigma. The subscales for received stigma, namely VA, HCN, SI and FoC, could be revised with items found during the in-depth interviews of this study. For the internal stigma section (NSP category), items like lack of self-care, suicidal thoughts, lack of self-acceptance, fear of disclosure and self-isolation could enrich the measure.

The *AIDS-related stigma measure* for stigmatisation by the community intends to show the stigmatising behaviour of individuals but in general this measure and the in-depth interviews did not correlate well, which suggests that a different measure for stigmatisation by the community needs to be explored. Items found during the in-depth interviews with the community could form the basis of such a new scale.

It is evident from this research that the context of stigma changes over time. Due to the interrelatedness of different manifestations of stigma and the changes in context over time, the stigma research field would likely benefit from collaboration between different disciplines from health and social sciences to incorporate multiple measures allowing for comparison of their validity and reliability.

The findings of this study suggest that interventions aimed at HIV stigma reduction at community level may also be important to reduce the impact of HIV stigma on the depression and total psychosocial well-being of PLWH and the community. It is thus recommended that future interventions should particularly focus on addressing aspects of depression and well-being. Such initiatives should foster a renewed dialogue about living with HIV and on what it is like to be stigmatised by the community, create opportunities to share experience and foster understanding among PLWH and their communities, as well as aim to reunite communities by reducing HIV stigmatising behaviour and providing meaningful community support.

A further recommendation for future research in the field of HIV stigma reduction would be to investigate the value of specifically including primary health care settings, in terms of their role to reduce HIV stigma and enhance responsible disclosure management. Primary health care settings are usually the first point for diagnosis, but could also be the first point of stigmatisation.

Appendix A: Ethics 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.

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

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

Appendix B: Consent to be a Research Subject

Community-based HIV Stigma Reduction “Hub” Network

A NRF Funded Study Conducted By Prof M Greeff and Team Members Of Author at the North-West University, Potchefstroom Campus

CONSENT TO BE A RESEARCH SUBJECT

1 PURPOSE OF THE STUDY

A team of researchers from various disciplines of the Faculty of Health Sciences of the North-West University are conducting a study on a *Community-based HIV Stigma Reduction “Hub” Network* in Extension 7, Ward 17, Potchefstroom, South Africa. You are being asked to participate in this study because you are a part of the community or a person living with HIV (PLHA).

2 PROCEDURE

If you agree to be in this study the following will occur:

- A set of measures on HIV stigma will be completed by you during July 2011 and November 2011
- 10 Community members and 10 PLHAs will be selected from the initial group and in-depth interviews conducted with them on their perceptions of HIV or their experiences of HIV stigma, in July 2011 and November 2011.

3 RISK/DISCOMFORTS

Should you have any discomfort while sharing perceptions or experiences of HIV stigma during the completion of the measures or during the interviews, you will have access to counseling. Your name will never be made known and no individual identifiers used in any publications resulting from the survey. Only the team of researchers will work with your data.

4 BENEFITS

By being involved in this research project will help in the reduction of HIV stigma in Ward 17. Your participation will help the researchers to develop a community-based HIV stigma reduction “hub” network.

5 COSTS

There will be no cost to you as a result of your participation in the study.

6 PAYMENT

You will receive no payment for participation.

7 QUESTIONS

You can talk to Ms Poncho Molale (research assistant) if you have any further questions concerning your consent. She can be reached at 018 299 2099.

8 PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.

You are free to decline to be in this study, or to withdraw from it at any point.

Should you be willing to participate you are requested to sign below.

I.....hereby voluntarily consent to participate in the above-mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study that the information will be kept confidential and not linked to my name at any stage. I also understand that I might benefit from the intervention. Should I experience any emotional discomfort I will be referred for counseling.

Date

Signature of the participant

Date

Signature of the person obtaining consent

Appendix C: Example of Naïve Sketches of Participants of the Understanding HIV Stigma Workshops

My experience of this workshop today was:

I found many important things. That I can accept a person who is HIV positive. And hope that how can I help. Other many things have opened my eyes. I have learnt a lot. What I have learnt will help me at some point in my life. And even to pass this education to others.

I feel:

I feel happy. My eyes have opened; I have learnt a lot of things.

My experience of this workshop today was:

I heard them saying that a person who has HIV must not be afraid to speak. When we speak about them we must not segregate them. Again we must treat them properly the person who has HIV, treat that person properly they must go to the clinic and eat proper food.

I feel:

I am very ok I understood a lot and I am only grateful.

My experience of this workshop today was:

I have being knowing that Stigma is there. But I have learnt a lot from this workshop. I believe that if we work together and be one from what we have heard about stigma, HIV and AIDS will reduce very much and the people that are living with the HIV disease will reduce, those that are using ARV'S will find more confidence during their treatment time, even though they know that this disease does not get healed but that will not bother them in their life. Again I wish the government would increase more teaching with people all over the country. I thank the government for the ARV'S.

I Feel:

I feel free I wish to always be part of this workshop, every time. I thank you.

My experience of this workshop today was:

I have learnt many things and I have accepted that I am a person living with HIV. Not knowing I am not the only one infected only to find out that we are so many. I am happy of the education I heard.

I feel:

I feel fine and happy let it be education that continues

My experience of this workshop today was:

I have learnt is what HIV/AIDS is. We also talked about Stigma to know what is Stigma. I am happy to come here because we understand each other we are all speaking. We will come again.

I feel:

I feel truly honored to come to this support.

My experience of this workshop today was:

The workshop has taught me things I did not know and I am afraid to say that mangi has Stigma. Now I know I am no more afraid. I will support a person who has stigma and help them and again remind them to take their medication or go to the clinic. You self be strong in the lord take care of you properly. Thank you. Our yes must be a yes, our no must be a no lets be together.

I feel:

I feel better and I am happy.

Appendix D: Example of Naïve Sketches of Participants of the Coping with HIV Stigma**Workshops****My experience of this workshop today was:**

I learnt that you must be able to cope. That when something is supposed to happen running away does not help. A person must problem solve in a right way.

I feel:

I feel good with this education.

My experience of this workshop today was:

I managed to learn and see that there are situations that can make you end up not being able to see the situations that you are in. But because of the workshop I have learnt how to cope with any situation. A support group teaches our community that, any situation you find yourself with in there is a way to solve the situation that you find yourself in at any time.

I feel:

I feel free to be able to speak about the situation I am in.

My experience of this workshop today was:

I found many things about Stigma. That what it is. And that a person who is HIV positive is not supposed to be stigmatised. I am grateful for those that were teaching they taught us about HIV stigma.

I feel:

I feel honored with much education

My experience of this workshop today was:

I learnt that when I am HIV positive I must accept myself and speak about it that how I must be treated or the person who has HIV how I must support them.

I feel:

I feel like I can have more knowledge and help were it is needed like the people that are sick and are unable to take care of themselves.

Appendix E: Example of Naïve Sketches of Participants of the Door-To-Door Education**My experience of this door-to-door education today was:**

People are talking about people about HIV. They are swearing at people who have AIDS. But aids is no more a bad thing.

I feel:

I feel much better about HIV/AIDS.

My experience of this door-to-door education today was:

I received many things today that are important. That another person must not point another person with a finger. This is because this disease is in all houses.

I feel:

I feel very happy today about this workshop

My experience of this door-to-door education today is:

That this training is teaching many people the spirit of compassion and caring in the community especially to those that have HIV. People must stop calling them with many names that make them uncomfortable

I feel:

I feel very honoured with this education because it helps many people.

My experience of this door-to-door education today was:

I have learnt a lot about the AIDS sickness. I have learnt that the disease of AIDS has grown. The disease of AIDS has no treatment that is why I learnt a lot about Stigma. I learnt that when you have AIDS you must take treatment. That the people who do not have AIDS must not separate people that have the disease of AIDS. I have learnt that a person must know their status.

I feel:

I feel honoured. I feel happy I believe I will come again.

My experience of this workshop today was:

A person who has HIV is just like everyone. We are not supposed to separate that person and to separate his/her dishes. We must give support so that they can have good health when we do not say bad words to the person and become friends with them and not separate them.

I feel:

I am happy with what I have been taught.

My experience of this door-to-door education today was:

Stigma is bad words that we say to people when they are sick with AIDS. We must treat them properly so that they can accept this disease when they have it and take their treatment at the clinic and at the hospital.

I feel:

To befriend a person who is HIV positive.

Appendix F: Example of Naïve Sketches of Participants of the Support Group**My experience of this support group today was:**

I have found that we can go and clean the houses of the people that cannot do it for themselves. And seeing how we can help the people that are HIV positive. Even the youth that run to the initiation programme and also those that take drugs how we can help them.

I feel:

I feel honored and that we can continue with this support group. Thank you.

My experience of this support group today was:

I found out that we were given food. You must give us support and we must give you support and not to leave the support group in the middle. Give us a hand to clean the houses for the people that cannot do it and even to help the people that are unable to take their medication.

I feel:

I am ok and I am healed

My experience of this support group today was:

Meeting people and speaking with them has taught me to be free and helping others that do not have the ability to do so.

I feel:

I feel ok and free.

My experience of this support group today was:

I find that it is good that I get to know about Stigma I believe that it will help to go to the people's houses.

My experience of this support group was:

Very happy it was very nice we were like true friends because I want to do more I will be one of the people for the workshop.

I feel:

I like to sit with people and we have fun, chatting, laughing having fun.

Appendix G: Example of a Section of an In-Depth Interview**Interview: Stigma Reduction Pre-Test-262-5**

(Please note: All inaudible or uncertain audio, including the spelling of names, is denoted with parentheses.)

Moderator We've already greeted each other.

Respondent Yes we have.

Moderator Okay thank you for being prepared to do this interview with me. I am, and I'm a research assistant working at the North-West University, and I'm part of the team looking at HIV stigma in the community. The purpose of the interview is to get to understand a little of your world as a person living with HIV and the stigma you experience. I'll be conducting several interviews with PLHA and community members to gain an understanding of their world with HIV stigma. It's going to take an hour to an hour-and-a half to do this interview. Everything you say will be kept confidential and your name never made known. It might be that I will be writing some notes during the interview just to follow you. You have given permission to be a participant and for the interview to be recorded and again to have an interview with you in November is that that correct?

Respondent Okay.

Moderator You are welcome to withdraw at any stage, but I wish you don't. Should you feel any discomfort after the interview and would like to talk to someone I can make some arrangements for you. Are there any questions from your side before we go ahead?

Respondent No.

Moderator I'm going to read the questions in English then I will explain them to you in Setswana. The first question says, you are a person living with HIV tell me about your experience in Ward 17 with HIV stigma? The second question says, what behavior have you experienced against you from the community because you are HIV positive? The third one is, tell me how you experienced this interview with me today? So let me go to the first question, you are a person living with HIV tell me about your experience Ward with HIV stigma?

Respondent I'm a person that likes to speak so I have been living with HIV since 1991; I have been going to the clinic every month for my medication. At some point my CD4 count went down and I started taking ARV's and I took them until I got better. Then I stayed for two months not going to the clinic because I was very ill and I had no one to help me. I then went back to the clinic and they ran tests and they found that it was still HIV. I started with (INAUDIBLE) then they did a pap smear and they found nothing. The only person I told was my mother and my sister, my sister then started acting differently towards me. She went around telling people that I had Aids but I accepted myself. Then I stayed alone until I found a partner but I told him that I can't be in a relationship because I have HIV. That man told me that he loves me with my Aids and I'm still with him today, he has never changed towards me.

- Moderator** I can hear that it's been a long time and the only real problem that you got was at home with your sister.
- Respondent** No at home I didn't have any problems.
- Moderator** No I mean with your sister?
- Respondent** I don't live at home I'm married now.
- Moderator** When I say at home I mean back at you parents home.
- Respondent** Yes.
- Moderator** Your husband accepted you and he said that he loved you with your Aids. Back home your mother accepted you?
- Respondent** Yes but it was hard.
- Moderator** It was hard? What do you mean it was hard?
- Respondent** She took time to understand that I had HIV she started showing some understanding of it when many people started talking about this but this was after she chased me out of her house.
- Moderator** So she treated you differently but.
- Respondent** She didn't let it show.
- Moderator** So we can say that she was pretending and only after did she.
- Respondent** Start to accept me.
- Moderator** Okay. Now before you got married and you had your husband how did you feel being mistreated by your mother?
- Respondent** It was difficult because I almost wanted to kill myself. That was a thought that stayed with me constantly.
- Moderator** What made you feel like you wanted to kill yourself?
- Respondent** It's a difficult life because this is something that stays in your mind all the time, so it made me want to die.
- Moderator** Why did you think that way?
- Respondent** Living a difficult life.
- Moderator** What makes you say that you live a difficult life?
- Respondent** Because my children were now starting to ask questions that their father used to go to the clinic all the time until he died so now why am I going to the clinic every month? So now I had to explain to my kids that I had HIV that's why I go to the clinic every month, because their father was in hospital for some time, so now I was scared of telling them that I had HIV because they know that this thing kills people. They weren't comfortable and free like other kids.
- Moderator** So this hurt you because you feared that the kids would stay in constant fear that you're ill and this would affect them?
- Respondent** Yes it would affect them greatly.
- Moderator** So I can see that this really breaks your heart?

- Respondent** Yes it breaks my heart very much because I want to tell them but now they see their father is in hospital and they don't go out and play like other children, they are always locked up in the house.
- Moderator** So that's a real problem.
- Respondent** Yes it really is.
- Moderator** Okay so at home your mother, doesn't she give you that support?
- Respondent** My mother has since passed.
- Moderator** Oh she passed on? And your sister how has your relationship with her been since?
- Respondent** We're actually step sisters so that's why we don't get along.
- Moderator** You said she used to talk about you was it close to home or around our ward?
- Respondent** (INAUDIBLE).
- Moderator** (INAUDIBLE). As you said talking to someone helps when they speak to you it helps a little. Speaking to me may help but if you feel that this is making you feel really sad then you must stop me. So you said the time you told your mother is was hurtful and it took some time for her accept you as her child and you even felt like killing yourself because you didn't get that support? And your sister was now also going around talking about you and?
- Respondent** Saying hurtful things to me. Whenever I would cook they would ask me how can I make them food when I know that I have Aids and she wouldn't use a glass that I used to drink water with. She started keeping record of the things I used so that she wouldn't use them because I would infect her.
- Moderator** So this shunning hurt you?
- Respondent** Yes it did.
- Moderator** Then you met your husband and he told you that he loved you with your Aids and you then moved to seven? So how has it been here in seven?
- Respondent** With my husband?
- Moderator** Yes as you live with your husband and in the community. What have you seen in terms of shunning where you currently live?
- Respondent** I can't really say there's a problem because I actually like being by myself. I wait for my children to come back from school because they are my friends. I don't want people coming to house because then they will end up influencing me in a bad way.
- Moderator** So you haven't even seen people here in seven shun anyone or treat them any other way?
- Respondent** No I haven't.
- Moderator** Does anyone know about your situation around here?
- Respondent** No one.
- Moderator** No one? So it's the two of you and you haven't told your children as well

Appendix H: Example of a Mobiliser's Field Notes

Observational: When I first saw her she looked like a person who had lost hope and did not know where to go. Her husband is at hospital but was still willing to come and do interview. She speaks openly about being HIV positive but the past wounds of stigma have not healed, as when I spoke about them she began to cry and said it is very hard and sometimes even thinking of killing herself. Her greatest fear is their children finding out their status. When she was crying she talked about pain now she said she had been carrying a burden and is happy to speak to someone and the burden has been removed. There was a change when she stood up and walked it was more firm and different from when she came in.

Methodological: An in-depth interview was done using a voice recorder with participant. Three questions were asked in English and explained in Setswana. The participant answered in Setswana.

Personal notes: I would have loved to ask more about why she finds she fears the children should know. Is it because of the stigma? But the way she cries there's so much pain and thinking that her husband is also in hospital. They have both not disclosed to the community this has made them not have any stigma.

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