

Change-over-time: A comprehensive community-based HIV stigma reduction and wellness enhancement intervention

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University

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LANGUAGE EDITOR DECLARATION

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18 November 2013

Ms HC Chidrawi
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Dear

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This is to confirm that I edited your thesis, *AN OVERVIEW OF LITERATURE ON HIV STIGMA IN RELATION TO PSYCHOSOCIAL WELL-BEING, HEALTH BEHAVIOUR AND COMMUNITY BASED HIV STIGMA REDUCTION INTERVENTIONS*, and that I indicated the necessary grammatical corrections.

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1 AN OVERVIEW OF LITERATURE ON HIV STIGMA IN RELATION TO PSYCHOSOCIAL WELL-BEING, HEALTH BEHAVIOUR AND COMMUNITY BASED HIV STIGMA REDUCTION INTERVENTIONS 1. INTRODUCTION Stigmas seem to be widely endorsed by the general public and can be viewed as phenomenal representations of the public's largely negative perceptions (Corrigan, 2000:48) about, and interactions with, persons or groups with stereotyped weaknesses. There are different viewpoints regarding the term stigma. Life examples like 'apartheid' and the 'AIDS pandemic' demonstrate different aspects of stigma-related social, economic and political devastation. Stigma, on the one hand, links to a concept like discrimination where for...

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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

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 allows for a brief literature review as well as the paradigmatic perspective that underpins the research and furthermore gives comprehensive overview of the planned research project and its detailed methodology. This is done in more detail than is possible in the articles.

Section B: A literature review

The literature review presents a critical synthesis of the body of knowledge pertaining to the research and to determine possible gaps that might need further exploration. The review offers an opportunity to critically reflect on the literature context, previous findings, the research results and possible newer literature.

Section C: Articles

The three articles report on the research findings about HIV stigma experiences of PLWH and stigmatization by PLC, psychosocial well-being of PLWH and PLC, and HIV health behaviour of PLWH. Referencing for this section is according to APA guidelines.

ARTICLE TITLE	JOURNAL FOR SUBMISSION
Article 1: Change-over-time in the HIV stigma experiences of people living with HIV and stigmatization by people living close to them following a comprehensive community-based HIV stigma reduction intervention in an urban and rural setting.	Aids Care
Article 2: Change-over-time in the psychosocial well-being of people living with HIV and people living close to them after a	African Journal of AIDS

comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and rural setting.	Research (AJAR)
Article 3: Health behaviour change of people living with HIV after a comprehensive community-based HIV stigma reduction intervention.	Journal of Social Aspects of HIV/AIDS (Saharah-J)

Section D: Conclusions, limitations and recommendations

Conclusions will be drawn, limitations discussed and recommendations presented regarding the comprehensive community-based HIV stigma reduction and wellness enhancement intervention for PLWH and PLC in an urban and a rural setting.

AUTHORS' CONTRIBUTIONS

This research study was planned and executed by three researchers from the African Unit for Transdisciplinary Health Research (AUTHeR) at the North-West University, Potchefstroom Campus and a collaborative researcher from Vrije University of Amsterdam. The contributions of each researcher to this study, is indicated in the table below:

Mrs H.C. Chidrawi	Ph.D. Nursing Science student, liable for the review of literature, conducting the research process, interpretation of quantitative data and writing of the text on the quantitative data.
Prof. Dr. M. Greeff	Promoter, project leader, researcher and critical reviewer of the study.
Prof. Dr. Q.M. Temane	Co-promoter, and critical reviewer of the study,
Prof. C.M. Doak	International collaborator and critical reviewer of the study.

The following is a declaration by the author and co-authors to confirm their role in the study and to agree that the article format is appropriate and acceptable for submission as a thesis. Title: Change-over-time: A comprehensive community-based HIV stigma reduction and wellness enhancement intervention.

Declaration

I hereby declare that I have approved the inclusion of all three (3) articles as mentioned above and that my role in this study complies with what is described above. I hereby grant permission that these articles may be published as part of the Ph.D thesis of Helena Christa Chidrawi.



Prof. Dr. M. Greeff



Prof. Dr. Q.M. Temane



Mrs H.C. Chidrawi



Prof. C.M. Doak

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The SANPAD project for the bursaries and financial support of the research as well as the generous student bursary.

Minrie Greeff has been professor in Research in the Africa Unit for Transdisciplinary Health Research of the Faculty of Health Science at North-West University since 2008. She is an acknowledged researcher and published widely in national and international scientific journals. She is a member of the Tau Lambda-at-Large Chapter and has recently been inducted into a prestigious international Nurse Researchers Hall of Fame. These are but a few of many awards and a broad impressive curriculum vitae. It has been an exceptional privilege to study under the mentorship and leadership of Prof Minrie Greeff during the development and growing pains of my doctorate. I have learned significant life lessons and have grown as a person and researcher. Prof Minrie's contagious passion for research, her motivational leadership, friendship and incredible work-capacity has been the driving force of this achievement.

Michael Temane was director of the School of Psychosocial Behavioural Sciences at the North-West University up to September 2013. He has a quiet strength and wonderful academic acumen. Round table discussions have always been pleasant, motivating and challenging. I look back over the years and recognise the professionally supportive and almost fatherly role that Prof Michael played. I am especially grateful for the competence he shared, the insights he brought and the balance he kept.

Amanda van der Merwe for excellent language editing.

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Poncho Malaudzi for fieldwork leadership and reporting.

Suria Ellis for statistical excellence and support.

This thesis is dedicated to my husband, Bernard. His tremendous loyalty, belief in me and my abilities coupled with his support during difficult times fuelled my commitment and effort. His

patience with my studies, books and papers all over the house and my frequent unavailability is deeply appreciated.

I share this achievement with my friend and study-buddy, Rini Prinsloo. We had many hours on the road, wonderful and challenging study experiences and more hours of collective effort to figure out how, to do what, next.

It is not possible to describe the spiritual road of the last three years. Our heavenly Father gave meaning to the struggle and led the way through every rough patch. I am exceptionally blessed and deeply thankful.

In honour of my parents Marcus and Roleen Strydom.

To God be the glory!

Al die eer aan die Here!

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

Stigma is fatal.

Stigma prevents people from getting tested, from talking about their positive status, and from seeking help.”

– Edwin Cameron (2008)

SUMMARY

This study forms part of a larger SANPAD project focusing on a comprehensive community-based HIV stigma reduction and wellness enhancement intervention, responding to the continuous burden of HIV stigma on both national and international levels and the paucity of research in sustainable HIV stigma reduction interventions. HIV stigma is considered all over the world as a complex, far-reaching and powerful phenomenon that continues to affect people living with HIV (PLWH) and also people living close to them (PLC). The impact of stigma has far reaching effects on aspects like the wellness of PLWH and PLC, but also on the health behaviour of PLWH. There is paucity in research on the lasting effect of HIV stigma reduction interventions, intervention within a community context, as well as in urban and rural settings.

The research objectives of this study were to test the change-over-time in HIV stigma experiences of PLWH and stigmatization by PLC with regard to the psychosocial well-being of PLWH and PLC, and with regard to health behaviour of PLWH in both urban and rural settings, following a comprehensive community-based HIV stigma reduction intervention. A quantitative experimental single system research design with a pre-test and repetitive post-tests were conducted by means of purposive voluntary sampling for PLWH and snowball sampling for PLC. The intervention was based on three tenets, namely a) the sharing of information on HIV stigma and coping with it, b) the equalisation of relationships between PLWH and PLC through increased interaction and contact, and c) empowerment of both PLWH and PLC towards leadership in HIV stigma reduction through practical knowledge and experiences of planning and implementing HIV stigma reduction projects in their own communities. Several valid and reliable scales and instruments were used to measure effect.

The initial analysis indicated no statistically significant difference between stigma experiences of PLWH and stigmatisation by PLC from urban and rural settings, or between psychosocial well-being of PLWH and PLC or health behaviour of PLWH from the two different settings. The urban-rural data was therefore pooled for the further analysis. The similarity of data could possibly be ascribed to the fact that most of the participants were Setswana-speaking and living in the North West Province. Stigma experiences as well as stigmatisation could be decreased

and the decrease could be sustained over a year through the comprehensive community-based HIV stigma reduction intervention. The findings also showed that changes-over-time in psychosocial well-being following the intervention were better sustained by the PLC than the PLWH. Results furthermore indicated that HIV stigma reduction positively influenced the health behaviour of the PLWH.

Recommendations for further HIV stigma reduction and wellness enhancement include the continued application of this comprehensive community-based HIV stigma reduction and wellness enhancement intervention, with its supporting tenets, content and methodology. This intervention should, however, be expanded into urban and rural communities, and to different cultures as well. It would be meaningful to build HIV stigma reduction community-based networks. More effort could be made to specifically include a workshop for PLWH on psychosocial well-being as well. HIV stigma interventions should be an indisputable part of health behaviour change workshops for PLWH.

Core concepts: change-over-time; community-based; health behaviour; HIV stigma; psychosocial well-being; stigmatization.

OPSOMMING

Hierdie navorsing is deel van 'n SANPAD-projek wat fokus op 'n omvattende gemeenskapsgebaseerde MIV-stigmavermindering- en welstandbevorderingsintervensie. MIV-stigma word regoor die wêreld erken as 'n komplekse, kragtige verskynsel met verreikende gevolge. Dit affekteer die belewenis van mense met MIV en dra by tot stigmatiserende optrede deur mense wat nie die virus het nie. Albei hierdie groepe word ook op psigososiale gebied beïnvloed, met 'n verdere invloed op die gedrag van persone wat met die virus geïnfekteer is. Daar is gebrekkige navorsing oor langtermyn-effekte van stedelike en landelike intervensies vir MIV-stigmavermindering.

Die navorsingsdoelwitte van hierdie studie fokus op moontlike verandering in die MIV-stigmabelewenisse van geïnfekteerdes, die stigmatiserende optredes van die mense naby hulle, die psigososiale welstand van albei groepe asook die gedrag van die MIV-geïnfekteerdes, as gevolg van die toegepaste intervensie. 'n Kwantitatiewe eksperimentele enkelsisteem-navorsingsontwerp met 'n voortoets en vier herhaalde natoetse is gebruik. Doelbewuste steekproefneming is gebruik vir die proefpersone wat met MIV lewe en sneeubal-steekproefneming vir die persone naby aan hulle.

Die omvattende gemeenskapsgebaseerde MIV-stigmavermindering en welstandbevoororderingsintervensie het op drie beginsels berus: die deel van inligting oor MIV-stigma en die hantering daarvan; die normalisering van die verhouding tussen die MIV-geïnfekteerdes en die persone naby aan hulle; en die bemagtiging van albei groepe om gesamentlik projekte vir MIV-stigmavermindering in die gemeenskap uit te voer. Verskeie geldige en betroubare meetinstrumente is aangewend vir die meting van verandering ná die intervensie.

Daar was geen statistiese beduidende verskille tussen die metings van stedelike en landelike gebiede nie. Die gebrek aan verskille kan waarskynlik toegeskryf word aan die homogeniteit van die twee groepe deelnemers, wat hoofsaaklik Setswanasprekende inwoners van die Noordwesprovinsie was. As gevolg daarvan is die stedelik-landelike data gesamentlik geanaliseer. Hieruit het geblyk dat die intervensie daarin geslaag het om 'n volhoubare verandering oor 'n jaar teweeg te bring. Daar was 'n afname in die ervarings van MIV-stigma van

die persone wat met MIV lewe, asook in die stigmatisering van die persone naby aan hulle. Verdere bevindinge het getoon dat die psigososiale welstand wat onmiddellik na die intervensie ingetree het, beter behoue gebly het vir diegene naby aan die persone wat met MIV lewe as vir hulleself. Resultate het wel getoon dat 'n afname in MIV-stigma 'n positiewe invloed gehad het op die gesondheidsgedrag van persone wat met MIV lewe.

Aanbevelings ten opsigte van verdere MIV-stigmavermindering en welstandsbevorderings het ingesluit dat die omvattende gemeenskapsgebaseerde MIV-stigmavermindering- en welstandsbevorderingsintervensie voortgesit moet word met dieselfde drie beginsels, inhoud en metodologie. Dit moet egter uitgebrei word na ander kulture, ander stedelik-landelike gebiede en ander provinsies. Gemeenskapstrukture en -netwerke is noodsaaklik en sou ontplooi kon word om persone wat met MIV lewe en diegene naby aan hulle te help om MIV-stigma af te breek en om psigososiale welstand en gedragsverandering te bevorder.

Kern begrippe: gemeenskapsgebaseerd; gesondheidsgedrag; MIV stigma; psigososiale welsyn/welstand; stigmatisering; verandering-oor-tyd.

SECTION A: OVERVIEW OF THE RESEARCH

The following overview gives rise to the planned study, its paradigmatic perspective, specific objectives and its detailed methodology. The study is funded by, and forms part of the bigger SANPAD project, namely: A comprehensive community-based HIV stigma reduction and wellness enhancement intervention (Reference number: 09/15) with Prof. Minrie Greeff as project leader.

1 Introduction and problem statement

The context within which this study will be undertaken includes aspects of HIV stigma and implications thereof for people living with the HI virus or AIDS (PLWH), and people living close to them (PLC), psychosocial well-being of PLWH and PLC, health behaviour and the quest for a community-based intervention that will effect change-over-time in terms of HIV stigma reduction and wellness enhancement.

The co-existence of stigma, as a deeply discrediting (Goffman, 1963:13) personal phenomenon, and AIDS, as a devastating pandemic playing itself out in the families and villages of Africa (Aggleton & Parker, 2002:9), sets a context of challenge and complexity. It is in this sense that Holzemer and Uys (2004:165) report that many health care workers in Southern Africa believe that unless stigma is conquered, the HIV and AIDS pandemic will not be defeated. Greeff *et al.* (2008a:78) add that even though traces of HIV stigma reduction are emerging, HIV and AIDS still remain a significantly stigmatised condition. Harvey (2001:175) explains that contextually, stigma refers to the spoiled social identity of those with an attribute that deviates from attributes considered normal and acceptable by their particular communities. Alonzo and Reynolds (1995:503) also mention that stigma operationalizes as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed by others. HIV could probably be seen as such a deviant attribute or social label and could thus lead to a reduced self-esteem and reluctant participation within community context. Further studies contributed to the broader context of HIV stigma with regard to the individual and the

community which is pertinent to contextualising this study. Holzemer and Uys (2004:166), along with Skinner and Mfecane (2004:161), suggested that stigma has an internal and external dimension, meaning that internal stigma can be “felt” (experienced/perceived) whilst external stigma refers to “enactment” or received behaviour, like stigmatising actions towards self or others.

Because HIV stigma is an individual as well as a community issue, Greeff and Phetlhu (2007:13) and Hilhorst *et al.* (2006:390) argue that a successful stigma reduction intervention will have to be community-based and will have to include aspects of the individual as well as aspects of the community. Naidoo *et al.* (2007:17) also point out that rural and urban communities differ and that HIV stigma may manifest differently in the two settings, with the result that the planned intervention will possibly not be equally effective in both settings. HIV stigma involves much more than the experience of particular individuals, and Parker and Aggleton (Holzemer *et al.*, 2007a:543) suggest the reframing of the current understanding of stigma in accordance with a conceptualisation of social processes and dynamics relating to issues like power and domination within communities. Holzemer *et al.* (2007a:541) therefore describe HIV stigma as a process activated or triggered by actions that lead to the labelling of people, whether by themselves or others, because they are HIV-positive. These authors developed a model that identified three types of stigma, namely received stigma, internal stigma and associated stigma, whilst exploring each of these types to the extent that it would crystallise the understanding of several dimensions of each type. Dlamini *et al.* (2009:396) also explore the phenomenon of (community) behaviour like verbal and physical abuse of PLWH. Individuals and communities alike seem to be confronted with challenges relating to individual and communal experiences, perceptions, values, culture, behaviour, attitudes, life choices and values like respect for self, others, life and even future generations.

Thus, for various reasons, the impact, effect and implications of HIV stigma significantly contribute to the complexities of the broader scope and management of HIV and AIDS and the fight against HIV and AIDS. Examples mentioned by different researchers relate to prevention strategies, wellness enhancement and sustainable positive health behaviour. Greeff *et al.* (2008a:318-321) found that stigma seems to limit PLWH’s access to support and it also seems

to be a powerful barrier that inhibits testing, disclosure of HIV status, access to anti-retroviral medication and even access to care services (Holzemer & Uys, 2004:165; Maughan-Brown, 2004:2-4; Skinner & Mfecane, 2004:161). Katz (Greeff *et al.*, 2008a:313) identifies avoidance behaviour, isolation and rejection, prejudice and discrimination as results of community stigmatisation. In the PURE-SA study, stigma has been found to be one of the main factors inhibiting positive health behaviour, with statistics showing that only 27.7% of 332 people who were newly diagnosed as being HIV positive and who were counselled and referred to local health clinics or hospitals, in fact visited a health care facility in the year following their diagnosis and post-test counselling (Kruger *et al.*, 2009:28). Another implication described by Uys *et al.* (2005:20) involves the socioeconomic impact of HIV and AIDS on the welfare of the total community, which could (in a more hopeful future) become indicators of change or improvement following an (effective) community-based stigma reduction and wellness enhancement intervention.

Kohi *et al.* (2006:408-411) emphasise six categories describing stigma in terms of the violation of human rights in five nominated African countries. These categories include (1) denial of health care or home care facilities for PLWH; (2) verbal and physical abuse, scolding and ridiculing of PLWH; (3) deprivation of food or deprivation of a chance to produce food; (4) denial of access to loans and denial of employment or income for PLWH; (5) rejection of PLWH in various ways; and (6) breach of confidentiality regarding peoples' HIV status. Naidoo *et al.* (2007:18) concur that stigmatisation could seriously impact on various facets of the stigmatised individual's life and that patterns of psychosocial well-being between urban and rural communities are complex and could differ.

The introduction so far has focused on HIV stigma and its impact on individuals and communities as well as stigma reduction within similar contexts. The focus will now shift to the context of wellness enhancement, as it forms part of the planned comprehensive community-based stigma reduction and wellness enhancement intervention. Wellness (enhancement) is described by Corbin (2002) and Baumgardner and Crothers (2010:18) as a subjective state of being relating to quality of life, life satisfaction, a sense of well-being, self-efficacy, the presence of positive affect and relative absence of negative affect. Concurring indicators of psychological

wellness mentioned by Wissing and Van Eeden (2002:32) refer to a sense of coherence, satisfaction with life and an affect-balance. The term “wellness enhancement” could possibly be expressed as the enhancement of “psychosocial well-being” in the context of linking the individual’s wellness with his/her socially related community wellness, whilst all these aspects seem critical for the context of a community-based HIV stigma reduction and wellness enhancement intervention. Psychosocial well-being will be unpacked in the following discussion and will be applied to different aspects of HIV stigma reduction and wellness enhancement for individuals and communities.

Keyes (2002:209) offers supportive thinking regarding psychosocial aspects of stigma and developed the Complete State Model of Health, which differentiates emotional, psychological and social well-being. He defines emotional well-being as representing intrapersonal feelings, psychological well-being as representing private and personal criteria of everyday functioning, and social well-being as epitomising the more public and social functioning criteria consisting of social coherence, social actualisation, social integration, social acceptance and social contribution. Keyes (2002:217; 2005:539) thus interprets psychosocial well-being as referring to private/personal criteria of daily functioning, intertwined with criteria of social functioning. It essentially means that behaviour operationalizes psychosocial well-being when individuals see themselves as thriving, or not, in their public and social lives (Keyes, 2005:542).

Fishbein and Ajzen (1975:336) indicate that behaviour, on the other hand, links with attitude. They describe it as an accumulation of information about an object, person, situation or experience and add that attitude becomes a predisposition leading to positive or negative behaviour or action towards a particular object, person, situation or experience. This relates to ways in which individuals and communities attribute meaning (predisposition/attitude) to the facts (accumulated information) regarding HIV or AIDS. It also relates to PLWH and their personal experiences and perceptions (internal stigma), the resulting enactment or behaviour (external stigma) of/or toward them as well as towards PLC associated with the PLWH (associated stigma) and their communities (Holzemer *et al.*, 2007a:541). The above insights connect behaviour (stigmatising and also health behaviour) with attitude or predisposition (stigma) that results in action or behaviour. Skinner and Mfecane (2004:158) describe the

process of, firstly, the development of feelings of superiority among those who are not affected by the stigmatising trait, and secondly, of the development of a feeling of shame in or towards those who are affected by the trait, and who are thus stigmatised. The attitude and behaviour demonstrated by individuals during stigma or stigmatisation are linked to discrimination, since it separates labels or categorises people.

The individual operates within a community context. Bakhtin (2007:5-7) expands “meaning attribution” (previous paragraph) as part of well-being and postulates that meaning is not pre-given, nor does it arise internally from within the individual. Rather, meaning is constructed actively and dialogically in our encounter with the other and emanates from the person’s encounter with his or her social world. He thus emphasises the notion of dialogue as an interchange of ideas between two equally responsive subjects and reminds of the influences of broader social and cultural factors on individual development. In addition, the traditional African perspective seems to position the individual and his/her well-being within a communal existence. Lundin and Nelson (2010:27) define ubuntu as a philosophy that considers the success of the group above that of the individual, since people exist because of their connection to the human community, which means that someone is a person through other human beings. Bakhtin, according to Mkhize (Ratele *et al.*, 2004:5-18), for instance argues that the individual’s health relates to a social context of *inter-individuality* where the small-group and broader collective forms of life mediate the broader psychosocial functioning. Psychosocial well-being is therefore more than *a good feeling inside some individuals*. It might be one of the keys to unlocking the power of individuals and communities with regard to community-based HIV stigma reduction.

Collective engagement by communities and the employment of innovative community-based processes (Bakhtin, 2007:5-7) could possibly ensure more effective HIV stigma reduction and more accurate deployment of limited and shared resources in Africa. Davids *et al.* (2009:160-162) discuss self-reliant participatory development that follows from an approach of building forums, structures and negotiations in which people throughout communities would be involved. Change (e.g. stigma reduction, wellness enhancement and health behaviour) would in this instance not involve the delivery of services to a passive citizenry, but would come from

within the individuals, groups and communities and would not be imposed from the outside. Winiarski (2004:36) noted that the practices leading to a rise in the HIV and AIDS epidemic often occur at community level, whilst most of the stigma reduction interventions in Sub-Saharan Africa to date were information-based awareness programmes aimed at reducing ignorance (Campbell *et al.*, 2005:404) on a more individual basis. Wong *et al.* (2009:220), for example, reported positive outcomes after individual disclosure of HIV status to others, namely behavioural changes regarding sexual activities, increased availability of social support from family and community members, recognisable spiritual resilience and more visible community involvement. Thomas *et al.* (2005:795) also reported that the experience of actual stigma could make individuals more determined to live and to experience an above-moderate quality of life: rise above stigma, avoid internalising their stigmatised feelings and work toward a better quality of life which would include psychosocial well-being. The HIV and AIDS burden does not end with the infected or gravely ill individual: it becomes the burden of society and the communities where the individual shares residence or work activities. Community-based approaches could thus be crucial for the success of future HIV stigma reduction and wellness enhancement interventions. Therefore, the measuring of the success of such programmes will be discussed below.

Accurate evaluation of the impact (change-over-time) of any intervention is important. In this study, change-over-time will be tested following a specific comprehensive community-based HIV stigma reduction and wellness enhancement programme in an urban and a rural area. The focus in change-over-time will be in terms of HIV stigma reduction, wellness enhancement and health behaviour. Holzemer and Uys (2004:172) noted that almost all research in this area lacked thorough empirical analysis and commented that very few studies measured stigma as such, or indicated how HIV stigma actually changed as a result of interventions. In addition, Nyblade (2006:337-339) reports that stigma reduction is central to most HIV and AIDS interventions across the spectrum of the prevention, care and treatment continuum and further emphasises the need for a wider variety of research which included a comprehensive set of measures to capture the complexity of HIV stigma and ensure appropriate evaluation of stigma reduction interventions. Brown *et al.* (2003:49) respond to remaining gaps relating to the scale or duration of impact after stigma reduction interventions and Nyblade (2006:335-

345) identify key gaps regarding the measuring of HIV stigma at the general population (community) level with regard to the cause of stigmatising behaviour, capturing of enacted stigma (discrimination), and distinguishing of compounded (layered) stigma.

Measuring/testing of change-over-time following an intervention is but one of the tools that will contribute to the bigger vision of HIV stigma reduction, and eventual eradication of stigma. The Holzemer and Uys (2004:172) review of published literature confirm the need for rigorous studies, empirical outcomes-based research and psychometric studies in terms of HIV stigma and stigma reduction, measurement of the better understanding and extent of stigma as well as the impact of stigma reduction interventions and measurable changes-over-time. Uys *et al.* (2009:1065) report on the evaluation of a health-setting based stigma intervention in five African countries and conclude that some change occurred in terms of measured decrease of HIV stigma and increase of self-esteem of PLWH, whilst the HIV testing behaviour of nurses increased significantly. Through the initial research subjects, further research needs were subsequently identified regarding randomisation, measuring of impact, changed health behaviour and broader community influence.

The proposed study will employ a quantitative measure of HIV stigma that was developed, tested and designed to measure perceived stigma, to create a baseline from which to measure change-over-time in stigma, and track potential progress towards reducing HIV stigma (Holzemer *et al.*, 2007b:1002). It would be helpful if change-over-time could be achieved through a comprehensive community-based approach in HIV stigma reduction. The study furthermore will track change-over-time in psychosocial well-being of PLWH and PLC and health behaviour of PLWH in particular. Polit and Beck (2008:81) support this, and articulate a number of salient aspects that would require more research, namely HIV and AIDS prevention and management; individuals and communities (particularly PLWH); the psychosocial well-being of individuals and communities (dialogism) and particularly PLWH and PLC; the health behaviour of PLWH; the interventions to address stigma; and the outcomes following an intervention.

Kohi *et al.* (2006:403), Genberg *et al.* (2007:772) and Mallory *et al.* (2007:359) cite examples of health behaviour and HIV prevention in different international settings that are influenced by HIV stigma. They all reiterate the value of measuring the extent to which HIV and AIDS stigma

and discrimination are barriers to prevention, voluntary counselling and testing uptake, accessing adequate health care in terms of adherence to HIV treatment and medication regimens and management of HIV and AIDS. Measuring of change-over-time is also needed for the establishment of effective interventions. In this regard Stein (2003:95) indicates that survey evidence exists to suggest that HIV or AIDS stigma has already diminished substantially over time both in South Africa and worldwide, but also admits that these surveys could be failing to effectively measure the changing face of HIV stigma. The results of the SANPAD research project, of which this study forms part of, under leadership of Prof. Minrie Greeff, contribute towards filling some of the gaps by providing scientific, empirical and collective leadership and resources.

Many Southern African health workers believe that HIV stigma is so powerful that unless this stigma is conquered, the scourge of HIV and AIDS will never be defeated (Holzemer & Uys, 2004:165). Developing countries, with South Africa in the forefront (UNAIDS, 2009), have made little progress in curbing the devastating AIDS pandemic. Visser *et al.* (2007:759) describe the effects of HIV stigma on the lives of HIV-infected persons as multidimensional and pervasive, which adds to the complexity of the overall management of HIV and AIDS. Stigma needs to be reduced drastically and sustainably, meaning that changes cannot be imposed on individuals and communities from the outside (Davids *et al.*, 2009:160). Duryea *et al.* (2007:26) argue that collective national and local community input and benefit should be engaged and new innovative processes and services should be initiated through interventions that will add value and make a significant impact in Africa's fight against HIV and AIDS. Sustained and sustainable change-over-time is needed for the establishment of strategic multilevel health promotion (Rütten *et al.*, 2000:35) in Africa. Few studies (if any) succeeded in measuring the scale or duration of impact following HIV stigma reduction interventions (Brown *et al.*, 2003:49; Nyblade, 2006:335-345; Holzemer & Uys, 2004:172).

Based on the paucity in research findings with regard to HIV stigma reduction and wellness enhancement of PLWH and PLC, this study will implement a comprehensive community-based HIV stigma reduction and wellness enhancement intervention, and then test change-over-time in HIV stigma reduction and aspects of wellness enhancement for both PLWH and PLC. It will

also address the existing gap in research with regards to the link between HIV stigma and compromising health behaviour of PLWH. The study will test the change-over-time in the HIV stigma experiences and concomitant health behaviour of PLWH after the comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and rural setting.

Research questions emanating from the literature overview and the problem statement are:

- Will there be urban-rural differences in the stigma experiences of PLWH and stigmatisation by PLC following the comprehensive community-based HIV stigma reduction and wellness enhancement intervention?
- Will the comprehensive community-based HIV stigma reduction and wellness enhancement intervention enhance psychosocial well-being for PLWH and PLC?
- Will the comprehensive community-based HIV stigma reduction intervention improve health behaviour of the PLWH?

2 Research objectives

This study forms part of the larger SANPAD-funded project “A comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and rural setting”. The focus of this study is on the quantitative measure as depicted in the objectives below.

The elected objectives for the research were as follows:

- To test the change-over-time in HIV stigma experiences of PLWH and stigmatization by PLC, after a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting.
- To test the change-over-time in psychosocial well-being of PLWH and PLC, following a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and a rural setting.

- To test the change-over-time in HIV health behaviour of PLWH, following a comprehensive community-based HIV stigma reduction.

3 The paradigmatic perspective

The paradigmatic perspective of this study includes meta-theoretical statements, theoretical statements, methodological assumptions and research hypotheses.

3.1 Meta-theoretical statements

My own philosophical paradigm was influenced by family, friends, educational and work/life experiences. My teens were conservative and my professional development as a nurse resonated with the Judaeo-Christian based philosophy of the Oral Roberts University Anna Vaughn School of Nursing (1990:136-142), which I later integrated into my own particular understanding of nursing as a spiritually sensitive nurturing interaction with people. I spent the last 15 years in the leadership of an NGO where I developed close collegial relationships with strong black leaders. This significantly changed my worldview since I learned during every day sharing and working together that Nsamenang (Duncan *et al.*, 2007:4-7) had a valid argument by regarding psychology in general as being based on the worldviews of the white middle class, to the exclusion of the worldviews and values of people in developing societies. The following statements briefly explore my personal meta-theoretical and subjective view of humanity, health and nursing.

3.1.1 Humanity

People are God-created physical-intellectual-spiritual beings, where the spiritual dimension includes the emotional and social aspects of humanity. The spiritual dimension could be further unpacked as meaning attribution, connectedness, transcendence, transformation and hopefulness (Chidrawi, 2000:132-134) and would be demonstrated in daily functioning through an on-going search for meaning, a multi-levelled connectedness, an ability to transcend beyond limitations and adversity, an ability to transform (change) if need be and an ability to sustain hope throughout life. I also humbly concur with Mkize (Duncan *et al.*, 2007:4-7) that a proper

understanding of a people should begin with an examination of the philosophies, languages and worldviews through which they experience the world and which continue to guide the lives of many people in traditional sectors of African society.

3.1.2 Health

Health is a dynamic state of physical-intellectual-spiritual integration, optimal personal functioning and continual multi-dimensional development and fitness. Development and fitness include exercising the body, developing intellectual strengths and practising the elements of spirituality, which includes psychosocial well-being as reflected in a multi-levelled connectedness that exists if people mutually become responsive to one another (Duncan *et al.*, 2007:4-23).

3.1.3 Nursing

Nursing is a profession with a specified scope of practice and ongoing responsibility to keep up to date with new developments in the field. It surpasses the boundaries of a job and finds innovative ways to respond proactively and reactively to people in need of care. Nursing is a dedicated, inspired and spiritually sensitive interaction with people whilst aiming to promote life, optimum health, respectful assistance, empathic support and skilful care. It advocates on behalf of patients whom cannot always accurately communicate their needs, pain or struggles to professionals or significant others.

3.2 Theoretical statements

The theoretical statements for this study comprise a central theoretical argument and conceptual definitions.

3.2.1 Central theoretical argument

HIV stigma is a powerful social phenomenon. Brown *et al.* (2003:49) tested a variety of interventions and reported that short-term and small-scale stigma reduction was achieved through some interventions, but that gaps still remain regarding larger scale stigma reduction as well as the duration of the impact of such interventions. On the other hand, certain positive

responses to stigma or stigmatisation have also been found by, among others, Thomas *et al.* (2005:795), who found it gave individuals a determination to rise above their circumstances and to improve their quality of life as a result of the stigma they experienced. Wong *et al.* (2009:220) also mention positive effects of empowerment for those who disclosed their HIV status to overcome the initial powerlessness caused by stigma and stigmatisation. It is within this context that the central argument for this study holds that sustainable change-over-time could be achieved if a comprehensive community-based intervention for HIV stigma reduction and wellness enhancement is effectively crafted and implemented.

3.2.2 Conceptual definitions

The core concepts HIV stigma, stigmatization, psychosocial well-being, HIV health behaviour, change-over-time and community-based will be significant in this study.

3.2.2.1 HIV stigma

Stigma is a powerful phenomenon that refers to the spoiled social identity of those with an attribute that deviates from attributes considered normal and acceptable by a particular society (Harvey, 2001:175). Initially, Holzemer and Uys (2004:166) suggested that stigma is best described in terms of an internal and external dimension, where the internal dimension relates to a stigma that can be “felt” (experienced/perceived) whilst the external dimension relates to behaviour where stigma can be “enacted” through actions of stigmatisation or stigmatising of self or others. A later study saw the development of a model by Holzemer *et al.* (2007a:541) that identified three types of stigma, namely received stigma, internal stigma and associated stigma. Stigma is further described as a phenomenon that can be activated or triggered by any actions that lead to the labelling of people, whether by themselves or by others, as being HIV-positive (Siyam’kela Report, 2003). Stigma is concisely defined by Alonzo and Reynolds (1995:503) as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people.

3.2.2.2 Psychosocial well-being

Baumgardner and Crothers (2010:18) generally relates wellness to a state of being that is subjective by nature and “can be defined in terms of quality of life, life satisfaction, a sense of well-being, the presence of positive affect and a relative absence of negative affect”. Wissing and Van Eeden (2002:32) similarly refer to “a sense of coherence, satisfaction with life and an affect-balance” as strong indicators of general psychological wellness. The above seem to relate mostly to the wellness of an individual. Keyes (2002:217) agrees, but also points out that aspects of daily activities and functioning, like decision making and behaviour refer to something called *psychosocial well-being*, which introduces the social context and inter-individuality, where the small group and the broader collective forms of life all relate to the individual’s health (Mkhize; *in* Ratele *et al.*, 2004:5-18).

Psychosocial well-being will, for the purpose of this study, refer to the optimal daily functioning of the individual within collective context. Personhood in the African thought is defined in relation to the community, and community then does not only mean a “mere collection of individuals each with a private set of preferences”. It refers to a sense of community that exists if people mutually recognise the obligation to be responsive to one another’s needs (Duncan *et al.*, 2007:4-23).

3.2.2.3 HIV health behaviour

HIV health behaviour refers to self-responsibility in issues like knowing one’s HIV status, making use of voluntary testing and counselling, accessing of care facilities, adherence to treatment regimens and decisions regarding male circumcision, sexual partners, disclosure of own status and prevention through condom use. Genberg *et al.* (2007:772) and Mallory *et al.* (2007:359) reiterate that HIV and AIDS stigma and discrimination are barriers to preventative health behaviour.

3.2.2.4 Change-over-time

Change-over-time refers to the measurable impact of the intervention. In this study it will refer to the sustained change caused by the HIV stigma reduction and wellness enhancement

intervention, but could possibly also be described in terms of social transformation. This, according to Prilleltenski and Nelson (Duncan *et al.*, 2007:2-3), refers to the initiatives that are aimed at helping to re-organise human relationships through challenging structures or relationships and changing the systems that represent injustice (which in this case could refer to HIV discrimination or stigma).

3.2.2.5 Community-based

The concept *community* refers to a sense of collective coherence that enables people to make sense of their collective social actions, social interactions and thought processes. Shared experiences among such people gathered in a community contribute to the creation of a common character (Thabane Ngonyama Ka Sigogo & Oscar Tso Modipa, *in* Duncan *et al.*, 2007:2-2) with a sense of collectivism as an underlying African assumption regarding community and well-being. This sense of collectivism is perceived as fostering social harmony and social continuity (Duncan *et al.*, 2007:2-8). An epidemic illness like HIV or AIDS has an impact on a total community and not on specific families or individuals only, which means that the involvement of the greater community is crucial (Uys *et al.*, 2005:20). It is in this context that the concept *community-based* is used, thus referring to action/interventions deeply based within a specific community and taking all community members into consideration.

3.3 Methodological statements

Botes (1995:1-22) describes her nursing research model as a holistic perspective of the overall research process. The model is based on three orders of research activities, namely a first order referring to the clinical practice of nursing; a second order referring to nursing research being conducted to contribute to the betterment of existing nursing knowledge and practice; and a third order giving consideration to the possible influence of the paradigmatic perspective of the researcher.

This three-order model of Botes (1995:6) demonstrates functional reasoning and will be applied in the current study on *change-over-time following a comprehensive community-based HIV stigma reduction and wellness enhancement intervention*. The three orders will be discussed in relation to the present study:

- HIV stigma could become apparent in everyday nursing practice (first order) if, for example, PLWH do not keep an HIV clinic appointment, discontinue their treatment regime or verbalise aspects of HIV stigma and stigmatisation. However, PLWH find themselves contextually linked to PLC and a community which could contribute to specific health behaviour through stigmatisation.
- Nursing research (second order) could broaden the existing knowledge base regarding aspects of HIV stigma and its influence on the nursing practice serving those particular PLWH and PLC. The second order, as it refers to research for the betterment of nursing practice, will in this study be a quantitative experimental research single system design with a pre-test and four repetitive post-test measures in one urban and one rural setting. This quantitative study will investigate aspects of HIV stigma and stigmatization. It will probe the possible change-over-time in the reduction of HIV stigma experiences in PLWH and stigmatization by PLC, the psychosocial well-being of PLWH and PLC as well as a possible change-over-time in the health behaviour of PLWH.
- The third order, according to Greeff (2010:207), relates to the paradigmatic approach of the researcher's basic philosophy. It includes theoretical and meta-theoretical statements, and the possible contributions of the research findings on the reduction of HIV stigma, the enhancement of psychosocial well-being and the improvement of health behaviour.

A brief contextualisation of positivism, post-positivism and pragmatism enriches the methodological argument for the envisaged study. De Vos *et al.* (2011:6), on the one hand, indicate that one of the inherent beliefs of positivism is that the methods and procedures of the natural sciences are appropriate to the social sciences. Post-positivism and pragmatism (Henderson, 2011:344), on the other hand, offer more flexible approaches to collecting data, like using more than one method. Pragmatism adds a methodology where the observed experience in practice could produce the basis of knowledge.

4 Research methodology

A quantitative research methodology will be used for this study, based on particular research questions that would be answered in terms of the statistical analysis of the specific measurement scales that have been documented.

4.1 Literature review

A literature review will contextualise the research and ensure sound theoretical grounding for the study. Apart from the traditional type of literature, the following databases will be used for the literature search in this research proposal: 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.

4.2 Research design

The quantitative study will be part of the bigger SANPAD “comprehensive community-based HIV stigma reduction and wellness enhancement intervention” project. An quantitative experimental single-system research design (De Vos *et al.*, 2005:137, 138, 145) with a pre-test and four repetitive post-test measures (01 x 02 03 04 05) will be used. This will involve one group in an urban setting and a similar group in a rural setting. The design will seek to quantitatively test change-over-time after a comprehensive community-based HIV stigma reduction and wellness enhancement intervention. The measuring instruments will test the reduction of HIV stigma experiences for PLWH and stigmatization by PLC, psychosocial well-being for PLWH and PLC and HIV health behaviour of PLWH.

4.3 Research method

The planned method, to test change-over-time after a comprehensive community-based HIV stigma reduction and wellness enhancement intervention, will make use of a test battery that will be used for the pre-test and repetitive post-test measuring.

4.3.1 Sample

Thorne (2008:88) indicates matters of representation, sample size and sampling procedures inherent to all research plans, and describes “sample” as the subset of a theoretical whole “population” that is intended to be located and engaged with since it might contribute to deeper insight regarding a certain phenomenon. This is significant in terms of the sample size of this study, which might seem small, but forms part of a bigger study endeavouring to truly reduce HIV stigma. It also makes allowance for both purposive sampling for PLWH and snowball sampling for the research aspect relating to PLC. Thus, the study will utilize a sample with two subsets, namely PLWH and PLC, which will be further described in terms of population, sampling and sample size.

4.3.1.1 Population

Geographically, the city of Potchefstroom, in the North West Province of South Africa, will be the urban focus of the study. The rural focus will be Ganyesa, also in the North West Province of South Africa. A research population, according to Burns and Grove (2005:40), offers all the elements that meet inclusion criteria in terms of a specific research interest. Potchefstroom and Ganyesa offer the required elements for the identification of PLWH and PLC in both urban and rural settings for this study.

4.3.1.2 Sampling

The PLWH in the sample are people living with the HI virus, who will be accessed through purposive voluntary sampling by existing community-based structures or key informants of the particular two urban and rural settings, and will form the first group. Such purposive voluntary sampling (Burns & Grove, 1997:306; Streubert & Carpenter, 1999:22) seems appropriate for accessing PLWH for this study. It allows for non-probability sampling theory, where the sampling is based on the judgement of the researcher (Strydom, in De Vos *et al.*, 2011:231-234) but, as Thorne (2008:90-91) indicates, it could also be described as “phenomenal” sampling in which the settings and specific individuals within them are recruited by virtue of some angle of the experience that might contribute towards a better understanding of such a phenomenon (e.g. HIV or AIDS). The importance of strategically planned sampling in purposive sampling is

emphasised by Thorne (2008:91), where main groupings or conditions that are needed as criteria for inclusion are identified and determined so that the eventual findings will seem reasonable to the intended audience. This will advance the progress of the study as it forms part of a bigger study and will apply repeated post-testing to minimise biases that can arise from innumerable sources, like complex human factors (Hartman *et al.*, 2002:26). Purposive sampling further refers to a process of strategic identification of “key informants” from the community who will be well equipped to provide access to what is happening in their community and possible reasons for why such happenings occur.

4.3.1.3 Criteria for inclusion of PLWH

PLWH who participate in this study, must be:

- Members of the Potchefstroom urban community or the Ganyesa rural community of the North West Province;
- literate individuals over 18 and conversant in Afrikaans or English or Setswana;
- HIV positive for a minimum of six months;
- willing to give informed consent for participation and the recording of participation in research;
- willing to participate in a workshop with a view to implement newly acquired skills in the “community” afterwards;
- willing to participate in HIV status disclosure workshops with other PLWH and PLC;
- willing/able to nominate (snowballing) PLC for research participation; and
- willing to undergo pre- and repetitive post-test measuring according to schedule and by standardised measures with documented validity and reliability.

The second group of the sample are the PLC to the PLWH. Snowball sampling identified the PLC groupings based on the nomination made by each of the PLWH. Snowball sampling involves approaching an individual (a single case) who is involved in the phenomenon to be investigated in order to gain information from similar persons (Strydom, in De Vos *et al.*, 2011:233). It could

be expected that there will not necessarily be a full grouping of each criteria. It nevertheless is planned to obtain six possible snowball groupings of PLC, namely partner/spouse, child (over 15 years of age), family member, close friend, spiritual leader and a community member of PLWH.

4.3.1.4 Criteria for inclusion as PLC

PLC who participate in this study, must be:

- Members of the Potchefstroom urban community or the rural Ganyesa community of the North West Province;
- literate individuals over 18 and conversant in Afrikaans or English or Setswana;
- willing to give informed consent for participation and the recording of participation in research;
- willing to undergo scheduled workshops with the particular PLWH group members;
- willing to participate in HIV status disclosure workshops;
- willing to undergo pre- and repetitive post-test measuring according to schedule and standardised measures with documented validity and reliability.

Preferably, PLC in this study will be any of the following:

- Married to/steady life partner of a participating PLWH for at least 6 months;
- a biological child over the age of 15 of a participating PLWH;
- a close family member of a participating PLWH (other than partner/spouse/child);
- a close friend (not family) of a participating PLWH for at least 6 months;
- involved as a traditional or church/religious leader of a participating PLWH; and
- a member of the same community as a participating PLWH, e.g. as a neighbour or a colleague at work, with regular contact with that PLWH for at least 6 months.

4.3.1.5 Sample size

For PLWH, twenty (20) PLWH will be included, of whom ten (10) PLWH will be from the Potchefstroom urban district and ten (10) PLWH from the rural Ganyesa district ($n = 20$). For PLC, a possible 120 (10 from each of the six groupings mentioned under sampling for both the urban and rural settings) will be included. Should a PLWH not have a member from the specific category, the size will accordingly be reduced.

4.3.2 Data collection

A “comprehensive community-based HIV stigma reduction and wellness enhancement intervention” will form part of the data collection enabling processes.

4.3.2.1 The intervention

The intervention will be adapted from the validated intervention manual of Uys *et al.* (2009:1059-1066) and will be based on the following three tenets:

- Sharing information on HIV stigma, personal strengths and coping to broaden knowledge and insight.
- Equalising the relationships between PLWH and PLC through increased interaction and contact amongst them.
- Empowering both groups towards leadership in HIV stigma reduction through knowledge and experience of project planning and implementation towards HIV stigma reduction.

4.3.2.2 Initial workshop for PLWH only

A two day lecture and activity-based workshop for PLWH (in urban Potchefstroom and rural Ganyesa) will focus on a personal understanding of HIV stigma, responsible disclosure management and personal wellness enhancement. These will be led by two facilitators (one HIV infected and one non-HIV infected person) in each group.

4.3.2.3 Workshops for PLWH and PLC together

The first two day workshop for PLWH will be followed by six workshops, where each of the PLWH will endeavour to get particular people living close to them (PLC) to accompany them. These workshops will again be led by two facilitators (one HIV infected and one non-HIV infected person) who will be a role model for a relationship of partnering and respect. The first of the six workshops will be for the PLWH who attended the first two-day workshop and who can now attend a workshop with their partners, if possible. The second will be for the PLWH to each attend with a child over 15 years of age. A third workshop will follow for the PLWH with a close family member; then a workshop where a close friend will accompany the PLWH; then a workshop for PLWH and their spiritual leaders; and lastly a workshop where a close community member should accompany them.

The six workshops attended by PLWH and their particular PLC will have a three day duration and will be lecture and activity based. The first day of the workshop will focus on understanding HIV stigma and how to cope with it, whilst day two will be on project planning/management, with a focus on leadership in the reduction of HIV stigma in the community. Each group will thus have a planned project that will focus on people in the community who are of the same designated group, like partners with partners, children with children, and other groups like close family members, close friends, spiritual leaders, colleagues or community members.

This will lead to six projects running in the urban Potchefstroom area and six projects in the Ganyesa rural area. These are planned to run for four weeks, whereupon a final one day follow-up workshop will be coordinated for the purpose of the PLWH and PLC presenting their projects. These will be evaluated by the researchers and prominent community members. The best projects in both the urban and rural settings will each receive a prize.

4.3.2.4 Pre-test post-test measures

The comprehensive community-based HIV stigma reduction and wellness enhancement intervention will be a fixed variable offering opportunities for quantitative research. Structured interviews with standardised measurement tools with documented validity and reliability will

be used to test change-over-time before and following the intervention with the Potchefstroom urban and Ganyesa rural PLWH and PLC.

A one group pre-test repetitive post-test design will be employed in the two sites. A pre-test and then four three-monthly post-tests will be conducted per group.

- Urban 01 X 02 03 04 05
- Rural 01 X 02 03 04 05

The pre-test of the quantitative data will be conducted at the onset of contact with the PLWH and PLC prior to the intervention and will employ instruments with documented validity and reliability (please refer to the three tables below). The test battery for PLWH as well as the test battery for PLC were compiled by the project leader, Prof. Minrie Greeff, for the SANPAD study (reference number: 09/15 (AUTHeR: 2011)).

Table 1: Ten (10) quantitative instruments for the PLWH test battery

Questionnaire	Items
Demographic survey (Holzemer <i>et al.</i> , 2007)	34
Perceived AIDS stigma instrument PLWA (HASI-P) English (Holzemer <i>et al.</i> , 2007)	33
Revised ACTG self-report adherence to medication measure (Dlamini <i>et al.</i> , 2009)	9
Revised self-care symptom management strategies (SSC-HIVrev) (Holzemer <i>et al.</i> , 2001) as a measure of health behaviour	74
HIV/AIDS-targeted quality of life instrument (HAT-QoL) (Holmes, 1999)	9
Mental Health Continuum Short Form (MHC-SF) (Keyes, 2006)	14
Coping self-efficacy scale (CSE) (Chesney <i>et al.</i> , 2006)	26
Patient health questionnaire (PHQ-9) (Kroenke <i>et al.</i> , 2001)	9
Spirituality well-being scale (SWBS) (Ellison & Smith, 1991)	20
Satisfaction with life scale (SWLS) (Diener <i>et al.</i> , 1985)	5
Total	233

Table 2: Seven (7) quantitative instruments for the PLC test battery

Questionnaire	Items
Demographic survey (Holzemer <i>et al.</i> , 2006)	34
AIDS related stigma measure (Maughan-Brown, 2004)	39
Mental Health Continuum Short Form (MHC-SF) (Keyes, 2006)	14
Coping self-efficacy scale (CSE) (Chesney <i>et al.</i> , 2006)	26
Patient health questionnaire (PHQ-9) (Kroenke <i>et al.</i> , 2001)	9
Spirituality well-being scale (SWBS) (Ellison & Smith, 1991)	20
Satisfaction with life scale (SWLS) (Diener <i>et al.</i> , 1985)	5
Total	147

These instruments will be discussed in terms of name, application, number of items, structure, reliability and validity. The above tables show that some will be used for PLWH, some for PLC and some for both groups (PLWH and PLC). The summary table below will reflect each instrument once only.

Table 3: Summary of test battery instruments for PLWH and PLC

Questionnaire (PLWH or PLC)	Items	Structure and Utilization	Reliability and Validity
Demographic survey (PLWH and PLC)	34	This questionnaire was used in the Africa HIV stigma study (Holzemer <i>et al.</i> , 2007b) and elicited data on demographics and illness. It included questions related to country, gender, age, education, marital status, work for pay, setting, years known HIV-positive, go to bed hungry at night, attended a support group in the past 3 months, and visited a clinic in the past 3 months (Dlamini <i>et al.</i> , 2009:379).	
Perceived AIDS stigma instrument	33	The instrument was developed by Holzemer <i>et al.</i> (2007b) for the measurement of stigma in PLWH. The stem for the instrument poses the	The Cronbach reliability coefficient

PLWA (HASI-P) English (PLWH only)		following question: "Please tell me how often it happened to you because of your HIV status." The rating scale is: 0¼ never, 1¼ once or twice, 2¼ several times, 3¼ most of the time. Dlamini <i>et al.</i> (2009:379) describes the HASI-P as an instrument containing 33 items that measure 6 aspects of HIV and AIDS-related stigma (verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion, workplace stigma). The instrument is scored by taking the mean of the total item score. The scale was validated with a sample of 1477 respondents from five African countries and according to Holzemer <i>et al.</i> (2007b) the stability was encouraging.	ranges from 0.76 to 0.90, and is 0.94 for the total scale (Holzemer <i>et al.</i> , (2007b).
AIDS related stigma measure (PLC only)	39	39 item scale (Maughan-Brown, 2004) for the measurement of community HIV stigma. Four indices were used to assess behaviour intentions, symbolic stigma, instrumental stigma and resource-based stigma. These four were combined to give a fifth index. A racial comparison amongst Africans, whites and coloureds was included with respondents between 15-23 years of age and 53% females and 47% males.	Factor analysis was used to test coherence and identified three different factors, namely behaviour, symbolic and instrumental stigma (Maughan-Brown, 2004).
Revised ACTG self-report adherence to medication measure (PLWH only)	9	The AIDS Clinical Trials Group's instrument (ACTG-Rev) initially consisted of 14 self-reported reasons for missing medications, such as wanted to avoid side effects, felt depressed, forgot. In 2006, Holzemer and colleagues reported on additional factor analyses conducted to reduce the ACTG-Rev to a 9-item instrument with a one-factor solution and Two scores are calculated from the revised 9-item scale as measure of health behaviour. Respondents rate how often in the past month they have missed their ARV medications for a particular reason, on a scale of	Cronbach reliability estimate of 0.96 for the total scale.

		1 to 4 (never too often). The resulting score ranges from 9 to 36, where higher scores mean the person missed more doses (Dlamini <i>et al.</i> , 2009:379).	
Revised self-care symptom management strategies (SSC-HIVrev) as measure of health behaviour. (PLWH only)	74	Holzemer <i>et al.</i> , (2001) refers to the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev). The SCC-HIVrev measures the intensity and frequency of 72 common signs and symptoms of HIV disease. The instrument includes 45 HIV related physical and psychological symptoms, 19 HIV related symptoms that do not cluster but may be clinically useful, and eight gynaecological symptoms for women. Only the 64 symptoms that are relevant to both males and females were used in this analysis. The HIV Sign & Symptom check-List (rev.) has been used extensively in Southern Africa (Dlamini <i>et al.</i> , 2009:379).	Reliability for the 45 HIV related physical and psycho-logical symptoms namely eleven factors. A total score of 0.76-0.91 emanated (Dlamini <i>et al.</i> , 2009:379).
HIV/AIDS-targeted quality of life instrument (HAT-QoL) (PLWH only)	9	Holmes and Shea (1999) developed this 9 item instrument to identify quality-of-life concerns of HIV positive individuals and to assess these concerns. Two studies were done with 42 (to generate content) and 201 (to identify fewer dimensions) respondents respectively. Study one subjects (76% male; 66% white; 55% gay/bisexual) identified concerns captured by 76 items. Factor analysis indicated that responses of study two subjects (78% male; 42% white; 55% gay/bisexual) could be summarised by nine dimensions. Conclusions: Five dimensions of the new HIV/AIDS-targeted quality of life instrument (overall function, disclosure worries, health worries, financial worries, and life satisfaction) exhibited good psychometric properties, including low ceiling/floor effects, good internal consistency (≥ 0.70), and evidence for construct validity (Holmes & Shea, 1999).	Multitrait/multi-item assessment indicated scaling success rates of $\geq 91\%$ for eight of nine dimensions. HIV mastery revealed 79%. Validity assessments indicated expected relationships for all dimensions (Holmes & Shea, 1999).

Mental Health Continuum Short Form (MHC-SF) (PLWH & PLC)	14	Keyes et al. (2008:181-192) developed this 14 items instrument measuring the presence of mental health described as flourishing, and the absence of mental health described as languishing. The scale was applied to 1050 Setswana-speaking adults in NW province of RSA (Lamers <i>et al.</i>, 2010:104). 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 2002). Findings revealed 20% were flourishing, 67.8% were moderately mentally healthy and 12.2% were languishing (Lamers <i>et al.</i>, 2010:106).	The internal reliability of the overall scale was 0.74. Factor analysis supported a hypothesis of 2 continuums for mental health (Keyes, 2006).
Coping self-efficacy scale (CSE) (PLWH & PLC)	26	Generalized Self-Efficacy Scale is a 26 item measure of one's confidence in performing coping behaviours when face with life challenges. The original 10-item scale aims to measured self-beliefs of 348 individuals to cope with a variety of difficult demands in life. In this later 26 item study, an additional item aiming to measure the stigma the person experiences was added (Chesney <i>et al.</i>, 2006:23).	The Cronbach reliability for the scale ranged from 0.80–0.91 (Uys <i>et al.</i>, 2009:1062).
Patient health questionnaire (PHQ-9) (PLWH & PLC)	9	The Patient Health Questionnaire (PHQ) assists with criteria-based diagnoses of depressive and other mental disorders commonly encountered in primary care. The diagnostic validity of the PHQ has recently been established in 2 studies involving 3,000 patients in 8 primary care clinics and 3,000 patients in 7 Obstetrics-gynecology clinics. At 9 items, the PHQ depression scale (which we call the PHQ-9) is half the length of other depression measures, has comparable sensitivity and specificity, and consists of the actual 9 criteria upon which the diagnosis of DSM-IV depressive disorders is based (Kroenke <i>et al.</i>, 2001:606-613).	The internal reliability of the PHQ-9 was excellent, with a Cronbach's of 0.89 in the PHQ Primary Care Study and 0.86 in the PHQ Ob-Gyn Study. Test-retest reliability of the PHQ-9 was also excellent (Kroenke <i>et al.</i>,

			2001: 606-613)
Spirituality well-being scale (SWBS) (PLWH & PLC)	20	Paloutzian & Ellison developed the scale in 1982 and then concurred that the scale was useful for research and as a global index of lack of well-being. Weaknesses like ceiling effects were found in evangelical samples where the typical respondent received the maximum score; thus, found the scale was not useful in distinguishing among individuals for purposes such as selection of spiritual leaders (Bufford <i>et al.</i> , 1991).	Test–retest and internal consistency reliability coefficients and descriptive data were confirmed by Paloutzian and Ellison, (1982).
Satisfaction with life scale (SWLS) (PLWH & PLC)	5	Pavot, Diener, Colvin, & Sandvik (1991:149) refers to one of their group members, Diener, that developed the scale 1985 as a measure of the judgemental component of subjective well-being mentioned that two studies were designed to validate the SWLS and used peer reports, a memory measure and clinical ratings as external criteria. The authors found it suited for use with a wide range of age groups and applications.	Pavot <i>et al.</i> , (1991:149) showed the SWLS as a valid reliable measure of life satisfaction.

4.3.3 Data Analysis

The Statistical Package for the Social Sciences (SPSS version 21) for Windows will be utilized for data analysis. Descriptive statistics of the outcome measures will be reported for each measurement period. Hierarchical linear modelling, taking into account the dependency on data collected from specific persons, will be used to examine *change-over-time* in the dependent variables (HIV stigma experiences, stigmatization, psychosocial well-being and HIV health behaviour) as well as the differences between urban and rural groups.

5 Ethical Considerations

Ethical permission for this SANPAD funded research component was obtained from the North West Provincial Department of Health, the School of Nursing Science as well as from the North-West University Faculty of Health Sciences Ethics Committee (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014).

A high standard of research will be a priority and continued supervision is envisaged. The bibliographical style of reference of Harvard as prescribed by the North-West University's guidelines for quoting sources (2012) will be used and the DENOSA (1998:1-7) guidelines for research will also be observed.

Participants' right to privacy, anonymity and confidentiality will be maintained by keeping documents linking names to data safely and securely locked up at all times. Names of participants will not be linked to the contents of data-capturing forms, except through the confidential code only known to the researcher and co-coder. This will also ensure limited access to the data. No kind of identity will be linked to collected data made available for analysis, which ensures anonymous reporting of data (Botma *et al.*, 2010:17-19).

The following procedures will demonstrate adherence to ethical considerations according to an analytical framework of the Belmont report (1979:1-40), which was an attempt to contain ethical challenges arising from research involving human subjects. A "notice of the Belmont report for public comment" discusses and concurs with the Belmont report (National Institutes of Health (NIH), 1979:1-11) on broader ethical concepts like the necessity for ethical principles and guidelines as well as the boundaries between practice and research. Three basic ethical principles are mentioned, namely respect for persons, beneficence and justice (1979:4-7) whilst the application of each of these ethical principles is demonstrated through activities that ensure informed consent, assessment of risk and benefits and ethically satisfactory selection of subjects (1979:7-10).

The application of the above-mentioned three basic ethical principles (Belmont Report, 1979:4-7) was developed as guidelines by Botma *et al.* (2010:17-23). The application of these guidelines in this study will be demonstrated in the following ways.

5.1 Respect for People

Added to the above, participants will receive written and verbal information on the comprehensive community based HIV stigma reduction and wellness enhancement intervention. A process ensuring participants' signing of informed consent will be in place prior to starting any data collection sessions. A preparatory workshop, including preparation of PLWH for possible disclosure of their HIV status, will be conducted.

5.2 Beneficence

The principle of beneficence is based on the understanding that a person has the right to be protected from harm and discomfort and should benefit from research if possible. It is about a risk/benefit ratio and could include benefits like gaining knowledge, enhancing personal worth or wellness or even receiving incentives like reduction of HIV stigma, acknowledging HIV status or changed relationships with people close to them as a result of being part of the study. Participants will also learn how to run a small project and experience aspects of evaluation of such a project.

5.3 Justice

Fair treatment will be ensured by explaining the objectives and processes of the study to participants prior to starting any data collection or the obtaining of their consent and cooperation. They will also be made aware that they could withdraw from the study at any time if they felt uncomfortable, embarrassed or violated in any way (Burns & Grove, 1997:200).

6 Summary

In the overview, a short review of the literature, the paradigmatic perspective and a detailed outlay of the planned research, was presented. A critical synthesis of the reviewed literature will feature in Section B.

7 References

- Aggleton, P. & Parker, R. 2002. A conceptual framework and basis for action: HIV/AIDS stigma and discrimination. Geneva: UNAIDS.
- Alonzo, A.A. & Reynolds, N.R. 1995. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social science & medicine*, 41(3):303-315.
- Anna Vaughn School of Nursing. (1990). Self-study report: Submitted to the Council of Baccalaureate and Higher Degree Programs, National League for Nursing for the Oral Roberts University. *Narrative by criteria*, 136-142. Tulsa, Oklahoma.
- Bakhtin, M. 2007. The dialogical imagination. Four essays by M. Holquist, *ed.* C. Emerson & M. Holquist, *Trans.* Austin, Tx: University of Texas Press. 444 p.
- Baumgardner, S.R. & Crothers, M.K. 2010. Positive psychology. London: Pearson. 338 p.
- Belmont Report see U.S. Department of Health, Education, and Welfare.
- Botes, A. 1995. 'n Model vir navorsing in verpleegkunde. Johannesburg: RAU. 22 p.
- Botma, Y., Greeff, M., Mulaudzi, F.M. & Wright, S.C.D. 2010. Research in health science. Pinelands: Cape Town. 370 p.
- Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS education and prevention*, 15(1):49-69.
- Bufford, R., Paloutzian, R. & Ellison, C. 1991. Norms for the Spiritual Well-Being Scale. *Journal of psychology and theology*, 19(1):56-70. PsycINFO, EBSCOhost, viewed 27 Nov. 2011.
- Burns, N. & Grove, S.K. 1997. The practice of nursing research: conduct, critique and utilization. 3rd ed. Philadelphia, Pa.: Saunders. 828 p.
- Burns, N. & Grove, S.K. 2005. The practice of nursing research: conduct, critique and utilization. 5th ed. St Louis, Mo.: Elsevier/Saunders. 780 p.

- Campbell, C., Foulis, C.A., Maimane, S. & Sibiya, Z. 2005. 'I have an evil child at my house': stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95:808-815.
- Chesney, M.A., Neilands, T.B., Chambers, D.B., Taylor, J.M. & Folkman, S. 2006. A validity and reliability study of the coping self-efficacy scale. *British journal of health psychology*, 11:421-437.
- Chidrawi, H.C. 2000. Die paraatheid van verpleegkundiges vir spiritueel-sensitiewe verpleging. Potchefstroom: Potchefstroomse Universiteit vir Christelike Hoër Onderwys. (Skripsie - MA (Psigiatrisiese Gemeenskapsverpleegkunde).) 195 p.
- Corbin, C.B. 2002. Definitions of wellness: dimensions of wellness. <http://www.definitionofwellness.com/wellness-resources.html>. Date of access: 26 Nov. 2011.
- Davids, I., Theron, F. & Maphunye, K. 2009. Participatory development in South Africa: a development management perspective. 2nd ed. Pretoria: Van Schaik Publishers. 252 p.
- De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. 2005. Research at grass roots: for the social sciences and human service professions. 3rd ed. Pretoria: Van Schaik Publishers. 471 p.
- De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. 2011. Research at grass roots: for the social sciences and human service professions. 4th ed. Pretoria: Van Schaik Publishers. 547 p.
- Denosa (Democratic Nurses Organization of South Africa). 1998. Ethical standards for nurse researchers. Pretoria: DENOSA.
- Diener, E., Emmons, R. A., Larsen, R. J. & Griffin, S. 1985. The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71–75.
- Dlamini, P.S., Wantland, D., Makoe, L.N., Chirwa, M., Kohi, T.W., Greeff, M., Naidoo, J., Mullan J., Uys, L.R. & Holzemer, W.L. 2009. HIV stigma and missed medications in HIV-positive people in five African countries. *Aids patient care and STDs*, 23(5):377-387.
- Duncan, N., Ratele, K., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. 2007. Self, community & psychology. 2nd ed. Lansdowne: UCT Press.

- Duryea, M., Hochman, M. & Parfitt, A. 2007. Measuring the impact of research. *Research global*: 8-9, 27, Feb.
- Ellison, C.W. & Smith, J. 1991. Toward an integrative measure of health and well-being. *Journal of Psychology and Theology*, 19, 35–48.
- Fishbein, M. & Ajzen, I. 1975. Belief, attitude, intention, and behavior: an introduction to theory and research. Reading, Mass.: Addison-Wesley. 578 p.
- Genberg, B.L., Kawichai, S., Chingono, A., Senday, M., Chariyalertsak, S., Konda, K.A. & Celentano, D.D. 2007. Assessing HIV/AIDS stigma and discrimination in developing countries. *Aids and behavior*, 12(5):772-780.
- Goffman, E. 1963. Stigma: notes on the management of spoiled identity. Englewood Cliffs, N.J.: Prentice Hall. 174 p.
- Greeff, M. 2010. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Potchefstroom: NWU. (Unpublished research proposal.) 12 p.
- Greeff, M. & Phetlhu, R. 2007. The meaning and effect of HIV/AIDS stigma for people living with AIDS and nurses involved in their care in the North West province, South Africa. *Curationis*, 39(2):12-23.
- Greeff, M., Phetlhu, R., Makoe, L.N., Dlamini, P.S., Holzemer, W.L., Naidoo, J.R., Kohi, T.W., Uys, L.R. & Chirwa, M.L. 2008a. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative health research*, 18(3):311-324.
- Hartman, J. M., Forsen, J. W., Wallace, M.S., & Neely, J.G. 2002. "Tutorials in Clinical Research: Part IV: Recognizing and Controlling Bias." *Laryngoscope* 112: 23-31. Web.
- Harvey, R.D. 2001. Individual differences in the phenomenological impact of social stigma. *Journal of social psychology*, 141(2):174-189.
- Henderson, K.A. 2011. Post-Positivism and the pragmatics of leisure research. *Leisure sciences: An interdisciplinary journal*, 33(4):2 341-346.

- Hilhorst, T., Van Liere, M.J., Ode, A.V. & De Koning, K. 2006. Impact of AIDS on rural livelihoods in Benue State, Nigeria. *Journal of social aspects of HIV/AIDS*, 3(1):382-393.
- Holmes, W.C. & Shea, J.A. 1999. HIV/AIDS-targeted quality of life instrument (HAT-QoL.) *Quality of life research*, 6(6):561-571.
- Holzemer, W.L., Hudson, A., Kirksey, K.M., Hamilton, M.J. & Bakken, S. 2001. The revised sign and symptom check-list for HIV (SSC-HIVrev). *Journal of the Association of Nurses in AIDS Care*, 12(5):60-70.
- Holzemer, W.L. & Uys, L.R. 2004. Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3):165-174.
- Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.Vv., Chirwa, M., Cuca, Y. & Naidoo, J. 2007a. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6):541-551.
- Holzemer, W.L., Uys, L.R., Chirwa, M.L., Greeff, M., Makoe, L.N., Kohi, T.W., Dlamini, P.S., Stewart, A.L., Mullan, J., Phetlhu, R.D., Wantland, D. & Durrheim, K. 2007b. Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). *AIDS care*, 19(8):1002-1012.
- Keyes, C.L.M. 2002. The mental health continuum: from languishing to flourishing in life. *Journal of health and social behavior*, 43(2):207-222.
- Keyes, C.L.M. 2006. If health matters: when will we stop saying one thing and doing another? Keynote address presented at the South African Conference on Positive Psychology: Individual, Social and Work Wellness, Potchefstroom, South Africa, 5 April. <http://www.puk.ac.za/opencms/export/PUK/html/fakulteite/gesond/psigsos/SAPPC/PreliminaryProgramme.pdf> Date of access: 20 Nov. 2013.
- Keyes, C.L.M., Wissing, M., Potgieter, J.P., Temane, M., Kruger, A., & Van Rooy, S. 2008. Evaluation of the Mental Health Continuum Short form (MHC-SF) in Setswana speaking South Africans. *Clinical Psychology and Psychotherapy*, 15, 181-192.

- Kohi, T.W., Makoe, L.N., Chirwa, M., Holzemer, W.L., Phetlhu, D.R. & Uys, L.R. 2006. HIV and AIDS stigma violates human rights in five African countries. *Nursing ethics*, 13(4):405-414.
- Kroenke, K., Spitzer, R.L. & Williams, J.B.W. 2001. The PHQ-9: Validity of a brief depression severity measure. *Journal of general internal medicine*, 16(9):606-613.
- Kruger, A., Greeff, M., Watson, M.J. & Fourie, C.M.T. 2009. Health care seeking behaviour of newly diagnosed HIV infected people from a rural and urban community in the North West Province of South Africa: the PURE-SA study. *Africa journal of nursing and midwifery*, 11(2):28-45.
- Lamers, S.M.A., Westerhof, G.J., Bohlmeijer, E.T., Ten Klooster, P.M., & Keyes, C.L.M. 2010. Evaluating the psychometric properties of the Mental Health Continuum---Short Form (MHC---SF). *Journal of Clinical Psychology*, 67, 99-110.
- Lundin, S. & Nelson, B. 2010. Ubuntu: the inspiring story about an African tradition of teamwork and collaboration. New York: Broadway Books. 133 p.
- Mallory, O., Johnson, T.B., Neilands, S.M., Dilworth, S.F., Morin, R.H., Chesney, R. & Chesney, M.A. 2007. The role of self-efficacy in HIV treatment adherence: validation of the HIV treatment adherence and self-efficacy scale (HIV-ASES). *Journal of behavioral medicine*, 30(5):359-370.
- Maughan-Brown, B. 2004. Measuring HIV/AIDS stigma. Cape Town: Centre for Social Science Research, University of Cape Town. (CSSR Working Paper No. 74.)
- Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *Medical journal of AIDS research*, 6(1):17-23.
- National Institutes of Health (NIH). 1979. Regulations and ethical guidelines: the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Pretoria: NIH.

Nyblade, L.C. 2006. Measuring HIV stigma: existing knowledge and gaps. *Psychology, health & medicine*, 11(3):335-345.

ORU (See Anna Vaughn School of Nursing).

Paloutzian, R. F., & Ellison, C.W. 1982. Loneliness, spiritual well-being, and quality of life. In L. A. Peplau & D. Perlman (Eds.), *Loneliness: A sourcebook of current theory, research and therapy*. New York: Wiley Interscience, 1982, 224-237.

Pavot, W., Diener, E., Colvin, C. & Sandvik, E. 1991. Further validation of the satisfaction with Life Scale: evidence for the cross-method convergence of well-being measures. *Journal of personality assessment*, 57(1):149-161.

Polit, D.F. & Beck, C.T. 2008. Nursing research: generating and assessing evidence for nursing practice. 8th Ed. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins. 796 p.

Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. 2004. Self, community & psychology. Cape Town: UCT Press.

Rütten, A., Von Lengerke, T., Abel, T., Kannas, L., Lüschen, G., Rodriguez Diaz, J.A., Vinck, J. & Van Der Zee, J. 2000. Policy, competence and participation: empirical evidence for a multilevel health promotion model. *Health promotion international*, 15(1):35-47.

Siyam'kela. 2003. HIV/AIDS stigma resource pack. The Policy Project. Pretoria: Centre for the Study of AIDS, University of Pretoria.

Skinner, D. & Mfecane, S. 2004. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of social aspects of HIV/AIDS*, 1(3):157-164.

Stein, J. 2003. HIV/AIDS: the latest dirty secret. *African journal of AIDS research*, 2(2):95-101.

Streubert, H.J., & Carpenter, D.R. (Eds.). 1999. Qualitative research in nursing. Advancing the humanistic imperative (2nd ed.). Philadelphia: Lippincott.

Thomas, B.E., Rehman, F., Suryananarayanan, D., Josephine, K., Dilip, M., Dorairaj, V.S. & Swaminathan, S. 2005. How stigmatizing is stigma in the life of people living with HIV: a study on HIV positive individuals from Chennai, South India. *AIDS care journal*, 17(7):795-801.

Thorne, S. 2008. Interpretive description. Left Coast, Calif.: Walnut Creek. 272 p.

UNAIDS. 2009. HIV related stigma and discrimination: a summary of recent literature. <http://www.unaids.org>. Date of access: 15 October 2011.

U.S. Department of Health, Education, and Welfare. 1979. The Belmont Report: ethical principles and guidelines for the protection of human subjects of research. Washington, D.C.: Department of Health, Education and Welfare. The National Commission for the Protection of Human Subjects of Biomedical & Behavioral Research. (DHEW Publication No. (OS) 78-0012.) 40 p.

Uys, L.R., Chirwa, M.L., Dlamini, P., Greeff, M., Kohi, T.W., Holzemer, W.L., Makoe, L.N., Dlamini, P.S., Naidoo, J.R. & Phletlhu, R. 2005. "Eating plastic", "winning the lotto", "joining the www": descriptions of HIV/AIDS in Africa. *Journal of the Associations of Nurses in AIDS Care*, 16(3):11-21.

Uys, L.R., Chirwa, M.L., Kohi, T.W., Greeff, M., Naidoo, J.R., Makoe, L.N., Dlamini, P.S., Durrheim, K., Cuca, Y. & Holzemer, W.L. 2009. Evaluation of a health setting-based intervention. *AIDS patient care and STDs*, 23(12):1059-1066.

Visser, M.J., Kershaw, T., Makin, J.D. & Forsyth, B.W.C. 2007. Development of parallel scales to measure HIV-related stigma. *Aids and behaviour*, 12(5):759-771.

Winiarski, M.G. 2004. Community-based counselling for people affected by HIV and AIDS. Cape Town: Longman. 153 p.

Wissing, M.P. & Van Eeden, C. 2002. Empirical clarification of the nature of psychological well-being. *South African journal of psychology*, 32(1):32-44.

Wong, L.H., Van Rooyen, H., Modiba, P., Richter, L., Gray, G., McIntyre, J.A., Schetter, C.D. & Coates, T. 2009. Test and tell: correlates and consequences of testing and disclosure of HIV

status in South Africa. (HTPN 043 project.) *Journal of Acquired Immunodeficiency Syndrome*, 50(2):215-222.

SECTION B: AN OVERVIEW OF LITERATURE

HIV STIGMA IN RELATION TO PSYCHOSOCIAL WELL-BEING, HEALTH BEHAVIOUR AND COMMUNITY-BASED HIV STIGMA REDUCTION INTERVENTIONS

“Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.”

(UN Secretary-General Ban Ki Moon, Washington Times, Aug 6th, 2008)

1. Introduction

Stigmas seem to be widely endorsed by the general public and can be viewed as phenomenal representation of the public's largely negative perceptions (Corrigan, 2000:48) about, and interactions with, persons or groups with stereotyped weaknesses. There are different viewpoints regarding the concept of stigma. Examples like 'apartheid' and the 'AIDS pandemic' demonstrate different aspects of stigma-related social, economic and political devastation. On the one hand, stigma is related to a concept like discrimination: for example, racism demonstrates a connection with deviance, power, beliefs and politics and the role of the racist and discriminatory behaviour (Link & Phelan, 2001:367). On the other hand, stigma focuses on those with a perceived weakness or less acceptable attribute (Sayce, 2003:628), like those infected with or even affected by the AIDS pandemic. Deacon (2006:424) argues that, although the UNAIDS Report (2004) bundled stigma, discrimination, fear, shame, ignorance and injustice on a worldwide scale all together, stigma would probably be better served if it were

conceptually narrowed down. Stigma is a feature of many chronic health problems and adds a hidden burden to an already heavy load of illness and vulnerability (Weiss *et al.*, 2006:277).

The conceptualisation of stigma thus seems complex and therefore requires special scientific focus. Link and Phelan (2001:365) point out that stigma is a multidisciplinary concern since it gripped the interest of psychologists, sociologists, anthropologists, political scientists and social geographers over a couple of decades. The Social Identity Theory, for example, has received considerable support over the years and seems to account for group behaviours like stigma since such behaviours derive from cognitive representations of the self in terms of group membership or a shared social category that demonstrates little or no psychological separation between self and the group as a whole (Yuki, 2003:166). Nyblade (2006:335) notes that HIV stigma is pervasive, hard to beat and prevalent in many communities and has actually become compounded, layered and complex in nature, which would require a good understanding of all related theories and issues if significant change were to be pursued. Ngozi *et al.* (2009:11) and Brown *et al.* (2003:49), on the other hand, concur that HIV stigma is still rife, although it has diminished over time and although a growing body of knowledge on HIV stigma contributed to stigma reduction. Holzemer *et al.* (2007:549) report on an HIV stigma study stretching over a six year period in five diverse African countries (Lesotho, Malawi, Swaziland, Tanzania and South Africa), where HIV stigma so significantly impacted on people living with HIV/AIDS (PLWH) that it culminated in the development of a conceptual model describing HIV stigma in an African context. Such a clarification and understanding of HIV stigma is important since this continent carries a serious burden of HIV infection and HIV stigma. And whilst Sub-Saharan African is known as a poverty-stricken area, five years ago already it was home to at least 20.0 million PLWH, placing a growing demand on resources and critically impacting on people's quality of life, their health care needs and access to adequate health care facilities (UNAIDS, 2007).

A more recent UNAIDS (2012:8) Global Report estimates that 34.0 million people were living with HIV at the end of 2011 but emphasises that Sub-Saharan Africa remains most severely affected, with nearly 1 in every 20 adults (4.9%) living with HIV and accounting for 69% of the people living with HIV (PLWH) worldwide. After Sub-Saharan Africa, the most heavily affected

regions are the Caribbean, Eastern Europe and Central Asia, where 1.0% of adults were living with HIV in 2011. The UNAIDS (2012:11) Global Report emphasises that whilst the comparison between 2001 and 2011 shows a 25% decrease in HIV infection, stigma, fear, ignorance and discrimination undoubtedly remain powerful (UNAIDS, 2012:78), with reports that 52% of PLWH in Zambia were verbally abused as a result of their HIV status, 21% PLWH in Nigeria were denied access to health services and 54% PLWH in Malaysia reported workplace discriminatory attitudes. Greeff *et al.* (2010:3) explored the relationship between stigma and quality of life and included a fascinating result in Chennai, India (Thomas *et al.*, 2005:795-801), where a group of just over two hundred PLWH reported that their fear of being stigmatised was greater than their actual experienced stigma.

This overview of the literature will firstly clarify the science philosophy, and will then explore the context, concept and process of HIV stigma, the possible urban and rural differences of stigma and the impact of HIV stigma on PLWH and PLC. Existing literature will furthermore provide insight regarding HIV stigma, the concept of psychosocial well-being and the psychosocial well-being of PLWH and PLC. It will explore different aspects of health behaviour relating to HIV stigma, appropriate health behaviour change models and theories and will in conclusion explore various HIV stigma reduction and wellness enhancement interventions in a community-based context.

2. Science philosophy of the study

Gerbi *et al.* (2012:8) point out the necessity of cross-disciplinary research into critical aspects of HIV and AIDS worldwide, since until now no discipline on its own could significantly diminish HIV stigma or the AIDS pandemic. It seems to have challenged and in some instances even to have surpassed the current body of knowledge, competence and effort to slow down and manage the pandemic and its potential societal devastation. This is true for both the natural and social sciences, as PlusNews (2012) reported on a group of scientists who received funding to break down *alone standing silos* of scientific disciplines and to unify efforts to create an AIDS vaccine. The report refers to a new generation of integration between the sciences which has

become a necessity since silo approaches have come up short on answers to HIV, AIDS and HIV stigma (PlusNews, 2012). The Harvard Mental Health Letter (July, 2010) suggests the employment of trans-disciplinary work and a combination of psychological, social and moral models to investigate HIV stigma. The point is not that scientists should have a common philosophy, but rather to understand that scientists philosophise through reflection on principles and activity of their discipline and that philosophy is inescapable in good science, which in turn simply is a detailed study of natural fact (Matthews, 2008:6). Attention should thus be given to some of the worldviews underpinning theoretical models and approaches aimed at influencing HIV stigma and steering this research. The subsequent discussion will firstly explore world view as a concept and will then highlight a consciousness of the implications of different science philosophies for this research.

2.1 World view as a concept

World view as a construct refers to the fundamental organisation of the mind, which Guba (1990: 17) defines as a basic set of beliefs that guides action. Cobern (1991:3) similarly describes it as an organised set of fundamental, cognitive presuppositions about reality. A world view is a culturally dependent, interpretive structure. By definition, a world view is a highly stable structure that nevertheless has an adaptive function which could accommodate change and evolution. Olthuis (1989:2-3) describes a world view as a framework or a set of fundamental beliefs through which we view the world. He argues that this is not limited to an individual and that such a vision can be collective in its scope and structure whilst it functions descriptively as well as normatively. It describes the norm of how the world ought to be and guides the way the holder of the world view lives his/her life. Olthuis (1989:5) points out that a world view shapes itself to the world but is constantly confronted by the demands of life in its entirety. He argues that human action is affected by the perceptions or world views held by particular individuals or groups; and conflicts in life, science and culture are often fuelled by differences in underlying world views or paradigms (Olthuis, 1989:1).

2.2 Implications of different science philosophies for the present research

Nursing research started establishing itself during the first half or the 20th century and was initially dominated by quantitative inquiry, the medical model and its associated positivist philosophy (Clark, 1998:1244-1245; Hope & Waterman, 2003:121) which, in the main, denied the importance of subjective, social, spiritual and interpretative aspects of the person, their relationships and psychosomatics. The basic assumptions of positivism, according to Henderson (2011:341), remain that truth is an independent part of a whole; theory should be deductive and a priori; rational cause and effect is possible; and scientific research is objective and value free. It seems, though, as if the shift to a more post-positivistic philosophy and qualitative inquiry now underpins contemporary empirical research activity. Science – according to Clark (1998:1246), Henderson (2011:341), Hope & Waterman (2003:123) – still requires precision, logical reasoning, interpretivism and attention to evidence but is not confined to that which could be directly perceived. Pure or strict positivism as reflected in true quantitative experiments rarely serves a profession like nursing research the best. Instead, pragmatism is starting to play a role in advancing scientific knowledge plainly through suggesting that an ideology or approach is true if it contributes to practical benefits and/or solutions to problems. Henderson (2011:342), Ryan (2006:12) and Stewart and Floyd (2004:445) explain that post-positivism provides another paradigm that can broaden the perspective of positivism so that it can examine real world problems in a more encompassing way. Post-positivism emphasises meanings and explicate social concerns by bringing together theory and practice whilst acknowledging the researcher's motivations and commitment to a topic and also recognising that many *correct* techniques and mixed methods can be applied to collecting and analyse data.

Pearce (2012:832) stated that throughout the late 20th century, a handful of sociologists have made strong arguments to reconsider the polemic frame of qualitative versus quantitative research, starting with Sieber (1973:1335-1359); and then Bryman (1984:75-92), Denzin (1989:7-18) and Smith (1991:1-17). With the explosion of interest in mixed method research, researchers began articulating further problems with dividing the world of research into qualitative and quantitative sides (Axinn & Pearce, 2006:1-27; Hanson, 2008:97-111). This rethinking of the epistemology that underpins our research choices (in a variety of fields) gave

rise to a third paradigm often called the 'pragmatic approach' (Creswell, 2003:3-14; Morgan, 2007:48-76). Morgan (2007:48-76) articulately outlines this middle ground where the seemingly deterministic ways of positivism and the over-deconstruction of the metaphysical approach are balanced. Lieberman (1992:1-15) argues for better attention to the probabilistic nature of human or social behaviour instead of deterministic language and hypotheses or the abandonment of quantitative analyses. The qualitative or constructivist paradigm, the quantitative or positivist paradigm and the newly developing pragmatic paradigm are currently the three most prominent paradigms of research. Pearce (2012:831) describes pragmatism as the epistemological base of mixed method research and promotes the merits of a variety of theoretical and methodological approaches. Although research designs are perhaps expected to be perfect, they are influenced by the researcher's methodological training in various methods, the proclivities of journal audiences, book reviewers and even funders. Morgan (2007:48-76) and Hanson (2008:97-111) argue for a pragmatic approach that suggests a type of abduction which complements the constant dialectic between inductive (qualitative) and deductive (quantitative) theoretical development and it also suggests an inter-subjectivity where pure objectivity is pursued within a reflexive recognition of subjectivity (Axinn & Pearce, 2006:1-27; Hanson, 2008:97-111) like the influence of actions, understandings, interpretations of a researcher, and the people and settings being studied. Niglas (2001:1) remarks that pragmatists do not agree that the connection between paradigms and methodology, and even paradigms itself, exists in such clear-cut fashion, as they rather accept a mutual influence and integration of different viewpoints.

A method of choice in nursing, namely Action Research, seems to link with the more traditional qualitative and quantitative approaches as such. Hope and Waterman (2003:120-126) refer to pragmatism as action research that offers the potential to enhance validity issues, go beyond the specific methods employed and even add value to the research since it addresses issues of power, participation and ethics that could add value to the work of qualitative researchers. Lewin (1958:10) coined the phrase 'there is no research without action and there is no action without research' and refers to Action Research as a reflective process of progressive problem solving led by individuals working with others in teams or as part of a community of practice to improve the way they address issues and solve problems. It aims at building the capacity of

individuals or organisations to move beyond current conditions and practice. The paradigmatic approach clarifies tension between earlier paradigms by giving recognition to all forms of data (Lincoln & Guba, 1985; Morgan, 2007) as being transferrable or leading to discoveries and the possible broadened development of theory. Pearce (2012:843) observes that it makes good research sense to combine methods of research and to draw on reported examples through time to continually improve our research designs and collaborations. The research field will continue to benefit from a cooperative approach that values all methods and evaluates them in their own right. The pragmatic approach will hopefully be enhanced to a holistic research process to which any researcher can contribute through either mono- or multi-method projects that all contribute towards the accumulation and interpretation of empirical evidence. This study, seeking clarity on change-over-time after a comprehensive community-based HIV-stigma reduction and wellness enhancement intervention and embedded in a larger mixed method design, seems to utilise a dialectic perspective with more than one paradigm (Creswell, 2003:14). It seems to move from a quantitative post-positivistic paradigm with a quasi-experimental design, linked with pragmatism in the planned intervention, and dealing with (health) behavioural consequences as well as the real-world practice related to HIV stigma and stigmatisation and even a problem-solving approach, through to constructivism for theory generation. A brief outline, adapted from various researchers in recent literature, could help to clarify current paradigms, research methodologies and examples of data collection methods. The outline in Table 4 presents the positivistic, post-positivistic, constructivist, interpretivist, transformative, participatory and pragmatist world views.

Table 4: An overview of paradigms, research methodologies and data collection methods

WORLD VIEW OR PARADIGM				
Positivist/ Post-positivist	Constructivist/ Interpretivist	Transformative	Participatory	Pragmatist
Experimental Quasi-experiment Correlation Reductionism	Naturalistic Phenomenological Hermeneutic Interpretivist Ethnographic	Critical theory Neo-Marxist Feminist Critical race theory	Political Empowerment issue orientated Collaborative	Consequences of actions Problem-centred Pluralistic Real-world

Theory verification Causal Comparative Determination Normative	Multiple participant meanings Social/historical construction Theory generation Symbolic interaction	Freirean Participatory Emancipatory Advocacy Grand narrative Empowerment issue orientated Change orientated Interventionist Queer theory Race specific Political	Change orientated (the participatory paradigm can also be categorised under the transformative paradigm)	practice Mixed models
PRIME METHODS OF PARTICULAR WORLDVIEW OR PARADIGM				
Mostly quantitative Not only	Mostly qualitative Not only	Qualitative Quantitative Mixed methods	Qualitative Quantitative Mixed methods	Either qualitative or quantitative matching purpose
DATA COLLECTION METHODS (EXAMPLES)				
Experiments Quasi-experiment Tests Scales	Interviews Observations Document reviews Visual data analysis	Diverse range of tools – particular focus on diverse participants	Diverse range of tools – particular focus on diverse participants	May include tools from positivist/interpretivist; e.g. interviews, observation, testing and experiments

Adapted and combined from Mackenzie and Knipe (2006:5-6); Mertens (2005:9) and Creswell (2003:13).

Below, the concept of HIV stigma and the impact of HIV stigma will be discussed, against the background of the science philosophy employed in recent and current literature.

3. Conceptualisation, contextualisation and impact of HIV stigma

The observed increase in HIV and AIDS stigma over the years indicates the complexity of the phenomenon and its insidious power to provoke intense value-laden reactions like fear, negativity and judgmental attitudes that pose barriers to prevention strategies (Valdiserri,

2002:341). In social psychology, stigma is described as a product of possessing an attribute that conveys a negatively valued identity comprising personal and social components of the self-concept of members of stigmatised groups (Ashburn-Nardo, 2010:508-509). South Africa's Justice Edwin Cameron made headlines around the world in 1999 when he publicly declared his HIV-positive status. Ashburn-Nardo (2010:510) explains that stigmatised individuals are certainly aware of public perceptions of their group. In an interview with Patricia Kahn, Cameron mentioned that he was encouraged by the fact that the AIDS activist movement was well structured and well organised in South Africa as it followed in the footsteps of the anti-apartheid resistance movement which set an excellent example. He added, though, that HIV stigma was significantly high outside of these activist circles and as such posed a complex challenge for the authorities to address critical issues like toxicity, monitoring of infection rates, access to care, availability of treatment and even compliance (Cameron, 2005:294-295). Progressing from this position Deacon (2006:419) suggests that HIV or AIDS provides case study material for reviewing the theoretical understanding of health-related stigma and the resulting complexities in a relation between stigma and existing forms of prejudice, disadvantage, discrimination and various types of responses to a stigmatised illness like HIV infection. Herek *et al.* (2013:51) conclude that the harm done by HIV stigma will require structural as well as individual interventions. Below, a deeper understanding of the concept of HIV stigma will be sought.

3.1 Conceptualisation of HIV stigma

The concept of HIV stigma involves the complex effect of HIV infection. Cross *et al.* (2012a:63) argue that the treatment for the disease will always be incomplete if such stigma is not essentially and effectively addressed. Thornicroft *et al.* (2008:15) identify ignorance, prejudice and discrimination as the three pillar-like elements of stigma, referring to problems of knowledge, problems of attitude and problems of behaviour. The slogan for the 2003 World AIDS day celebrations focused on the fact that 'everybody has an HIV status' and the sub-slogan asked whether STIGMA in fact kept many people from knowing theirs (www.heart-intl.net/HEART/010105/everyonehasanHIV.htm). Holm-Hansen (2009:1-2) argues that stigma often is more subtle than overt, and that it results in attitudes and beliefs that lead individuals

to internalise feelings of shame and embarrassment. Goffman (1963:103-108) has found that stigma results in ambivalence within an individual who becomes aware of a particular social identity that has been added to their usual personal identity. In the next section, HIV stigma as a phenomenon and the models and types of HIV stigma will be discussed.

3.1.1 The phenomenon of HIV stigma

Stigma is not a new phenomenon in public health and also not unique to HIV. The history of illnesses like leprosy, epilepsy and cholera provides an abundance of examples of prejudice, discounting, discrediting and discrimination (Valdiserri, 2002:341). Literature contributes to the conceptualisation of HIV stigma and whilst pioneers like Goffman (1963) endeavoured to accurately define the phenomenon, others added contributions over the last five decades in terms of a continuous debate on the usefulness of the HIV stigma concept as such (Link *et al.*, 2004:512). Attell (2013:5-6) points out a void in literature, since it describes the prevalence and implications of HIV stigma but is almost silent on the origin and definition of the phenomenon; and because literature is inclined to focus on the dichotomy between those who are infected and those who are not, which in itself perpetuates stigma. Searching for a definition of HIV stigma in literature, though, often starts with the primal work where stigma was understood as a spoiled social identity of those with an attribute that deviates from attributes considered normal and acceptable by their particular communities. Goffman (1963:3) defines it as an attribute that is deeply discrediting and as such reduces the bearer from a normal whole person to a tainted, discounted one that might be trying to (still) interact normally in society but now carries a social identity of deviance (Goffman, 1963:130). Alonzo and Reynolds (1995:305) liken stigma to a powerful tainting social mark or label that discredits an individual and radically changes the way individuals view themselves and are viewed by others. Bryan (2000:65), Harvey (2001:175) and Nyblade (2006:336) concur with the concept of social tainting and the Harvard Mental Health Letter (2010) observes that if HIV is seen as such a discrediting attribute or label, HIV-infected people will be dealt with in terms of the consequences of such a social discrediting label and the associated prejudices. Van Brakel (2006:307), Molero *et al.* (2011:609) and Link *et al.* (2004:511) relate HIV stigma to the older and more familiar stigmas linked to various other chronic health and mental health conditions, and in particular to mental

illnesses, 'deviant' social conduct and 'different' cultural belief systems. These authors (Van Brakel, 2006:307; Molero *et al.*, 2011:609; Link *et al.*, 2004:511) all refer to the existence of stigma for those with schizophrenia, leprosy, tuberculosis, epilepsy, cancer, AIDS and labelled groupings like foreigners, immigrants, homosexuals, the poor, criminals and even some racial, political or religious groupings.

As part of the quest for a more precise definition of HIV stigma, Sayce (1998:331) started another debate in the 1990s, urging that a specific descriptive term or phrase should be found which could powerfully express a public mood of disapproval for a so-called perceived weakness or unacceptable attribute like homosexuality or some health challenges. Deacon *et al.* (2005:IX), in an official document of the South African HSRC, emphasises the quest for new terminology since the term *stigma* has become so all-inclusive and vague that it had become a type of easy excuse for the public's disinterest in finding an appropriate response to issues like HIV and AIDS health campaigns and the efforts of ensuring access to employment, treatment, care, testing and a reasonable quality of life for PLWH. The powerful term or concept that is sought, should serve the purpose of breaking down the general participation in and tolerance of HIV stigma and bring it more in line with something like racism, which has become a disapproved act of discrimination. According to Deacon *et al.* (2005:IX), powerful terminology could perhaps also motivate mobilised and collective action against stigma rather than harbouring tendencies of condoning marginalisation by one group and leaving the stigmatised individuals and groups (like the PLWH and PLC) to internalise the stigma or to be exposed to stigma-induced suffering or even discrimination. Deacon and Stephney (2007:5) and Yang and Kleinman (2008:399) agree that the term *stigma* is overused and that much of the research on HIV stigma has conflated stigmatising beliefs within itself, like unjustified negative beliefs about others, which involve moral judgement and the internalising of stigma that give rise to stigmatising or discriminatory behaviour by others. Herek *et al.* (2013:41) refer to HIV stigma as a socially constructed undesired differentness that disempowers the stigmatised people through ostracism, discrimination and other stigma enactments.

The function of stigma thus is to reinforce social norms by defining deviance (Taylor, 2001:792). Stigmatisation, if seen in this way, becomes an exercise of power over people and possibly even

a means of social control by marginalising or excluding some people or groups from the wider community, and so reinforcing societal likes and values (Gilmore & Somerville, 1994:1342). It is along these lines that knowledge regarding the meaning or definition of stigma, on its own, proves to be insufficient for effective management of the stigma phenomenon, and especially the HIV stigma. Link and Phelan (2001:378) suggest further exploration towards a better understanding of relevant social pressures that actually allow one group's views to dominate, so as to produce consequences for another group. Literature offers diverse views regarding a link between stigma and acts of discrimination and it is significant that wars and freedom struggles were historically based on discrimination, prejudice and intolerance. As mentioned above, the very function of stigma is to identify and act on perceived weaknesses and contemporary society is often based upon power imbalances, discrimination and prejudice (Molero *et al.*, 2011:609). Labelling groups of people like foreigners, homosexuals, drug addicts, prostitutes, whites, blacks, workers, the illiterate, people with leprosy, epilepsy or mental illness, people with TB, HIV or AIDS tends to create and maintain a 'them and us' stigmatising and discriminatory social phenomenon (Molero *et al.*, 2011:609). A conceptual framework for HIV stigma developed by Mahajan *et al.* (2008:19) maintains that the inequalities in social, political and economic power are the foundation on which stigmatisation is promulgated and also that structural violence and pre-existing stigmas potentiate the power of stigmatisers and enable even more intense stigmatisation and discrimination.

In contrast, Deacon and Stephney (2007:5) argue on strength of their extended literature review that stigma and discrimination are not inextricably connected; that all stigmatising beliefs do not necessarily result in discrimination; and that all discrimination is not always due to stigma. They further argue in terms of HIV (stigma) that marginalised people, even without stigmatisation, would be more likely to contract HIV and become PLWH since the pandemic itself exacerbates existing inequalities. Schmitt and Branscombe (2002:168) also point out that prejudice and discrimination are intergroup power phenomena that control passage, acceptance and positioning in social structures to the point where people often consciously choose to attempt to pass as members of the other (privileged) group. In particular those with 'invisible stigmas' like PLWH who have not disclosed and even publicly deny their sero-status, do so in order to fit into a different or more privileged group or existing social structure which

they feel would be to their advantage (Schmitt & Branscombe, 2002:174). Boyd *et al.* (2010:1064) and Link *et al.* (2004:512-513) each add a range of facets ranging from emotional aspects, such as blame, anger, embarrassment, shame, fear, alienation and sympathy, to cognitive aspects such as perceived persistence and perceived seriousness, to behavioural aspects such as social distance ('us and them' sentiments) and reproductive restriction. HIV stigma is like a social process in which HIV and AIDS are preventable, HIV-causing behaviour identifiable and possible to associate with other people that could be blamed for the infection and should therefore be socially controlled and even be disadvantaged (Deacon, 2006:420-421).

The terms *prejudice* and *discrimination* thus seem to be linked to HIV stigma and add a specific focus area to the general stigma discussion and necessitate further mechanisms for dealing with it in terms of HIV, PLWH and PLC. Sayce's (1998:2) view that the HIV stigma concept might not be the most useful conceptual framework and that it does not provide a rallying point for collective strategies to improve access or challenge prejudice based on an argument that HIV stigma, is basically stigmatising within itself since it implies that there is something wrong with the individual(s) in concern, like PLWH. Discrimination, on the other hand, puts the onus of 'something wrong' on those individuals and groups that are practising the stigmatisation. Link *et al.* (2004:512) mention cognitive and behavioural aspects on the part of both 'stigmatiser' and the stigmatised and Kohi *et al.* (2006:408-411) emphasise six example categories which place HIV stigma directly in the context of active discriminatory violation of human rights. These categories include denial of health care or home care facilities for PLWH; verbal and physical abuse of PLWH and PLC; scolding and ridiculing of PLWH; food deprivation or deprivation of an opportunity to produce food; denial of loans or finance options; denial of employment and related income for PLWH; rejection of PLWH in leadership and various other ways; and breach of confidentiality regarding their HIV status (Kohi *et al.*, 2006:408-411). Corrigan (2004:114) furthermore explains HIV stigma in terms of stereotyping, followed by four similar behaviour patterns (categories) of prejudice and discrimination towards PLWH and PLC and where HIV stigma would manifest in the form of withholding help, avoidance of the stigmatised, segregation and coercion. Link *et al.* (2004:512-513) add similar types categories of

stigmatising and unjust behaviour, like labelling, stereotyping, separation, breaking down of status and other acts of discrimination.

Van Brakel (2006:307) identifies five categories within the manifestation or operationalisation of HIV stigma, namely the experience of being 'affected'; the experience of actual discrimination or participation in restrictions and demonstrated attitudes; perceived felt stigma (self or internalised); discriminatory and stigmatising practices in health services or legislation; and the messaging of publishing media and educational campaigns and materials. Stutterheim *et al.* (2009:2354) measure eleven manifestations of HIV stigma, namely increased physical distance, awkward social interaction, indifference, avoidance, blaming, exaggerated kindness, aggression, exclusion, excessive hygienic measures, being told to disclose one's status and being told to conceal one's status. Almost two decades ago Sayce (1998:1) already described stigma in terms of its operationalising intent of unfair treatment and the socio-economic exclusion patterns, suggesting that the attribution or a mark of shame should reside with those who behave in stigmatising unjust ways rather than with the traditionally stigmatised, like the PLWH.

The work of Link and Phelan (2001:375, 379) add a further dimension to the above discussion on discriminatory behaviour by describing HIV stigma as a persistent predicament that is dependent on power and power-driven relations. Parker and Aggleton (*in* Holzemer *et al.*, 2007a:543) also conclude that stigma is dependent on social, economic or political power dynamics and thus suggest that all stigma models should include attention to power differences and the use or abuse of power. Lee (2005:1) supports this view, arguing that HIV is a health and development issue linked to gender inequality and violence against women and professes that power relations are at the heart of the HIV pandemic that disproportionately affects women and young girls. A quantitative study by Stutterheim *et al.* (2009:2354) also found that stigmatising reactions to PLWH manifest across a range of social settings like friends, family, partners, the health care sector, work and leisure activities and that these stigma experiences were most strongly related to psychological distress. Chirwa *et al.* (2009:20) for instance point out that a predictable amount of job dissatisfaction among nurses in five African countries could be ascribed to HIV stigma experiences and outcomes. Ramirez-Valles (2005:101-102), by

way of illustration, mention that stigma concerning homosexuality can have serious consequences for many gay men, and can become more severe with added labels, like belonging to an ethnic minority or being HIV positive. With more reference to power imbalances, stigma exists when labelling, stereotyping, separation/status loss and discrimination in the setting of power imbalance converge (Mahajan et al. 2010:19).

3.1.2 Models and types of HIV stigma

The models and types of HIV stigma as such have been studied by various researchers. Although a number of these scientists tried to define stigma, explore its correlates and endeavoured to measure it, Greeff *et al.* (2010:2) explain that there was not always clarity on or clear distinctions between different aspects, causes, behaviours and even outcomes of HIV stigma. Holzemer and Uys (2004:166), along with Skinner and Mfecane (2004:161), suggest that stigma has two dimensions that manifest in society respectively as internal 'felt' stigma and external stigma, like stigmatising actions towards others. Stigma thus boils down to an internal and external experience of debilitating shame or fear on grounds of a (visible or invisible) weakness of an individual or group which in many cases supersede the most extreme of health symptoms. Even friends or family, partners, colleagues and friends, care and health care workers (Greeff *et al.*, 2008b:87), children or neighbours often suffer because they are associated with PLWH and therefore fall victim to associated stigma by virtue of stigmatising behaviour towards them. Taylor (2001:792-798) uses an illustrative model showing that HIV and AIDS are not merely medical issues, but rather complex social constructs with the potential to impact on political, economic and social spheres and describes the stigma process as the function of stigma for the individual, the four-phased impact of stigma, strategies to manage stigma, health behaviour and the experiences of stigma-related health care. Another HIV stigma process model, a cyclic cognitive-affective-behavioural model from Pachankis (2007:328-345), focuses on the almost invisible aspect of stigma, namely the psychological implications of concealing a stigma like HIV for a shorter or longer period of time. This model basically proclaims that such concealment leads to preoccupation and intrusive thought processes that result in fears and anxieties and that influence the behaviour of the concealing individual or group of PLWH – which then starts the repetition of a cyclic process. The model also discusses

strategies to break the cycle and although it seems to implicitly refer to disclosure of personal HIV status, this remains the choice of the PLWH. A stigma model for China proposes a three-layered approach, focussing on the changes that stigma causes in societal factors, moral aspects and in the subjective/individual, collective and interpersonal aspects of the interaction of PLWH with their environment (Yang & Kleinman, 2008:305). Rensen *et al.* (2011:712) in turn suggest a conceptual framework where the relationships between the different aspects, types and impact of stigma are visualised. The essence is that negative attitudes towards PLWH will reduce their participation and increase their perceived and internalised levels of stigma. A resulting reduced self-esteem and self-efficacy will be part of the impact but will thus further increase the stigma levels. The model also takes the PLC or community into account, with results similar to those of the PLWH.

In a systematic comparison of 18 key conceptual models of stigma and prejudice, Phelan *et al.*, (2008:358-367) concluded that, excluding specific focus and emphasis, the models have much in common. One important distinction was the type of human characteristics that could be identified as the primary focus of the models, e.g. deviant behaviour and identity or disease and disability. They found that the function of stigma is to exploit or dominate the stigmatised people, to enforce the preferred norms of the stigmatiser and to avoid people that are different or have a disease. An earlier conceptual model of patient outcomes was developed by Wilson and Cleary (1995:59-63) and linked clinical variables with health-related quality of life. These authors identify five levels of outcomes, namely biological and physiological factors, symptoms, functioning factors, general health perceptions and overall quality of life. In addition, the model identifies specific causal relationships between the levels of outcomes in terms of linking traditional clinical variables to measures of health-related quality of life (Wilson & Cleary, 1995:63). On strength of this work, Holzemer *et al.* (2007:541-551) made a significant contribution and introduced another conceptual HIV and AIDS stigma process model with interacting variables. The HIV stigma process is defined as a four-dimensional process with triggers (testing, diagnosis, disease, disclosure), stigmatising behaviours (blame, insult, avoidance, accusation, suspicion), types of stigma (received, internal, associated) and stigma outcomes (poorer health, decreased quality of life, denied access to care, violence, poorer quality of work life), all functioning within the interactive context of the environment, the

health care system and the agents or people involved. It thus depicts an interactive context of a potentially changing environment, variety of health care systems and uniquely involved agents as the reality of stigma with its dynamic nature. It is in this dynamic context that the triggers, behaviours, types and outcomes of stigma develop and manifest. A trigger can set the process off and can be something like an HIV test. The process model then suggests that the stigma moves towards behaviour such as labelling or other behaviour that gives rise to any of the three types of stigma (received, internal or associated), which will turn out an outcome for the stigmatised person, such as abuse or limited access to services. Greeff *et al.* (2008b:87) expand these types of stigma and identify various dimensions as subcategories to each of three types of the Holzemer *et al.* (2007:541-551) model. The dimensions of received stigma are neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping. The dimensions of internal stigma are identified as perceptions of self, social withdrawal, self-exclusion and fear of disclosure, and the dimensions for associated stigma are linked with stigma attitudes and behaviour directed at people living close (PLC) to PLWH, like family, friends, a partner or health care workers. The Holzemer *et al.* (2007:541-551) model provides a theoretical grounding for the present research and its findings but is utilised in an open-ended manner to allow for inclusion of other models and possible theory generation if required.

Different authors use different terms to refer to types of HIV stigma. Holzemer *et al.* (2007:541-551) as well as Rensen *et al.* (2011:712) refer to *internal stigma* but other terms, like *self-stigma* (Mak *et al.*, 2007:1555; Siyam'kela, 2003:19) and *emic stigma* (Weiss *et al.*, 1992:819-830) are also used. Herek *et al.* (2013:42) define self-stigma as a choice to internalise and accept the validity of the stigma, whilst another response – like righteous anger or indifference – could just as well have been chosen. *Received stigma*, as used by Holzemer *et al.* (2007:547), is otherwise referred to as *external stigma* (Siyam'kela, 2003:14), *perceived* or *anticipated stigma* (Link *et al.*, 2004:511-541; Mak *et al.*, 2007:1555), *enacted stigma* (Boyd *et al.*, 2010:1063-1070; Herek *et al.*, 2013:43) *etic stigma* (Weiss, *et al.*, 1992:819-830), *felt stigma* (Siyam'kela, 2003:19; Rensen *et al.*, 2011:712) and *stereotype awareness* or *public stigma* (Herek *et al.*, 2013:42). With concern to received stigma, Herek *et al.* (2013:49) found a moderate relation between self-stigma and felt stigma and concluded that although these are distinct constructs, both were significantly correlated with symptoms of depression and anxiety

(although felt stigma was more powerful in this regard). With reference to a third type of stigma, which is directed at people living close to PLWH (PLC), like the partners or children of PLWH, their family, friends or workplace colleagues, Ogden and Nyblade (2005:31) and Holzemer *et al.* (2007:541-551) prefer the term *associated stigma* whilst Salter *et al.* (2010:558) refer to *secondary stigma*. These consequences or experienced discriminatory behaviour could in some countries be as devastating as the illness itself, since it promotes institutionalised forms of discrimination linked to power over the stigmatised and associated with continual disrespect for human rights (Salter *et al.*, 2010:558).

A different approach to the identification of types of stigma in the aforementioned overview is described on the website of an organisation named Avert (s.a.). They distinguish between different kinds of stigma, such as stigma and discrimination through non-efficiency of governments, injustices through the legal system, issues of healthcare inaccessibility, lack of confidentiality, resource-poverty for those stigmatised, community manifestations like ostracism, rejection and verbal or physical abuse, issues like restrictions on travel and residence of PLWH and even family judgementalness and responses leading to personal and psychological distress all round.

Figure 1: Summary of common terminology for types of HIV stigma affecting PLWH and PLC

TYPES OF STIGMA		
PLWH		PLC
Internal Stigma (Holzemer <i>et al.</i> 2007:541-551; Siyam'kela, 2003:19; Mak <i>et al.</i> , 2007:1555)	Received Stigma (Holzemer <i>et al.</i> 2007:541-551; Siyam'kela, 2003:14; Mak <i>et al.</i> , 2007:1555)	Associated Stigma (Holzemer <i>et al.</i> 2007:541-551, Siyam'kela, 2003:14).
Self Stigma (Holzemer <i>et al.</i> 2007:541-551; Siyam'kela, 2003:19; Mak <i>et al.</i> , 2007:1555)	Perceived/Anticipated Stigma (Link <i>et al.</i> , 2004:511-541; Mak <i>et al.</i> , 2007:1555)	Secondary Stigma (Ogden <i>et al.</i> , 2005:31)
Emic Stigma (Insider) view (Weiss, <i>et al.</i> , 1992:819-830; Rensen, <i>et al.</i> , 2011:711-719)	Etic Stigma (Outsider) view (Weiss, <i>et al.</i> , 1992:819-830)	
	External Stigma (Boyd, 2010:1063-1070; Herek <i>et al.</i> , 2013:43)	
	Enacted Stigma (Boyd, 2010:1063-1070; Herek <i>et al.</i> , 2013:43; http://wikiEducator.org , 2013)	
	Felt Stigma (Holzemer <i>et al.</i> 2007:541-551; Siyam'kela, 2003:14; Herek <i>et al.</i> , 2013:42; http://wikiEducator.org , 2013)	

3.2 Contextualisation of HIV stigma in urban and rural areas

Researchers disagree on whether HIV stigma is experienced similarly in urban and rural areas. A brief overview of the findings and opinions of researchers will be presented below, primarily with regard to ordinary beliefs, attitudes and practices of individuals and collectives in urban and rural communities to their own people living with HIV. Voeten *et al.* (2004:481) explain that the HIV epidemics in Sub-Saharan Africa started in urban areas and were spurred by urbanisation in the 1970s and 1980s, when many males were employed in urban areas while their families resided in rural settings. The results of a cross-sectional study in Kenya demonstrated that sexual behaviour for women was more risky in terms of HIV/sexually transmitted disease in rural than in urban areas, since they were reportedly less frequently being virgins at marriage, had more lifetime partners and less consistent condom use with non-spousal partners (Voeten *et al.*, 2004:483). The same study found that the risk for men, on the

other hand, was equally high in urban and rural areas in Kenya. Naidoo *et al.* (2007:21-23) emphasise the differences in terms of social structures and general life experiences of urban and rural communities, which raises the question of whether there are differences in the HIV stigma and stigmatisation experiences of urban and rural communities.

A study in Nigeria came to the conclusion that fertility in rural areas is higher than in urban areas and that the age at first sexual intercourse, first marriage and first birth are on average two years earlier in rural than in urban areas (Adebimpe *et al.*, 2011:32). Sliep *et al.* (2001:57) found evidence that HIV stigma is more prevalent in rural areas. The social structure of rural areas is often one of closer knowledge of others and according to the Rural Centre for AIDS/STD Prevention (1994:1), people in rural areas often experience stigma and stigmatisation as a result of a lack of privacy, anonymity and confidentiality. Ankrah (1993:5) adds that rural Africa is characterised by a social network of people mostly connected by kin or blood relations, where the social network functions as a kind of central human social unit or clan to which all members automatically belong, and where anonymity and confidentiality are almost impossible and stigma harsher. The Rural Centre for AIDS/STD Prevention (1994) points out that this, in essence, would reduce participation of PLWH in prevention strategies like accessing and utilising voluntary counselling and testing, treatment and care and support groups (Naidoo *et al.*, 2007:23).

Wissing (2006:59, 141) indicates that the deeper one enters rural areas, the more obvious it becomes that the context of being healthy differs according to culture and accepted ritualistic form. Heckman *et al.* (1998:138) shed further light on the complexity of the exposure of rural people to HIV stigma, in that rural PLWH have lower levels of satisfaction with life, lower perceptions of social support from family and friends, reduced access to medical and mental health care, elevated levels of loneliness, higher levels of community HIV stigmatisation and more maladaptive coping strategies than their urban counterparts. The fact that rural PLWH also demonstrated a heightened personal fear that their HIV sero-status will become known to others, could be interpreted as an indicator of recognisable HIV stigmatisation in such communities (Heckman *et al.*, 1998:139). Naidoo *et al.* (2007:22) concluded that urban people experience 'received' stigma in all forms more often than people in rural areas. Further

observations included that urban PLWH seem more inclined to self-stigmatise and most frequently struggle with fear of contagion, labelling, pestering and gossiping in terms of received stigma whilst rural PLWH reported avoidance of them as individuals as their most experienced 'received' stigma.

Naidoo (2007:21) mentions that in urban areas the internal HIV stigma and specifically the 'fear of disclosure' ranked very high. Ramirez-Valles *et al.* (2005:102-105) researched the effects of community involvement like volunteerism and activism on PLWH in two cities (urban areas) and found that participation in social services in such urban environments could buffer the adverse effects of homosexual stigma, poverty, homophobia and racism that lead to psychological outcomes like burnout, depression, loneliness and damaged self-esteem. Naidoo *et al.* (2007:21-23) venture the view that social networks, different socio-economic factors and distinct literacy differences could have contributed to higher levels of reporting of perceived and internalised stigma in urban areas. Naidoo *et al.* (2007:17) also ascribe some of experiential differences between urban and rural areas to rural communities being more personal, with less anonymity and secrets, and being organised around the hub of land ownership, child care, social rituals and extended family support. Urban societies have become more dependent on nuclear families built around employment, home ownership and busy external support services which may treat people more like numbers than human interacting individuals. This ties in with the observation by Foster and Williamson (2000:277) that the roles of the PLC, the extended family and the community in coping with HIV orphans and HIV stigma are in flux and that urbanisation in particular contributes to the weakening of extended family safety nets and of children ending up in a variety of vulnerable situations, such as homelessness, street living, child employment, and child-headed households. The role of PLC in the lives of PLWH might further be compromised by HIV stigma and the growing dilemma of an estimated one billion people living in suburban slums as a hallmark of the poverty and violence-ridden twentieth century without the luxury of traditional or extended family support (Muggah, 2012:61).

In the South African context, Bradshaw (2008:51-54) also includes a fourfold onus of disease that refers to issues like a) poverty and underdevelopment, b) chronic illnesses, c) injuries and d) HIV and AIDS. These four elements, plus high levels of illiteracy, topped with different forms

and dimensions of (HIV) stigma, together contribute to the existing challenges relating to health status of PLWH and communities of urban and rural populations (Bradshaw 2008:53). Such life difficulties are especially meaningful in terms of a study by Greeff (2010:6) that, in a specific study, found no significant difference between the overall life satisfaction scores of urban and rural participants. This is confirmed by a previous finding by Wissing (2006:59 & 141) that different people, groups or cultures (no matter where they live) think differently about psychological wellness, life satisfaction and the manifestations of well-being.

The above challenges extend to PLC (people living close to PLWH) and Mswela (2009:188) accordingly refers to the lack of education of especially illiterate women in remote rural areas of Africa, which contributes to their predicament as they often only become aware of their HIV-status once AIDS symptoms set in. This is linked to HIV stigma because any disclosure of HIV or AIDS includes the risk of rejection by male partners or husbands and even exposure to violence within families and communities of PLWH (Mswela, 2009:188). A study in a rural area in the Mpumalanga Province of South Africa revealed this reality of HIV stigma and that HIV infected children and sick partners were being banished from their families. This demonstrates that HIV stigma often touches PLC (those who are close to PLWH), such as family members and in particular even their home caregivers (Ogunmefun *et al.*, 2011:87). PLC could literally be judged and stigmatised by virtue of their association with an HIV positive family member or relative (PLWH) and this would lead to everyday life being structured around secrecy and disavowal of HIV or AIDS (Ogunmefun *et al.*, 2011:87).

3.3 Impact of HIV stigma on different populations

Although HIV stigma is considered a major barrier to effectively curb the persistent and perniciously natured AIDS pandemic, stigma reduction in its complexity seems to be relegated to the bottom of AIDS response priorities and resources in many countries (Mahajan *et al.*, 2008:67). Bryan (2000:65), Schmitt and Branscombe (2002:177); Stein (2003:95); Link *et al.* (2004:511-513) and Strangl and Nyblade (UNAIDS, 2007:9) concur that HIV stigma and stigmatisation breed powerful and hurtful consequences for both PLWH and PLC in their quest for well-being since HIV stigma is a 'process of devaluation' in society and a powerful negative attribute which sets PLWH and PLC apart from others and leads to feelings of exclusion, low

self-esteem, fear and anxiety, depression and resistance to testing and disclosure. Gilbert and Walker. (2010:139) found broad-scale consensus suggesting that HIV and AIDS-related stigma is a compromising factor with regard to the well-being of PLWH and they reiterate that the impact, effect and implications of HIV stigma significantly contribute to the complexities of the fight against HIV and AIDS, which heavily depends on prevention, treatment and care for those most vulnerable to, or living with HIV. Corrigan (2000:48) draws a comparison between HIV and mental illness that has always been critically influenced by stigma and stigmatisation or discrimination and emphasises that addressing a disease medically only will never be sufficient, since the improvement of the course and outcomes of such severe illness is dependent on the remediation of societal stigma and discrimination.

The complexity of HIV stigma is aggravated among others by the fact that stigma in some respects can be seen as a social process that layered onto other forms of inequality such as class, race, ethnicity, sexual orientation, gender, HIV status, nationality, social status and even demographic positioning. Such societal and social processes place stigma in the cadre of attitude and behaviour since stigma can be seen as a negative attitude or level of ignorance resulting in acts of identifying, labelling, isolation or different types of discrimination. The pioneering work of Fishbein and Ajzen (1975:336) during the 1970s contributed to the psychological clarification of behaviour (like stigmatisation), and its relation to attitude (like prejudice). Attitude is derived from an accumulation of information about an object, person, situation or experience and then becomes a predisposition that leads to behaviour or action (towards a particular object, person, situation or experience linked to the original accumulated information). Such a process, underpinning behaviour, relates to ways in which individuals and communities attribute meaning (predisposition/attitude) to the facts (accumulated information).

In other words, it would influence the way individuals and communities attribute meaning to something like HIV or AIDS. The problem is that so-called facts or accumulated information could sometimes be based on subjectivity, perception or myth. These insights connect behaviour (stigmatising and also health behaviour) with attitude or predisposition (stigma) that results in action or further reactionary or discriminatory behaviour. This then relates to PLWH

and their personal experiences and perceptions (internal stigma), the resulting enactment or behaviour (external stigma) of/or toward them as well as towards PLC and others associated with the PLWH (associated stigma) and their communities (Holzemer *et al.*, 2007:541). Behaviour, though, is a learned attribute and can therefore change. Accordingly, Spangolo *et al.* (2008:187) argue that stigma and stigmatising attitudes are changeable, despite the pervasive nature of stigma; likewise, the negative consequences associated with such attitudes and the resulting discriminatory or stigmatising behaviours are also changeable.

The variability of the manifestation of HIV stigma in terms of cultural, intrapersonal and societal aspects makes it difficult to effectively measure the HIV stigma and assess its impact as a stepping stone towards reducing the phenomenon (Mahajan, 2008:68). Cross *et al.* (2012a:63) describe the effects of stigma as both brutal and subtle: it is brutal in terms of discrimination and indignity and subtle in terms of labelling, stereotyping and separation that lead to loss of identity, self-esteem and sense of purpose for the stigmatised as well as diminished access to care. The following paragraphs will therefore briefly focus on the more specific impact of HIV stigma on PLWH and PLC.

3.3.1 The impact of HIV stigma on PLWH

The consequences or outcomes of HIV stigma on PLWH are outlined by Holzemer *et al.* (2007:54) and Chirwa *et al.* (2009:16) and in their view fall in categories of decreased physical and mental health, verbal or physical violence, poor quality of life and reduced access to care. These vulnerabilities are also mentioned by other researchers and include further life-intruding consequences of HIV stigma.

3.3.1.1 Diminished physical/mental health and psychosocial well-being

The physical and mental health of PLWH whilst living with HIV can deteriorate if health care facilities and prescribed treatment are not accessed and PLWH are not supported. The problem, according to Maughan-Brown (2004:2-4), Holzemer and Uys (2004:165), Skinner and Mfecane (2004:161), Greeff *et al.* (2008a:318-321), Greeff *et al.* (2009:476) and Phillips (2009:iv), is that HIV stigma often is a limiting factor in the health support of PLWHs since it creates powerful barriers to HIV testing, disclosure of HIV status, access to anti-retroviral

medication and access to medical care services. Naidoo *et al.* (2007:18) and Philips (2009:iv) furthermore claim that HIV stigma and stigmatisation not only impact on the PLWH's physical health but add complexity to their patterns of psychosocial well-being. All the above closely relates to the PLWH often having to face moral judgement, blame, ostracism by people at 'home', like relatives and friends, or harsher enactments like being verbally and/or physically abused or discriminated against in matters like delayed, poor or denied access to services or care (Gilbert *et al.*, 2010:141). Spangolo *et al.* (2008:187) concur with these barriers; as does Katz (Greeff *et al.*, 2008a:313), who describes behaviour of community members towards PLWH like avoidance behaviour, isolation and rejection, prejudice and discrimination as resulting from community stigmatisation, which could include health care personnel and PLC.

On the other hand, it is argued that the psychosocial well-being of PLWH could benefit from those who are stigmatised but managed to assume resilience and empowerment and have genuinely overcome stigma to an extent that they are flourishing in society. This is the refreshing view of Shih (2004:175), who believes that PLWH can overcome stigma by moving beyond a coping model and adopt a model of empowerment wherein the PLWH are active participants in a society who seeks to understand their social world and create positive outcomes through replenishing and enriching processes that is not draining in itself but actually energising for the individuals. The processes reviewed by Shih are a) compensation-like through having a pleasant disposition, b) strategic and chosen interpretations of the social environment rather than just being a victim thereof and c) focusing on multiple identities that could help stigmatised people to handle prejudice and discrimination and to focus on healthy and strong parts of the self instead of on the stigma as such (Shih, 2004:180-182).

3.3.1.2 Fears and decreased social participation

Taylor (2001:793). Genberg *et al.* (2007:772), Mallory *et al.* (2007:359) and Greeff *et al.* (2010:2) refer to the growing vulnerabilities of the PLWH in terms of perceptions and a variety of fears relating to rejection, isolation, loss of social standing or social roles, disempowerment, dependence on paternalistic medical staff who are controlling the HIV treatment, access to treatment and treatment regimens. These fears include a fear for unknown symptoms and the nature of access to primary and secondary HIV and AIDS care and prevention services. Gilbert

et al. (2010:139) refer to this as a the level of 'felt and anticipated' stigma that is so intense for many PLWHs that it affects all dimensions of their lives, and Corrigan (2004:119) describes a type of self-stigma that could even drive the stigmatised person to reflect (demonstrate) own stigma in a way that could endorse notions such as that he/she is not capable of holding down a responsible job or live independently. Rensen *et al.* (2011:712-713) emphasises that PLWH respond with decreased social participation resulting from the negative attitudes caused by HIV stigma. The consequences are that PLWH demonstrate poor participation in timeous accessing of health care and care facilities, less participation and commitment in relationship building and even less participation in employment activities (Foster & Gaskins, 2009:1309; Greeff *et al.*, 2008a:318-321; Greeff *et al.*, 2009:476; Holzemer & Uys, 2004:165; Maughan-Brown, 2004:2-4; Skinner & Mfecane, 2004:161; Spangolo *et al.*, 2008:187).

3.3.1.3 Personal and emotional responses, vulnerabilities and loss

The above-mentioned lack of social participation by PLWH and the elicited impact of HIV stigma on personal/emotional responses of PLWH where their self-esteem and self-efficacy seem to be compromised, are aggravated by reactions of PLWH as described by Rensen *et al.* (2011:712), like poor quality of life resulting from poor disclosure practices, poor behavioural responses, loss of significant relationships, harbouring fears and vulnerabilities and basically allowing verbal, mental and physical abuse as well as accepting psychosocial distress, economic vulnerabilities, employment worries and altered social roles (Corrigan, 2004:119; Genberg *et al.*, 2007:772; Gilbert *et al.*, 2010:139; Greeff *et al.*, 2010:2-9; Mallory *et al.*, 2007:359; Spagnolo *et al.*, 2008:187;). The International Centre for Research on Women (2005) also identify significant losses resulting from these vulnerabilities, like the loss of income/livelihood, loss of marriage and childbearing options, withdrawal of caregiving in the home, loss of hope and feelings of self-worth and loss of reputation. Skinner and Mfecane (2004:158) and Naidoo *et al.* (2007:18) theorised about the HIV stigma process and described it as firstly being the development of feelings of superiority among those who are not affected by the stigmatising trait, and secondly as the development of a feeling of shame in or towards those who are affected by the trait, and who are thus stigmatised. Taylor (2001:794) moreover refers to a 'social identity theory' where the self-concept of the 'in-group' is bolstered and that of the 'out-

groups' are judged less favourably, leading to stigma attitudes and stigmatising behaviour that facilitate separation, labelling or categorising of 'the other'. Taylor (2001:794), Skinner and Mfecane (2004:158), Corrigan (2004:117-118), Kohi *et al.* (2006:405), Genberg *et al.* (2007:772), Mallory *et al.* (2007:359), Holzemer *et al.* (2007:541) and Naidoo *et al.* (2007:18) concur that HIV is causal to separating and isolating people and that processes of pre-conceived thinking, as demonstrated within HIV stigma, actively influence the psychosocial well-being and health behaviour of PLWH, PLC communities at large and around the globe. Asiedu (2010:137) found that PLWH often at first feel despair when they discover that they are HIV positive and almost immediately demonstrate concern for the emotional burden and consequences of HIV stigma on their families. Some literature indicates that PLWH engage in self-isolating behaviour to prevent HIV-transmission and in particular to minimise secondary (associated) stigma directed at their families (Salter *et al.*, 2010:558).

3.3.1.4 Quality of life outcomes

Cahill and Valadez (2013:12) describe the effect of HIV stigma on the quality of life of PLWH as the internalisation of feelings of shame, guilt, anger, fear and self-loathing, which often lead to experiences of social avoidance, real or perceived loss of friends, a perceived discomfort of others in the presence of PLWH, depressive symptoms coupled with anxiety, hopelessness and a diminished sense of attractiveness. Greeff *et al.* (2010:9) emphasise that perceived HIV stigma has a significantly negative and constant impact upon life satisfaction and quality of life for PLWH. There seems to be useful similarities between quality of life matters resulting from HIV stigma and those resulting from mental illness. Corrigan *et al.* (2006:880) and Spagnolo *et al.* (2008:187) describe stigma and discrimination as a two-edged sword which, on the one hand, interferes with stigmatised persons' achieving of social roles, work progress and possible independent living opportunities consistent with higher levels of quality of life. On the other hand, though, the societal reaction to severe mental illness results in stigma and discrimination that unjustly impede the affected person from attaining work, affiliation, and independent living opportunities. Such diminishing 'quality of life' matters give rise to an understanding of internal, emotional and behavioural processes surfacing with regard to HIV stigma. PLWH also

experience quality of life difficulties such as seeking a way forward, having to make certain life choices and the aging process.

Cahill and Valadez (2013:14-15) suggest social marketing campaigns to support processes for adult PLWH to deal with the complex intersection of stigmata linked to HIV, aging, homosexuality and other life style or health issues. Furthermore, a better quality of life for PLWH requires support with regard to the increased understanding and management of treatment interactions regarding different comorbidities, such as HIV treatment, hypertension, high cholesterol, heart failure or other illnesses. Greeff *et al.* (2010:11) conclude that if stigma reduction interventions were to be successful, life satisfaction (including quality of life) will be aided and will be evidenced by increased life enjoyment, a sense of control in life, increased social interactivity, an increase in perceived health status and utilisation of available life opportunities. Cahill and Valadez (2013:14-15) observe that HIV stigma reduction will decrease PLWH's depression symptoms, improve their adherence to treatment regimens and contribute to the success of overall HIV and AIDS strategies.

3.3.1.5 Disclosure dilemma and management

Sero-status disclosure by PLWH is part of the discussion on the impact of HIV stigma. Foster and Gaskins (2009:1309) stress how difficult disclosure can be and found that certain PLWH would stop sexual activity or friendships rather than to disclose their HIV status. They also found that family members were most likely to be chosen to disclose to and were often identified as the major source of social support for PLWH (Foster & Goskins, 2009:1310). Asiedu (2010:5), on the other hand, found that PLWH prefer to disclose their sero-status to educated friends with a deeper sense of awareness, whom they believe are most trustworthy. The workplace seems especially challenging and Foster and Gaskins (2009:1309) and Kasapoglu *et al.* (2011:1512) report that PLWH seldom felt safe enough to share the HIV status with colleagues or employers since they feared losing their jobs because of instrumental and symbolic stigma and discrimination.

In their relations with health professionals, Kasapoglu *et al.* (2011:1512) found that PLWH suffer because of medical professionals' and carers' fear of contagion, the lack of immediacy in

initiating treatment and at times a lack of confidentiality where their HIV status was exposed to family, friends or colleagues without their participation in or control regarding such disclosure. Philips (2009: iv-v) found that health care workers reported HIV stigma experiences similar to what PLC experience, especially if they have a family member or relative who is HIV positive. Pachankis (2007:328), on the other hand, points out the stress of concealing an invisible stigma like HIV infection during pre-symptom phase. Such non-disclosure could have a powerful, negative impact on an individual's daily life since it influences the individual's cognitive thought processes and self-talk and leads to a negative appreciation of self, which in turn can negatively impact on opportunities of open, free and easy-going friendships, relationships, intimacy and behaviour. The need to 'keep the HIV secret' could even precipitate refusal to timeously attend to personal health vulnerabilities and wise preventative decisions and health behaviour. An interesting finding with regard to disclosure in a social structure like that in Ghana is that there is no room for secrets in their collectivist-type culture, where individuals are defined within a (family) group and not as individuals (Asiedu, 2010:137).

Besides these outcomes of stigma for PLWH, there is also the impact of stigma on the ability of PLWH to negotiate and/or change their lifestyle and often risky sexual behaviour practices. This can be a matter with far-reaching consequences, which was demonstrated in one of the findings of the PURE-SA study (Kruger *et al.*, 2009:28). The study showed that only 27.7% of 332 people who were newly diagnosed as HIV positive, duly counselled and clearly referred to local health clinics or hospitals, did in fact visit a health care facility in the year following such diagnosis, counselling and referral. This raises concern about the impact of HIV stigma on PLWH but also about the impact on people other than PLWH.

3.3.2 The impact of HIV stigma on PLC and the community

HIV stigma is no longer a personal or individual experience of PLWH alone. It impacts on the community at large and also critically impacts on the PLC in question, like the children, partners, family, friends, colleagues or spiritual supporters of PLWH. This type of HIV stigma manifestation, by its very nature, refers to the impact of associated or secondary stigma (as defined under 3.1.2), emphasising the burden of individuals or communities within

communities being compromised by the persistent stigma linked to a devastating pandemic that undermines public health goals and social cohesion.

3.3.2.1 Socioeconomic impact

The impact of HIV stigma on the PLC and the community in question is no doubt multileveled and complex, as pointed out by Uys *et al.* (2005:20), who relate the socioeconomic impact of HIV stigma to the impact on the general community welfare and its resources. Vulnerabilities exposed by socioeconomic threats refer to stigma-induced job losses of PLWH or PLC, resulting in lost opportunities to make a living and to provide for old age. The family and even the community at large are also impoverished because of the loss of the labour contributions of such families. Foster and Gaskins (2009:1307) report that, in an effort to save their income and further distress for PLC, PLWH are often cautious to share their HIV status with co-workers or employers for fear of discrimination in the workplace. They also fear the stigma and the associated gossiping and loss of social standing, which can diminish the socioeconomic strength of the family or the community. Asiedu (2010:5), reporting on a Ghanaian study, confirms the vulnerabilities of the PLC and the communities in question, as even PLC are at risk of losing their jobs because of the fear of contagion by co-workers or employers.

3.3.2.2 Social and psychosocial impact

Taylor (2001:792) emphasises that stigma is a social construct with a significant impact on the PLWH as well as on the PLC to the PLWH and the community affected by these HIV diagnoses. Asiedu (2010:5), in the above-mentioned Ghanaian study, also identifies vulnerabilities of the PLC and communities of the PLWH such as the possibility that the PLC could lose friends, potential difficulty with 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. Thus, they are subjected to the same types of fear and discrimination as PLWH, like bullying or social isolation. At a social level, stigma and discrimination result in distinction, exclusion and diminishing of equal enjoyment and human rights. Stigma seems powerful enough to set people against each other and to undermine social cohesion by dividing and breaking down different manifestations of community and society. Communities may

sanction an entire family because one member is ill, and this may lead to problems in terms of psychosocial adjustments and to vulnerabilities in the community and family structure. The tightly woven supportive units in which African communities historically functioned, are under threat by issues such as stigmatisation and the discord and distrust that it might bring (Foster & Williamson, 2000:227). The loss of support systems such as the built-in African clan system results in the continuous erosion of the historically strong extended family safety nets (Foster & Williamson, 2000:277). The situation is aggravated by the added pressure of having to deal with additional emotional, nursing, medical and economical care for the sick (Uys *et al.*, 2005:20). In South Africa terms like *ingculazi* ('associated with germs'), *gawulayo* ('the disease that decimates') and *ulwazi* ('that thing') are used to refer to HIV and AIDS - this stresses the intensity of HIV stigma and the discomfort of people to call it by its proper name or to be associated with it (Gilbert *et al.*, 2010:145).

PLC to PLWH was included in the results of a qualitative study that was done in Turkey about 'AIDS related stigma in social relations' by Kasapoglu *et al.* (2011:1496-1516), which studied the stigma in the relations amongst PLWH and their PLC from the perspective of the PLWH. The study explored the social relations of PLWH by focussing on the PLWH's descriptions of stigma and their family members, stigma and their friends, stigma and sexual partners, stigma and co-workers or employers as well as their descriptions of stigma and their specific health professionals. The results demonstrate certain similarities with other studies (Foster and Gaskins, 2009:1309), although the support offered to PLWH by family, friends and sexual partners seem to be more consistent in Turkey than in other countries (Kasapoglu *et al.*, 2011:1512). An HIV diagnosis of one individual often reflects on the family and the family members thus are ultimately considered responsible for the behaviour of individuals in the family. Kasapoglu *et al.* (2011:1511) report that many of the PLWH participants and their families in Turkey developed semantic reconstructive ways of referring to 'HIV-positive' instead of 'AIDS' and often shifted the meaning from 'deadly' to curable, chronic, manageable or treatable. Together with this, the cultural view in Turkey that occurrences like HIV is *God's wish*, is an example of a culturally anti-stigmatising attitude.

3.3.2.3 Impact on public health and health behaviour

As a result of the intensity of HIV stigma experiences of PLWH and the visible stigmatisation behaviour towards PLWH, the PLC to them and even other members of communities where PLWH reside, fear contagion and exposure of their connection with PLWH (Asiedu, 2010:5; Foster & Gaskins, 2009:1309). Gilbert *et al.* (2010:139) therefore sketches a bleak picture from a public health perspective and notes that HIV stigma will deter people from getting tested, from following treatment regimens and from acknowledging and changing their own risky health behaviour. It often is easier to continue unchanged in secrecy and denial, since sexual behaviour involves more than one person and is therefore difficult to negotiate without certain levels of honesty and determination.

Taylor (2001:792) asserts that HIV stigma is experienced uniquely by each individual and that even such experiences change throughout the course of the illness trajectory. People close to PLWH, like partners, children, friends, colleagues, spiritual leaders or other community members, will thus also be unique in their experiences through the course of the illness.

3.3.2.4 Impact on the children of PLWH

Stigma reduction efforts could be most effective if positive information is given to children at an early stage, when they first develop attitudes and beliefs about health or when they might already be exposed to teasing or bullying caused by stigmatisation (Holm-Hansen, 2009:3). Mueller *et al.* (2011:67) says that little is known about the content and impact of mushrooming interventions with children of PLWH in South Africa and that published literature is often to be seen as 'grey literature', where research for instance lacked methodological control and rigor. A six-year long follow-up intervention in the USA seemed to have been successful in protecting HIV related children against substance abuse and emotional or behavioural problem behaviour (Rotheram-Borus *et al.*, 2006:175). The questionnaire used by Mueller *et al.* (2011:69) for their quasi-experimental evaluation of art therapy for children of PLWH in a community-based context focused specifically on self-esteem, self-efficacy, depression and emotional-behavioural difficulties. An interesting result was that the study found no association between intervention exposure and increased self-esteem, depression or emotional and behavioural problems. The

only association shown was that of self-efficacy which enhanced a sense of stronger personal control within the children. Mueller *et al.* (2011:64) report that the other vulnerabilities that were identified, can only be addressed if there is a reduction of community stigma and less exposure to violence. It was also found by Foster and Williamson (2000:282) that the impact of HIV and AIDS on children in developing countries is not significantly different from that in developed countries, since children normally show psychological reactions to the illness and death of parents. Stigmatisation, dropping out of school, friends who have changed, increased workload that often includes care for a sick parent, discrimination and social isolation of orphans all increase the stress and trauma for the affected children.

3.3.2.5 Impact on spiritual support

Religious groups have a reputation for responding rather moralistically to HIV, with typical reactions driven by fear of contagion and ostracism of the PLWH (Council for World Mission by the World Association for Christian Communication, 2007:91-92). This is ironic, since religious communities are usually interwoven into the wider community and excellently positioned to offer care, support and change, but are often found to be judgmental of PLWH and PLC instead of acting as PLC and offering neighbourly spiritual connectedness as a key towards faith, hope, change and stigma reduction (Campbell & Rader, 2005). In a consultation of the UNAIDS with Botswana church leaders, the above-mentioned authors found that their stigma perspective almost invariably changed on visiting PLWH and PLC at their homes and that their compassion deepened and their commitment to further involvement grew, as they realised that the link between care and change is relational. A fairly recent study by Bauer (2013:100-118) focused on Protestant Christian church leaders and the impact of HIV stigma on the church members and leaders, whilst dealing with an environment of traditional beliefs about sexuality, stigmatisation and discrimination against homosexuality, initial invisibility of HIV, restricting policies on sermon content, marginalised outreach, ignorance about HIV, moral judgement, blame and assumptions about PLWH (Bauer, 2013:100-118).

3.3.2.6 Impact on psychosocial well-being

The full impact of stigma and ‘stigma by association’ on PLWH and PLC is not yet fully understood. Salter *et al.* (2010:558), in a Vietnam-based study, analysed qualitative data on the experiences of people learning their HIV status, making disclosure decisions, family reactions, and stigma from family and community. Potential psychological and social effects are thus emerging for PLWH personally, but also for their families and PLC, who in the Vietnamese culture form the centre of society and of community social well-being. This finding conceptually links to a fourth-wave psychology that brings to mind the important balance between the well-being of the individual and that of the collective (community of the individual) as well as a holistic enhancement of people’s combined working, loving, playing, learning, wisdom sharing and growth (Wissing, 2000:96-97). These, as the opposite of self-isolating or individualistic behaviour, open the debate to the tenants of psychosocial well-being. The opposite side of such psychosocial well-being often is a consequence of HIV-related stigma that refers to prejudice, negative attitudes, abuse and maltreatment of PLWH. These are far reaching since it results in individual PLWHs being shunned by family, peers and their wider community as well as the erosion of their access and rights with regards to health care services and facilities (Avert, s.a.:1). Stigma thus inhibits psychosocial well-being since it causes psychological and psychosocial damage and has negative effects on the willingness of PLWH to participate in HIV testing and treatment.

4 HIV Stigma and psychosocial well-being

An exploration of the literature on psychosocial well-being, on the self, on people close to an infected individual and on change potential is critical to understanding the response of PLWH and PLC to HIV stigma. Valdiserri (2002:341) indicates that stigma is a complicated issue that has deep roots in the convoluted domains of gender, race, ethnicity, class, sexuality and culture and that it has not been easily understood or addressed. Wissing (2000:98) emphasises the importance of an adequate professional broad spectrum approach grounded in at least the psychological, health and social sciences for the enhancement of psychosocial well-being. She

warns of a practice without theory and suggests that whilst wellness programmes gain popularity and often demonstrate art and poetry, it will have to be science, theory and research that cement the development of psychosocial well-being for the future generations. Kalichman (2013:1) relates prejudice and stigma and argues that it is a central area of social psychology. People with HIV or AIDS have been victims of stigmatisation ever since the epidemic began in the 1980s and it therefore impacts on the psychological well-being of PLWH over and above the fact that they are physically and otherwise challenged by a serious chronic and life-threatening disease (Herek *et al.*, 2009:43; Mak *et al.*, 2007:1549). The next section will thus explore the conceptualisation of psychosocial well-being and will then focus on the impact of HIV stigma on such psychosocial well-being of PLWH and PLC to them.

4.1 Conceptualisation of psychosocial well-being

Williamson and Robinson (2006:4-25) explain the origin of the term *psychosocial* as the dynamic inter-relationship between psychological and social dimensions of human suffering resulting from armed conflict where biological and material needs were especially obvious. The proper context of the term, when separated from human suffering, is the achievement of broad spectrum individual and collective well-being that facilitates the well-being within an overarching collaborative framework of safety, participation and development (Williamson & Robinson, 2006:4-13). The specific theoretical framework suggests fulfilment on at least seven interrelated and somewhat inter-dependent areas following each other in a hierarchical manner, starting from a biological well-being base to material, social, emotional, mental, spiritual and cultural well-being at the top of a triangle.

The Psychosocial Working Group (www.forcedmigration.org/psychosocial/) developed a unique framework for psychosocial well-being. This framework focuses on the social, cultural and psychological influences effecting psychosocial well-being. The model is presented as three interlinking ovals representing the three core domains: 'human capacity', 'social ecology' and 'culture and values'. The significance of these capacity domains lies in its response capabilities derived from the mental/physical health, knowledge or skills of the individuals. Each domain holds the human capacity, social capacity or cultural capacity to appropriately respond to critical challenges such as HIV stigma (Naidoo *et al.*, 2007:19). In other words; the social,

cultural and psychological influences on psychosocial well-being are bolstered, protected and restored through utilising 'human capacity', 'social ecology' and 'culture and values' of individuals and community which demonstrate the measure (capacity) of psychosocial resilience that exists in order to ensure psychosocial well-being. The century old experience with stigma in the mental health field motivated Corrigan (2000:49) to introduce a descriptive model for stigma that describes its dynamics as the interrelationship between stigma signals (cues), stereotypes (attitudes) and behaviours (discrimination). Taylor (2001:797) focuses on 'felt' and 'enacted' stigmata as powerful forces in the interrelating processes between society and individuals that could continuously change the dynamics of managing HIV and AIDS within a community. The self-determinism theory is based on human motivation, personality development and well-being and Ryan (2009:1-2) argues that the theory mainly focusses on volitional or self-determined behaviour and the social and cultural conditions that promote such behaviour.

The 'Complete State Model of Health' is a theoretical framework developed by Keyes (2002:209) and differentiates between emotional, psychological and social well-being and forms the basic conceptual framework for exploration of psychosocial well-being within this study. He defines emotional well-being as representing intrapersonal feelings; psychological well-being as private and personal criteria of everyday functioning; and social well-being as epitomising the more public and social functioning criteria consisting of social coherence, social actualisation, social integration, social acceptance and social contribution. Keyes (2002:217 & 2005:539) thus interprets psychosocial well-being as referring to private/personal criteria of daily functioning, interconnected with criteria of social functioning. It essentially means that behaviour facilitates psychosocial well-being when individuals see themselves as thriving, or not, in their public and social lives (Keyes, 2005:542). To simplify the understanding of well-being, Keyes *et al.* (2008:181) introduce two compatible traditions reflecting subjective well-being: one that focuses on feelings towards life (hedonic, emotional well-being) and another that focuses on functioning in life (eudemonic well-being). The hedonic tradition briefly describes emotional well-being (EWB) with maximised short-term positive feelings and overall long-term life satisfaction. The eudemonia tradition results in positive functioning in life and can be measured in terms of psychological well-being (PWB) and social well-being (SWB). These

authors also make use of a continuous assessment and categorical diagnoses of the presence of mental health, described as flourishing; and of the absence of mental health, described as languishing; and of a middle category of moderately mentally healthy if the adults do not fit the criteria for either flourishing or languishing (Keyes *et al.*, 2008:182).

Keyes *et al.* (2008:181) probably lead the way in terms of understanding psychosocial well-being of the individual but Fife and Wright (2000:56) add a dimensionality and impact of HIV stigma upon especially the self-esteem, personal control and body image of the individual. Sanjuan *et al.* (2013) describe well-being as affect balance, self-acceptance and environmental mastery whilst Ryan and Deci (2001:143) explain that psychosocial well-being is much more than an euphoric type of feeling of 'happiness', but rather a state of dynamic functioning based on an on-going mindfulness and self-regulation of that same well-being (Ryan, 2009:1). Baumgardner and Crothers (2010:18) concur with a number of the concepts describing well-being as a state of being subjective by nature but bolstering quality of life, life satisfaction, a sense of well-being, the presence of positive affect and a relative absence of negative affect.

Wissing and Van Eeden (2002:32) identify a sense of coherence, satisfaction with life and an affect-balance as strong indicators of general psychological wellness. Mkhize (Ratele *et al.*, 2004:5-18) focuses on the social context of psychosocial well-being and introduces inter-individuality, where the small group and the broader collective forms of life all relate to the individual's psychosocial well-being and optimal daily functioning of the individual that occurs within a collective context. Mkhize (Ratele *et al.*, 2004:5-18) explains that personhood (individualism) in the African context is defined in terms of *community*, where *community* does not only mean a mere collection of individuals each with a private set of preferences, but actually refers to a sense of community that exists if people mutually recognise the obligation to be responsive to one another's needs (Duncan *et al.*, 2007:4-23). It thus seems necessary to explore the psychosocial impact of HIV stigma whilst starting with a better understanding of the self, as such.

4.2 Impact of HIV stigma on psychosocial well-being

The self of an individual arises through the process of interaction with others, which in itself explains aspects of the term *psychosocial* and means that stigma can have a negative impact on the individual's self-concept and on interactive social responses if such stigmatisation takes on forms of social rejection, economic discrimination, internalised shame and social isolation (Fife & Wright, 2000:51-52). The complexity of stigma is experienced subjectively and is partly dependent on existing values and perceptions with regard to deviant behaviour and the responsibility of an individual as well as the social circumstances or environment of the individual, such as participating in a homosexual lifestyle (Fife & Wright, 2000:51-52). Pinel and Bosson (2013:55-63) suggest the use of an objective self-awareness analysis of stigma to find middle ground between opposing views, respectively stating that stigma impacts negatively on the self and that only public stigma harms the self-esteem. Pinel and Bosson (2013:61) conclude that relief for the stigma-targeted individual could be found in exercising the mind to avoid focusing on a stigmatised status but rather focusing on personal values and goals. This is in line with Alonzo and Reynolds (1995:303), who more than a decade ago contributed to the understanding of HIV stigma in terms of its trajectory of four phases as experienced by the HIV-positive individual. Firstly, the risk phase is associated with pre-stigma and 'the worried well'; secondly, the diagnosis phase is a confrontation with an altered identity; thirdly, the latent phase involves living between illness and health; and fourthly, the manifest phase is basically the passage to social and physical death.

The psychosocial impact of HIV and AIDS in developing countries seems overwhelming and could certainly impact on both PLWH and PLC (Foster & Williamson, 2000:281). Mak *et al.* (2007:1555) tried to test an explanatory model regarding the relation between HIV stigma and the mental health of PLWH, but found that the medical status of PLWH did not contribute to their level of self-stigma or mental health. It was found, though, that the subjective, phenomenological experience and the social, interpersonal context in which the PLWH live, are more pivotal to their overall subjective well-being (Mak *et al.*, 2007:1555). Although Makoe *et al.* (2008:1362) found that community-level stigma could be decreasing, they also observe that the quality of life for those living with HIV remains fragile and often dependent on continued

efforts by health care providers to reduce and eradicate stigma (Makoe *et al.*, 2009:1362). Greeff *et al.* (2009:475) came to a conclusion from a cohort study involving 1457 HIV positive persons in a one year longitudinal design that perceived HIV stigma has a significantly negative and constant impact upon life satisfaction and the 'quality of life' of people living with HIV infection or AIDS. Greeff *et al.* (2009:475) therefore note that in the absence of any intervention to address and reduce stigmatisation, individuals will continue to report poorer life satisfaction evidenced by reduced living enjoyment, a sense of loss of control in life, decreased social interactivity and decreased perceived health status. A subsequent study by Greeff *et al.* (2010:10) refers to social capital as component of a better quality of life that will embrace social networks with trust and tolerance amongst members. Internalised stigma in PLWH was found to have a significantly negative correlation with Quality of Life (QoL) in the psychological domain as well as a significantly negative correlation in the environmental domain (Greeff *et al.*, 2009:319; Greeff *et al.*, 2010:3; Makoe *et al.*, 2009:1358).

A lack of access to work, possible reduced income, change of employment status as well as change in social roles for people living with HIV need to be addressed in stigma programmes, and Nyblade (2006:341) stresses the need for more people to become aware of stigma as socially inappropriate or undesirable behaviour. Ghanaian women will for example support their husbands when they have HIV or AIDS, but men in that country will abandon their wives who are HIV positive (Asiedu, 2010:5). Greeff (2010:2) found that themes such as the ability to maintain life functioning, isolation, getting sick and continuous hardships were all variables that affected the quality of life of persons living with HIV and AIDS.

Ensuring psychosocial well-being for PLWH and PLC in spite of stigma experiences poses serious challenges and Yang and Kleinman (2008:403) go as far as to use the term *social death* instead of *stigma*. They combine the psychological and sociological models and propose that stigma is a moral experience that encompasses a set of social norms and obligations that constitute the essence of life for people living in a particular community. 'Social death' refers to the power of people in a society holding attitudes and behaviour that turn the stigmatised person into an 'other' or a non-person with a differentness because of which they are made to endure dehumanising behavioural treatment such as jokes being made about them. 'Social death'

(stigma) requires adjustment life strategies and determined intentions towards quality of life if psychosocial well-being were to emerge from stigma experiences (Yang & Kleinman, 2008:403). Foster and Williamson (2000:282) believe that PLWH are vulnerable to feelings of self-hatred and add that stigmatisation could very well be associated with a low self-esteem and adverse mental health for PLWH.

However, the most distressing aspect is probably the influence of the AIDS pandemic and HIV stigma on the psychosocial well-being of children of PLWH as a result of their early exposure to the stark realities of painful life and death experiences concomitant with received stigma. Foster and Williamson (2000:282) report on a Ugandan study where it was found that most children felt hopeless or angry when their parents became sick or died. The typical consequences of this issue are stigmatisation, dropping out of school, changing friendships, increasing workload to include care for parents or siblings, discrimination and social isolation of orphans. Foster and Williamson (2000:282) found that children react critically to the trauma relating to parental illness and death. They feared the death of their parents and developed levels of depression with feelings of little hope for the future, for a job, or to ever get married and raise a family of their own. These factors contribute to the vulnerability of these children and as a result they often employ coping mechanisms like becoming sexually active at an early age to overcome peer pressure, economic suffering, inadequate care and insecurity. The situation is exacerbated because they have weak or no supervision.

HIV stigma-related vulnerabilities like the above-mentioned give rise to a need for coping and problem-solving skills. Makoe *et al.* (2008:140-141) described 17 such life strategies that could assist PLWH in five African countries to deal with HIV stigma and found that 44.9% of these strategies were emotional coping strategies whilst 55.1% were of a problem-solving nature. The problem-solving coping strategies involve addressing the problem directly and engaging with others about it, like engaging with other PLWH, joining a group, disclosing their sero-status, receiving counselling, helping others, changing lifestyle, keeping busy, acquiring more knowledge and learning from others (Makoe *et al.*, 2008:141-143). Pachankis (2007:334-337), Makoe *et al.* (2008:137), Latrofa *et al.* (2009:85) and Molero *et al.* (2011:610) support the essence of the 'rejection-identification' theory of Schmitt and Branscombe (2002:184),

suggesting that members of stigmatised groups find it easier to cope with prejudice and discrimination and to strengthen their psychosocial well-being if they identify with other similarly 'stereotyped' people and if they find an acceptable place and meaningful role in that 'community' or part of society. This would presuppose disclosure (of HIV status) and could counteract the effects of concealment such as preoccupation, vigilance and suspicion, which in turn activate affective implications like anxiety, depression, hostility, demoralisation, guilt and shame; which on their part again will influence future behaviour (Pachankis, 2007:330).

Makoe *et al.* (2008:145) commented that the above coping strategies appear to be mostly self-taught and only modestly helpful in managing perceived stigma. A number of reliable and validated measuring tools were chosen to scientifically contribute to strategically building psychosocial strengths for PLWH and PLC. A 26-item measure of perceived ability to cope effectively with life's challenges was originally developed by Chesney *et al.* (2006:421-437) in collaboration with Bandura (Van Wyk, 2010:19) to investigate the efficacy of a Coping Efficacy Training intervention for reducing psychological distress and increasing positive mood in people coping with chronic illness. The particular scale (SCE) showed potential to also test change-over-time in self-coping efficacy in terms of three aspects, namely 'Use Problem-Focused Coping,' 'Stop Unpleasant Thoughts and Emotions', and 'Get Support from Friends and Family' (Van Wyk, 2010:19).

The literature that was consulted also mentions positive effects of stigma or stigmatisation. Thomas *et al.* (2005:795) found negative correlations between internalised stigma and the psychological and environmental domains, and placed stigma in a cultural context which made some individuals determined to rise above their circumstances and to improve their quality of life as a direct result of the stigma they experienced. Pachankis (2007:339-340) pointed out that selective and genuine disclosure of HIV status by PLWH often triggers genuine interaction, deeper support and trusted feedback. Wong *et al.* (2009:220) also mention the positive effects of empowerment for those who disclosed their HIV status and manage to overcome the initial feelings of powerlessness caused by stigma and stigmatisation and who can then engage in positive life strengthening activities.

5 HIV stigma and health behaviour

The member states of the United Nations founded the World Health Organisation on 7 April 1948 with one fundamental objective in mind: the highest possible level of health for all people. Health was then defined in the opening statement of the WHO as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (Jadad & O’Grady, 2008:1363; Wissing, 2000:101-102). Two important health paradigms emerged over the years and Wissing (2000:101-102) describes a traditional pathogenic paradigm that focuses on illness and vulnerabilities and a salutogenic paradigm that focuses on health, strengths, capacities and well-being (Wissing, 2000:101-102). Health promotion then, according to Dines and Cribbs (1993:24), seeks to improve the health status of individuals and communities through health behaviour that contributes to optimum health of individuals, families and communities. Fitzpatrick and Whall (1996:197) describe health as a state of well-being that is facilitated in a context of culture, values and expression. Pinkoane (2005:13) also indicates that health problems often stem from disrespect for, or a misunderstanding of, social and cultural activities and behaviour. From an African perspective, disease can for instance be seen as intentionally caused by God, the ancestors, witches or even by pollution as a result of people’s interaction (behaviour) with the external environment. The remedial action which is planned accordingly, explains why a traditional healer and biomedical staff may be consulted simultaneously (Pinkoane, 2005:14).

Dines and Cribbs (1993:9) suggest that a linear continuum between health and disease (ease and dis-ease) could be too polarised and simplistic to represent reality since one aspect of health, such as emotional health or well-being may be good whilst physical health could be very poor; or physical health could be excellent whilst mental health could be poor. Brettelle (1991:126) maintains that harmful (health) behaviour could be the root cause of ill health but also remarks that it is learnt behaviour that could be unlearnt or changed. Kelly *et al.* (1993:1025) indicated more than a decade ago that the behavioural sciences were challenged to develop theory-based programmes to reduce risky health behaviour (habits) and increase healthy behaviour directed at learning and maintaining unquestionable health behaviour through new habits.

Fishbein (2000:274) suggests that efforts to remedy behaviour should best focus on specific behaviour and be directed at a single rather than at multiple behaviours and factors. His argument is based on the four basic elements of behaviour, namely action, target, context and timing; and also on how these would relate to variables like attitude, skill, intention and environmental constraints, since these all influence habitual behaviour. Fishbein (2000:274) explains the process of how action (using), target (condom), context (vaginal sex with two partners) and timing (always/sometimes) interact with attitude and intention toward risky or healthy behaviour. The four elements also connect with self-efficacy or the skill to say no or actually correctly use a condom, or the skill to negotiate peer pressure or environmental circumstances like violence, substance abuse or poverty. All these at times influence behavioural activity. According to Bonell and Imrie (2001:155) all HIV behavioural remedy actually aim to alter behaviour that renders individuals vulnerable to disease like HIV infection and related implications like stigma. Taylor (2001:793); Genberg *et al.* (2007:772), Mallory *et al.* (2007:359) and Greeff *et al.* (2010:2) concur with this and add that health and disease as well as health behaviour towards health or disease seldom remain an individual concern, since its influence undoubtedly broadens to include community and societal issues like HIV and AIDS, risky health behaviour and barriers to preventative health behaviour or stigma and discrimination. Along these lines, Dlamini *et al.* (2009:386) demonstrate that perceived stigma has a significant correlation with the health behaviour of PLWH, for example when PLWH choose to miss medication, which implies greater vulnerability to the disease and a greater chance of spreading HIV, but which safeguards them against exposure to stigma and stigmatisation for the time being.

5.1 Operationalisation of health behaviour

Duncan *et al.* (2005:18) found that even if PLWH were not stigmatised and their perceived risk of HIV infection were high, it did not necessarily translate into a change in their high-risk behaviour. Link and Phelan (2001:381) suggest that a successful change intervention will have to succeed in changing attitudes and belief systems as well as power relations that underpin the ability of dominant individuals or groups to stigmatise others. Corrigan (2004:115) also describes the notion that advocacy as well as research can play a significant role in changing

stigma, whilst research will have to offer technical and theoretical wisdom to facilitate advocacy and change. Setswe (2009:5-6) questions the mechanisms and effectiveness of health behaviour change methodologies and also whether the motivator of behaviour and behaviour change resides in dimensions of character or attitude, willpower, physical/psychological/mental strengths, peer pressure, psychosocial interaction or spiritual well-being. Setswe (2009:5-6) concludes that current methodology does not deal with risk management and the vulnerabilities of PLWH specifically enough.

A number of prevalent HIV-specific preventative activities that function within the context of HIV stigma involve health behaviour and are aimed at behaviour change. These will firstly be discussed, and will be followed by a section on general behaviour change theories and models that might offer useful elements, principles and methodologies to bridge the gaps in behaviour change efforts directed at HIV prevention and especially HIV stigma reduction and eradication.

5.1.1 Acceptance of HIV and AIDS within the context of a lifetime illness

As with many chronic health problems, Weiss *et al.*, (2006:277) argue that health-related stigma contributes to a hidden burden of illness and the affected individual or community has to come to grips with this pain. Holzemer (2012:76) reports that in the USA, HIV has shifted from being a death sentence to being viewed as just another manageable chronic disease like diabetes or hypertension. The management of a long-term illness like HIV and AIDS requires the cooperation of the infected person and therefore their acceptance of their HIV status as motivator and commitment to appropriate activities for health behaviour modification (Foster & Gaskins, 2009:1310). In a context that can be applied to HIV, Mashadi (2012:10) suggests that the sick could utilise voluntary cognitive behaviour strategies like positive goal setting, the identification of their personal strengths and scheduled distraction activities to counteract negativity and to direct determined behaviour and new habits like changed sexual practices and preferences.

5.1.2 Increased information, education, condom use and sexual preference

Increased information and effective communication are critical in a hyper-endemic country like South Africa and should reach key populations while still ensuring that the general population is

well informed and able to prevent and mitigate the effects of HIV and HIV stigma (according to the National Strategic Plan 2012-2016 (NSP), SANAC, 2011:15). Bonell and Imrie (2001:161) found that the offering of HIV awareness and education yielded deeper understanding of HIV, skilled condom use, more discreet choices of sexual partners and even changed lifestyle strategies, which have all been increasingly effective over the last decade. Setswe (2009:5-6) offered practical ways to cater for all possible risks and vulnerabilities to ensure more successful HIV prevention and HIV stigma reduction through processes of purposeful engagement, where PLWH share information and education sessions in a group context, share past experiences, social pressures, risk perceptions, difficult choices regarding the number of sexual partners, condom use and negotiations as well as other personal concerns and motivation.

5.1.3 Regular HIV counselling and testing (HCT)

The South African National Strategic Plan (NSP) 2012-2016 prioritises HIV testing to such an extent that a sub-objective under the second strategic objective of this policy document (SANAC, 2011:16) states that everyone in South Africa should be tested annually. HIV counselling and testing (HCT) are probably among the more important health behaviours expected to stem the tide of HIV. According to Bonell and Imrie (2001:158), this could link to the sociological theories because of the potential sociological advantages of HCT. 'Knowing one's HIV status' gives a sense of control to people living with the HI virus and those who were feeling uncertain. It provides freedom and motivation to build a new 'rest of my life' strategy. According to Bonell and Imrie (2001:157), these strategies could include careful consideration of risky sexual behaviour, choices of sexual partners, preparedness for condom use or abstinence or careful consideration of treatment 'buddies' or support partners. Importantly, Uys *et al.* (2009a:1065) have found in an African intervention that included nurses, that although they did not experience a change in associated stigma or self-esteem within themselves after exposure to a specific stigma reduction intervention, their own testing behaviour increased significantly.

HCT follows on the foundation laid by voluntary counselling and testing (VCT) which has been central to the South African government's strategy of HIV and AIDS prevention and care and

support for those living with the HI virus for the last decades (Birdsall *et al.*, 2004:1). The national AIDS Helpline was one of the communication strategies that were used since the late 1980s, and some focus group data in 2003 revealed that VCT calls to the Helpline generally related to one of four main themes, namely reluctance to test for HIV, safety and accuracy of HIV testing, understanding of HIV test results and the lack of counselling (Birdsall *et al.*, 2004:3). The UNAIDS suggestion of a policy statement on HIV testing, underwritten by the WHO, was published in the same year as the above-mentioned report on the AIDS Helpline. Mention was made in the same policy document of the proclamation of the '3Cs' principles of VCT/HCT to be followed, namely Confidentiality, Counselling and Consent (UNAIDS, 2004:2-3). An interesting study on a dynamic HIV and AIDS workplace programme in five African countries reported that educational and promotional activities sparked a positive response for employees and their spouses but that the average uptake of the VCT offering of this multinational brewing company varied between 15% and 32% only (Van der Borghet *et al.*, 2010:195). Another workplace study, in a mining sector workplace, also demonstrated a significant gap between VCT (being exposed to voluntary counselling and testing) and the uptake of treatment (Bhagwanjee *et al.*, 2008:271). Some of the reasons will be dealt with in the next section regarding treatment and adherence.

5.1.4 Access and adherence to treatment

Barriers to the uptake of treatment after testing in the above-mentioned mining sector workplace were found to be related to perceived confidentiality violations on the part of healthcare staff, fear of having to cope with the illness itself and fear of organisational HIV stigmatisation and discrimination (Bhagwanjee *et al.*, 2008:271). Dlamini *et al.* (2009:377) provide evidence of a significant and stable correlation between perceived HIV stigma and self-reported reasons for missed medications over a one year period. These findings suggest that poor adherence to ARV medications over time and a delay in seeking care or starting treatment (Makoe *et al.*, 2009:1357) are amongst others linked to the HIV stigma experience of people living with HIV. In addition, people fear that their HIV status will become known if they take ARV, and they would rather miss dosages than risk disclosure (Makoe *et al.*, 2009:1361). The stress about disclosure is increased if they must bring along a treatment partner, as is a

requirement in some countries or public programmes. As HIV stigma decreases in the environment of PLWH, fewer instances of missed medication dosages are reported (Dlamini *et al.*, 2009:377).

Greeff *et al.* (2008a:320) found that counselling and the provision of information, education and advice facilitate the uptake of treatment. They emphasise the challenges of coping with the side-effects of some of the ARV regimes and the HIV stigma challenges in accessing medication, taking it at specific predetermined times and missing dosages. The UNAIDS (2004:1-3) explains the importance of up-scaling antiretroviral treatment into low and middle income countries, with the proviso that emphasis will be on improved protection against HIV stigma and discrimination as well as assured access to integrated prevention, treatment and care services. Bonell and Imrie (2001:157) suggest that social psychological models too often overlook situational and HIV stigma factors that might actually shape health behaviour in everyday life.

One such example could be to take time off work on a regular basis to access health care services. Zimmerman *et al.* (2000:1409) also explain that adherence lapses or a relapse during a treatment programme should be accommodated and viewed as normal in terms of the degree of difficulty and challenge that can be experienced, rather than be viewed as failure on the side of PLWH or their physicians, since their goal should be long-term self-maintenance (Zimmerman *et al.*, 2000:1409). Setswe (2009:5-6) also highlights the differences between the mechanical effectiveness of health behaviour change and motivating aspects driving behaviour and habits that could reside in dimensions of character or attitude, willpower, physical/psychological/mental strengths, peer pressure, psychosocial interaction or even spiritual well-being. This relates to the Value Expectancy Theory that suggests that people normally only engage in behaviour that provide benefits (Hubley, 1988:134). Dlamini *et al.* (2009:386) stress the importance that HIV stigma challenges should be discussed in depth with PLWH before they are offered ARV regimens at all. A further aspect to consider in terms of accessing and adherence to treatment is emphasis of the NSP 2012-2016 (SANAC, 2011:16) on dual protection against HIV and HIV stigma, with reference to a the plan to increase access to a package of sexual and reproductive health services for PLWH, medical male circumcision for

adults and neonates, provision of both male and female condoms, termination of pregnancy and provision of contraception.

5.1.5 Responsible HIV disclosure management

Literature seems to vacillate between those who profess and those who question the value of disclosure, since the step could be life changing. Greeff *et al.* (2008a:320) found similar reasons for refusal to disclose HIV status as those described in other literature, such as anxiety to face the moment of telling, denial of the diagnosis, comfort in keeping the secret and to continue living as before, fear of the unknown effects that disclosure might have on family or associated others, fear of being ridiculed, rejected, and fear of being blamed for having the disease. The study also acknowledged that it is not to be assumed that disclosure necessarily is the right and best thing to do for all people at any given time. Hubley (1988:134) explains that the choices regarding whom to disclose to and how to disclose as well as the disclosing person's perceived likelihood of possible adverse consequences of such an act of disclosure, determines an individual's attitude or intention towards whether to disclose or not. Greeff *et al.* (2008a:320) report that counselling and provision of information, education and advice often ensure better disclosure management by PLWH.

With reference to the significance of disclosure of HIV status, Watson (2002:170-172) emphasises cultural sensitivity, culture-congruent communication, acceptance of the person, genuine caring and respectful interaction as factors influencing the attitude and decision-making process leading to disclosure. Greeff *et al.* (2008a:312-313) theoretically defined categories of disclosure and explored the factors that influence decisions of disclosure. They found that most people living with HIV have disclosed their HIV status to at least one other person. Responses received varied from acceptance and support, to rejection or subtle distancing. In contrast, Foster and Gaskins (2009:1310-1313) found that PLWH stated that they would not disclose their HIV status or expect any meaningful support from a church-like setting or institution. Greeff *et al.* (2008a:312-313) point out the dichotomy that disclosure can be therapeutic to some, but a significant and recurrent stressor for others.

Wissing (2006:141), although in a different context, promotes openness as a way to move from a fearful problem-solving attitude (with constant worry about disclosure) to an approach of openness, appreciation of own strengths and a dynamic and open-ended psychosocial well-being with goal-directed planning for the rest of their lives. A study with 225 participants in five African countries (Greeff *et al.*, 2008a:318-323) revealed disclosure as a significant strategy to address stigma on different levels and to also address prevention and care. It also revealed the motivational factors for disclosure of HIV status. These were a number of personal needs, namely to break the silence and seek understanding, to find support and prayer, to receive funds to access medical services and to ensure correct care for developing symptoms. It was also mentioned that disclosure should be for the sake of others, to help them not to make similar mistakes, to provide them with enough knowledge on the spreading of HIV in the community, to ensure sufficient support and clarity for PLWH family members, to protect vulnerable children and to change community stigma perceptions regarding HIV and AIDS. Greeff *et al.* (2010:11) report that PLWH who disclosed to a friend had higher baseline scores on a social activity inquiry scale regarding their quality of life. The element of 'negotiated safety' is relevant to this, and according to Bonell and Imrie (2001:155) it is aimed at the negotiations between partners for promotion of 'condom-protected sex' between individuals of different sero-status and possible agreed unprotected sex with each other only by disclosing partners of the same HIV status.

5.1.6 Support-seeking behaviour

The health behaviour of PLWH is often influenced by the fear of being stigmatised and losing personal care and support. Relf *et al.* (2005:14-22) studied the message voiced by PLWH at an urban clinic setting and concluded that high levels of HIV stigma were associated with decreased quality of life and a need for compassion, care, acceptance, openness, friendship, sharing and respect (Relf *et al.*, 2005:17). PLWH also referred to job security as a crucial part of the support they needed and this was linked to the burden of protecting their PLC, such as like their family, partners, children, colleagues or friends (Relf *et al.*, 2005:19-20). Foster and Gaskins (2009:1310-1311) identified spiritual beliefs and such personal practices as a great support, although almost all PLWH felt unsafe and unsupported by their various churches or

pastors. Support groups have traditionally been recognised for their value to provide emotional support to individuals and although they do not replace typical psychotherapy or counselling, they offer a place of sharing of experiences and ideas on how to deal with common demands and difficulties and contribute to a mutual objective of giving and receiving support (Social Tract 2:37-2).

5.2 Health behavioural change in context of change theories in general

The Chinese word for change is wei ji, which means “two things in the same concept”. It means both crisis and opportunity ...

(Salerno & Brock, 2008:170).

Many behaviour change and behaviour change communication models, techniques and studies have been documented. Mirembe (2012:Sept. 24) warns that there is no single solution when it comes to behaviour change communication focused on HIV stigma reduction and the spread of HIV, since the end result would be best if the design of the behaviour change communication accurately speaks to specific outcomes, needs and contexts.

Moore and Charvat (2007:67) found that current health-related behaviour change efforts had limited effectiveness with regard to sustained change-over-time. The last two decades brought an understanding that no singular profession or discipline on its own had exhaustive answers to the challenges offered by HIV stigma and the broader pandemic. Nicolescu (2007:2) explores transdisciplinarity as a possible solution in seeking knowledge across the boundaries of specific disciplines. It refers to explanatory and meaningful contributions made ‘beyond disciplines’ by trans-disciplinary partnerships that have been emerging as an innovative approach to health behaviour change interventions since about a decade ago in the work of researchers like Jordan and Bazzarre (2002:500). The focus of such a partnership would be on common elements that drive behaviour across the spectrum of health risk habits through the lenses of different disciplines. UNESCO (1998:41) started conceptualising a broader perspective on diversity, respectful confrontation and mutual transformation of disciplines with people striving towards

synergy and with an aim of meeting one another across barriers and genuinely enjoying such an encounter of people with scientifically transformed minds. UNESCO (1998:41) compares transdisciplinarity to an orchestra where everybody plays a part to harmonise together into a meaningful symphony.

A summary of behaviour change theories will be offered below. These change theories or models guide change processes in general but they can be applied in different circumstances, for a variety of preferred outcomes and in different cultures, when in fact the participants themselves become the change agents within their own skin, circumstance and culture (Gladwell, 2002:19). These theories will be explored in order of date of references, to illustrate that they are appropriate and applicable for health-related behaviour change:

- Longo (2011:22/05 blog) describes the 1947 pioneering change management work of Kurt Lewin and his change model as one of the first of its kind and as forming the basis of many other change process models. It is a simplistic model with three stages (unfreeze, change, re-freeze) as its fundamentals. The 'unfreeze' stage is a pre-stage of change and prepares the ground, builds up urgency and understanding of the need to change and sells the outcome of such change. The 'unfreeze' stage is followed by the 'change' stage, when the changing of behaviour should occur. Once the changes have been implemented and results are starting to show, a new stability is sought and then the 're-freeze' stage starts as new behaviour is internalised and becomes the norm.
- Fishbein and Ajzen (1975:405-410) developed the Theory of Reasoned Action Model for behaviour change based on three basic theoretical assumptions: information and integration theory; expectancy-value theory; and predicting attitude towards a behaviour theory. The Theory of Reasoned Action is effective for the prediction of behavioural intention, spanning predictions of attitude and predictions of behaviour. There was a subsequent development in psychology, where the Theory of Planned Behaviour is seen to link beliefs and behaviour with each other and thus as an improvement of the original Theory of Reasoned Action (Ajzen, 1991:179-211). The concept, proposed by Icek Ajzen, improved on the predictive power of the theory of reasoned action by including perceived

behavioural control and is therefore one of the most predictive persuasion theories available to be used in behaviour change interventions.

- Prochaska and DiClemente (1983) developed the Trans-theoretical Model for Behavioural Change (TTM) as a model of intentional change that focuses on the decision-making capabilities of the individual rather than the social and biological influences on behaviour as many other approaches tried to do. The critical *assumptions* of the TTM include stages, processes, self-efficacy and decisional balances of change (Prochaska & Velicer, 1997:38-48). Norcross *et al.* (2011:143) explain that the trans-theoretical model (TTM) describes behaviour change basically as a process that unfolds *over time* and involves progression through five stages of a) pre-contemplation, b) contemplation, c) preparation, d) action and e) maintenance. The changing person moves from no real awareness through conscious action towards an eventual maintaining of change *lasting for at least six months*. Marshall and Biddle (2002:229) saw the strength of the trans-theoretical model in the fact that it views change as 'dynamic' rather than an 'all or nothing' phenomenon. The TTM gleaned elements from about 400 different psychotherapies for the promotion of behaviour change. Marshall and Biddle (2002:242) and Norcross *et al.* (2011:143-154) reported on about 10 basic processes of change that were found to be generically present in these mentioned psychotherapies and eventually gave rise to the TTM development. Zimmerman *et al.* (2000:1410-1412) note that the TTM incorporated the locus of control theory, health belief model, motivational interviewing, cognitive-behavioural therapy and the applied twelve-step programme in its mechanism to facilitate a person's movement through different stages of change.
- Kersell and Milsum (1985:119) introduced a systems model of health behaviour change levelled at the individual in relation to the subsystem of health behaviour. The model integrates social, environmental, psychological, and physiological factors in describing the health behaviour change process. It is not intended to be quantitatively predictive of behaviour change, but rather focuses on the surrounding system(s) as well as the attitude within the individual. In reality this could be seen as the dilemma created by stigma where the experiences of social rejection, disapproval and discrimination may inflate the shame felt by PLWH and may lessen their motivation to maintain optimal health.

- The BASNEF model (Hubley, 1988:134-138) refers to a model compiled by the community perspective checklist of constructs, namely **B**eliefs, **A**ttitudes, **S**ubjective, **N**orm and **E**nabling **F**actor. Whilst these constructs are crucial in the response to social pressure and empowerment within the community, a decision-making process for health education and promotion needs to adhere to the following aspects: a) ensuring improved health, b) realistic modification, c) provision of empowerment, d) mitigation of social pressure, e) identification of beliefs and attitude and f) establishment of locus of control.
- The health belief model (HBM) (Stretcher *et al.*, 1997:71-91) is a psychological model that explains and predicts health behaviour. The model focuses on an explanation of the a) attitudes, b) beliefs and c) health behaviour of an individual. It furthermore holds core assumptions regarding the individual's health-related actions when negative outcomes can be avoided and, lastly, the model uses six components of perception to predict threats or advantages, namely a) perceived susceptibility, b) perceived severity, c) perceived benefits, d) perceived barriers, and e) cues to action and self-efficacy.
- Marshall and Biddle (2002:229-230) build their mostly reactionary type model on three factors to mediate a change process. The process starts with the identification of a specific problem and proceeds through a) the individual's 'self-efficacy for change', b) the 'decisional balance statement' of perceived advantages and disadvantages of the planned change, and c) the 'modification strategies and techniques' for achieving change of thoughts, feelings and behaviour, as the three powerful mediating factors ensuring the change.
- Kotter and Cohen (2002:179-181) developed a change motivation model based on an assumption that people do not normally like change and that they only become more motivated for change when they a) recognise and confront their reality as it truly is, when they b) feel their fear, frustration and discomfort and when they c) then have a change of heart or an inner transformation that d) bravely articulates into determined changed behaviour.
- Gladwell (2002:19) indicates three possible change agents in his book *the tipping point*, which specifically deals with ways to address an epidemic/pandemic like HIV and HIV

stigma. These three change agents are the 'Law of the Few', the 'Stickiness Factor', and the 'Power of Context'. Any of these three change agents could be the 'tipping force' that changes the equilibrium of an epidemic. The HIV epidemic can, through the eyes of Gladwell (2002:19), be seen as a function of the people who transmit the HI virus (law of the few), the HI virus itself (stickiness factor), and the environment in which the HI virus is operating (power of context). These change agents could have bearing on the approach applied for change when focussing on HIV prevention and stigma reduction. The law of the few deals with a relatively small number of people that can infect many and affect even more; the message for those who are infected and affected should be catchy or 'sticky' enough to stick in their minds; and thirdly the context could be the social standing or peer pressure and should not be underestimated, since it could powerfully influence the change capacity.

- Harvard Business School (2003:33-49) presented a model of guiding elements necessary for change to take place. It identifies seven steps that always need to be present if change is to occur: a) mobilise energy and commitment, b) develop a shared vision, c) identify leadership, d) focus on results and activities, e) start change at the periphery and let it spread inwardly, f) institutionalise success through formal policies, systems and structures, and g) monitor and adjust strategies in response to challenges in the change process. The Harvard Business School (2003:60-62) gives significant guidelines in terms of relentless communication to keep the change process stable and intact.
- A stigma-change model produced by Corrigan (2004:113-121) was developed for mental illness stigma but its fundamentals are useful for HIV and AIDS-related stigma as well. It is a target-specific stigma change model which essentially targets two elements of stigma, namely a) powerful groups (like landlords, employers, health care providers) and b) discriminatory behaviour (like not allowing stigmatised people to rent a place to stay, or to acquire a sustainable job, or to access care facilities, medicine and sound medical advice or treatment). Corrigan (2004:118) explains that there is a crosswalk between the attitude of powerful people and the discriminatory behaviour that follows. Behaviour is more likely to change when strategies to reduce stigma target attitudes that directly correspond with the specific targeted behaviour.

- Kotter and Rathgeber (2006:30-132) used a colony of penguins to tell the story of change in a relaxed manner, with the title 'The iceberg is melting'. The eight steps in their change model revolves around setting the stage by a) creating a sense of real urgency for change; b) pulling together the guiding team; c) deciding what to do through developing a change vision and strategy; d) making the change happen; e) applying communication towards understanding and buy-in; f) empowering others to act and produce; g) short-term wins to celebrate and to not ever let up; and h) creating a new culture that would make the change stick.
- The causal modelling approach for behaviour modification of Hardeman *et al.* (2005:676-687) is similar to the targeted model of Corrigan (2004:118). The causal model plans its behaviour modification according to clearly identified dependent and independent causes and outcomes. Behaviour can cause physiological and biochemical variables and therefore health outcomes. Health outcomes, on the other hand, can motivate behaviour modification, which will then alter health outcomes (Hardeman *et al.*, 2005:676-687).
- Moore and Charvat (2007:66) describe the Appreciative Inquiry Model (AI), which is an abundance type model with a four-D-cycle at its core. The D-cycle opens new dimensions of possibilities, strengths and values rather than problems or deficiencies. The four elements of the Appreciative Inquiry model all start with the letter 'D': **d**iscovery, **d**reaming, **d**esigning and **d**elivery. The Appreciative Inquiry is based on eight general principles that can be summarised as a process which systematically question, find and appreciate (discover) the best (deeper values) from the past and present that could form the basis of what is envisioned (dreamt) for the future of what might be, and included in an in-depth dialogue process about the creation (design) of what will be (delivery). This process moves away from focussing on a problem to be solved towards innovatively embracing the mystery of what might be. Health behaviour change strategies in terms of the Appreciative Inquiry approach are based on affirmative philosophies (Moore & Charvat (2007:67) realised through methods like motivational strength seeking a) interviewing (dialogue), b) learned resourcefulness (prioritising), c) imagery (mind-body intervention) and d) asset management (resilience).

- Boon (2007:59-60) introduces what he calls the best African way to bring about change. It mainly professes 'an interactive leadership' way where nothing happens without genuine 'bottom up involvement' of the community in its own culture. It explains continuous change as inevitable and as something that should be seen as a part of life. A strong case is made for the first step in any change effort to be plotting the individual's (or community's) current situation, flaws, baggage, weaknesses and strengths before embarking on an honest participatory route to engage in change processes.
- Salerno and Brock (2008:25) describe the full process of what they call 'The Change Cycle' model. They focus on six stages (loss, doubt, discomfort, discovery, understanding and integration), where each of these six stages harbours feelings, thoughts and behaviour. The loss includes feelings of fear, thoughts of caution and behaviour of being paralysed. Doubt includes resentment, scepticism and resistance. Similarly, discomfort involves anxiety, confusion and being unproductive; while discovery involves anticipation, resourcefulness and being energised. Understanding includes confidence, pragmatism and productivity. The sixth stage, integration, includes feelings of satisfaction, thoughts of clarity and focus and behaviour of generosity. This six-stage model is presented in a circle which includes the spaces for feelings, thoughts and behaviour within each stage and allows for exact pinpointing of change progress movement through the whole process on the circle. The model is not in the first place focused on health-related change but is exceptionally adaptable to any type of change for individuals as well as groups.
- Setswe (2009:11) focuses on a behaviour change communication model and suggests a three-tier model where stages in a 'behaviour change continuum' are firstly addressed; followed by the 'enabling factors' towards change; and finally the 'channels of communication'.

All the above-mentioned behaviour change models have a similar process in common, as they often start with the decision (or decision-making process), which includes the creation of urgency or need for change; then progress towards the selling of ideas and working towards buy-in, consulting broadly, identifying leadership and finally managing a chaotic phase with possible resistance, avoidance and disintegration. The settling down stage normally involves an exciting process of engaging participation, co-creation of a new 'future' or 'behaviour future'

whilst utilising techniques and methods that maximise participation. The adaptability of these models is clear, as they fit in well with existing processes of health behaviour change.

In addition to the above models, some researchers made contributions that are not necessarily integrated in a model but assist in understanding behaviour change and provide some extra structure for HIV stigma-reduction related behaviour change. Corrigan (2004:115) suggested that changing approaches in terms of public stigma could be grouped into three processes, namely protest, education and personal contact with PLWH. Kendra *et al.* (2012:57-61) and Boyd *et al.* (2010:1063-1070) both explored possible change of attitude through education and contact with PLWH. Boyd *et al.* (2010:1066) further suggested that contact with the stigmatised could lessen anger, blame, a need for social distance and the disproportionate apportionment of danger from the stigmatised (fear). Kendra *et al.* (2012: 57-61) also focused on education as a means of reducing HIV stigma and found that traditional lecture style teaching was less effective than personal teaching or an approach that included contact and experiential learning techniques.

Thus, HIV, AIDS and HIV stigma are first and foremost a consequence of behaviour and therefore need to be addressed by focussing upon behaviour and behaviour change (Bonell & Imrie, 2001:155; Fishbein, 2000:273). Setswe (2009:3-4) suggests that work should be planned and implemented on at least four levels, namely an individual level, a group level, a community level and a societal level. The next section will specifically focus on community-based work relating to the context of HIV stigma.

6 HIV stigma and community-based interventions

“Ants, and all other insects that live in colonies, appear to be hard wired to serve. By doing so, they ensure their survival. An anthill can survive and feed itself in some of the most hostile environments. No single ant knows how it all works – nor does it need to. Individually, ants are not that smart, but together they are very intelligent. The ant serves the anthill, which in turn serves the ant. The community the ants create and work to support is well equipped to cope with the challenge of change. In other words, the ant and the colony it belongs to is a good example of high level collaborative intelligence.”

Stephen James Joyce (2007:1)

HIV stigma is complex, multifaceted and multileveled and will have to be addressed through the changing of attitudes, beliefs and power relations that facilitate stigma and stigmatisation (Link & Phelan; 2001:381). Heijnders and Van der Meij (2006:353) create awareness, from their overview of stigma reduction strategies and interventions, that too little assessment has been done on the effectiveness of these strategies, which mostly concentrated on the individual and the community levels and which need to be extended further, since stigma is increasingly recognised as having a major impact on public health as such.

6.1 Conceptualisation of a community-based approach

Hatch *et al.* (1993:28) clarifies the term *community* by emphasising the identity of a particular community unit and the way it drives its own internal concerns, solution seeking, centre of influence and common activities. Hatch *et al.* (1993:27-31) identify four types of 'community partnerships' that could enable community-based interventions and help with the conceptualisation of these, namely 1) community representatives as advice and consent givers; 2) influential community representatives as endorsers of the programme; 3) community members as advisors, but without significant roles or influence over processes; and 4) community members as participants in identifying the direction and focus of the programmes. Hawe (1994:220) interprets *community* as meaning a geographic, demographic or social entity that could be broken down into three different functionality community concepts common to community-based interventions. *Community* could, according to Hawe (1994:201), mean a population of many people, the community as a geographic or functional setting, or the community as an ecosystem with capacity to work towards solutions for itself and its own identified problems within a particular community social system.

The sociological sciences offer considerable guidance for the design of community-based behavioural change interventions because they relate the actions of individuals to the societies in which they live (Bonell & Imrie, 2001:158). Whitehead (2002:1-8), a community health anthropologist, opens a programmatic perspective by defining *community* and *community-based* as clearly separate concepts that are both linked to effective operationalising of programmes. He describes and categorises seven different types of programmes that apparently describe themselves as community-based, namely 1) indigenous initiative without

any external support, 2) indigenous initiative with recruitment of outside technical expertise or support as needed, 3) programmes where individuals or community-based organisations pursue external funding for a specific target community, 4) programmes in which individuals or organisations indigenous to the target community themselves recruit external expertise and funding, 5) programmes initiated by external change agencies without initial input from target community, 6) programmes planned and initiated by outside agencies but inviting the community to participate on lower level as volunteers or on advisory committees, and 7) programmes which are planned and implemented as an equitable partnership between community-based organisations and an external change agency or technical organisation (Whitehead, 2002:3-4).

All the above descriptions of community, community programming and community partnerships contribute to aspects of a better understanding of the design for community-based HIV stigma reduction and wellness enhancement. Since communities consist of individuals, it is necessary to briefly consider the community and the individual.

6.2 Community and the individual

The individual operates within a community context and Bakhtin (2007:5-7), by way of illustration, expands on ‘meaning attribution’ as part of well-being and postulates that meaning is not pre-given, nor does it arise internally from within the individual. Rather, meaning is constructed actively and dialogically in our encounter with the other and emanates from the person’s encounter with his or her social world. He thus emphasises the notion of dialogue as an interchange of ideas between equally responsive subjects and reminds of the influences of broader social and cultural factors on individual development. In addition, the traditional African perspective seems to position the individual and his/her well-being within a communal existence. Lundin and Nelson (2010:27) define ubuntu as a philosophy that considers the success of the group above that of the individual, since people exist because of their connection to the human community, which means that someone is a person through other human beings. An understanding of this context can strengthen the community-based approach and design of any stigma reduction programme or intervention and conjoins with the opinion of Whitehead (2002:2) that a ‘top-down’ approach rarely achieves desired outcomes.

Ankrah (1993:5) is of the opinion that the African clanship system could become the locus of AIDS well-being and family continuation, where its leadership finds creative ways to sustain structures among communities devastated by the AIDS pandemic or fragmented by stigma. These new associations based on common emotional bonds of caring beyond kingship ties will be necessary to support some members and will prove durable in the troubled socio-economic context of Sub-Saharan Africa. Mkhize (*in* Ratele *et al.*, 2004:5-7) uses the dialogism theories to emphasise the importance of the concept of self in the psychology, but to then also strengthen the importance of dialogue as an interchange of ideas between equal individuals. It thus places the individual's health into a social context of inter-individuality where the small-group and broader collective forms of life mediate the broader psychosocial functioning. Psychosocial well-being therefore is more than a good feeling inside some individuals and dialogism could enable us to theorise about the relationship between the individual and society without falling victim to a kind of antithesis of the individual versus the society or community (Ratele *et al.*, 2004:5-18).

6.3 HIV stigma in a community-based context

The HIV and AIDS pandemic is a continuously evolving, progressive disaster and the resultant consequences of the pandemic seem dynamic and unstable (Foster & Williamson, 2000:277). There are many HIV stigma factors in communities that undermine HIV programmes and even enable the spread of HIV because stigma inhibits people to test, seek counselling or participate in prevention programmes, for fear of being stigmatised and socially cut off (Asiedu, 2010:152). Greeff and Phetlhu (2007:13) and Hilhorst *et al.* (2006:390) argue that any successful stigma reduction intervention will have to be community-based and will have to include aspects reaching both the individual and the community.

Bakhtin (2007:5-7) postulates that collective engagement by communities and the employment of innovative community-based processes could ensure more effective HIV stigma reduction and more accurate deployment of limited and shared resources in developing countries. Davids *et al.* (2009:160-162) discuss self-reliant participatory development that follows from an approach of building forums, structures and negotiations in which people throughout communities would be involved. Lasting change (e.g. stigma reduction, wellness enhancement

and positive health behaviour) would in this instance not involve the delivery of services to a passive citizenry, but would come from within communities where participatory individuals and groups are based and would not be imposed upon a community from the outside. Winiarski (2004:36) notes that the practices leading to a rise in the HIV and AIDS epidemic often occur at community level, whilst most of the stigma reduction interventions in Sub-Saharan Africa to date were information-based awareness programmes aimed at reducing ignorance (Campbell *et al.*, 2007:404) on an individual basis. Corrigan (2004:117-118) feels that a community-based focus on both discriminatory behaviour and attitude change strategies will ideally lead to mutual respect and behaviour change amongst the members of such targeted community (which includes PLWH, PLC and others). He suggests a paradigm shift based on the assumption that community-based 'stigma behaviour change' interventions would be more effective if it were to specifically target powerful groups like landlords and employers. Other clearly discriminatory behaviours like disempowering, alienating or exclusion from life opportunities on grounds of stigma could be targeted similarly (Corrigan, 2004:118).

Wong *et al.* (2009:220) link the individual and community approaches when they reported positive outcomes for PLWH and PLC after individual disclosure of HIV status by PLWH. Behavioural changes regarding sexual activities, increased social support from family and community members, recognisable spiritual resilience and more visible community involvement were emerging. Thomas *et al.* (2005:795) report that the experience of stigma sometimes make PLWH more determined to live and to experience an above-moderate quality of life that rises above stigma, avoids internalising their stigmatised feelings and works toward a better quality of life which would include psychosocial well-being and maintained changed health behaviour within their communities. Along with these positive views, Whitehead (2002:4) recognises that community-based programmes are crucial to prevent HIV infection and stigma and to encourage healthier communities. Four critical success factors for effective community-based programmes were identified by Whitehead (2002:4) and could be used as guidelines for such programmes: Assured conceptual strength and comprehensive design of the programme; rigorous discipline in implementation; effective social-cultural sensitivity, relevancy and competence; and process-oriented implementation and evaluation.

Uys *et al.* (2005:20) point out that the community's view of HIV or AIDS and the PLWH in African countries still seem to be mainly negative, derogatory and harmful and characterised by name calling and blaming terminology. These common beliefs are what perpetuate HIV stigma in communities (Asiedu, 2010:134). Uys (2005:20) recommended the consistent and deliberate use of factual references to HIV or AIDS by the health professionals and assistance for communities to figure out the impact of the AIDS pandemic on a total community. A further recommendation was that communities should be assisted with carefully planned health education, targeted anti-stigma messaging and community engagement on psychosocial well-being and health behaviour issues (Uys *et al.*, 2005:20).

6.4 HIV stigma reduction and community-based Interventions

Many stigma reduction interventions implemented in communities claim to be community-based. The attribution-model discussed by Corrigan (2000:60) aims at effectively replacing incorrect attributions and beliefs in the community with more accurate ones. It suggests three approaches for strategising anti-stigma and stigmatising programmes and to remediate poor or risky health behaviour. The three strategies are protest, education and contact. Protest, as a reactive strategy, is about diminishing negative public attitudes through groups protesting inaccurate and hostile representations of an illness as a way to challenge the stigmas they represent. Education provides information and creates better understanding regarding the stigma and discrimination and prompts more informed perceptions in order to reduce negative stereotyping. Stigma is further diminished by the effects of strategic contact between (stigmatising) public and stigmatised individuals (Corrigan, 2000:60). Foster and Williamson (2000:282) describe research regarding the impact of HIV and AIDS on children in Sub-Saharan Africa. They stress that gaps remain and that more research is needed with children of PLWH, affected communities and community-based organisations as partners in such studies.

Heijnders and Van der Meij (2006:361) concluded that community-based interventions are difficult to compare as they seldom use a common set of measurements or target groups to facilitate such comparison of outcomes. Hohmann and Shear (2002:202) emphasise the fact that a community-based intervention can never only be a replica of a randomised clinical trial, since it has to consider a whole new set of issues and has to draw conclusions from research

and interventions that could at any time be interrupted by everyday events in a community setup. These authors make the point that research collaboration with qualitative experts and statisticians familiar with longitudinal intervention designs could be the best basis for ensuring effective community-based interventions (Hohmann & Shear, 2002:205). Stein (2003:95) found some evidence that HIV stigma has diminished but also suggests continuous exploration and research to direct community-based work and ensure measureable stigma reduction. Brown *et al.* (2003:52-53) reviewed 21 HIV stigma reduction interventions and concluded that many interventions were tested and found effective on a smaller scale but were not tested with regard to their long-term impact. The types of stigma reduction interventions that were reviewed, included a) those that were information-based and targeted at the general population, b) acquisition of coping skills for dealing with HIV stigma, c) counselling approaches, and d) approaches building tolerance through personal contact with PLWH. The review among others showed that although total elimination of HIV stigma may not be attainable at the moment, the interventions can contribute towards reducing HIV stigma. It seems that using another intervention strategy – in addition to sharing basic information – increases the effectiveness of the stigma reduction. The review also shows that community-based interventions in developing countries cannot easily be rigorously evaluated.

It is clear from the review that few studies assessed sustained changes in attitudes and behaviours over time, since most post-intervention tests were conducted immediately after the intervention, without considering the possible longer-term impact of the intervention. Some of the intervention strategies, especially those for the acquisition of coping skills, were mostly offered to PLWH only (Brown *et al.*, 2001:9-16). As a follow-up on the above-mentioned review, Pulerwitz *et al.* (2010:273) summarised the range of tested innovative stigma reduction strategies at the institutional and community levels for the purpose of achieving individual, social and environmental change in HIV stigma. These intervention strategies are a) recognising stigma in institutions, e.g. hospitals, b) addressing social stigma and the environment, c) responding to the needs of stigmatised populations, d) utilising the media to show the human face of HIV, e) involving PLWH in service delivery, f) engaging the community, and g) expanding antiretroviral therapy. Pulerwitz *et al.* (2010:279) further describe four key dimensions of stigma that have been articulated and tested through the findings of the review: inappropriate

fear of contagion, negative judgments about PLWH, enacted stigma or discrimination and compounded stigma.

Another desktop review of stigma reduction strategies and interventions prior to 2007 was reported by Heijnders and Van der Meij (2007:354-360), who categorised the strategies as those on a) intrapersonal level, b) interpersonal level, c) organisational or institutional level, d) community level and e) governmental or structural level. They identified numerous interventions within these levelled strategies, such as treatment, counselling, cognitive behavioural therapy, empowerment, group counselling and self-help, advocacy or support groups on an intrapersonal level. At an interpersonal level, care and support, home care teams and community-based rehabilitation were suggested; and training programmes and policy development on an organisational level. On community level, the focus was on education, contact, advocacy and protest; and on governmental or structural level it was on stigma reduction strategies like legal and policy interventions as well as rights-based approaches. They concluded that interventions associated with cognitive therapy, counselling, home-based care, education and contact appeared to be more effective. Uys *et al.* (2009a:1059-1066) developed an HIV stigma intervention based on the Holzemer *et al.* (2007) conceptual model of stigma and combined information sharing, increasing contact with affected and improved coping through empowerment as its basic tenants. Although the intervention yielded positive outcomes within health settings in African context, its sustainability was not tested and applicability within community-based settings was not confirmed (Uys *et al.*, 2009a: 1059-1066).

Yet another and recent systematic review of 19 HIV interventions for the reduction of HIV stigma was published by Sengupta *et al.* (2011:1075-1087) and aimed at determining the quality of these studies (even if some formed part of other reviews) and their effectiveness to reduce HIV stigma. The elements of this review were firstly to search for more interventions that effectively measure HIV stigma reduction pre and post intervention, secondly to assess the risks of bias at design and outcomes levels and thirdly to make recommendations for future planning of stigma reduction interventions. These authors started with 515 abstracts and after elimination they reviewed 19 studies and found 14 to be effective for reducing HIV stigma. They reported the following gaps in the overview of stigma reduction interventions: a) too few

interventions specifically targeting HIV stigma, b) disparate and inadequate measuring of HIV stigma reduction, c) unclear public health benefits from statistically significant HIV stigma reduction interventions, and d) lack of internal validity (Sengupta *et al.*, 2011:1082-1083).

Rotheram-Borus *et al.* (2011:315) observe that until recently there were no frameworks to guide core elements of interventions and they nominate four common challenges after a thorough overview of 'interventions for families affected by HIV'. These nominally are to maintain physical health, acquire positive mental health, stop transmission and deal with relationships and its complexities. Rotheram-Borus *et al.* (2011:315) identify these relationships as those with family and partners (including parenting), with friends and acquaintances, with co-workers and with health care providers as the four major types of social relationships impacted by HIV. In each of these four challenging domains and the four types of relationships, disclosure, stigma and the management of HIV as a chronic illness are addressed by all the interventions in the overview (Rotheram-Borus *et al.*, 2011:315). A refreshingly frank article by Cross *et al.* (2012a:62-70) resulted from a workshop aimed at setting guidelines for health-related stigma reduction interventions. It criticises the position that efforts to identify possible interventions are frustrated by the fact that the evidence supporting such interventions is often sparse and/or weak. They concur with some of the above overviews, like Brown *et al.* (2003:52-53) and Heijnders and Van der Meij (2006:354-360), that some interventions are perhaps effective in the short term but generally lack common measurement and comparison. It further appears as if multi-method approaches are more promising, for example a combination of information sharing and skills building, or information with personal contact approach (Cross *et al.*, 2012a:62-70, Brown *et al.*, 2003:52-53). The measurement of stigma reduction following an intervention remains a challenge and often forms a secondary part of a programme on discrimination, transmission or prevention, in which case the stigma in its complex, identifiable types of manifestation and power relations is not directly targeted or as such measured (Cross *et al.*, 2012a:64).

Campbell *et al.* (2007:405) contributed a six-factor model to address the gap between information and skills building and the re-working thereof to shape cognitions at the unconscious, community and macro-social levels that can lead to practical HIV stigma reducing

interventions. They provided guidelines to inform such interventions like the facilitation of HIV stigma awareness with regard to causes and consequences of stigma challenge communities to become nurturing environments (Campbell *et al.*, 2007:404-405). A further contribution was made by Uys *et al.* (2009a:1059-1060), who studied HIV stigma interventions in health care settings of five African countries and emphasised a) increased contact with PLWH and b) improved coping through empowerment as added categories covered by existing HIV stigma reduction interventions. The study involved a two-day workshop for PLWH, with nurses to teach them principles of project management, like design, implementation and evaluation processes. The participants were given one month in which to orchestrate a stigma reduction project with the support of facilitators in their health care setting. It was found that after the programme, participants had an improved understanding and knowledge of HIV stigma, and nurses reported an increase in HIV testing (Uys, *et al.*, 2009a:1064). However, contrary to this type of strategic community-based contact with PLWH, a study in Ghana found that community-based work is superseded by the collectivistic family life approach and PLWH sometimes have to relocate to free themselves from HIV stigma and to keep their HIV positive status secret. The risk of spreading HIV is low on their priority of life choices, and less important than for instance having a family of their own (Asiedu, 2010:134).

Uys *et al.* (2009a:1065) suggest that further research should explore and test the social dimensions of the stigma experience and its interaction with other social processes, such as stigma consciousness, self-esteem, self-efficacy, and coping. Greeff *et al.* (2008a:323) found that the disclosure of one's HIV status could form part of a comprehensive stigma reduction process in communities and 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. It could bring about anti-discriminatory laws at all levels and could lead to the strengthening of counselling capacity in local communities, strategies to increase membership of support groups, and build social capacity to stop negative effects on the progression of the disease in HIV positive individuals. Gaps still remain in the developing body of knowledge about the impact of stigma reduction. Interventions should be designed and tested for their successful and change-over-time impact on PLC and even the broader community (Uys *et al.*, 2009a:1065). Holm-Hansen (2009:4) summarises the multi-disciplinary

interventions provided in literature, among others that stigma reduction efforts are most effective when they address the underlying causes of stigma, especially inaccurate attitudes and beliefs, or if they are part of a comprehensive long-term stigma reduction approach that specifically addresses behaviour, or if they provide opportunities for self-reflection and discussion of new information. Furthermore, the intervention should be target-specific, carefully aligning the message, the intended audience and the delivery mechanism. A broad range of specific target groups should also be considered, such as landlords, employers, educators, health care providers and policy makers. She reiterates that professional social marketing can play an important role in combatting health related stigma.

The recent report regarding community-based interventions for HIV stigma reduction published by Horizons (<http://www.popcouncil.org/pdfs/horizons/litrvwstigdisc.pdf>) is an update of their regular overview. The 2000 publication summarised the interventions of the previous decades into four broad categories: decreasing health risk through promotion; facilitation of effective coping with illness; helping with symptom management; and addressing psychopathologies. Brown *et al.* (2011:1) express the opinion that all interventions seem to be somewhat effective in HIV stigma reduction but that there is no reliable evidence to indicate any preferred strategy since none of the studies assessed long-term sustainability and change-over-time. In addition, few studies were applied on a broad scale or as a national programme, with rigorous research and evidence (Brown *et al.*, 2011:2). Obrien (2012) recently summarised sixteen different interventions on her website and concluded that communities are still required to find proactive ways to work together in culturally-based, evidence-based and community-based interventions for HIV prevention, stigma reduction and continuous HIV and health behaviour education (<http://www.slidshare.net/Yvonneo1/community-based-hiv-interventions>).

In their overview of stigma reduction strategies and interventions, Heijnders and Van der Meij (2007:361) conclude that stigma firstly is a social construct, which suggests that the general public should be meaningfully involved in stigma reduction; and secondly that PLWH should become active agents in stigma reduction processes. Cross *et al.* (2012b:71-78) describe the outcomes of a working group comprising academics and experienced field personnel in the HIV stigma arena and specifically nominated to develop guidelines for interventions to reduce

stigma. They concluded that it is too complex to set up guidelines for generic stigma reduction interventions that would apply to all health conditions as such, but offered instead a stigma intervention matrix for cross-checking the development of situational stigma interventions and adherence to strategic guidelines of stigma reduction. The matrix consists of a left column of identified levels of stigma, namely intrapersonal, interpersonal, organisational and community or governmental levels, and of rows of identified components of stigma, namely labelling, stereotyping, separation, status loss and discrimination (Cross *et al.*, 2012b:77). The working group further contributed another valuable strategy in terms of stigma reduction, known as a social capital strategy and aimed at incorporating combinations of current stigma reduction intervention elements like training, contact and advocacy, whilst working on intrapersonal, interpersonal, organisational and community levels in a context of social marketing. The essential characteristics of social marketing are problem identification, clarification of targets, the technology of change and the evaluation of process and outcome. With reference to community-based interventions, Mahajan *et al.* (2010:20) summarises the stigma reduction strategies in literature as involving five levels: an intrapersonal level (counselling, cognitive behavioural therapy, self-help and support groups, treatment), an interpersonal level (care and support, home care teams), a community level (education and social marketing, contact with PLWHs), an institutional level (training programmes, policy development,) and a governmental/structural level (legal interventions and rights-based approaches).

Thus, a growing research base is developing regarding the underlying causes of HIV stigma and the strategies to counteract the spreading of such a stigma. Important gaps that still need to be addressed are matters like limited emphasis on behaviour change, insufficient examination of long-term effectiveness and insufficient comparisons across cultural groups (Holm-Hansen, 2009:4).

7 Concluding comments

The face of the HIV and AIDS pandemic is changing. Two to three decades ago the first wave of the pandemic was marked by HIV infections; this was followed by a second wave of devastating

signs and symptoms of HIV, full-blown AIDS and death for many. The current fight is against HIV stigma and is as central to the global AIDS challenge as the disease itself. HIV stigma thus is the third wave of the pandemic, created by a social, cultural, economic and political reaction to HIV and AIDS. It has the power to render the efforts of many years fruitless because the reduction or eradication of HIV stigma is extremely complex and closely linked to, or dependent on factors like fear, ignorance, insecurity, poverty, dependencies, resource-poverty and discrimination. HIV stigma is as destructive as any other kind of stigma. It seems like society is packed with layer upon layer of different prejudices and stigmas, and eradication on a social level seems much less achievable than finding ways to overcome stigma on levels of spirituality and functionality. Tolerance and endurance are commendable attributes but in this case might perpetuate stigma and allow victimisation whilst those who are stigmatised keep internalising the stigmatisation. Stigma can be conceptualised and defined, it can be contextualised and studied inside out, but marginally effective reduction and limited success in eradicating the stigma will hardly change the layers of prejudice that seem to dominate society and that have gone far beyond HIV alone. Acknowledging stigma is like acknowledging love or hate: a superficial recognition is pointless without a change of heart. Ways to overcome stigma will have to be sought on different levels of humanity and in the resourcefulness of the human spirit, in spite of societal and personal vulnerability and exposure. HIV stigma is either reduced or fuelled by determination and skills or the lack thereof.

All possible human capacity and resources need to be applied to access treatment, ensure adherence, change assumptions/attitudes, learn self-efficacy, responsibly manage disclosure, negotiate life and death choices with partners and to change the behaviour of individuals, communities, health care workers, policy makers, PLWH and PLC alike. The question is how to design, initiate and mobilise effective HIV reduction interventions in spite of limited resources of all kind or how to find different ways in which to dismantle the power of HIV stigma, prejudices and inequalities, and to build a healthy nation with an overarching psychosocial well-being. The African Union and United Nations Development Programme has recently shown some leadership in this area and activated a fifty year plan to redress gender inequalities, guarantee equal access to opportunities or rights and to empower African women to be equal

partners in the continent's development agenda to be at peace within and enabled to value, respect and utilise its own human and other resources to its fullest capacity by 2063.

8 References

- Adebimpe, W.O., Asekun-Olarinmoye, E., Bamidele, J.O. & Abodurin, O. 2011. A comparative study of socio-demographic determinants and fertility pattern among women in rural communities in South Western Nigeria. *Continental journal of medical research*, 5(1):32-40.
- Ajzen, I. 1991. The theory of planned behavior. *Organizational behavior and human decision processes*, 50:179-211.
- Alonzo, A.A. & Reynolds, N.R. 1995. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social science & medicine*, 41(3):303-315.
- Ankrah, E.M. 1993. The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS care: psychological and socio-medical aspects of HIV//aids*, 5(1):5-22.
- Ashburn-Nardo, L. 2010. The importance of implicit and explicit measures for understanding social stigma. *Journal of social issues*, 66(3):508-520.
- Asiedu, G.B. 2010. "Once it's your sister, they think it's in the bloodline": impact of HIV/AIDS-related stigma in Ghana. Manhattan, Kans.: Kansas State University. 187 p. (Thesis - DPhil.)
- Attell, B.K. 2013. Social contact theory: a framework for understanding AIDS-related stigma. *Journal of public and professional sociology*, 5(1):1-23.
- Avert. s.a. HIV & AIDS stigma and discrimination. <http://www.avert.org/hiv-aids-stigma.htm>. Date of access: 03 March 2013.
- Axinn, W.G. & Pearce, L.D. 2006. Mixed method data collection strategies. New York: Cambridge University Press. 244 p.

- Bakhtin, M. 2007. *The dialogical imagination. Four essays.* Austin, Tex.: University of Texas Press. 444 p.
- Bauer, E. 2013. Enacting support within church communities for people living with HIV or AIDS. *Mental health, religion and culture*, 16(1):100-118.
- Baumgardner, S.R. & Crothers, M.K. 2010. *Positive psychology.* London: Pearson. 338 p.
- Bhagwanjee, A., Petersen, I., Akintola, O. & George, G. 2008. Bridging the gap between VCT and HIV/AIDS treatment uptake: perspectives from a mining-sector workplace in South Africa. *African journal of AIDS research*, 7(3):271-279.
- Birdsall K., Hajiyanis, H., Nkosi, Z. & Parker, W. 2004. Voluntary counseling and testing (VCT) in South Africa: analysis of calls to the national AIDS Helpline. *Centre for AIDS development, research and evaluation (Cadre)*: 1-9.
- Bonell, C. & Imrie, I. 2001. Behavioural interventions to prevent HIV infection: rapid evolution, increasing rigour, moderate success. *British medical bulletin*, 58(1):155-170.
- Boon, M. 2007. *The African way: the power of interactive leadership.* 3rd ed. Cape Town: Zebra Press. 159 p.
- Boyd, J.E., Katz, E.P., Link, B.G. & Phelan, J.C. 2010. The relationship of multiple aspects of stigma and personal contact with someone hospitalized for mental illness, in a nationally representative sample. *Socio psychiatric epidemiology*, 45:1063-1070.
- Bradshaw, D. 2008. *Determinants of health and their trends.* Durban: Health Systems Trust. (South African health review.)
- Brette, R.P. 1991. HIV and harm reduction for injection drug users. *AIDS*, 5:125-136.
- Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS education and prevention*, 15(1):49-69.

Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV and AIDS stigma: What have we learned? *AIDS education and prevention*, 15(1):49-69. doi: 10.1521/aeap.15.1.49.23844

Brown, L., Trujillo, L. & Macintyre, K. 2011. Interventions to reduce HIV/AIDS stigma: what have we learned? *International initiative for impact evaluation: systematic review*: 1-3. <http://www.popcouncil.org/pdfs/horizons/litrwvstigdisc.pdf> Date of access: 27 August 2012.

Bryan, P. 2000. Stigma of mental illness and ways of diminishing it. *Advances in psychiatric treatment*, 6:65-72.

Bryman, A. 1984. The debate about quantitative and qualitative research: a question of method or epistemology? *British journal of sociology*, 35(1):75-92.

Cahill, S. & Valadez, R. 2013. Growing older with HIV/AIDS: new public health challenges. *American journal of public health*, 3(3):7-15.

Cameron, E.J.B. 2005. AIDS, South-Africa, stigma, vaccines: a conversation with Justice Edwin Cameron. (In Kahn, P.K. AIDS vaccine handbook: voices AIDS, South Africa, stigma, vaccines. 2nd ed. New York: AIDS Vaccine Advocacy Consultation. p. 293-298.)

Cameron, E.J.B. 2008. Justice Edwin Cameron adds a new dimension to China-Africa relations. (In UNAIDS/Zhou Dao: Positive Art Workshop, You and Hospital, Beijing.) <http://www.unaids.org/en/resources/presscentre/featurestories/2008/october/20081031justicecameron>. Date of access: 07 May 2012.

Campbell, C., Nair, Y., Maimane, S. & Nicholson, J. 2007. "Dying twice": a multilevel model of the roots of AIDS stigma in two South African communities. *Journal of health psychology*, 12:403-416.

Campbell, D. & Rader, A. 2005. HIV/AIDS, stigma and religious responses. 5 p. http://www.heart-intl.net/HEART/052505/HIV_AIDSStigmaandreligiousresponses.htm. Date of access: 21 April 2013.

- Chesney, M.A., Neilands, T.B., Chambers, D.B. Taylor, J. & Folkman, S. 2006. A validity and reliability study of the coping self-efficacy scale. *British journal of health psychology*, 11:421-437.
- Chirwa, M.L., Greeff, M., Kohi, T.W., Naidoo, J.R., Makoae, L.N., Dlamini, P.S., Kaszubski, C., Cuca, Y.P., Uys, L. & Holzemer, W.L. 2009. HIV stigma and nurse job satisfaction in five African countries. *Journal of the Association of Nurses in Aids Care*, 20(1):14-21.
- Clark, A.M. 1998. The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation. *Journal of advanced nursing*, 27:1242-1249.
- Cobern, W.W. 1991. World view theory and science education research. San Diego, Calif.: National Association for Research in Science Teaching. (NARST Monograph No. 3.)
- Corbin, C.B. 2002. Definitions of wellness: dimensions of wellness. <http://www.Definitionofwellness.com/wellness-resources.html>. Date of access: 26 November 2011.
- Corrigan, P.W. 2000. Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical psychology: science and practice*, 7(1):48-67.
- Corrigan, P.W. 2004. Target-specific stigma change: a strategy for impacting mental illness stigma. *Psychiatric rehabilitation journal*, 28(2):113-121.
- Corrigan, P.W., Watson, A.C. & Barr, L. 2006. The self-stigma of mental illness: implications for self-esteem and self-efficacy. *Journal of social and clinical psychology*, 25(9):875-884.
- Council for World Mission by the World Association for Christian Communication. 2007. Responding to HIV and AIDS: a toolkit for youth peer educators. Author. 257 p.
- Creswell, J.W. 2003. Research design: quantitative, qualitative, and mixed methods approaches. 2nd ed. Thousand Oaks, Calif.: Sage.
- Cross, H., Heijnders, M., Dalal, A., Sermrittirong, S. & Mak, S. 2012a. Interventions for stigma reduction, Part 1: Theoretical considerations. *Disability, CBR & inclusive development*, 22(3):62-70.

- Cross, H., Heijnders, M., Dalal, A., Sermrittirong, S. & Mak, S. 2012b. Interventions for stigma reduction, Part 2: Practical applications. *Disability, CBR & inclusive development*, 22(3):71-80.
- Davids, I., Theron, F. & Maphunye, K. 2009. Participatory development in South Africa: a development management perspective. 2nd ed. Pretoria: Van Schaik Publishers. 252 p.
- Deacon, H. 2006. Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature. *Journal of community & applied social psychology*, 16:418-425.
- Deacon, H. & Stephney, I. 2007. HIV/AIDS, stigma and children: a literature review. Pretoria: Human Sciences Research Council. 81 p.
- Deacon, H., Stephney, I. & Prosalendis, S. 2005. Understanding HIV/AIDS stigma: a theoretical and methodological analysis. Pretoria: Human Sciences Research Council. 120 p.
- Denzin, N.K. 1989. The research act: a theoretical introduction to sociological methods. Englewood Cliffs, N.J.: Prentice Hall.
- Dines, A. & Cribbs, A. 1993. Health promotion: concepts and practice. Oxford: Blackwell Science.
- Dlamini, P.S., Wantland, D., Makoe, L.N., Chirwa, M., Kohi, T.W., Greeff, M., Naidoo, J., Mullan J., Uys, L.R. & Holzemer, W.L. 2009. HIV stigma and missed medications in HIV-positive people in five African countries. *Aids patient care and STDs*, 23(5):377-387.
- Duncan, C., Harrison, M.G., Toldson, I.A., Malaka, D. & Sithole, S. 2005. Social stigma, HIV/AIDS knowledge and sexual risk: a cross-cultural analysis. *Journal of applied biobehavioral research*, 10(1):1-26.
- Duncan, N., Ratele, K., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. 2007. Self, community & psychology. 2nd ed. Cape Town: University of Cape Town Press.
- Fife, B.L. & Wright, E.R. 2000. The dimensionality of stigma: a comparison of its impact on the self of Persons with HIV/AIDS and cancer. *Journal of health and social behavior*, 41:50-67.
- Fishbein, M. 2000. The role of theory in HIV prevention. *Aids care*, 12(3):273-278.

Fishbein, M. & Ajzen, I. 1975. Belief, attitude, intention, and behavior: an introduction to theory and research. Reading, Mass.: Addison-Wesley. 578 p.

Fitzpatrick, J. & Whall, A.L. 1996. Conceptual models of nursing: analysis and application. Stamford, Conn.: Appleton & Lange. 356 p.

Foster, G. & Williamson, J. 2000. A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS*, 14(suppl. 3):275-284.

Foster, P.P. & Gaskins, S.W. 2009. Older African Americans' management of HIV/AIDS stigma. *Aids care*, 21(10):1306-1312.

Genberg, B.L., Kawichai, S., Chingono, A., Senday, M., Chariyalertsak, S., Konda, K.A. & Celentano, D.D. 2007. Assessing HIV/AIDS stigma and discrimination in developing countries. *Aids and behaviour*, 12(5):772-780.

Gerbi, G.B., Habtemariam, T., Robnett, V., Nganwa, D. & Tameru, B. 2012. Psychosocial factors as predictors of HIV/AIDS risky behaviours among people living with HIV/AIDS. *Journal of AIDS and HIV research*, 4(1):8-16.

Gilbert, L. & Walker, L. 2010. My biggest fear was that people would reject me once they knew my status: stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, SA. *Health and social care in the community*, 18(2):139-146.

Gilmore, N. & Somerville, M.A. 1994. Stigmatization, scapegoating and discrimination in sexually transmitted diseases, overcoming 'them' and 'us'. *Social science and medicine*, 39:1339-1358.

Gladwell, M. 2002. The tipping point: how little things can make a big difference. Boston, Mass.: Little, Brown. 301 p.

Goffman, E. 1963. Stigma: notes on the management of spoilt identity. Englewood Cliffs, N.J.: Prentice Hall. 174 p.

Greeff, M. 2010. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Potchefstroom: North-West University. (Unpublished research proposal.) 12 p.

Greeff, M., Hoogstad, H., Kruger, A., Paolini, M. & Watson, M. 2010. Know and understand the world of health. (Study guide for WVGW 221 E.) Potchefstroom, North-West University. Potchefstroom Campus. Faculty of Health Sciences. Potchefstroom: Platinum Press. 68 p.

Greeff, M. & Phetlhu, R. 2007. The meaning and effect of HIV/AIDS stigma for people living with AIDS and nurses involved in their care in the North West province, South Africa. *Curationis*, 39(2):12-23.

Greeff, M., Phetlhu, R., Makoe, L.N., Dlamini, P.S., Holzemer, W.L., Naidoo, J.R., Kohi, T.W., Uys, L.R. & Chirwa, M.L. 2008. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative health research*, 18(3):311-324.

Greeff, M., Uys, L.R., Holzemer, W.L., Makoe, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J.R. & Phetlhu, R.D. 2008. Experiences of HIV/AIDS stigma of persons living with HIV/AIDS and nurses involved in their care from five African countries. *Africa journal of nursing and midwifery*, 10(1):78-108.

Greeff, M., Uys, R.L., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P. Kohi, T.W., Mullan, J., Naidoo, J.R., Cuca, Y. & Holzemer, W.L. 2010. Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: a longitudinal study. *International journal of nursing studies*, 47(4):475-486.

Guba, E. 1990. The paradigm dialogue. Newbury Park, Calif.: Sage.

Hanson, B. 2008. Wither qualitative/quantitative? Grounds for methodological convergence. *Quality and quantity*, 42:97-111.

Hardeman, W., Sutton, S., Griffen, S., Johnston, M., White, A., Wareham, N.J. & Kinmonth, A.L. 2005. The causal modelling approach to the development of theory-based behaviour change

programmes for trial evaluation. *Health and education research: theory and practice*, 20(6):676-687.

Harvard Business Essentials. 2003. Managing change and transition. Boston, Mass.: Harvard Business School Press. 139 p.

Harvard Mental Health Letter. 2010. The evolving understanding of stigma: theories differ about why it is so pervasive and so hard to eradicate. Boston, Mass.: Harvard Health Publications.

Harvey, R.D. 2001. Individual differences in the phenomenological impact of social stigma. *Journal of social psychology*, 141(2):174-189.

Hatch, J., Moss, N., Saran, A., *et al.* 1993. Community research: partnership in black communities. *American journal of preventive medicine*, 9(6)(Suppl.):27-31.

Hawe, P. 1994. Capturing the meaning of community in community intervention evaluation: some contributions from community psychology. *Health promotion international*, 9(3):199-210.

Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. 1998. Psychosocial differences between urban and rural people living with HIV/AIDS. *Journal of rural health*, 14:138-145.

Heijnders, M. & Van der Meij, S. 2006. The fight against stigma: an overview of stigma reduction strategies and interventions. *Psychology, health and medicine*, 11(3):353-363.

Henderson, K.A. 2011. Research reflection: post-positivism and the pragmatics of leisure research. *Leisure sciences*, 33:341-146.

Herek, G.M., Gillis, J.R. & Cogan, J.C. 2009. Internalized stigma among sexual minority adults: Insights from a social psychological perspective. *Journal of counselling psychology*, 65:32-43

Herek, G.M., Saha, S. & Burack, J. 2013. Stigma and psychological distress in people with HIV/AIDS. *Basic and applied social psychology*, 35:41-54.

Hilhorst, T., Van Liere, M.J., Ode, A.V. & De Koning, K. 2006. Impact of AIDS on rural livelihoods in Benue State, Nigeria. *Journal of social aspects of HIV/AIDS*, 3(1):382-393.

Hohmann, A.A. & Shear, M.D. 2002. Community-based intervention research: coping with the 'noise' of real life in the study design. *American journal of psychiatry*, 159:201-207.

Holm-Hansen, C. 2009. Stigma reduction: promoting greater understanding of mental health. *Wilder research*, August. (Snapshot pages.)

Holzemer, W.L. 2012. A 25-year program of research on living with HIV infection. (23rd International Nursing Research Congress: Creating a legacy through nursing research, innovation and global collaboration, 30 July-3 August 2012. Brisbane, Australia. Sigma Theta Tau International Congress, Special Session: Program book.)

Holzemer, W.L. & Uys, L.R. 2004. Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3):165-174.

Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.V., Chirwa, M., Cuca, Y. & Naidoo, J. 2007. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6):541-551.

Hope, K.W. & Waterman, H.A. 2003. Methodological issues in nursing research: Praiseworthy pragmatism? Validity and action research. *Journal of advanced nursing*, 44(2):120-127.

Hubley, J. 1988. Understanding behaviour: the key to successful health education. *Tropical doctor*, 18(3):134-138.

ICRW **see** International Centre of Research on Women

International Centre of Research on Women (ICRW). 2005. HIV-related stigma across contexts: common at its core. <http://www.icrw.org/publications/common-its-core-hiv-related-stigma-across-contexts>. Date of access: 26 March 2013.

Jadad, A.R. & O'Grady, L. 2008. How should health be defined? *British medical journal*, 337:1363-1364.

- Jordan, O.M.G. & Bazzarre, T. 2002. The behaviour change consortium: setting the stage for a new century of health behaviour-change research. *Health education research journal*, 17(5):500-511.
- Kalichman, S. 2013. Teaching tip sheet: stigma and prejudice. <http://www.apa.org/pi/aids/resources/education/stigma-prejudice.aspx>. Date of access: 9 March 2013.
- Kasapoglu, A., Saillard, E.K., Kaya, N. & Turan, F. 2011. AIDS related stigma in social relations: a qualitative study in Turkey. *Qualitative report*, 16:1496-1516.
- Kelly, J.A., Murphy, D.A., Sikkema, K.J. & Kalichman, S.C. 1993. Psychological interventions to prevent HIV infection are urgently needed: new priorities for behavioural research in the second decade of AIDS. *American psychologist*, 48(10):1023-1034.
- Kendra, S.K., Cattaneo, L.B. & Mohr, J.J. 2012. Teaching abnormal psychology to improve attitudes toward mental illness and help-seeking. *Teaching of psychology*, 39(1):57-61.
- Kersell, M.W. & Milsum, J.H. 1985. A systems model of health behavior change. *Behavioral science*, 30(3):119-126.
- Keyes, C.L.M. 2002. The mental health continuum: from languishing to flourishing in life. *Journal of health and social behavior*, 43(2):207-222.
- Keyes, C.L.M. 2005. Mental illness and/or mental health? Investigating axioms of the complete state model of health. *Journal of consulting and clinical psychology*, 73(3):539-548.
- Keyes, C.L.M., Wissing, M., Potgieter, J.P., Temane, M., Kruger, A. & Van Rooy, S. 2008. Evaluation of mental health continuum-short form (MHC-SF) in Setswana-speaking South Africans. *Clinical psychology and psychotherapy*, 15:181-192.
- Ban, K.M. 2008. The stigma factor. *Washington Times*, 6 August.
- Kohi, T.W., Makoe, L.N., Chirwa, M., Holzemer, W.L., Phetlhu, D.R. & Uys, L.R. 2006. HIV and AIDS stigma violates human rights in five African countries. *Nursing ethics*, 13(4):405-414.

Kotter, J.P. & Cohen, D.S. 2002. *The heart of change: real-life stories of how people change their organizations*. Boston, Mass.: Harvard Business School Press. 190 p.

Kotter, J.P. & Rathgeber, H. 2006. *Our iceberg is melting: changing and succeeding under any conditions*. New York: St. Martin's Press. 147 p.

Kruger, A., Greeff, M., Watson, M.J. & Fourie, C.M.T. 2009. Health care seeking behaviour of newly diagnosed HIV infected people from a rural and urban community in the North West Province of South Africa: the PURE-SA study. *Africa journal of nursing and midwifery*, 11(2):28-45.

Latrofa, M., Vaes, J., Pastore, M. & Cadino, M. 2009. 'United we stand, divided we fall!' The protective function of self-stereotyping for stigmatised members' psychological well-being. *Applied psychology: an international review*, 58(1):84-104.

Lee, P. 2005. *No nonsense guide to HIV/AIDS, gender equality and communication*. Canada: World Association for Christian Communication (WACC).

Lewin, K. 1958. *Group decision and social change*. New York: Holt, Rinehart & Winston. 201 p.

Lieberson, S. 1992. Einstein, Renoir, and Greeley: some thoughts about evidence in sociology. *American sociological review*, 57:1-15.

Lincoln, Y.S. & Guba, E.G. 1985. *Naturalistic inquiry*. Beverly Hills, Calif.: Sage.

Link, B.G. & Phelan, J.C. 2001. Conceptualizing stigma. *Annual review of sociology*, 27:363-385.

Link, B.G., Yang, L.H., Phelan, J.C. & Collins, P.Y. 2004. Measuring mental illness stigma. *Schizophrenia bulletin*, 30(3):511-541.

Longo, R. 2011. Is Lewin's change management model still valid? *HR professionals, Blog*, Sunday 22 May 2011. Date of access: 24 September 2012.

Lundin, S. & Nelson, B. 2010. *Ubuntu: the inspiring story about an African tradition of teamwork and collaboration*. New York: Broadway Books. 133 p.

- MacKenzie, N. & Knipe, S. 2006. Research dilemmas: paradigms, methods and methodology. *Issues in educational research*, 16(2):193-205.
- Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Ortiz, D., Szekeres, G. & Coates, T.J. 2008. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*, 22(Suppl. 2):67-79.
- Mak, W.W.S., Cheung, R.Y.M., Law, R.W., Woo, J., Li, P.C.K. & Chung, R.W.Y. 2007. Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social science & medicine*, 64:1549-1559.
- Makoe, L.N., Greeff, M., Phetlhu, R.D., Uys, L.R., Naidoo, J.R., Kohi, T.W., Dlamini, P.S., Chirwa, M.L. & Holzemer, W.L. 2008. Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in Aids Care*, 19(2):137-146.
- Makoe, L.N., Portillo, C.J., Uys, L.R., Dlamini, P.S., Greeff, M., Chirwa, M., Kohi, T.W., Naidoo, J., Mullan, J., Wantland, D., Durrheim, K. & Holzemer, W.L. 2009. The impact of taking or not taking ARV's on HIV stigma as reported by persons living with HIV infection in five African countries. *Aids care*, 21(11):1357-1362.
- Mallory, O., Johnson, T.B., Neilands, S.M., Dilworth, S.F., Morin, R.H., Chesney, R. & Chesney, M.A. 2007. The role of self-efficacy in HIV treatment adherence: validation of the HIV treatment adherence and self-efficacy scale (HIV-ASES). *Journal of behavioral medicine*, 30(5):359-370.
- Marshall, S.J. & Biddle, S.J.H. 2002. The transtheoretical model of behaviour change: a meta-analysis of applications to physical activity and exercise. *Annals of behavioural medicine*, 23(4):229-246.
- Mashadi, L. 2012. Applying a cognitive behavioural model to understanding stigma. *Serenity neuroscience newsletter*, 10(2):9-11.
- Matthews, M.R. 2008. Teaching the philosophical and worldview components of science. *Science & education*, 18:6-7.

- Maughan-Brown, B. 2004. Measuring HIV/AIDS stigma. Cape Town: University of Cape Town. Centre for Social Science Research. (CSSR Working Paper No. 74.)
- Mertens, D.M. 2005. Research methods in education and psychology: integrating diversity with quantitative and qualitative approaches. 2nd ed. Thousand Oaks, Calif.: Sage.
- Miremba, I. 2012. It is time to give more than just information to address HIV. *Daily Monitor*, Sept 24.
- Mkhize, N. 2004. Psychology: an African perspective. (In Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. Self, community and psychology. Landsdowne: UCT Press. Ch. 5:1-31.)
- Molero, F., Fuster, M.J., Jetten, J. & Moriano, J.A. 2011. Living with HIV/AIDS: a psychosocial perspective on coping with prejudice and discrimination. *Journal of applied social psychology*, 41(3):609-626.
- Moore, S.M. & Charvat, J. 2007. Promoting health behavior change using appreciative inquiry: moving from deficit models to affirmation models of care. *Family & community health*, 30:S64-S74.
- Morgan, D.L. 2007. Paradigms lost and pragmatism regained: methodological implications of combining qualitative and quantitative methods. *Journal of mixed methods research*, 1(1):48-76.
- Mswela, M. 2009. Cultural practices and HIV in South Africa: a legal perspective. *Potchefstroom electronic law journal*, 12(4):172-214.
- Mueller, J., Alie, C., Jonas, B., Brown, E. & Sherr, L. 2011. A quasi-experimental evaluation of a community-based art therapy intervention exploring the psychosocial health of children affected by HIV in South Africa. *Tropical medicine and international health*, 16(1):67-66.
- Muggah, R. 2012. Researching the urban dilemma: urbanization, poverty and violence. Ottawa: International Development Research Centre. 106 p.

- Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *Medical journal of AIDS research*, 6(1):17-23.
- Ngozi, C.M., Van den Borne, B. & De Vries, N.K. 2009. Stigma of people with HIV/AIDS in Sub-Saharan Africa: a literature review. *Journal of tropical medicine*. Article ID 145891. 14 p.
- Nicolescu, B. 2007. Transdisciplinarity as methodological framework for going beyond the science-religion debate. *Global spiral*, 9(4):1-137.
- Niglas, K. 2001. Paradigms and methodology in educational research. (Paper presented at the European Conference on Educational Research, Lille, 5-8 September 2001.)
- Norcross, J.C., Krebs, P.M. & Prochaska, J.O. 2011. Stages of change. *Journal of clinical psychology*, 67(2):143-154.
- Nyblade, L.C. 2006. Measuring HIV stigma: existing knowledge and gaps. *Psychology, health & medicine*, 11(3):335-345.
- O'Brien, Y. 2012. Community-based HIV interventions. <http://www.slideshare.net/Yvonneo1/community-based-hiv-interventions>. Date of access: 3 October 2012.
- Ogden, J. & Nyblade, L. 2005. Common at its core: HIV-related stigma across context. Washington, D.C.: International Center for Research on Women. 43 p.
- Ogunmefun, C., Gilbert, L. & Schatz, E. 2011. Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of cross-cultural gerontology*, 26(1):85-102.
- Olthuis, J.H. 1989. On worldviews. (In Marshall, P.A., Griffioen, S. & Mouw, R.J., eds. *Stained glass: worldviews and social science*. Landham, Md.: University Press of America. p. 1-12.)
- Pachankis, J.E. 2007. The psychological implications of concealing a stigma: a cognitive-affective-behavioural model. *Psychological bulletin*, 133(2):328-345.
- Pearce, L.D. 2012. Mixed methods inquiry in sociology. *American behavioural scientist*, 56(6):829-848.

- Phelan, J.C., Link, B.G. & Dovidio, J.F. 2008. Stigma and prejudice: one animal or two? *Social science & medicine*, 67:358-367.
- Phillips, R.E. 2009. Nurses' experience with HIV stigma in five African countries. San Francisco, Calif.: University of California. (Thesis - PhD.)
- Pinel, E.C. & Bosson, J.K. 2013. Turning our attention to stigma: an objective self-awareness analysis of stigma and its consequences. *Basic and applied social psychology*, 35:55-63.
- Pinkoane, M.B. 2005. Incorporation of the traditional healers into the national health care delivery system. Potchefstroom: North-West University. (Thesis - PhD.)
- PlusNews. 2012. World: HIV/AIDS: breaking science "silos" to find a vaccine. *PlusNews global HIV/AIDS news and analysis*, 21 October.
- Prochaska, J.O. & Di Clemente, C.C. 1983. Stages and processes of self-change of smoking: toward an integrative model of change. *Journal of consulting and clinical psychology*, 51(3):390-395.
- Prochaska, J.O. & Velicer, W.F. 1997. The transtheoretical model of health behavior change. *American journal of health promotion*, 12(1):38-48.
- Psychosocial Working Group. 2011. Forced migration online: a world of information on human displacement. *Psychosocial working group*. <http://www.forcedmigration.org/psychosocial/>. Date of access: 24 September 2012.
- Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L. & Mahendra, V. 2010. Reducing HIV-related stigma: lessons learned from Horizons Research and programs. *Public health reports*, 125:272-281.
- Ramirez-Valles, J. 2005. Confronting stigma: community involvement and psychological well-being among HIV-positive Latino gay men. *Hispanic journal of behavioural sciences*, 27(1):101-119.
- Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. 2004. Self, community and psychology. Cape Town: UCT Press.

- Relf, M.V., Mallinson, K., Pawlowski, L., Dolan, K. & Dekker, D. 2005. HIV-related stigma among persons attending an urban HIV clinic. *Journal of multicultural nursing & health*, 11(1):14-23.
- Rensen, C., Bandyopadhyay, S., Gopal, P.K. & Van Brakel, W.H. 2011. Measuring leprosy-related stigma: a pilot study to validate a toolkit of instruments. *Disability and rehabilitation*, 33(9):711-719.
- Rotheram-Borus, M.J., Stein, J.A. & Lester, P. 2006. Adolescent adjustment over six years in HIV-infected families. *Journal of adolescent health*, 39:174-182.
- Rotheram-Borus, M.J., Swendeman, D., Lee, S., Amani, B. & Nartey, M. 2011. Interventions for families affected by HIV. *TBM*, 1:313-326.
- Rural Centre for Aids/Std Prevention. 1994. HIV infection and AIDS in rural America. *Rural prevention report*, 1(1), Spring. (Online newsletter.) <http://www.indiana.edu/aids/newsletters1.html#contents>. Date of access: 24 September 2013.
- Ryan, A.B. 2006. Post-positivist approaches to research. (In Antonesca, M., Fallon, H., Ryan, A.B., Ryan, A. & Walsh, T. Researching and writing your thesis: a guide for postgraduate students. Maynooth, Ireland: MACE. National University of Ireland. p. 12-28.)
- Ryan, R.M. 2009. Self-determination theory and wellbeing. *Social psychology*, 84:822-848.
- Ryan, R.M. & Deci, E.L. 2001. To be happy or to be self-fulfilled: a review of research on hedonic and eudemonic well-being. *Annual review of psychology*, 52:141-166.
- Salerno, A. & Brock, L. 2008. The change cycle: how people can survive and thrive in organizational change. A practical guide to navigating the 6 stages of change. San Francisco, Calif.: Berrett-Koehler Publishers. 199 p.
- Salter, M.L., Go, V.F., Le Minh, N., Gregowski, A., Vit Ha, T., Rudolph, A., Latkin, C., Celentano, D.D. & Quan, V.M. 2011. Influence of perceived secondary stigma and family on the response to HIV infection among injection drug users in Vietnam. *AIDS education prev.*, 22(6):558-570.
- Sanjuan, P., Molero, F., Fuster, M.J. & Nouvilas, E. 2013. Coping with HIV related stigma and well-being. *Journal of happiness studies*, 14(2):709-722.

- Sayce, L. 1998. "Stigma, discrimination and social exclusion: what's in a word?" *Journal of mental health*, 7(4):331-343.
- Sayce, L. 2003. Beyond good intentions. Making anti-discrimination strategies work. *Disability & society*, 18:625-642.
- Schmitt, M.T. & Branscombe, N.R. 2002. The meaning and consequences of perceived discrimination in disadvantaged and privileged social groups. *European review of social psychology*, 12(1):167-199.
- Sengupta, S., Banks, B., Jonas, D., Miles, M.S. & Smith, G.C. 2011. HIV interventions to reduce HIV/AIDS stigma: a systematic review. *AIDS behaviour*, 15(6):1075-1087.
- Setswe, G. 2009. HIV / AIDS prevention strategies. (Presentation at PDM Summer School, University of Stellenbosch, 16 January 2009. 16 p.)
- Shih, M. 2004. Positive stigma: examining resilience and empowerment in overcoming stigma. *Annals of the American academy of political and social science*, 591(1):175-185.
- Sieber, S.D. 1973. The integration of fieldwork and survey methods. *American journal of sociology*, 78(6):1335-1359.
- Siyam'kela. 2003. HIV/AIDS stigma resource pack. The Policy Project. Pretoria: University of Pretoria. Centre for the Study of AIDS.
- Skinner, D. & Mfecane, S. 2004. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of social aspects of HIV/AIDS*, 1(3):157-164.
- Sliep, Y., Poggepoel, M. & Gmeiner, A. 2001. The experience of HIV-reactive patients in rural Malawi, part 1. *Curationis*, 24(3):56-65.
- Smith, J. 1991. A methodology for twenty-first century sociology. *Social forces*, 70(1):1-17.
- South African AIDS Council (SANAC). 2011. National Strategic Plan (NSP) on HIV, STIs and TB 2012-2016. 86 p. <http://www.sanac.org.za> Date of access: 21 April 2013.

- Spagnolo, A.M., Murphy, A.A. & Liberia, L.A. 2008. Reducing stigma by meeting and learning from people with mental illness. *Psychiatric rehabilitation journal*, 31(3):186-193.
- Stein, J. 2003. HIV/AIDS stigma: the latest dirty secret. *African journal of AIDS research*, 2(2):95-101.
- Stewart, W. & Floyd, M. 2004. Visualizing leisure. *Journal of leisure research*, 36(4):445-460.
- Stretcher, V. & Rosenstock, I.M. 1997. The Health Belief Model. (In Glanz, k., Lewis, F.M. & Rimer, B.K. *Eds.*, Health Behaviour And Health Education: Theory, Research And Practice (2nd ed.). San Francisco, CA: John Wiley & Sons. p. 45-66).
- Stutterheim, S.E., Pryor, J.B., Bos, A.E.R., Hoogendijk, R., Muris, P. & Schaalma, H.P. 2009. HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings. *AIDS*, 23:2353-2357.
- Taylor, B. 2001. HIV, stigma and health: integration of theoretical concepts and the lived experiences of individuals. *Journal of advanced nursing*, 35(5):792-798.
- Thomas, B.E., Rehman, F., Suryananarayanan, D., Josephine, K., Dilip, M., Dorairaj, V.S. & Swaminathan, S. 2005. How stigmatizing is stigma in the life of people living with HIV: a study on HIV positive individuals from Chennai, South India. *AIDS care journal*, 17(7):795-801.
- Thornicroft, G., Brohan, E., Kassam, A. & Lewis-Holmes, E. 2008. Reducing stigma and discrimination: candidate interventions. *International journal of mental health systems*, 2:1-7.
- UNAIDS. 2004. UNAIDS/WHO policy statement on HIV testing, June 2004. http://www.who.int/entity/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf_ Date of access: 27 August 2012.
- UNAIDS. 2007. Reducing HIV stigma and discrimination: a critical part of national AIDS programmes. Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. 2012. Report on the global AIDS epidemic. Geneva: UNAIDS.

UNESCO. 1998. Transdisciplinarity: stimulating synergies, integrating knowledge. Paris: UNESCO, Division of Philosophy and Ethics.

Uys, L.R., Chirwa, M.L., Dlamini, P., Greeff, M., Kohi, T.W., Holzemer, W.L., Makoe, L.N., Dlamini, P.S., Naidoo, J.R. & Phletlhu, R. 2005. "Eating plastic", "winning the lotto", "joining the www": descriptions of HIV/AIDS in Africa. *Journal of the Associations of Nurses in AIDS Care*, 16(3):11-21.

Uys, L.R., Chirwa, M.L., Kohi, T.W., Greeff, M., Naidoo, J.R., Makoe, L.N., Dlamini, P.S., Durrheim, K., Cuca, Y. & Holzemer, W.L. 2009a. Evaluation of a health setting-based intervention. *AIDS patient care and STDs*, 23(12):1059-1066.

Valdiserri, R.O. 2002. HIV/AIDS stigma: an impediment to public health. *American journal of public health*, 92(3):341-342.

Van Brakel, W.H. 2006. Measuring health-related stigma: a literature review. *Psychology, health & medicine*, 11(3):307-334.

Van der Borgh, S.F., Schim Van der Loeff, M.F., Clevenberg, P., Kabarega, J.P. Kamo, E., Van Cranenburgh, K., Rijckborst, H., Lange, J.M. & Rinke De Wit, T.F. 2010. Long-term voluntary counselling and testing (VCT) uptake dynamics in a multicountry HIV workplace program in sub-Saharan Africa. *AIDS care*, 22(2):195-205.

Van der Walt, B.J. 2003. Understanding and rebuilding Africa. Potchefstroom: Institute for Contemporary Christianity in Africa (ICCA). 120 p.

Van Wyk, M.M. 2010. Validation of a coping self-efficacy scale in an African context. Potchefstroom: North-West University, Potchefstroom Campus. (Dissertation - MA.) 41 p.

Voeten, H.A.C.M., Egesah, O.B. & Habbema, J.D.F. 2004. Sexual behaviour is more risky in rural than in urban areas among young women in Nyanza Province, Kenya. *Sexually transmitted diseases*, 31(8):481-487.

- Watson, M.J. 2002. Kultuurkongruenteberaming van die moeder en haar baba binne 'n kultuurdiverse gemeenskap. Potchefstroom: Potchefstroomse Universiteit vir CHO. (Verhandeling - MA.)
- Weiss, M.G., Doongaji, D.R., Siddhartha, S., Wypij, D., Parhare, S., Bhatawdekar, M., Bhave, A., Sheth, A. & Fernandes, R. 1992. The explanatory model interview catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *British journal of psychiatry*, 160(6):819-830.
- Weiss, M.G., Ramakrishna, J. & Somma, D. 2006. Health related stigma: rethinking concepts and interventions. *Psychology, health & medicine*, 11(3):277-287.
- Whitehead, T.L. 2002. Community based interventions, definitions and types. The cultural ecology of health change (CEHC). College Park, Md.: University of Maryland. (Working Paper: working paper #2.)
- Williamson, J. & Robinson, M. 2006. Psychosocial interventions, or integrated programming for well-being? *Intervention*, 4(1):4-25.
- Wilson, I.B. & Cleary, P.D. 1995. Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *JAMA, the journal of the American Medical Association*, 273(1):59-65.
- Winiarski, M.G. 2004. Community-based counselling for people affected by HIV and AIDS. Cape Town: Longman. 153 p.
- Wissing, J.A.B. 2006. Psychological well-being in cultural context: measurement, patterns and relevance for practice. Potchefstroom: North-West University. Potchefstroom Campus. (Dissertation - MA.)
- Wissing, M.P. 2000. Wellness: construct clarification and a framework for future research and practice. (Keynote address: First South African National Wellness Conference, 2-5 May, 2000. Potchefstroom.)

- Wissing, M.P. & Van Eeden, C. 2002. Empirical clarification of the nature of psychological well-being. *South African journal of psychology*, 32(1):32-44.
- Wong, L.H., Van Rooyen, H., Modiba, P., Richter, L., Gray, G., McIntyre, J.A., Schetter, C.D. & Coates, T. 2009. Test and tell: correlates and consequences of testing and disclosure of HIV status in South Africa. *Journal of acquired immunodeficiency syndrome*, 50(2):215-222.
- Yang, L.H. & Kleinman, A. 2008. 'Face' and the embodiment of stigma in China: the cases of schizophrenia and AIDS. *Social science and medicine*, 67:398-408.
- Yuki, M. 2003. Intergroup comparison versus intragroup relationships: a cross-cultural examination of social identity theory in North American and East Asian cultural contexts. *Social psychology quarterly*, 66(2):166-183.
- Zimmerman, G.L., Olsen, C.G. & Bosworth, M.F. 2000. The 'stages of change' approach to helping patients' change behaviour. *American family physician*, 61(5):1409-1416.

SECTION C: ARTICLES

ARTICLE 1: Change-over-time in the HIV stigma experiences of people living with HIV and stigmatization by people living close to them following a comprehensive community-based HIV stigma reduction intervention in an urban and rural setting.

JOURNAL: AIDS Care

Referencing in this article is according to the requirements of the Journal it is prepared for, but the formatting style remains consistent with the rest of the thesis. (Guidelines for the submission of an Article to AIDS Care is in Appendix C)

Proof of submission to journal attached.

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Change-over-time in the HIV stigma experiences of people living with HIV and stigmatization by people living close to them following a comprehensive community-based HIV stigma reduction intervention in an urban and rural setting.

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Abstract

This article reports on changes in HIV stigma and stigmatization outcomes in relation to a larger SANPAD-funded HIV stigma reduction research project. The study responded to the continuous burden of HIV stigma on both national and international levels, the scant participation of people living with HIV (PLWH) in health care opportunities and the paucity of research in HIV stigma reduction interventions. It aimed at testing change-over-time in stigma experiences of PLWH and stigmatization by people living close to them (PLC), before and after a community-based HIV stigma reduction intervention in both an urban and a rural setting of the North West Province, South Africa. An experimental quantitative single system research design with a pre-test and four repetitive post-tests were conducted through purposive voluntary and snowball sampling. The 'Perceived AIDS Stigma Instrument for HIV stigma reduction in PLWH' and the 'AIDS Related Stigma measure for HIV in the community' were used. The results indicate no significant difference between urban and rural settings, but significant change-over-time in HIV stigma and stigmatization after the intervention. Recommendations include the retention of the tenets and methodology of this HIV stigma reduction intervention. Activities to ensure diverse cultural sensitivity and guidelines for replication could be added.

Key Words: Change-over-time; Community-based intervention; Experiences; HIV; Stigma; Stigmatization.

1 Introduction

HIV infection remains a globally stigmatized condition (Aggleton & Parker, 2002; Greeff et al., 2008) and the stigma creates a sense of shame and disgrace, social unacceptability and feelings of being stigmatized, being an outcast or marked as different (Mandal, 2013). Although one would expect stigma to decrease with increased visibility of HIV, the MRC (Visser, 2007) found no such evidence in Sub-Saharan Africa where HIV stigma is one of the biggest challenges. Worldwide, there were 700 000 fewer new HIV infections in 2011 than in 2001. Asia, Oceania and Nepal report up to 91% decrease in HIV infections. Africa managed to cut AIDS-related

deaths by a third since 2006 (UNAIDS, 2012). Yet, the UNAIDS 2012 World AIDS day report states that the Middle East, North Africa, Eastern Europe and Central Asia had a 25-35% increase in HIV infections between 2001 and 2011.

The fight against HIV and AIDS must be seen in the context of the three waves of the pandemic described by Aggleton and Parker (2002). The first and second waves of the AIDS pandemic were respectively the catastrophic transmission of HIV and the reality of AIDS as a devastating illness. The third wave of the pandemic is a strong wave of stigmatization, discrimination, blame and collective denial (Aggleton & Parker, 2002). This study focused on an intervention effecting sustained reduction of HIV stigma experiences of people living with HIV (PLWH), and stigmatization by people living close to them (PLC).

1.1 Conceptualisation of HIV stigma

Some fifty years ago, Goffman (1963) described generic stigma as a deeply discrediting personal phenomenon. Alonzo and Reynolds (1995), Harvey (2001) and Nyblade (2006) refer to stigma as a spoiled social identity or powerful tainting label or social mark that discredits an individual and radically changes the way individuals view themselves and are viewed by others. The Harvard Mental Health Letter (President and Fellows Harvard College, 2010) identifies HIV as such a potential discrediting attribute, and predicts that PLWH will experience the consequences of such social discrediting prejudice. A stronger term for *stigma*, similar to *racism*, which refers to a publically disapproved act of discrimination, could benefit the fight against HIV stigma and the quality of life for PLWH and PLC (Deacon & Stephney, 2007; Deacon, Stephney & Prosalendis, 2005; Yang & Kleinman, 2008).

1.2 Manifestation of HIV stigma

HIV stigma refers to a socially constructed 'undesired differentness' that disempowers stigmatized people through definite acts of ostracism, discrimination, social control, marginalization and social domination (Herek, Saha & Burack, 2013). This emphasizes acts like labeling, stereotyping, separation, diminishing and discrimination (Link, Yang, Phelan & Collins, 2004). Some authors contextualize HIV stigma as a violation of human rights and categorize it as the denial of health or home care facilities, verbal and physical abuse, scolding and ridiculing,

food deprivation, denial of employment and income opportunities, refusal of leadership positions and a breach of confidentiality regarding their HIV status (Kohi et al., 2006). Aspects of psychological distress of stigmatized PLWH include manifestations like increased physical distance, awkward social interaction, indifference, avoidance, blaming, exaggerated kindness, aggression, exclusion, excessive hygienic measures and being told to disclose or not (Stutterheim et al., 2009). These complexities led to Holzemer et al. (2007) championing a four-dimensional process model for HIV stigma in Africa. The model firstly describes HIV stigma within an interactive context of the environment, the health care system and the agents (people) involved. The interactive model potentiates a functional process of triggers, behaviors, types and outcomes of HIV stigma. In this way, something like an HIV test can trigger a set of behavioral responses, give rise to different types of stigma and cause a set of outcomes of stigma for the PLWH. This model forms a basic theoretical framework for further exploration.

1.3 Types of HIV stigma

Recent literature refers to various types of HIV stigma. Internal stigma is a first type of HIV stigma described by Holzemer et al. (2007), Mak et al. (2007) and Siyam'kela (2003). This refers to an internalized or self-stigma that Weiss et al. (1992) and Rensen, Bandyopadhyay, Gopal and Van Brakel (2011) describe as an insider's view or emic stigma. Received stigma is the second type of HIV stigma (Holzemer et al., 2007, Siyam'kela, 2003 & Mak et al., 2007). It is linked to various other descriptive terms, like *perceived* or *anticipated* stigma (Link et al., 2004 & Mak et al., 2007), *etic* stigma, or an *outsider-view* stigma (Weiss, et al., 1992), *external* or *enacted* stigma (Boyd, Katz, Link & Phelan, 2010; Herek et al., 2013) and *felt* stigma (Siyam'kela, 2003; Herek et al., 2013). The third type of HIV stigma refers to associated stigma (Holzemer et al., 2007 and Siyam'kela, 2003) or secondary stigma (Ogden & Nyblade, 2005) stemming from an association with PLWH. The various types of HIV stigma expose elements of one's personal contribution to one's own stigma, imposed stigma by stigmatizing outsiders and the stigmatizing of those associated with stigmatized persons.

Figure 2: Types of HIV Stigma

PLWH		PLC
Internal Stigma (Holzemer et al. 2007; Siyam'kela, 2003; Mak et al., 2007)	Received Stigma (Holzemer et al., 2007; Siyam'kela, 2003; Mak et al., 2007)	Associated Stigma (Holzemer et al., 2007, Siyam'kela, 2003).
Self Stigma (Holzemer et al. 2007; Siyam'kela, 2003; Mak et al., 2007)	Perceived/Anticipated Stigma (Link et al., 2004; Mak et al., 2007)	Secondary Stigma (Ogden et al., 2005)
Emic Stigma (Insider) view (Weiss, et al., 1992; Rensen, et al., 2011)	Etic Stigma (Outsider) view (Weiss et al., 1992)	
	External Stigma (Boyd, 2010; Herek et al., 2013)	
	Enacted Stigma (Boyd, 2010; Herek et al., 2013; http://wikiEducator.org , 2013)	
	Felt Stigma (Holzemer et al. 2007; Herek et al., 2013; http://wikiEducator.org , 2013)	

1.4 Outcomes of HIV stigma for people living with HIV

The literature mentions broad areas of life-intrusive outcomes of HIV stigma.

Diminished physical and mental health is partly caused by repeated verbal or physical abuse or violence that discourages the PLWH from utilizing health services, medical treatment and care facilities (Greeff et al., 2009; Holzemer & Uys, 2004; Maughan-Brown, 2004; Phillips, 2008; Skinner & Mfecane, 2004).

Isolation or decreased social participation from PLWH fearing HIV stigma and minimizing their exposure to others (Genberg et al., 2007; Gilbert & Walker, 2010; Greeff et al., 2010; Mallory et al., 2007; Rensen et al., 2011). This leads to poor participation in health care opportunities, in relationships and in employment (Foster & Gaskins, 2009; Greeff et al., 2010; Maughan-Brown, 2004; Skinner & Mfecane, 2004; Spangolo, Murphy & Liberia, 2008). PLWH sometimes become self-isolating to prevent HIV-transmission and to minimize secondary (associated) stigma directed at those living close to them (Salter et al., 2011).

Personal and emotional frailty of PLWH can lead to internalized self-stigmatization, shame and a compromised self-efficacy (Naidoo et al., 2007; Skinner & Mfecane, 2004). This can cause social avoidance, real or perceived loss of friends, perceived discomfort of those they are in contact with, symptoms of depression and feelings of anxiety, hopelessness and unattractiveness (Cahill & Valadez, 2013).

Decreased quality of life results as an outcome of HIV stigma relates to poor disclosure practices, poor sexual choices or quality of life decisions driven by a debilitating internalized fear for the loss of significant relationships for consequences of positive life choices (Greeff, 2010; Rensen et al., 2011). Ogden and Nyblade (2005) add that PLWH face losses like income/livelihood, marriage, childbearing, family care, hope, self-worth and reputation.

The dilemma of disclosure practices is another consequential outcome of HIV stigma where PLWH do not trust the reactions and confidentiality of others. They fear for their emotional safety, the loss of their livelihood, changed attitudes towards them and even reactive fear of contagion (Foster & Gaskins, 2009; Kasapoglu, Saillard, Kaya & Turan, 2011). Such fear of HIV stigma impedes the confidence to pursue life opportunities, relationships, intimacy and relaxation (Greeff, 2013). The burden of powerful negative thought processes and self-talk becomes worse if the PLWH decide not to disclose their HIV status (Pachankis, 2007).

Positive outcomes of HIV stigma are possible if PLWH accept the inevitable, demonstrate a pleasant disposition, choose positive interpretations of social interactions, refuse a victim role and focus on health, resilience, strengths and capacity to flourish in society (Shih, 2004).

1.5 Outcomes of HIV stigma on people living close to people living with HIV

Literature reveals that HIV stigma has persistent consequential manifestations in the community and on PLC, like the partners, children, family, friends, spiritual leaders and close community members of PLWH.

The socio-economic impact of HIV stigma on the PLC stems from the fear of contagion that gives rise to acts of discrimination, deteriorating health, actual job losses and therefore decreased

labor potential of PLWH, leading to impoverishment of themselves and their dependants (Asiedu, 2010; Foster & Gaskins, 2009; Uys et al., 2005).

The psychosocial impact of HIV stigma on PLC stems from stigma as a social construct that influences social structures and dynamics like social change, loss and potential psychological effects (Taylor, 2001). PLC could face bullying, gossip and potential loss of social support, friends, partner relations, social standing, family networks or leadership roles due to their association with PLWH (Asiedu, 2010). *The impact of HIV stigma on health care services* includes fear of contagion by staff and public, discriminatory events, fear of stigma by association, fear of exposure by third parties and expectations of up-to-date medical and nursing expertise (Uys et al., 2005). Public health services in most countries are already stretched (Foster & Gaskins, 2009; Asiedu, 2010) And HIV stigma adds to the burden by deterring people from accessing care, adhering to treatment and changing health-risk-behavior patterns (Gilbert & Walker, 2010).

The impact of HIV stigma on children of PLWH often stems from associated stigma and includes psychological reactions in children burdened by a sick or dying parent (Foster & Williamson, 2000). The stigma by association furthermore gives rise to bullying, dropping out of school, changing friendships, cruelty, discrimination, social isolation or other life intrusive changes on social and psychological levels (Taylor, 2001).

The impact of HIV stigma on the spiritual dimension of the PLC relates to personal spirituality, shared support and spiritual leadership. These are often faith/religion based, moralistic, prejudiced, punitive and discriminatory but also influential and fully resourced by their members who may happen to be HIV positive (Campbell & Rader, 2005). The community-based religious fraternity may seek earnest participation of PLWH and PLC whilst being confronted by fear of contagion and prejudice rather than spiritual connectedness and transcendence beyond sickness or sin (Bauer, 2013).

The impact of HIV stigma on the psychosocial well-being of PLC lies in the erosion of confidence levels and basic rights to participate in health care opportunities, treatment and support structures (Avert, n.d.). HIV stigma potentially causes discord in families and communities and

thus disturbs critical social and relational balances and undermines the psychosocial well-being of PLWH and PLC (Asiedu, 2010; Salter et al., 2011; Taylor 2001).

1.6 Differences of HIV stigma in urban and rural areas

Researchers disagree on urban-rural differences in the manifestation or prevalence of HIV stigma. One of the factors is urbanization, which involve families migrating between urban employment and rural homesteads. Full understanding of HIV was delayed in rural areas (Voeten, Egesah & Habbema, 2004). Naidoo et al. (2007) emphasize that urban PLWH face more received stigma than their rural counterparts and that urban structures facilitate higher reporting on HIV stigma. Heckman et al. (1998) found that urban and rural PLWH in the USA did not differ in age, education, employment, income or HIV symptomatology but that rural PLWH rated the severity of barriers to competent and compassionate care higher than urban PLWH. These barriers included a shortage of competent health professionals, long distances to medical facilities, a lack of public transport and experiences of stigmatization. Ankrah (1993) added a lack of privacy, anonymity and confidentiality as common aspects of HIV stigma in rural areas and Mswela (2009) emphasizes that harsh treatment of sick relatives is more common in rural areas.

1.7 Community-based HIV stigma reduction interventions

Only limited success for alleviating the effects of HIV stigma on community, national, and global levels were recorded over the first 25 years of the pandemic. Interventions were based on five levels of strategies, namely intrapersonal, interpersonal, community, institutional and governmental strategies (Heijnders & Van der Meij, 2006; Mahajan, et al., 2008). Critical elements for community-based HIV stigma reduction were gleaned from existing interventions. The first set of four elements refers to information-based targeting of the general population, tolerance building approaches through personal contact with PLWH, the acquisition of coping skills for dealing with HIV stigma and applied counselling (Brown, Macintyre & Trujillo, 2003). Another set of three elements taken from the attribution model specifically aims at replacing incorrect attributions/beliefs with correct ones through protesting against inaccurate information and myths, ensuring responsible HIV education, and facilitating contact between

stigmatized and stigmatizing people (Corrigan, 2000). Uys et al. (2009) use three basic elements for the successful testing of an intervention in Africa, namely accurate information, personal contact with the stigmatized and skills to cope with stigma. Various authors promote multi-method approaches, like a combination of information sharing and skills building, or education combined with personal contact (Brown, et al., 2003; Cross, Heijnders, Dalal, Sermirittirong & Mak, 2012; Holm-Hansen, 2009).

Sengupta, Banks, Jonas, Miles and Smith (2011) reviewed 19 HIV stigma reduction interventions in East Asia and Pacific, South Asia, Europe and CIS, Sub-Saharan Africa and North America and reported gaps in the targeting, measuring, benefits and internal validity. Cross Heijnders, Dalal, Sermirittirong & Mak, (2011) describe a matrix framework for the development of situational stigma interventions and adherence to strategic stigma reduction guidelines that used levels of stigma (intrapersonal, interpersonal, organizational and community or governmental) and cross-referencing components (labelling, stereotyping, separation, status loss and discrimination).

2 Problem statement

There is growing international concern about the incidence, causes, types and impact of HIV stigma on PLWH and PLC in different communities all over the world. A variety of HIV stigma reduction strategies and interventions in urban and rural areas measured successful on a small scale. The challenge is to achieve lasting change-over-time in the HIV stigma experiences of PLWH and the stigmatization by PLC on a bigger scale. There is a need for HIV stigma reduction and eradication in many international communities, in spite of the complexity of social structures and response patterns.

3 Research questions

The study seeks clarity on three research questions. Firstly, will there be a difference between urban and rural PLWH and PLC following the comprehensive community-based HIV stigma reduction intervention? Secondly, will the comprehensive community-based HIV stigma reduction intervention reduce the stigma experiences of PLWH? Thirdly, will the comprehensive community-based HIV stigma reduction intervention reduce HIV stigmatization by PLC?

4 Research objective

The research objective was to test the change-over-time in HIV stigma experiences of PLWH and change-over-time in HIV stigmatization by PLC in both urban and rural settings, following a comprehensive community-based HIV stigma reduction intervention.

5 Research design

A quantitative experimental single system design (De Vos, Strydom, Fouche & Delport, 2005) with a pre-test and four repetitive post-test measures (01 x 02 03 04 05) was conducted. Both an urban and a rural setting were included.

6 Research method

6.1 Sample

The sample of the study comprised two groups, namely PLWH and PLC in both an urban and a rural setting which, according to Thorne (2008), represent a subset of a theoretical whole population to be engaged with. The two subsets form part of a bigger study aiming at enhancing a deeper understanding of HIV stigma and coping with it, enhancing relationships between PLWH and PLC, as well as activating leadership of both PLWH and PLC to reduce HIV

stigma. The number of participants had to be small because the therapeutic nature of the intervention (Thorne, 2008) required meaningful small group interaction. It started with PLWH and then extended to larger groups involving both PLWH and PLC. Initial purposive sampling for PLWH was followed by snowball sampling for the PLC. The PLWH could choose people living close to them from each of the six designated groups to participate in the study: partners, children, family, friends, spiritual leaders and community members.

18 PLWH were identified by purposive voluntary sampling through existing NGOs and health care clinics working with PLWH, through mediators who had trusting relationships with PLWH in the particular urban and rural settings. The inclusion criteria for PLWH were that participants had to be over 18 years old; conversant in either Afrikaans, English or Setswana; HIV positive for a minimum of six months; and willing to give informed consent for participation and recording. PLWH participants were also required to share in HIV status disclosure workshops with other PLWH, willing/able to nominate PLC for further workshops and participation in the various workshops of designated groups involving both PLC and PLWH. Eventually, 10 PLWH were selected from the Potchefstroom urban district and 8 PLWH from the rural Ganyesa district of the North West Province, South Africa (Table 5 refers). All the PLWH were black South Africans. 12 finished school with Grade 10 or higher, 7 hold a post-school certificate and 1 a diploma. 10 persons had no post-school education.

Table 5: Sample distribution

PLWH	URBAN			RURAL			Total
	Female	Male	Sub total	Female	Male	Sub total	
	9	1	10	5	3	8	18
PLC	URBAN			RURAL			Total
	Female	Male	Sub total	Female	Male	Sub total	
Partners	0	2	2	1	0	1	3
Children	3	1	4	5	2	7	11
Family	2	0	2	4	1	5	7
Friend	2	0	2	6	0	6	8
Spiritual Leader	2	4	6	7	3	10	16
Community Member	6	1	7	8	0	8	15
Total	15	8	23	31	6	37	60

PLWH participated in snowball sampling by exercising a choice to nominate six people as PLC, one from each of the six designated categories – a spouse or partner, a child over 15 years of age, a family member, a close friend, a spiritual leader and a community member. These designated members then formed six designated groups. The further inclusion criteria for PLC were similar to the PLWH, except that the PLC did not have to be HIV positive. All PLWH might not have been able to nominate a person from each designated group since they might not have known someone appropriate for each grouping. A total of sixty (n=60) PLC were identified (Table 5 refers). There were 23 urban and 37 rural participants, of whom most were Setswana-speaking and residing in communities in the same province. Ethnically, the PLC sample included 93.3% black, 4.8% colored and 0.3% Indian participants. Of the 60 PLC, 83.3% passed Grades 10, 11 or 12, whilst 55% had no post-school education, 41.7% obtained a post-school certificate and 3.4% a diploma or degree.

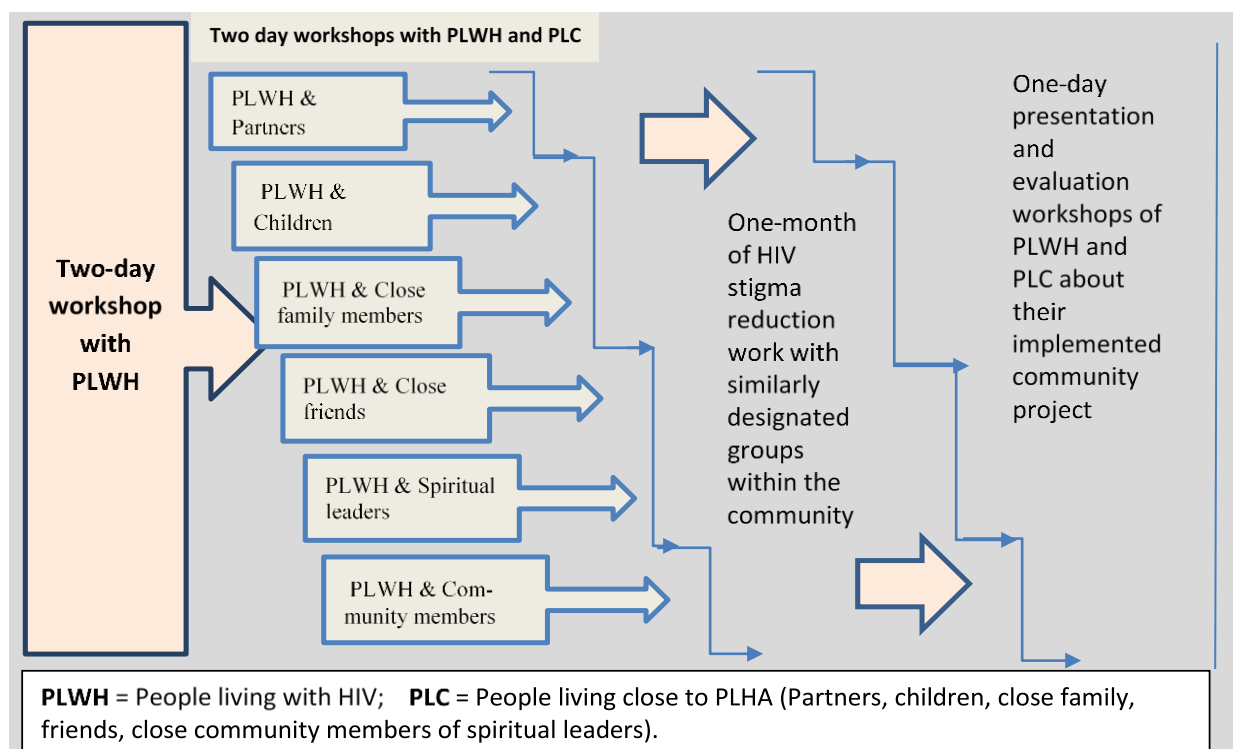
6.2 The intervention

The intervention was adapted from the validated intervention manual of Uys et al. (2009) and was based on three tenets, namely the a) sharing of information on HIV stigma and coping with HIV stigma, b) the equalising of relationships between PLWH and PLC through increased interaction and contact amongst them by grouping them together, and c) the empowerment of members of both groups towards leadership in HIV stigma reduction through practical knowledge and experience of project planning towards HIV stigma reduction and implementation in their communities.

The comprehensive community-based HIV stigma reduction intervention primarily involved three processes (see figure 3) and ran over a five month period in both the urban and rural settings. There was firstly a two-day presentation and activity-based workshop for PLWH only, which focused on their personal understanding of HIV stigma, identification of their personal strengths and enhancing their responsible disclosure management to prepare them for the rest of the workshops in the intervention. The initial two-day workshop with only PLWH was followed by a series of six three-day workshops attended by all PLWH and their particular PLC from a designated group; first the group of spouses/partners, then the group of children over 15, then family members, friends, spiritual leaders and lastly neighbours or community members. The workshops were two weeks apart and led by two facilitators (one HIV infected

and one non-HIV infected person) in each group. The first day of these workshops focused on an understanding of and coping with HIV stigma and the relationship between PLWH and PLC. The second day focused on learning how to plan a project and then on planning an actual HIV stigma reduction project with a group similar to the specific designated group, e.g. partners with partners. Each of the 12 groups had a four-week period to implement their projects in their community whilst receiving support from the facilitators. On the third day, the different groupings presented their project reports to community members whom they invited and to the research team. Small prizes were awarded.

Figure 3: The comprehensive community-based stigma reduction and wellness enhancement intervention



6.3 Data collection

The data collection process made use of two structured, valid and reliable measuring instruments, namely the 'Perceived AIDS stigma instrument PLWA (HASI-P)' (Holzemer et al., 2007) and the 'AIDS related stigma measure for community HIV stigma' (Maughan-Brown,

2004). A pre-test and four repetitive post-tests were conducted on a three-monthly basis over a one-year period for PLWH and PLC in urban and rural settings to test change-over-time in the stigma experience of PLWH and the stigmatization by PLC.

The Perceived AIDS stigma instrument PLWA (HASI-P) is a 33-item instrument developed by Holzemer et al. (2007) and measures six dimensions of HIV and AIDS-related stigma (verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion and workplace stigma) experienced by PLWH. It was validated with a sample of 1 477 respondents from five African countries. Holzemer et al. (2007) report that stability was encouraging with a Cronbach reliability coefficient of 0.94 for the total scale.

The AIDS related stigma measure for community HIV stigma is a 39-item instrument that measures AIDS related stigma for community HIV stigma and was developed by Maughan-Brown (2004). Four indexes, namely policy/resource-based stigma (PI), behaviour intention stigma (BI), symbolic stigma (SS) and instrumental stigma (IS), are measured on subscales and a combined score is computed to yield a fifth index indicating general stigma (GS). Maughan Brown (2004) reported that initial reliability was established by factor analysis with an alpha coefficient of 0.76 for the factor relating to behaviour intention stigma, 0.59 for the factor relating to symbolic stigma and 0.55 for the factor relating to instrumental stigma.

The comprehensive community-based HIV stigma reduction intervention was preceded by training to prepare research assistants. They were taught how to conduct the interviews, use the instruments and ensure accurate reporting of the process. As the names of the participants became available through the mediators, a research assistant made appointments with them and participants were transported to and from the North-West University campus for data collection and workshops. They were offered a light lunch.

6.4 Data analysis.

The data analysis for the quantitative data was computed with the Statistical Package for the Social Sciences (SPSS) version 21 software for Windows. Descriptive statistics, namely mean, standard deviation, mean square error, p-values and effect sizes, were calculated. Hierarchical

linear modeling was used to estimate variability between urban-rural groups whilst taking into account the dependency on data collected from specific persons over time (McCoach, 2010).

7 Ethical Considerations

Ethical approval was obtained from the School of Nursing Science as well as from the North-West University Ethics Committee (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014). Permission was also obtained from the North West Provincial Department of Health as well as district health authorities. Proceedings were guided by basic ethical principles, like respect for human subjects, benevolence and justice, as described by Botma, Greeff, Mulaudzi and Wright (2010). Respect for the participants was displayed by presenting the participants with information regarding the criteria for their inclusion on a voluntary basis, efforts to safeguard their privacy and anonymity through computer coding, without linking their identity to collected data, analysis or reporting. Their partial confidentiality was ensured through a group contract with members. Participants were free to withdraw at any time. They signed a consent form if they were satisfied with the information, circumstances and intentions of the research team. The best interest of participants was ensured by offering them knowledge and clarification about HIV stigma, identifying their personal strengths and educating PLWH about responsible disclosure management. Their best interest was also pursued through enhanced relationships between PLWH and PLC, the acquisition of knowledge about HIV stigma reduction and coping with it, as well as basic skills to manage projects in the community. Fair treatment of participants was important and therefore possible risks to them were identified. Counselling was made available.

8 Results and Discussion

The hierarchical linear models indicated no statistical significance in the interaction effects of the urban and rural groups in any of the analyses, and no statistical significance in the main effect of urban versus rural groups. The urban/rural results were therefore pooled and the first

research question – whether there would be a difference between urban and rural PLWH and PLC following the comprehensive community-based HIV stigma reduction intervention – was answered in the negative, in that no significant difference was found.

8.1 Stigma experiences of people living with HIV

The subscales of '*Perceived AIDS stigma instrument PLWA (HASI-P)*' for PLWH indicated internal reliability with a Cronbach alpha value for health care neglect (HCN) at 0.62 and alpha values ranging between 0.77 and 0.85 for the other four subscales. As the limited number of 18 PLWH may offer insufficient statistical power to indicate significant differences, effect sizes between timelines were included for analysis of practical significance.

Time one items (see table 6) reflect the pre-intervention scores on five different HIV stigma dimensions for PLWH. The comprehensive community-based HIV stigma intervention was implemented between times one and two. In describing effect sizes, time one scores are compared with each of the remaining timeline scores for subscales.

Although not statistically significant with $p = 0.10$, the mean ($\bar{X}$) scores on the verbal abuse (VA) subscale decreased from $\bar{X} = 12.1$ at time one to $\bar{X} = 9.8$ at time two and $\bar{X} = 8.3$ at time five, indicating a decreased tendency in the experience of verbal abuse by PLWH. The effect sizes between times one and two, one and three, one and four as well as one and five are all well larger than 0.5. This is an indication of practical significance. The negative self-perception (NSP) scores of the PLWH are not statistically significant ($p = 0.26$) but the effect sizes of the decrease between times one and three and times one and five clearly indicate practical significance with values of 0.55 and 0.49. The health care neglect (HCN) subscale indicates a statistically significant improvement in the HIV stigma experience of PLWH with $p = 0.03$ and the four effect sizes ranging between 2.89 and 3.64. The subscale of social isolation (SI) was not statistically significant but had effect sizes between 0.71 and 0.96 (> 0.5) on the four timeline comparisons to time one, indicating practical significance and an improvement in the social isolation experienced by PLWH. Fear of contagion (FC) indicated statistical significance with $p = 0.03$. All five dimensions of HIV stigma on the HASI-P scale increased either with statistically significant

or practically significant margins and thus indicate an improvement in the experiences of PLWH after the intervention.

The summation of the scores of each of the timelines yield a total stigma score for each (see table 6). $p = 0.02$ indicates statistical significance of change-over-time on these total scores. The effect sizes on total stigma indicate larger differences between times one and three of verbal abuse (VA), negative self-perception (NSP) and health care neglect (HCN). It also reveals larger effect sizes between times one and five of the social isolation (SI) and fear of contagion (FC) scales. The second research question is thus answered by confirming that stigma experiences of PLWH decreased following the comprehensive community-based stigma reduction intervention.

Table 6: HIV stigma dimensions experienced by PLWH

Dimensions	Mean scores							Effect sizes			
	Time 1	Time 2	Time 3	Time 4	Time 5	MSE	p	1 with 2	1 with 3	1 with 4	1 with 5
VA	12.1	9.8	8.2	8.2	8.3	1.25	0.1	2.06	3.49	3.49	3.4
NSP	7.39	6.8	6.19	6.69	6.32	4.76	0.26	0.27	0.55	0.32	0.49
HCN	7.6	7.1	7.04	7.1	6.97	0.03	0.03	2.89	3.23	2.89	3.64
SI	6.7	5.75	5.51	5.51	5.42	1.78	0.38	0.71	0.89	0.89	0.96
FC	7.7	6.63	6.31	6.42	6.08	0.34	0.03	1.84	2.38	2.2	2.78
Tot	43.61	37.94	35.01	35.47	34.69	12.61	0.02	1.6	2.42	2.29	2.51

NB: VA=Verbal abuse; NSP=Negative self-perception; HCN=Health care neglect; SI=Social Isolation; FC= Fear of contagion; Tot=Total; MSE = means square error.

Linear correlation coefficients on the HASI_P are significant amongst almost all the HIV stigma dimensions. Only the negative self-perception (NSP) and health care neglect (HCN) dimensions do not demonstrate a significant correlation with each other (see table 7). Stigma dimensions can be measured separately but are often experienced in correlation with each other and thus contribute to the complexity of the stigma experience of PLWH.

8.2 Stigmatization by people living close to people living with HIV

The 'AIDS related stigma measure for community HIV scale' measures five indexes of HIV stigmatization. In this study, it was utilized for people living close to people living with HIV (PLC). The five indexes are the policy/resource-based (PI) index, the behaviour intention (BI)

index, the symbolic stigma (SS) index, the instrumental stigma (IS) index and a general stigma (GS) index. The independent factor analysis for items on the policy/resource-based (PI) and behaviour intention (BI) indexes for this study did not prove to be reliable on the Cronbach alpha coefficient and are therefore excluded from the analysis. These were ($\alpha = 0.17$) for policy/resource based (PI) intention and ($\alpha = 0.14$) for behaviour intention (BI). The subscales for symbolic stigma (SS), instrumental stigma (IS) and general stigma (GS) indexes tested reliable with Cronbach alpha scores of 0.54, 0.69 and 0.53 respectively.

Table 7: Correlations between dimensions of HIV stigma

Dimensions	VA	NSP	HCN	SI	FC
VA	1.00				
NSP	.799**	1.00			
HCN	.374*	0.12	1.00		
SI	.778**	.601**	.435**	1.00	
FC	.637**	.462**	.324*	.788**	1.00

VA=Verbal abuse; NSP=Negative self-perception; HCN=Health care neglect; SI=Social Isolation; FC= Fear of contagion. **correlation coefficient is significant on the 0.01 level (two-tailed), *correlation is significant at the 0.05 level (two-tailed).

Table 8 shows statistically significant increases for the symbolic stigma (SS), instrumental stigma (IS) and general stigma (GS) indexes. Symbolic stigma (SS) refers to a moralistic, value-based position or prejudice based on what HIV symbolizes for the PLC (Maughan-Brown, 2004). The mean score for symbolic stigma (SS) at time one ($\bar{X} = 9.2$) reflects the pre-intervention measure for PLC and increases to $\bar{X} = 10.6$ at time five. This is statistically significant ($p < 0.01$). Effect sizes between the compared timelines on symbolic stigma (SS) indicated practical significance as well, but those between times one and three and one and four were exceptionally large, measuring 0.70 and 0.65 respectively. An increase on this scale suggests a change over time from the initial prejudice or intention.

Instrumental stigma (IS) refers to personally useful stigmatizing thoughts or actions used for self-protection by PLC. For instance, a personal fear of contagion can make someone refuse to share cups or cutlery, avoid touch or refrain from intimacy (Maughan-Brown, 2004). The

instrumental index (IS), at time one pre-intervention, was ($\bar{X} = 10.7$) and increased to ($\bar{X} = 11.6$) at time five. The $p = 0.01$ value indicates a statistically significant difference and the effect size of times one and five was 0.50. This may indicate that the intervention with its HIV knowledge sharing, relationship equalization and personal empowerment could start to replace initial stigmatizing thoughts and actions. The general stigma (GS) index for PLC also gives a statistically significant result, with an increase from $\bar{X} = 38.5$ at time one to $\bar{X} = 42.1$ at time five and $p < 0.01$. There also is an indication of practical significance with all four effect sizes larger than 0.50, which suggests improvement (change over time) in the general stigmatizing of PLC following the intervention. The third research question – whether the comprehensive community-based HIV stigma reduction intervention would reduce HIV stigmatization by PLC – is thus confirmed.

Table 8: AIDS related stigma measure for community HIV (Stigmatization by PLC)

	Time 1	Time 2	Time 3	Time 4	Time 5	Estimate Residual	p	Effect size of each time with time 1			
Dimensions	Mean	Mean	Mean	Mean	Mean			1 with 2	1 with 3	1 with 4	1 with 5
SS	9.16	10.4	10.96	10.82	10.59	6.56	<0.01	0.19	0.27	0.25	0.22
IS	10.66	10.81	11.53	11.34	11.61	3.59	0.01	0.04	0.24	0.19	0.26
GS	38.46	41.44	42.42	42.85	42.06	33.19	<0.01	0.09	0.12	0.13	0.11

NB: PLC=People living close to PLWH; SS=Symbolic stigma; IS=Instrumental stigma; GS=General stigma.

9 Conclusions

No significant differences were found between urban-rural groups over time. This could have been due to the study being conducted in the North West Province among a mainly Setswana-speaking population. No cultural tension became evident either. The PLWH responses to each of the subscales on the first measure, confirmed the presence of stigma on all five dimensions of HIV stigma. The scale demonstrated either statistical or practical significance in the decline of the stigma experiences of PLWH on all the dimensions: verbal abuse, negative self-perception, health care neglect, social isolation by others and fear of contagion. The total stigma score showed a statistically significant change over time in the overall stigma experiences of PLWH and thus indicated that the comprehensive community-based stigma reduction intervention

was successful. The third timeline measure, about three months after the intervention, revealed large effect sizes. These could be indicative of personal benefits derived from the comprehensive community-based HIV stigma reduction intervention. The linear correlation amongst the five HIV stigma dimensions indicate the tangency and even complexity of HIV stigma, which necessitates a multi-dimensional approach during the intervention.

Although only three of the five indexes for stigmatization by PLC were used in the analysis, they demonstrated statistically significant change. Similar to the findings of the experiences of PLWH, large effect size scores featured at the third measure about three months after the intervention, as PLC started to internalize effects of the intervention. The symbolic enhancement is indicative of a change in PLC's moralistic behavior and fewer prejudices. PLC also realized that they probably did not need the symbolic behavior to protect themselves from becoming infected. This could be due to the increased contact between PLWH and PLC. The type of prejudice-based HIV stigma intent measured by symbolic, instrumental and general stigma scales included the opinion that HIV was punishment for sleeping around, refusal to admit HIV positive children to public schools and fear of touching someone with HIV. All these stigmatization thoughts and actions of the PLC showed reduced incidences. It could thus be concluded that stigmatization by PLC could also be reduced through the intervention.

The change-over-time in the HIV stigma experiences of PLWH occurred hand-in-hand with the change-over-time in the HIV stigmatization behavior by PLC. These changes in stigma experiences and stigmatization could be sustained over a one-year period after the intervention, showing that the impact on both PLWH and PLC was tangible. The preparation of PLWH to understand HIV stigma, manage their disclosure responsibly and identify their strengths laid a foundation for the rest of the workshops with PLC. Using a team of infected and non-infected facilitators as well as bringing both PLWH and PLC together in the same workshop emphasized the importance of equal relationships. They were modeling equality, acceptance and working together. The fact that both the stigma experiences and stigmatization were effectively changed, indicates that the manner of work and the content of the intervention were useful. The interaction and contact amongst participant's normalized togetherness, offered opportunities to share and activated support for each other. The projects that were

undertaken by the PLWH and the PLC, together, as leaders in stigma reduction in their own community could have contributed to a reduced fear of contagion. Both PLWH and PLC regained some control after the devastating news that HIV became a reality in their lives. If the full circle of PLC surrounding the PLWH can be included, a more comprehensive reaction to the stigmatization process may be found. The intensity and time that went into the intervention over a four-month period could be somewhat intense for PLWH but it had meaningful results. The participants benefitted from the therapeutic nature of the intervention that offered skilled facilitators, a limited number of participants and a structured environment. The comprehensive community-based HIV stigma reduction intervention contributed towards bridging existing gaps in the quest for successful HIV reduction interventions.

10 Limitations of the study

The sample size of the PLWH may seem small but the therapeutic nature of the intervention included small group interaction, relationship building and pairs of skilled facilitators, which made big numbers of participants unpractical. Snowball sampling for the recruitment of PLC was dependent on PLWH and the researcher was uncertain of numbers and availability of potential participants for the six specified categories (spouses, children, family members, friends, spiritual leaders, neighbors/community members).

11 Recommendations

The comprehensive community-based HIV stigma reduction intervention could become a useful tool in many communities. The snowball sampling of PLC may be done without the restriction of designated categories. An aspect of culture sensitivity can be added to ensure success in diverse communities. The basic tenets, methodology, participation, ethical considerations and programmatic expertise should be adhered to without adapting them. Groups should be kept small enough to ensure therapeutic benefit and PLWH should never be exposed to intervention content without being well prepared. A set of guidelines should be compiled for future

implementation of the intervention. It would be helpful to have the intervention tested in a variety of cultures and locations with a view to building community-based networks and structures to eradicate HIV stigma and enhance wellness in the community at large. A booster type intervention at time three may contribute to long-term sustainability of change-over-time in the reduction of HIV stigma experiences and stigmatization after such intervention.

12 References

- Aggleton, P., & Parker, R. (2002). *World AIDS Campaign (2002–2003). A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub02/jc891-wac_framework_en.pdf
- Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social science & Medicine*, 41(3), 303-315.
- Ankrah, E. M. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care: Psychological and Socio-medical aspects of HIV/AIDS*, 5(1), 5-22. doi: 10.1080/09540129308258580
- Asiedu, G. B. (2010). *“Once it’s your sister, they think it’s in the bloodline”: impact of HIV/AIDS-related stigma in Ghana* (Doctoral thesis). Retrieved from <http://krex.k-state.edu/dspace/bitstream/handle/2097/6698/GladysAsiedu2010.pdf?sequence=1>
- Avert. (n.d.). *HIV & AIDS Stigma and Discrimination*. Retrieved from <http://www.avert.org/hiv-aids-stigma-and-discrimination.htm>
- Bauer, E. (2013). Enacting support within church communities for people living with HIV or AIDS. *Mental Health, Religion and Culture*, 16, 1, 100-118. doi: 10.1080/13674676.2011.645801
- Botma, Y., Greeff, M., Mulaudzi, F. M., & Wright, S. C. D. (2010). *Research in health science*. Pinelands: Cape Town.
- Boyd, J. E., Katz, E. P., Link, B. G., & Phelan, J. C. (2010). The relationship of multiple aspects of stigma and personal contact with someone hospitalized for mental illness, in a

- nationally representative sample. *Socio Psychiatric Epidemiology*, 45, 1063–1070. doi: 10.1007/s00127-009-0147-9
- Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*, 15(1), 49-69. doi: 10.1521/aeap.15.1.49.23844
- Cahill, S., & Valadez, R. (2013). Growing older with HIV/AIDS: New public health challenges. *American Journal Public health*, 3(3), 7-15. doi: 10.2105/AJPH.2012.301161
- Campbell, D., & Rader, A. (2005). *HIV/AIDS, Stigma and Religious Responses: An overview of issues relating to stigma and the religious sector in Africalan*. USA: Christian Connections for International Health [CCIH]. Retrieved from <http://www.heart-intl.net/HEART/080105/HIVAIDSStigma.htm>
- Corrigan, P. W. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical psychology: Science and practice*, 7(1), 48-67. doi: 10.1093/clipsy.7.1.48
- Cross, H., Heijnders, M., Dalal, A., Sermrittirong, S., & Mak, S. (2011). Interventions for Stigma Reduction – Part 1: Theoretical Considerations. *Disability, CBR & Inclusive Development*, 22(3), 62-70. doi:10.5463/dcid.v22i3.70.
- Cross, H., Heijnders, M., Dalal, A., Sermrittirong, S., & Mak, S. (2012). Interventions for Stigma Reduction – Part 2: Practical Applications. *Disability, CBR & Inclusive Development*, 22(3), 71-80. doi:10.5463/dcid.v22i3.72.
- Deacon, H., & Stephney, I. (2007). *HIV/AIDS, Stigma and Children*. Cape Town: HSRC Press. Retrieved from www.hsrbpress.ac.za
- Deacon, H., Stephney, I., & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma; A theoretical and methodological analysis*. Cape Town: HSRC Press. Retrieved from www.hsrbpress.ac.za
- De Vos, A. S., Strydom, H., Fouche, C. B., & Delport, C. S. L. (2005). *Research at grass roots: for the social sciences and human service professions* (3rd ed.). Pretoria: Van Schaik Publishers.

- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans' management of HIV/AIDS stigma. *AIDS Care: Psychological and Socio-medical aspects of HIV/AIDS*, 21(10), 1306-1312. doi: 10.1080/09540120902803141
- Foster, G., & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS* 2000, 14(3), 275-284.
- Genberg, B. L., Kawichai, S., Chingono, A., Senday, M., Chariyalertsak, S., Konda, K. A., & Celentano, D. D. (2007). Assessing HIV/AIDS stigma and discrimination in developing countries. *Aids and Behavior*, 12(5), 772-780. doi: 10.1007/s10461-007-9340-6
- Gilbert, L., & Walker, L. (2010). My biggest fear was that people would reject me once they knew my status: Stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, SA. *Health and Social care in the Community*, 18(2), 139-146. doi: 10.1111/j.1365-2524.2009.00881.x
- Goffman, E. (1963). *Stigma: Notes on the management of spoilt identity*. Englewood Cliffs, N.J.: Prentice Hall.
- Greeff, M. (2010). *A comprehensive community-based HIV stigma reduction and wellness enhancement intervention*. Unpublished manuscript, Faculty of Health Sciences, AUTHeR, North-West University, Potchefstroom, South Africa.
- Greeff, M. (2013). Disclosure and stigma: A cultural perspective. In P. Liamputtong (Ed.), *Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective* (pp. 71-95). Netherlands: Springer.
- Greeff, M., Uys, L. R., Holzemer, W. L., Makoe, L. N., Dlamini, P. S., Kohl, T. W.... Pletlhu, R. D. (2008). Experiences of HIV/AIDS stigma of persons living with HIV/AIDS and nurses involved in their care from five African countries. *Africa journal of nursing and midwifery*, 10(1), 78-108.
- Greeff, M., Uys, R. L., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P. S... Holzemer, W. L. (2010). Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: a longitudinal study. *International journal of nursing studies*, 47, 475-486. doi:10.1016/j.ijnurstu.2009.09.008
- Harvey, R. D. (2001). Individual differences in the phenomenological impact of social stigma. *Journal of social psychology*, 141(2), 174-189. doi: 10.1080/00224540109600545

- Heckman, T. G., Somlai, A. M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C. A... Kelly, J. A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas, *AIDS Care: Psychological and Socio-medical Aspects of HIV/AIDS*, 10(3), 365-375. doi: 10.1111/j.1748-0361.1998.tb00615.x
- Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma reduction strategies and interventions. *Psychology, Health and Medicine*, 11(3), 353-363. doi: 10.1080/13548500600595327
- Herek, G. M., Saha, S., & Burack, J. (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and applied social psychology*, 35(1), 41-54. doi: 10.1080/01973533.2012.746606
- Holm-Hansen, C. (2009). Stigma reduction: promoting greater understanding of mental health. *Wilder Research Snapshot*, 1-4.
- Holzemer, W. L., & Uys, L. R. (2004). Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3), 165-174.
- Holzemer, W. L., Uys, L. R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., ... Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541- 551. doi: 10.1111/j.1365-2648.2007.04244.x
- Kasapoglu, A., Saillard, E. K., Kaya, N., & Turan, F. (2011). AIDS related stigma in social relations: A qualitative study in Turkey. *The qualitative report*, 16(6), 1496-1516. Retrieved from <http://www.nova.edu/ssss/QR/QR16-6/kasapoglu.pdf>
- Kohi, T. W., Makoe, L. N., Chirwa, M., Holzemer, W. L., Phetlhu, D. R., & Uys, L. R. (2006). HIV and AIDS stigma violates human rights in five African countries. *Nursing ethics*, 13(4), 405-414. doi: 10.1191/0969733006ne865oa
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3), 511-541.
- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres. G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, 22(2), 67-79. doi: 10.1097/01.aids.0000327438.13291.62

- Mak, W. W. S., Cheung, R. Y. M., Law, R. W., Woo, J., Li, P. C. K. & Chung, R. W. Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine*, 64(8), 1549-1559. doi:10.1016/j.socscimed.2006.12.003
- Mallory, O., Johnson, T. B., Neilands, S. M., Dilworth, S. F., Morin, R. H., Chesney, R., & Chesney, M. A. (2007). The role of self-efficacy in HIV treatment adherence: Validation of the HIV treatment adherence and self-efficacy scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359-370. doi: 10.1007/s10865-007-9118-3
- Mandal, A. (2013, November 18). AIDS-Stigma. *News Medical*. Retrieved from <http://www.news-medical.net/health/AIDS-Stigma.aspx>
- Maughan-Brown, B. (2004). *Measuring HIV/AIDS stigma: Working Paper No. 74*. Cape Town: Centre for Social Science Research [CSSR], University of Cape Town. Retrieved from http://www.commerce.uct.ac.za/Research_Units/CSSR/Working%20Papers/papers/wp74.pdf
- McCoach D. B. (2010). Hierarchical linear modeling. In G. R. Hancock & R. O. Mueller (Eds.), *The reviewer's guide to quantitative methods in the social sciences* (pp. 123-140). New York: Routledge.
- Mswela, M. (2009). Cultural practices and HIV in South Africa: A legal perspective. *Potchefstroom Electronic Law Journal*, 12(4), 172-360. doi: <http://dx.doi.org/10.4314/pelj.v12i4.50053>
- Naidoo, J. R., Uys, L. R., Greeff, M., Holzemer, W. L., Makoe, L., Dlamini, P., ... Kohi, T. (2007). Urban and rural differences in HIV/AIDS stigma in five African countries. *Medical journal of AIDS research*, 6(1), 17-23. doi: 10.2989/16085900709490395
- Nyblade, L. C. (2006). Measuring HIV stigma: existing knowledge and gaps. *Psychology, health & medicine*, 11(3), 335-345. doi: 10.1080/13548500600595178
- Ogden, J., & Nyblade, L. (2005). *Common at its core: HIV-related stigma across context*. Washington DC: International Center for Research on Women (ICRW). Retrieved from <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>

- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: a cognitive-affective-behavioural model. *Psychological bulletin*, 133(2), 328-345.
- Phillips, R. E. (2008). *Nurses' experience with HIV stigma in five African countries* (Doctoral thesis). Retrieved from http://www.nursing.arizona.edu/Library/091_Baird_martha.pdf
- President and Fellows Harvard College. (2010). Cognitive enhancement therapy for schizophrenia. Harvard Mental Health Letter, Oct. Retrieved from <http://cetcleland.org/about/Research/Harvard%20Mental%20Health%20Oct-2010.pdf>
- Rensen, C., Bandyopadhyay, S., Gopal, P. K., & Van Brakel, W. H. (2011). Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 33(9), 711-719. doi:10.3109/09638288.2010.506942
- Salter, M. L., Go, V. F., Le Minh, N., Gregowski, A., Vit Ha, T., Rudolph, A., ... Quan, V. M. (2011). Influence of perceived secondary stigma and family on the response to HIV infection among injection drug users in Vietnam. *AIDS Education and Prevention*, 22(6), 558-570. doi: 10.1521/aeap.2010.22.6.558
- Sengupta, S., Banks, B., Jonas, D. Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS behaviour*, 15(6), 1075-1087.
- Shih, M. (2004). Positive stigma: Examining resilience and empowerment in overcoming stigma. *The ANNALS of the American academy of political and social science*, 591(1), 175-185. doi: 10.1177/0002716203260099
- Siyam'kela. (2003). *HIV/AIDS resource pack: To reduce stigma related to HIV and AIDS*. Pretoria: Centre for the study of AIDS.
- Skinner, D., & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*, 1(3), 157-164.
- Spagnolo, A. M., Murphy, A. A., & Liberia, L. A. (2008). Reducing stigma by meeting and learning from people with mental illness. *Psychiatric rehabilitation journal*, 31(3), 186-193. doi: 10.2975/31.3.2008.186.193
- Stutterheim, S. E., Pryor, J. B., Bos, A. E. R., Hoogendijk, R., Muris, P., & Schaalma, H. P. (2009). HIV-related stigma and psychological distress: The harmful effects of specific stigma

- manifestations in various social settings. *AIDS*, 23(17), 2353-2357. doi: 10.1097/QAD.0b013e3283320dce
- Taylor, B. (2001). Nursing theory and concept development or analysis. HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals. *Journal of advanced nursing*, 35(5), 792-798. doi: 10.1046/j.1365-2648.2001.01912.x
- Thorne, S. (2008). *Interpretive description*. Left Coast, Calif.: Walnut Creek.
- UNAIDS. (2012). World AIDS Day Report 2012: Results. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/JC2434_WorldAIDSday_results_en.pdf
- Uys, L. R., Chirwa, M. L., Dlamini, P., Greeff, M., Kohi, T. W., Holzemer, W. L., ... Phletlhu, R. (2005). "Eating plastic", "winning the lotto", "joining the www": descriptions of HIV/AIDS in Africa. *Journal of the Associations of Nurses in AIDS Care*, 16(3), 11-21. doi:10.1016/j.jana.2005.03.002
- Uys, L. R., Chirwa, M. L., Kohi, T. W., Greeff, M., Naidoo, J. R., Makoe, L. N., ... Holzemer, W. L. (2009). Evaluation of a health setting-based intervention. *AIDS patient care and STDs*, 23(12), 1059-1066. doi:10.1089/apc.2009.0085
- Visser, P. (2007). *HIV/AIDS and stigma*. South African Medical Research Council [MRC]. Retrieved from <http://www.mrc.ac.za/public/facts17.htm>
- Voeten, H. A. C. M., Egesah, O. B., & Habbema, J. D. F. (2004). Sexual behaviour is more risky in rural than in urban areas among young women in Nyanza Province, Kenya. *Sexually transmitted diseases*, 31(8), 481-487.
- Weiss, M. G., Doongaji, D. R., Siddhartha, S., Wypij, D., Parhare, S., Bhatawdekar, M., ... Fernandes, R. (1992). The explanatory model interview catalogue (EMIC): Contribution to cross-cultural research methods from a study of leprosy and mental health. *The British Journal of Psychiatry*, 160, 819-30. doi: 10.1192/bjp.160.6.819
- Yang, L. H., & Kleinman, A. (2008). 'Face' and the embodiment of stigma in China: The cases of schizophrenia and AIDS. *Social Science & Medicine*. 67(3), 398-408. doi: 10.1016/j.socscimed.2008.03.011

ARTICLE 2: Change-over-time in the psychosocial well-being of people living with HIV and people living close to them after a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and rural setting.

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Change-over-time in the psychosocial well-being of people living with HIV and people living close to them after a comprehensive community-based HIV stigma reduction and wellness enhancement intervention in an urban and rural setting.

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Abstract

HIV stigma continues to affect the psychosocial well-being of people living with HIV (PLWH) and people living close to them (PLC), globally. Literature unequivocally holds the view that HIV stigma and psychosocial well-being interact with and impact on each other. This study is part of a larger SANPAD-funded research project, responds to the lack of interventions mitigating the impactful interaction of HIV stigma and psychosocial well-being, and tests one such intervention. The research objectives were to test the change-over-time in the psychosocial well-being of PLHA and PLC in both an urban and a rural setting, following a comprehensive community-based HIV stigma reduction and wellness enhancement intervention. An experimental quantitative single system research design with a pre- and four repetitive post-tests was used, conducting purposive voluntary sampling for PLWH and snowball sampling for PLC. The five measuring instruments used for both groups were the mental health continuum short form scale, the patient health questionnaire, the satisfaction with life scale, the coping self-efficacy scale and the spirituality well-being scale. No significant differences could be found between the urban-rural settings and data was pooled for analysis. The findings show that initial psychosocial well-being changes after the intervention were better sustained (over time) by the PLC than by the PLWH. Recommendations included that the intervention should be re-utilized and that its tenets, content and activities be retained. A second intervention three to six months after the first should be included to achieve more sustainability and to add focused activities for the enhancement of psychosocial well-being. The control of the PLC group sizes could be changed by cutting out specific designated categories. PLWH and PLC are to be encouraged to engage with innovative community mechanisms to make psychosocial well-being a way of life in the community at large.

Key words: change-over-time; community-based intervention; HIV; psychosocial well-being; stigma.

1 Introduction

Psychological well-being in the context of this study refers to the psychosocial aspects of humanity and partly builds on the historic work of Keyes (2002 & 2005). This author interprets psychosocial well-being as a combined occurrence of private, personal and social criteria of daily functioning operationalized by behavior. The 'Complete State' model (Keyes, 2002 & 2005) differentiates between emotional well-being (intrapersonal feelings), psychological well-being (private and personal criteria of everyday functioning) and social well-being (social coherence, social actualization, social integration, social acceptance and social contribution) that interact in the behavior that operationalizes psychosocial well-being. The model was further developed into a measuring instrument that was applied in this article. Keyes *et al.* (2008) introduced two compatible traditions reflecting subjective well-being: one that focuses on feelings towards life (hedonic, emotional well-being) and another that focuses on functioning in life (eudemonic well-being). The hedonic tradition briefly describes emotional well-being (EWB) with maximized short-term positive feelings and overall long-term life satisfaction. The eudemonia tradition results in positive functioning in life and can be measured in terms of psychological well-being (PWB) and social well-being (SWB). These authors suggested continuous assessment and categorical diagnoses of the presence of mental health, described as flourishing; and the absence of mental health, described as languishing. Moderate mental health describes a condition where people are neither flourishing nor languishing (Keyes *et al.*, 2008). Keyes *et al.* (2008) probably lead the way in terms of understanding psychosocial well-being of the individual.

Other authors in this field, like Ryan and Deci (2001) and Ryan (2009), find that psychosocial well-being is not a euphoric feeling of happiness, but a state of vital and full functioning based on an on-going mindfulness and psychosocial self-regulation. Fishbein and Ajzen (1975) introduce behavior, as predetermined by attitude, into the discussion; similar to prejudice. This interplay poses a critical challenge for those living with HIV (PLWH) (Varni, Miller, McCuin, & Solomon, 2012) or people living close to them (PLC), in the form of coping as part of psychosocial well-being. These researchers concluded that peoples' ability to cope with HIV stigma depends on their ability to cope with everyday stress relating to interaction with others

and the context of psychosocial well-being. The intervention in this study engaged PLWH, together with PLC, in workshops and an opportunity to conduct community projects together. The PLWH were carefully prepared for responsible disclosure management. The cornerstone tenets of the study deal with sharing information on HIV stigma and coping with it, equalizing the relationship between PLWH and PLC through increased interaction and contact, and empowering members of both groups towards leadership in HIV stigma reduction, all of which clearly fit into a psychosocial context. HIV stigma- and stigmatization-related psychosocial well-being requires a broad-spectrum approach grounded in at least the psychological, health and social sciences to enhance such well-being (Wissing & Van Eeden, 2002).

The combined psychological and social human dimensions of HIV stigma suggest an ideal subjective sense that could affect the psychosocial well-being of both PLWH and PLC, impacting on their life satisfaction, self-efficacy, coherence and the presence of positive affect (Wissing & Van Eeden, 2002; Baumgardner & Crothers, 2010). Foster and Williamson (2000) confirm that HIV stigma affects human processes like behavior, attitude and quality of life issues, as these are all part of psychosocial well-being. Naidoo *et al.* (2007) also observe that complex psychosocial patterns, particular social structures and communal practices, could lead to differences in the psychosocial well-being of PLWH and those associated with them in urban or rural communities.

1.1 Conceptualization of HIV stigma

Over the decades, Goffman (1963), Alonzo and Reynolds (1995) and Harvey (2001) described stigma as a spoiled social identity of those with an attribute that deviates from the norm. HIV stigma appears to be a powerful discrediting and tainting social label that changes an individual's self-perception, social participation and exposure to prejudicial attitudes and discriminatory behaviour by others (Holzemer & Uys, 2004; Skinner & Mfecane, 2004; Kohi *et al.*, 2006). HIV stigma results from prejudice and discrimination based on a low self-esteem, entailing that people enhance their sense of self-worth by hating others and condoning social behaviour like stereotyping, economical competition, ethnocentrism in terms of own culture norms and power-related conflict. According to Corrigan (2000) it functions as an interrelationship between stigma signals (cues), stereotypes (attitudes) and behaviours

(discrimination), whilst Taylor (2001) identifies 'felt' and 'enacted' stigmata as the more powerful forces of the interrelating processes between society and individuals. The self-determinism theory based on personal motivation, personality development and personal well-being, admits to a forced interrelatedness with the social and cultural environment that promotes the individual's own volition and resulting behaviour (Ryan, 2009). Such interrelating processes continuously change the dynamics of HIV and AIDS and HIV stigma within any community and thus accentuate the complexity of HIV stigma. Holzemer *et al.* (2007) developed a model to simplify the complexity of HIV stigma. The Process Model for HIV stigma in Africa describes HIV stigma as a four-dimensional process operating in an interactive context of continuous interaction between the environment, the health care system and the people involved. The four dimensions comprise triggers of stigma, behaviors towards PLWH, three categories of stigma and the outcomes of stigma (Holzemer *et al.*, 2007). The stigma process is then operationalized within the interactive context when it is triggered by something like an HIV test, which evokes behavioral responses that give rise to one or more types of stigma and subsequently a set of outcomes that affect PLWH in different ways, such as their quality of life. This model serves as a theoretical framework for understanding HIV stigma in this study.

1.2 Conceptualization of psychosocial well-being

The work of Keyes (2002, 2005), as mentioned above, offers a theoretical grounding for this study with regard to psychosocial well-being. Fife and Wright (2000) emphasize the impact of HIV stigma upon the self-esteem, personal control and body image of the individual. Sanjuan, Molero, Fuster and Nouvilas (2012) describe well-being as affect balance, self-acceptance and environmental mastery. Baumgardner and Crothers (2010) concur with a number of the concepts describing well-being as a state of being that is subjective by nature but that bolsters quality of life, life satisfaction, a sense of well-being, the presence of positive affect and a relative absence of negative affect. Wissing and Van Eeden (2002) also identify a sense of coherence, satisfaction with life and an affect-balance as strong indicators of general psychological wellness. Mkhize (2004) focuses on the social aspects of psychosocial well-being and introduces inter-individuality, where the small group and the broader collective forms of

life all relate to the individual's psychosocial well-being and optimal daily functioning within a collective context.

The origin of the term *psychosocial* is the dynamic inter-relationship between psychological and social dimensions of human suffering during armed conflict, with pronounced biological and material needs (Williamson & Robinson, 2006). These authors developed a theoretical framework to conceptualize the term *psychosocial* and suggest a triangle of fulfillment with a multi-leveled individual and collective well-being within an overarching collaborative framework of human safety, participation and development. The triangle describes a psychosocial human equilibrium comprising seven hierarchical but interrelated areas, starting with a base of biological well-being, progressing to material, social, emotional, mental and spiritual well-being, and ending with cultural well-being at the top of the triangle (Williamson & Robinson, 2006). A further model of psychosocial well-being deepens our understanding from yet another angle: the Psychosocial Working Group (2011) developed a unique framework for psychosocial well-being that shows the social, cultural and psychological human domains influencing psychosocial well-being. The three domains are like three partially overlapping ovals ('human capacity', 'social ecology' and 'culture and values'), serving as the human capacity to respond to critical challenges like stigma and to restore psychosocial resilience. This article is based on multi-leveled insights from different theories and models, but is mostly grounded in The 'Complete State' model of health mentioned earlier (Keyes, 2002, 2005).

1.3 Contextualization of HIV stigma-related psychosocial well-being

HIV stigma is a complicated issue with deep roots in the convoluted domains of gender, race, ethnicity, class, sexuality and culture (Valdiserri, 2002). Yang and Kleinman (2008) suggest changing the term *stigma* to *social death*, to emphasize the victimization and dehumanization associated with stigma. HIV stigma affects the psychosocial well-being of PLHA and PLC but conversely, psychosocial well-being affects stigma experiences, stigmatization and the subjective sense of well-being, like the affect balance, self-acceptance, environmental mastery, active coping and even avoidant coping (Sanjuan et al., 2012). Kalichman (2013) describes prejudice and stigma as a central area of social psychology and relates it to the situation where PLHA have been victims of stigmatization ever since the epidemic began in the 1980s. It

therefore impacts on the psychological and social well-being of PLWH over and above their struggle with physical discomfort and a serious chronic and life-threatening disease (Mak et al., 2007; Herek, Gillis & Cogan, 2009). The HIV stigma and stigmatization directed at PLWH also impact on the PLC who are in relationships and in interaction with the PLWH. They may fear contagion or even experience stigma by association (Ogden & Nyblade, 2005). This increases the contextual complexity, since PLC can also stigmatize the PLWH or display psychosocial reactions that interfere with the relationships between PLWH and PLC (Duncan et al., 2007).

1.4 The impact of HIV stigma on psychosocial well-being of PLWH and PLC

The psychosocial impact of HIV stigma can be devastating in developing countries and underdeveloped settings where basic human needs are given priority over psychosocial needs, even whilst HIV stigma is rife (Foster & Williamson, 2000). Similarly, self-stigmatizing or internalization of received HIV stigma like labeling, prejudice, discrimination, exclusion and various types of abuse can reduce the psychosocial well-being and quality of life of PLWH and PLC. Different studies by researchers in five African countries during 2008/9 reflect on the impact of HIV stigma on aspects of psychosocial well-being. Makoe *et al.* (2009) concluded that the quality of life of PLWH wholly depends on stigma reduction and eradication. Greeff *et al.* (2009:475) conducted a cohort study involving 1457 HIV positive persons in a one year longitudinal design. They concluded that perceived HIV stigma has a significantly negative and consistent impact upon life satisfaction and 'quality of life' of PLWH, evidenced by reduced living enjoyment, loss of control in life, decreased social interactivity and decreased perceived health status. A subsequent report by Greeff (2010) on internalized HIV stigma found a significantly negative correlation with quality of life in the psychological and the environmental domains. Chirwa *et al.* (2009) found that perceived HIV stigma was a significant predictor of the job dissatisfaction (an aspect of psychosocial well-being) of nurses working with PLWH in these five African countries.

Individuals are vulnerable to feelings of self-hatred and stigmatization that could very well be associated with a low self-esteem and adverse mental health (Foster & Williamson, 2000). A change in social standing, or in employment status or changed social roles have such a negative impact on PLWH that it drives the need for stigma reduction programs to address these issues

and emphasizes the inappropriateness and undesirability of stigmatization (Nyblade, 2006). Greeff (2010) reports that themes such as the inability to maintain life functioning, isolation, getting sick and continuous hardships are all variables that affected the quality of life of PLWH and argues for the value of communal social capital as a component of a better quality of life that will embrace social networks with trust and tolerance amongst members. A study in Uganda found that children of PLWH had inadequate psychosocial life skills to deal with parental illness and death, stigmatization, loss of friends, care for sick parents or siblings, discrimination and social isolation. Some were deeply traumatized, orphaned, feeling hopeless, angry or depressed and often dropped out of school, as they became psychosocially un-well, with little hope for the future (Foster & Williamson, 2000).

1.5 HIV stigma-related psychosocial well-being in urban and rural settings

Literature reflects a discourse about urban-rural differences in the psychosocial well-being of PLWH and PLC. Naidoo *et al.* (2007) assert that rural people are more vulnerable to received HIV stigma and therefore tend to avoid disclosure, whilst urbanites often have more social connectedness and different possibilities of available psychosocial support. Kohi *et al.* (2010) observe that 91.6% of urban nurses in five African countries wanted to migrate due to HIV stigma experiences, whereas only 8.4% of their rural counterparts considered the option.

Attributing factors in the urban/rural controversies include higher reporting rates of HIV stigmatization in urban areas, ease of transport, differences in the barriers to life care services, the influences of social networks, socio-economic factors, employment opportunities and the distinct differences in levels of literacy and HIV knowledge (Heckman *et al.*, 1998; Naidoo *et al.*, 2007). Reif, Golin and Smith (2005) describe similar barriers to care but specifically add HIV stigma and dire needs for mental health services and rehabilitation facilities in rural areas. Greeff (2010) refers to a higher likelihood for peri-urban participants than rural participants to keep up their involvement with interventions, but points out that overall life satisfaction scores do not reflect a significant difference between urban and rural participants.

Heckman, Somlai, Kalichman, Franzoi and Kelly (1998:138), though, found in an earlier study that rural people had lower levels of satisfaction with life, lower perceptions of social support from family and friends, reduced access to medical and mental care, elevated levels of

loneliness, more community stigma and more maladaptive coping strategies than their urban counterparts as well as heightened personal fear of out-of-their-control exposure of their HIV status. The social human dimension has a critical influence on the psychosocial well-being within the traditional African perspective, as the individual and his/her well-being are positioned within a communal existence and where the individual's health directly relates to a social context of *inter-individuality* (Mkhize, 2004). This social haven has been disturbed more and more by urban-rural migration practices in countries like Zambia, where those who feared being stigmatized or endeavoured to find employment moved away and returned home only to visit or when they were ill and in need of social support (Foster & Williamson, 2000). Ankrah (1993) and Chin (2007) both point out that the AIDS pandemic has caused adverse psychosocial and economic consequences and changed the family structures and ordinary capacity of the African clan (traditional central human social unit) to respond to vulnerable members and their special needs.

1.6 HIV stigma-related psychosocial well-being strategies and interventions

The community-based HIV stigma reduction interventions of the past decades can be summarized into four categories, respectively addressing health promotion, coping with HIV, management of symptoms and dealing with psychopathologies (Brown, Trujillo & Macintyre, 2011). There is a lack of evidence with regard to large-scale or even national interventions or long-term preferred strategies (Brown et al., 2011). In an overview of 16 intervention strategies, Obrien (2012) concludes that there still is paucity in proactive culturally-based, evidence-based and community-based HIV prevention and stigma-reduction interventions.

Stigma, in general, is defined as a social construct. Stigma experiences and stigmatization involve people and therefore the fight against HIV stigma should also involve people, including PLWH and PLC (Heijnders & Van der Meij, 2006). Sociologists base their intervention planning on the assumption that human desire can serve as a motivation to get involved in action against prejudice and HIV stigma. Cross, Heijnders, Dalal, Sermrittirong and Mak (2012) initiated a stigma intervention matrix to facilitate the development of situational HIV stigma interventions and adherence to relating strategic guidelines. This followed upon a realization among a designated working group that it would be extremely complex to set up guidelines for generic

stigma reduction interventions that apply to all health conditions. The intervention matrix aims to ensure that interventions deal with intrapersonal, interpersonal, organizational and community/governmental stigma levels interacting with labeling, stereotyping, separation, status loss and discrimination as the identified components of stigma (Cross et al., 2012). In addition to the stigma intervention matrix, the working group suggested the use of a social capital strategy for stigma reduction in a social marketing context. They suggest a combination of the intrapersonal, interpersonal, organizational and community stigma levels with tested reduction intervention elements like training, personal contact and advocacy. They also describe social marketing essentials like clear problem identification, target setting, use of change technology, evaluation and re-planning techniques to combat stigma, prejudice and discrimination (Mahajan et al., 2008; Cross et al., 2012).

Thus, various authors reviewed stigma reduction strategies combined with some form of psychosocial context and contributed useful ideas. In spite of smaller gains, though, there are still no large-scale success and no mass action strategies that have been tested and preferred. HIV stigma appears to be the complex link between a health condition, psychological disease and social disconnectedness.

2 Problem statement

The impact of HIV stigma on psychosocial well-being of PLWH and PLC is pertinent and its dynamics undeniably interrelated. The universal need for psychosocial well-being of the general population requires accentuation of such well-being, especially for PLHA and PLC, since HIV stigma and stigmatization continuously deplete this human capacity. The challenge is to establish sustainability in the HIV stigma interventions and to ensure that related psychosocial well-being of both PLWH and PLC is also addressed. An optimum level of psychosocial well-being should be the focus to ensure quality of life, life satisfaction, a self-awareness of well-being, the presence of positive affect and the absence of negative affect (Baumgardner & Crothers, 2010). The question is whether a comprehensive community-based stigma reduction and wellness enhancement intervention will make a difference to the psychosocial well-being

of PLHA and PLC. This could be achieved if PLWH and PLC work together to enhance their insight, coping, relationships and leadership in the face of HIV stigma and stigmatization.

3 Research questions

The following research questions can be asked: Will there be differences between the psychosocial well-being of urban and rural PLWH and PLC following a comprehensive community-based stigma reduction and wellness enhancement intervention? Will the comprehensive community-based HIV stigma reduction and wellness enhancement intervention result in enhanced psychosocial well-being of PLWH? Will the comprehensive community-based HIV stigma reduction and wellness enhancement intervention result in enhanced psychosocial well-being of PLC?

4 Research objective

To test the change-over-time in the psychosocial well-being of PLHA and PLC in both an urban and rural setting, following a comprehensive community-based HIV stigma reduction and wellness enhancement intervention.

5 Research design

A quantitative experimental single system design (De Vos, Strydom, Fouche & Delport, 2005) with a pre-test and four repetitive post-test measures (01 x 02 03 04 05) was implemented. An urban as well as a rural setting were included.

6 Research method

6.1 Sample

The sample of the study consisted of an urban and a rural group of PLWH and PLC as representative of subsets of the theoretical whole population (Thorne, 2008). As the intervention was of a therapeutic nature and built on interaction amongst PLWH and PLC (Thorne, 2008) smaller numbers were the ideal. Purposive sampling was used for PLWH, followed by snowball sampling for the PLC. The PLWH could choose people living close to them from each of the specific designated groups to participate in the intervention: partners, children, family, friends, spiritual leaders and community members.

Purposive voluntary sampling was utilized to identify PLWH through public benefit organizations and health clinics with the help of mediators who had trusting relationships with PLWH. 18 PLWH were identified, of whom 10 were from the Potchefstroom urban district in the North West Province, South Africa, and 8 from the rural Ganyesa district in the same province. The inclusion criteria for PLWH required participants to be over 18 years old, conversant in either Afrikaans, English or Setswana, HIV positive for a minimum of six months and willing to give informed consent for the recording of proceedings. They also had to consent to participate in a workshop revealing their HIV status and agree to nominate PLC in the above-mentioned designated groups for participation in follow-up workshops. They had to be willing to undergo pre- and repetitive post-test measuring according to schedule. The PLWH were all black, Setswana-speaking South Africans. 38.9% of them had passed Grade 10, 11.1% Grade 11 and 16.7% Grade 12. 55.6% had no post-school education whilst 38.9% obtained a post-school certificate and 5.6% had a diploma as highest qualification.

The PLC were identified through snowball sampling. Each PLWH had to nominate six people as PLC. Children who were PLC had to be over 15 years of age. The inclusion criteria for PLC were similar to the PLWH except that they did not have to be HIV positive but only needed to fit into one of the above-mentioned designated groups. The researchers were aware that not all PLWH might be able to nominate a person from each designated group, since they might not all know someone appropriate in each group. There were a total of 60 (N = 60) PLC. 23 were from the

urban and 37 from the rural setting. Most of these participants (93.3%) were Setswana-speaking, with a synonymous understanding of social and cultural practices. There was a small representation of colored people (6.6%). Although 55% of PLC had no post-school education, 41.7% had a post-school certificate and 3.4% had either a diploma or a degree. 38.3% had matric, 28.3% passed Grade 11 and 16.7% passed Grade 10 as their highest qualification.

See table 9 for an outlay of the sample distribution.

Table 9: Sample distribution

PLWH	URBAN			RURAL			Total
	Female	Male	Sub total	Female	Male	Sub total	
	9	1	10	5	3	8	18
PLC	URBAN			RURAL			Total
	Female	Male	Sub total	Female	Male	Sub total	
Partners	0	2	2	1	0	1	3
Children	3	1	4	5	2	7	11
Family	2	0	2	4	1	5	7
Friend	2	0	2	6	0	6	8
Spiritual Leader	2	4	6	7	3	10	16
Community Member	6	1	7	8	0	8	15
Total	15	8	23	31	6	37	60

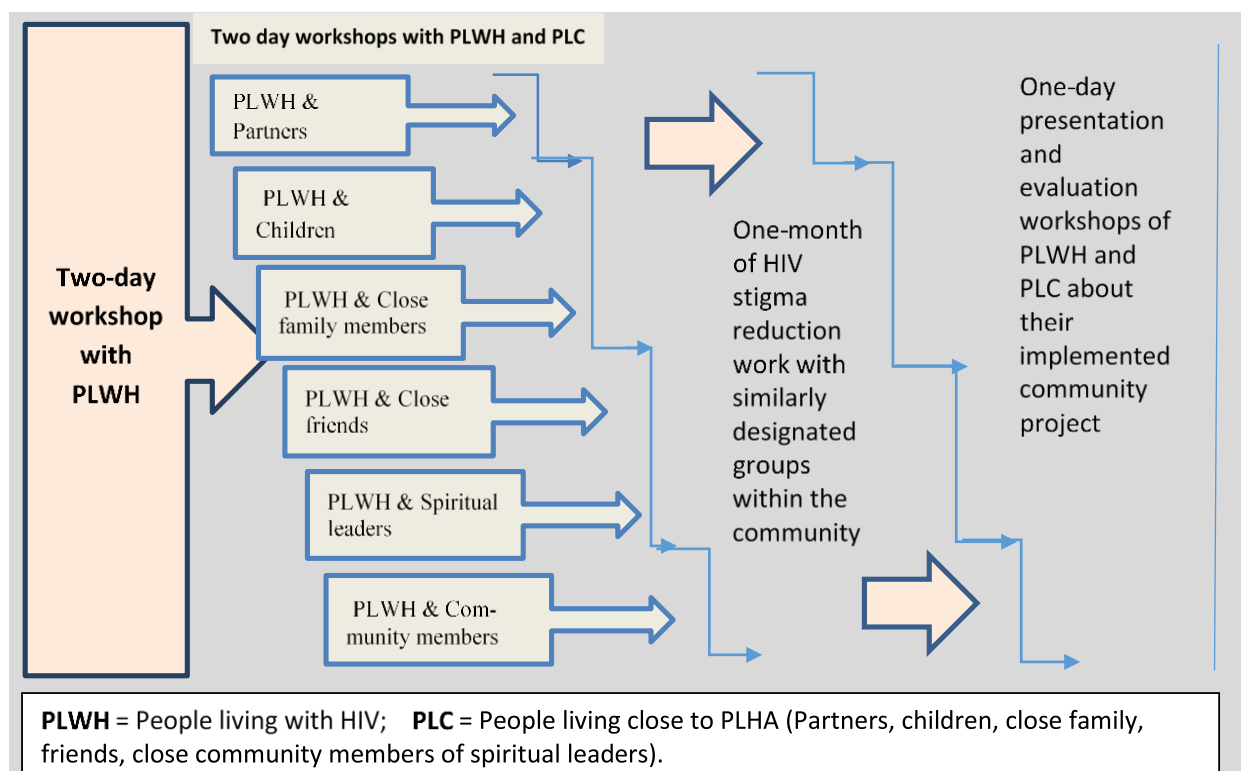
6.2 The intervention

The intervention for this study was adapted from the validated intervention manual of Uys *et al.* (2009). It is based on three tenets, namely a) sharing of HIV stigma information and ways to cope with it, b) equalising relationships of PLHA and PLC through interaction and contact between them, and c) empowerment of members of both groups towards leadership in HIV stigma reduction.

The comprehensive community-based HIV stigma reduction and wellness enhancement intervention comprised three core processes (see figure 4). There was firstly a two-day plenary and activity-based workshop for PLWH in both urban and rural settings which focused on their individual understanding of HIV stigma, their identification of own strengths and their preparation for responsible disclosure management. The initial two-day workshop for PLWH as

a group was followed by a series of six three-day workshops for the PLWH and the designated PLC groups together. The designated categories were the spouses/partners; children over 15; family members; friends; spiritual leaders; and community members. The first day of these three-day workshops focused on enhancing an understanding of HIV stigma and ways to cope with it. It also focused on enhancing the relationship between PLWH and PLC. All the activity-based and interactive workshops were facilitated by two trained facilitators, of whom one was HIV positive. The second day focused on project-planning skills to be used when participants had to implement a community project for HIV stigma reduction and wellness enhancement with a designated group similar to theirs. Each of the 12 groups had a four-week period to plan and implement their HIV stigma reduction projects in their communities. Thus, six projects were running in the Ganyesa area (rural setting) and six projects in Potchefstroom (urban setting) at the same time. On the third and last day of the intervention the different groups presented their projects to guest community members whom they invited to join the research team for presentation and evaluation. The groups with respectively the most impressive urban and rural project were acknowledged and rewarded with small prizes.

Figure 4: The comprehensive community-based stigma reduction and wellness enhancement intervention



6.3 Data collection

The data collection involved a pre-test followed by four repetitive post-tests with three-month intervals. Trained research assistants utilized five structured, valid and reliable instruments to measure the psychosocial well-being of both PLWH and PLC.

The *Mental Health Continuum short form (MHC-SF)* (Keyes et al., 2008) is a 14-item scale originally tested with 1050 Setswana-speaking adults in the North West Province of South Africa. Empirical evidence was found of validity and reliability, with Cronbach alpha at 0.74 for the total scale. It was 0.75 for PLWH and 0.78 for PLC in this study. The three-factor composition of the instrument measures degrees of emotional well-being (three items), social well-being (five items) and psychological well-being (six items) (Keyes et al., 2008).

The *Patient health questionnaire (PHQ-9)* contains nine items with original internal reliability of Cronbach alpha at 0.89 in the PHQ Primary Care Study and 0.86 in the PHQ Ob-Gyn Study. The test-retest reliability of the PHQ-9 as a short depression measure was also found to be excellent, as the diagnosis of DSM-IV depressive disorders resembles the PHQ-9 criteria (Kroenke, Spitzer, & Williams, 2001). The Cronbach alpha in this study was 0.84 for the PLWH and 0.69 for the PLC.

The *Satisfaction with life scale (SWLS)* is a five-item scale developed in 1985. It measures an individual's own satisfaction with life according to personal standards. Each item is rated on a seven-point scale and the authors reported test-retest reliability ranging from 0.83 to 0.50 over two years. The construct validity was between 0.61 and 0.84 and the scale is suited for a wide range of age groups and applications (Pavot, Diener, Covin, & Sandvik, 1991). The Cronbach alpha in this study was 0.63 for the PLWH and 0.70 for the PLC.

The *Coping self-efficacy scale (CSE)* is a 26-item self-rating scale that measures personal confidence in one's own ability to perform coping behaviors when faced with life challenges. It measures three types of coping, namely problem solving (PFC) (12 items), stopping of unpleasant emotions (SUE) (nine items) and acquiring support from family and friends (SFF) (five items). It has summative scoring on a self-rating scale of one to a desired ten. The scale was validated by Chesney, Neilands, Chambers, Taylor and Folkman (2006), with Cronbach

alpha scores ranging between 0.80 and 0.91. The Cronbach alpha for this study ranged between 0.72 and 0.94.

The *Spirituality well-being scale (SWBS)* is a 20-item self-report scale comprising spiritual, existential and religious well-being dimensions. A factor analysis supported the dimensional structure of the scale and Genia (2001) examined the psychometric qualities of the scale with 202 religiously heterogeneous college students. A ceiling effect was found with a group of young Christian respondents, but researchers could still report a Cronbach alpha ranging from 0.76 - 0.93 for the spiritual well-being scale, 0.78 - 0.91 for the existential well-being scale and 0.87 - 0.91 for the religious well-being scale (Bufford, Paloutzian & Ellison, 1991). For this study the Cronbach alpha for PLWH was 0.78 - 0.80 and a lower of 0.56 on the total scale for PLC.

The comprehensive community-based HIV stigma reduction and wellness enhancement intervention was preceded by the preparatory training of research assistants two weeks prior to the intervention to collect the data as well as to facilitate the workshops. This allowed for time to collect the names of participants from the community mediators and to schedule appointments with the potential participants. An adequately equipped meeting room at the North-West University campus was the setting for the intervention workshops, where participants were warmly welcomed and informed of ethical and logistical considerations.

6.4 Data analysis

Version 21 of the SPSS software was utilized for the quantitative data analysis. Hierarchical linear models were used to estimate the degree of HIV stigma-relatedness within the urban and the rural groups. This type of modeling takes into account the dependency on repeated data collection from identified people and explains the variability within and between urban-rural groups over time (McCoach, 2010). Descriptive statistics included the calculations of mean scores, mean square error, p-values and effect sizes on all subscales of the five instruments. Interpretation of scales followed the guidelines for each instrument and results were presented in easily accessible table format.

7 Ethical considerations

Ethical approval was obtained from the School of Nursing Science, the North-West University Ethics Committee (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014) as well as from the North West Provincial Department of Health and district health authorities. Basic ethical principles, like respect for human subjects, benevolence and justice, were the guiding principles for research activities (Botma, Greeff, Mulaudzi & Wright, 2010).

Respect for human subjects was demonstrated by giving the participants clear information about the aims and schedule of the research and the intention of the research team to safeguard their person and identity. They were also reminded that their participation was voluntary and that confidentiality and their anonymity could only be partial since they might be known to other members of the groups during the intervention. They had a say in the type of contract upon which the group members agreed to guide their conduct as group members. The research team promised not to link any personal details to particular data that was collected.

Benevolence for participants included their receiving of knowledge on HIV stigma and coping with it, possible relationship enhancement between PLWH and PLC and their learning of basic project management skills. Counseling was offered by prior arrangement if participants needed to ventilate unresolved emotional discomfort that arose from group interaction or HIV disclosure.

Justice towards participants was served by managing risks like expensive transport, lack of sustenance and environmental discomfort. They were responsibly transported to the venue and back, and they received refreshments and a light lunch as well as a protected environment on the campus. Participants were requested to sign a consent form if they were satisfied with the information, circumstances and intent of the research and they were reminded that they could withdraw at any stage.

8 Findings and discussion

The difference in psychosocial well-being between urban and rural PLWH and PLC groups over time were compared in hierarchical linear models (McCoach, 2010). With the p-values larger than 0.05, no statistical significance between urban and rural results over time were indicated and neither was there a significant difference in the main effect for these groups. The urban-rural results were therefore pooled for analysis on five quantitative instruments to examine the effect over time. The research question of whether there would be a difference between urban-rural groups could not be answered affirmatively.

The combined urban-rural results for PLWH are presented in table 10, and for PLC in table 11. The discussion of these findings will deal with each of the scales consecutively. In each instance it will firstly focus on PLWH and then on PLC.

The *Mental health continuum – Short form (MHC-SF) scale* is a self-appraisal of subjective well-being with an overall scale and three subscales. A score of 70 on the total scale indicates maximized subjective well-being and the absence of mental illness, and is categorized as flourishing. *Languishing* refers to a minimized subjective well-being and moderate mental health falls between the two extremes. The subscale for emotional well-being (EWB) measures a hedonic subsystem concerning the maximization and duration of positive feelings and the minimization of negative or unpleasant feelings. The social well-being (SWB) subscale indicates maximization of social integration, social contribution, social coherence, social actualization and social acceptance of an individual. The psychological well-being (PWB) subscale measures the maximization 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 (Keyes et al., 2008).

The mean scores of PLWH on times 1 to 5 of the MHC-total scale ($\bar{X} = 53.39$, $\bar{X} = 55.69$, $\bar{X} = 52.72$, $\bar{X} = 54.68$, $\bar{X} = 50.80$ respectively) reflect inconsistency. Reworked into the categorical calculation of Keyes *et al.* (2008), the pre-intervention scores indicate that 78.3% of the group were flourishing, 4.3% were languishing and 17.4% had moderate mental health. Neither of the changes on the three subscales for PLWH are statistically significant but the effect sizes on

emotional well-being (EWB) between time 1 and 2 (0.43) and 1 and 3 (0.42) show practically significant increases, relating to the maximization of positive feelings and minimizing of negative feelings. The social well-being score (SWB) shows a practically significant increase (time 1 with 4) but also a practically significant decrease of social well-being of PLWH on times 3 and 5. The psychological well-being (PWB) of PLWH increased above time 1 ($\bar{X} = 24.42$) at time 2, with a practically significant increase (0.57). The opposite happened between times 1 and 5, with a practically significant decrease (0.55). There was no statistical significance, and little evidence of practically significant change-over-time for PLWH after the intervention on the MHC-SF mental health scale.

The PLC pre-intervention scores commenced with 75.8% of the group on a flourishing level. The mean scores on all MHC-SF subscales indicated an increasing trend, as they were higher at time 5 than at time 1, although not statistically significant over time ($p = 0.08$). The emotional well-being (EWB) of PLC mean scores increased marginally and ended marginally higher ($\bar{X} = 10.36$) at time 5 than the pre-intervention score ($\bar{X} = 10.05$). This was neither statistically nor practically significant. The social well-being (SWB) increased statistically significantly, although not with practical significance. There is an upward tendency on the psychological well-being (PWB) scores, although not of statistical or practical significance. The means shifted from $\bar{X} = 24.41$ at time 1 to $\bar{X} = 25.88$ at time 5.

The *Patient health questionnaire (PHQ-9)* is commonly described as a depression diagnostic and severity measure. In essence it explains the individual's broad world of emotions. The nine-item instrument with a score range of 0-27 can be self-administered and its composition requires scores to decrease as a sign of improved well-being. Scores between one and four indicate no depression severity and scores between five and nine indicate mild severity, requiring medical follow-up. The last question benchmarks functional impairment globally (Kroenke et al., 2001).

The PLWH mean score started at $\bar{X} = 6.51$ pre-intervention time, came down to $\bar{X} = 3.50$ at time 2, $\bar{X} = 2.74$ at time 3 and an excellent $\bar{X} = 3.13$ at time 5. The time 4 score, however, tested higher, with $\bar{X} = 5.04$. A score of $p = 0.01$ confirms statistical significance. There were also large

effect sizes between times 1 and 2 (1.01), times 1 and 3 (1.27), times 1 and 4 (0.50) and (1.14) for times 1 and 5. The scores thus moved from a mild depression severity to no depression severity.

The PLC results reflect statistically significant improvement, with decreasing mean scores and $p = <0.01$. Time 1 started on a high level of mild depression severity with a mean score of $\bar{X} = 8.02$. The means at time 2, after the intervention, decreased to $\bar{X} = 7.66$, at time 3 to $\bar{X} = 4.33$, and at time 4 to $\bar{X} = 4.18$. Between times 1 and 3, and times 1 and 4 the effect sizes varied between 0.73 and 0.76. Although the mean score at time 5 increased to ($\bar{X} = 5.77$) it was still practically significantly below the baseline, with an effect size of 0.45. The PLC thus moved from the higher end of mild depression severity to the lower end of mild depression severity.

The *Satisfaction with life scale (SWLS)* reflects an individual's personal assessment of life-satisfaction according to personal criteria. The most ideal score on this scale is 35 and the five questions are posed in a way that could guide individuals to set personal targets for their lifestyle or habits and to ensure future improvement in their satisfaction with life (Pavot et al., 1991).

The PLWH started pre-intervention with a mean score of $\bar{X} = 18.91$ and although there was an important increase at time 2 to $\bar{X} = 21.38$, with effect size of 0.49, their score declined to $\bar{X} = 16.32$ at time 5, with effect size of 0.51. The p-value of 0.13 indicates that the change was not significant.

The PLC group results, on the other hand, reflect a marginal increase of the mean scores over time. There was thus consistency, but neither statistical significance nor practical significance, with the satisfaction with life scores ranging from $\bar{X} = 20.42$ to $\bar{X} = 21.65$ at time 5.

The *coping self-efficacy (CSE) subscales* explore the measure of an individual's confidence to cope when faced with adversity. The three subscales refer to *problem-focused coping* (PFC), *stop unpleasant emotions* (SUE) and *get support from friends and family* (SFF). It has a summative scoring according to each category on a one to ten rating for each of 26 items (Chesney et al., 2006).

There was an immediate time 2 increase for the PLWH on all three scales directly after the intervention. The effect sizes of 0.75, 0.46 and 0.42 for PFC, SUE and SFF scales respectively indicate practical significance of change at time 2. For the rest of the scale, all the mean scores for the PLWH declined over time to a score below the time 1 measure. The differences over time on the *problem-focused coping* (PFC) scale was statistically significant, with $p = 0.02$. There was practical significance in the declining effect sizes of 0.95 between (1 with 3) and 0.64 between (1 with 5) on the *seek support from friends and family* (SFF) scale. It thus seems that the change upon time 2 could not be maintained and showed a downward movement.

For the PLC, the pattern over five times shows an increase on the PFC ($\bar{X} = 87.66$ to $\bar{X} = 92.08$) and SUE ($\bar{X} = 68.08$ to $\bar{X} = 70.26$) subscales. The latter is a statistically significant change ($p = 0.04$). The *seek support from friends and family* (SFF) subscale increased to time 2 and then decreased again at time 5 ($\bar{X} = 33.69$) to a value lower than at the pre-intervention score ($\bar{X} = 35.81$). The difference over time was statistically significant ($p = 0.01$). The PLC started showing intentions to solve the problems and increasingly stopped experiences of unpleasant emotions, but showed a decline in their scores regarding the seeking of support from friends and family.

The *spiritual well-being scale* (SWBS) is a self-measure that gives an overall score of spiritual well-being (SW) which captures the vertical (relationship with God) and horizontal (purpose and satisfaction with life) in the existential well-being (EW) subscale and religiosity on the religious well-being (RW) subscale. This scale does not have an exact interpretation. The highest score is 120 but an example of typical scores for a random medical outpatients group suggested 99 for spiritual well-being (SW), 48 for existential well-being (EW) and 51 for religious well-being (RW) (Bufford et al., 1991).

The PLWH showed a decline with practical significance at time 2 directly after the intervention, on all three scales, with effect sizes of 0.55 for spiritual well-being (SW), 0.49 for existential well-being (EW) and 1.07 for religious well-being (RW). The spiritual well-being (SW) declined from $\bar{X} = 47.44$ at pre-intervention, to $\bar{X} = 41.17$ directly post-intervention at time 2 and then further to $\bar{X} = 37.94$ at time 3. The scale indicated practical significance on all timelines. The

existential well-being (EW) indicates strong practical significance with large effect sizes in the declining trend on each timeline. The religious well-being scores are worse: starting at $\bar{X} = 20.35$ pre-intervention, it decreased to $\bar{X} = 17.89$ after the intervention and then decreased even further to $\bar{X} = 14.05$ at time 3, and to $\bar{X} = 15.11$ at both times 4 and 5. This decrease for the PLWH on the religious well-being scale is statistically significant, with $p = 0.03$.

The PLC reflect a statistically significant ($p = 0.01$) increase on both their overall spiritual well-being (SW) scale and on their existential well-being (EW) scale ($p = <0.01$). Despite the small effect sizes between times 1 and 3 (0.24) 1 one and 4 (0.34), it could be concluded that there might be a tendency to improve.

Table 10: PLWH – Psychosocial well-being scales over five times

PLWH - Means of psychosocial well-being scales over five times								Effect between Time 1 and other times:			
Instrument	Time 1	Time 2	Time 3	Time 4	Time 5	MSE	p	Time 2	Time 3	Time 4	Time 5
MHC_Tot	53.39	55.69	52.72	54.68	50.80	85.73	0.66	0.25	0.07	0.14	0.28
MHC_EWB	10.70	12.04	12.00	11.17	11.74	9.58	0.57	0.43	0.42	0.15	0.34
MHC_SWB	17.83	16.69	14.88	19.22	16.60	8.64	0.10	0.39	1.00	0.47	0.42
MHC_PWB	24.42	26.48	25.72	25.03	22.42	13.26	0.29	0.57	0.36	0.17	0.55
PHQ-9	6.51	3.50	2.74	5.04	3.13	8.87	0.01	1.01	1.27	0.50	1.14
SWLS_Tot	18.91	21.38	18.04	17.74	16.32	25.50	0.13	0.49	0.17	0.23	0.51
CSE_PFC	85.00	96.80	81.17	85.71	83.32	245.40	0.02	0.75	0.24	0.05	0.11
CSE_SUE	66.77	71.17	68.58	66.74	63.91	90.22	0.45	0.46	0.19	0.00	0.30
CSE_SFF	33.19	36.60	25.57	31.62	28.07	64.57	0.07	0.42	0.95	0.20	0.64
SWBS_SW_Tot	47.44	41.17	37.94	38.47	38.28	129.45	0.07	0.55	0.83	0.79	0.80
SWBS_EW	27.09	23.13	23.42	22.86	22.60	64.08	0.22	0.49	0.46	0.53	0.56
SWBS_RW	20.35	17.89	14.05	15.11	15.11	5.32	0.03	1.07	2.73	2.27	2.27

Note. MHC-SF = Mental Health Continuum short form, PHQ-9 = Patient health questionnaire, SWLS = Satisfaction with life scale, CSE = Coping Self-efficacy scale, SWBS_SW_Tot = Overall spiritual well-being scale, EW=existential well-being, RW= religious well-being, MSE = mean square error.

Table 11: PLC – Psychosocial well-being scales over five times

PLC - Means of psychosocial well-being scales over five times								Effect between time 1 with other times			
Instrument	Time 1	Time 2	Time 3	Time 4	Time 5	MSE	p	Time 2	Time 3	Time 4	Time 5
MHC_Tot	47.82	50.30	49.13	49.56	52.32	138.09	0.08	0.21	0.11	0.15	0.38
MHC_EWB	10.05	10.26	10.23	10.62	10.36	16.40	0.94	0.05	0.04	0.14	0.08
MHC_SWB	13.35	15.51	13.71	13.25	15.52	40.15	0.03	0.34	0.06	0.02	0.34
MHC_PWB	24.41	24.91	24.53	24.51	25.88	26.34	0.26	0.10	0.02	0.02	0.28
PHQ-9	8.02	7.66	4.33	4.18	5.77	25.44	<0.01	0.07	0.73	0.76	0.45
SWLS_Tot	20.42	20.98	20.58	20.61	21.65	60.57	0.79	0.07	0.02	0.02	0.16
CSE_PFC	87.66	91.37	88.67	91.39	92.08	310.72	0.11	0.21	0.06	0.21	0.25
CSE_SUE	68.08	69.03	73.67	71.62	70.26	182.14	0.04	0.07	0.41	0.26	0.16
CSE_SFF	35.81	36.96	31.83	34.02	33.69	97.04	0.01	0.12	0.40	0.18	0.22
SWBS_SW_Tot	61.40	63.98	66.75	67.91	68.23	103.22	<0.01	0.25	0.53	0.64	0.67
SWBS_EW	34.98	37.22	39.31	39.75	41.45	66.92	<0.01	0.27	0.53	0.58	0.79
SWBS_RW	27.49	28.09	28.97	29.60	28.61	39.30	0.32	0.10	0.24	0.34	0.18

Note. MHC-SF = Mental Health Continuum short form, PHQ-9 = Patient health questionnaire, SWLS = Satisfaction with life scale, CSE = Coping Self-efficacy scale, SWBS_SW_Tot = Overall spiritual well-being scale, EW=existential well-being, RW= religious well-being, MSE = mean square error.

9 Conclusions

The findings show no real differences in the changes-over-time in psychosocial well-being between the urban and the rural groups of both PLWH and PLC due to the intervention. The urban and rural data was thus pooled. This could possibly be ascribed to the cultural similarity among the two groups, who both included mainly Setswana-speaking people of the North West Province. However, changes-over-time were found in terms of psychosocial well-being of the PLWH and the PLC due to the intervention. More regressive changes were noted in most of the psychosocial well-being measures of PLWH and more positive changes in those of the PLC. The scores on the Mental Health Continuum Scale for both the PLWH and the PLC before the intervention show that most participants were already on the flourishing side of the scale (78.3% and 75.8% respectively) with very few on the languishing side of the scale. Although PLWH showed no statistically significant changes on the total scale after the intervention there were practically significant changes in the subscales and they mainly remained on the

flourishing side of the scale. The reason for this could be that PLWH were truly confronted by the reality of their illness during the intervention and could be in less of a denial.

Time 5, almost a year after the intervention, showed a sudden decrease on the mental health scale for the PLWH. This could reflect a process of confronting the reality instead of negating it, or internalizing uncomfortable health-related or lifestyle truths. The PLC, as a group, started on a lower level of flourishing in their mental health than the PLWH but demonstrated consistent practically significant improvement across the spectrum of the measurement after the intervention with a statistically significant change in social well-being. This might be indicative of personal gain for the PLC regarding their mental health after the intervention. It could stem from a relief of not being HIV positive themselves, a sense of relief to be interacting freely and with more empathy with PLWH about their HIV status, learning new skills for interacting with them, and experiencing support from both PLWH and the other PLC during the intervention in the group.

On the depression scale the PLWH showed the biggest positive change in psychosocial well-being, moving from a mild depression severity to no depression severity, which is statistically significant. It can thus be concluded that PLWH experienced the intervention as positive, possibly felt less isolated and thus no longer felt depressed. The PLC measured on the higher end of mild depression severity at the onset of the intervention, possibly because of the burden of having to take care of PLWH and experiencing an additional responsibility. In the group, however, they were among others in similar situations and did not feel so isolated. Although they moved to the lower end of the scale (mild depression severity), they remained depressed. The building of meaningful relationships between PLWH and PLC as well as acquisition of new skills towards becoming leaders in HIV stigma reduction in their communities could have left both groups feeling hopeful, empowered and less depressed.

The life satisfaction of the PLWH started lower than that of the PLC. PLWH started with an average satisfaction with life that showed a practically significant increase after the intervention, possibly because they were among supportive people. This then decreased again, however. The HIV stigma reduction intervention clearly brought about a deepened confrontation with the reality of being HIV positive. It could have activated an awareness of

aspects of dissatisfaction with life on more levels than just the physical. The PLC, on the other hand, rated themselves as fairly consistent and even as improving slightly over time but neither with a statistical nor practical significance: they have to keep on facing the reality that they must take care of a person living with HIV. In the intervention, though, they became aware that they were not the only people facing this difficulty.

The immediate increases in the coping self-efficacy of PLWH directly after the intervention may have been the result of being among people with whom they could share their experiences and their initial courage and confidence. This change, however, cannot be sustained over time. The process of dealing with their reality and internalizing aspects of their situation would probably require more time. The HIV stigma reduction and wellness enhancement intervention possibly created the awareness needed to activate the first steps of coping self-efficacy. For PLC, both the scales of *problem focus coping* and *stop unpleasant emotions* increased. In some ways it offered examples of how to solve problems with shared knowledge on HIV stigma and how to cope with it. It suggested mechanisms of how to stop unpleasant emotions in important relationships, to equalize such relationships, and to share more freely. The *seek support from friends and family* scale, however, decreased at a statistical significant level, most probably because they now were among supportive people and no longer had to avoid rejecting behavior from others in the community.

A further aspect of psychosocial well-being lies in the spiritual dimension of people. On this scale, both PLWH and PLC measured low at the onset of the intervention with PLWH – lower than the PLC. In the case of PLWH, the scores declined, with religious well-being decreasing on a statistically significant level. In the case of PLC, the spiritual and existential well-being showed a statistically significant improvement due to the intervention; but not in the case of religious well-being, which remained low. It can thus be concluded that both PLWH and PLC suffer in terms of their spiritual well-being. This could stem from a struggle to find peace with their HIV status, or a depletion of spiritual energy because of such a struggle in the midst of a lack of support. It could stem from self-prejudice based on expected religious prejudices because of the stigma associated with HIV, or a lifestyle that caused the HIV infection. It could also stem from concerns for the future, a lack of hope for going forward and a longing for spiritual

attributes like connectedness and transcendence beyond pain. Concerns like an existential search for meaning, procreation, family life, fulfilling relationships and healthy children could all be a factor. The intervention sharpened a spiritual consciousness as well as a consciousness of a heavily stigmatized disease with a dreaded outcome.

It could be concluded that the HIV stigma reduction intervention had a positive impact on the psychosocial well-being of both PLWH and PLC. There were distinct improvement at times 2 or 3 of the mental health, depression severity, satisfaction with life, coping self-efficacy and spiritual well-being scales, directly after the intervention. The only exception was spiritual well-being. For PLC the intervention seems to have brought about major changes in their psychosocial well-being. The extent of change, however, was not the same for the two groups. By including both PLWH and PLC in the same intervention, giving them knowledge and understanding of HIV stigma, showing them how to cope with it, giving them opportunities to build relationships and to face HIV stigma head-on, they apparently were able to regain some control. The PLC found that the intervention created an environment of awareness and a longing for meaningful psychosocial well-being. PLWH, however, need more time to change the effect of their painful experiences of being diagnosed with the illness, and a long-term process of internalization is needed. They can no longer deny their illness. Changes could not be sustained over time, but the comprehensive community-based HIV stigma reduction and wellness enhancement intervention was successful in initiating various aspects of psychosocial well-being.

10 Limitations

The researchers had no control over the sample size for PLC, since PLWH were not always able to nominate people close to them for each of the six designated groups. Some of them simply did not have a partner, child, family member, friend or spiritual leader that they could nominate. The comprehensive approach of the intervention is resource-demanding since it is of a therapeutic nature and has to focus on small group interactivity, which limits numbers of participants.

11 Recommendations

It is recommended that the comprehensive community-based HIV stigma reduction and wellness enhancement intervention, as planned and executed, should be valued and utilized. The following aspects are core strengths of the intervention and should not be neglected or changed. The small group interaction remains critical to the work done in terms of relationships between PLWH and PLC; and it is just as important to involve them together in the same intervention. The therapeutic nature of the intervention also demands small groups. The pairing of non-infected facilitators with PLWH enhanced role modeling of affective relationships, but PLWH should always be prepared before the intervention by empowering them with an understanding of HIV stigma, responsible disclosure management skills and identifying their own personal strengths. PLC could be chosen from among any persons living close to PLWH and not necessarily from among specific designated groups only. This choice should be left to the PLWH. More attention could be given specifically to psychosocial well-being exercises as a clear link was found between HIV stigma and psychosocial well-being.

It could be worthwhile to expand the work to include other urban and rural communities and other cultural groups as well. The differences in measures could be affected by seasonal changes and it could be meaningful to record this more specifically in further research. A follow-up intervention after three to six months could ensure greater sustainability of initial psychosocial changes for both PLWH and PLC. This could ensure sustainability, and ways of achieving this need to be developed. Such interventions may be similar, with a level of repetition, or it could focus on specific weaker aspects, like life satisfaction or spiritual well-being. Engagement in and creation of innovative community mechanisms to counteract ignorance about HIV stigma and to establish psychosocial well-being could re-kindle hope in society.

12 References

- Alonzo, A.A. & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social science & medicine*, 41(3), pp. 303-315.
- Ankrah, E.M. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care: Psychological and socio-medical aspects of HIV/aids*, 5(1), pp. 5-22. doi: 10.1080/09540129308258580
- Baumgardner, S.R. & Crothers, M.K. (2010). *Positive psychology*. London, Pearson.
- Botma, Y., Greeff, M., Mulaudzi, F.M. & Wright, S.C.D. (2010). *Research in health science*. Pinelands, Pearson education
- Brown, L., Trujillo, L. & Macintyre, K. (2011). *Interventions to reduce HIV/AIDS stigma: What have we learned?* Louisiana, Horizon program. doi: 10.1521/aeap.15.1.49.23844
- Bufford, R, Paloutzian, R, & Ellison, C. (1991). Norms for the Spiritual Well-Being Scale. *Journal of Psychology and Theology*, 19(1), p. 56-70.
- Chesney, M.A., Neilands, T.B., Chambers, D.B., Taylor, J.M., & Folkman, S. (2006). A validity and reliability study of the coping self-efficacy scale. *British Journal of Health Psychology*, 11, pp. 421-427. doi: 10.1348/135910705X53155
- Chin, J. (2007). *The AIDS pandemic: The collision of epidemiology with political correctness*. Oxford, Radcliffe Publishing.
- Chirwa, M.L., Greeff, M., Kohi, T.W., Naidoo, J.R., Makoe, L.N., Dlamini, P.S., Kaszubski, C., Cuca, Y.P., Uys, L. & Holzemer, W.L. (2009). HIV stigma and nurse job satisfaction in five African countries. *Journal of the Association of nurses in Aids care*, 20(1), pp. 14-21. doi: 10.1016/j.jana.2008.10.001
- Corrigan, P.W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical psychology: Science and practice*, 7(1), pp. 48-67. doi: 10.1093/clipsy.7.1.48
- Cross, H., Heijnders, M., Dalal, A., Sermittirong, S., & Mak, S. (2012). Interventions for stigma reduction – Part 2: Practical applications. *Disability, CBR & Inclusive Development*, 22(3), pp. 71-80. doi:10.5463/dcid.v22i3.72.

- De Vos, A.S., Strydom, H., Fouche, C.B., & Deport, C.S.L. (2005). *Research at grass roots for the social sciences and human service professions*. (3rd edition). Pretoria, Van Schaik Publishers.
- Duncan, N., Ratele, K., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. (2007). *Self, community & psychology*. (2nd edition). Lansdowne, UCT Press.
- Fife, B.L. & Wright, E.R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41, pp. 50-67.
- Fishbein, M. & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: an introduction to theory and research*. Reading, Addison-Wesley.
- Foster, G. & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS*, 14(Suppl. 3), pp. 275-284.
- Genia, V. (2001). Evaluation of the spiritual well-being scale in a sample of college students. *International journal of the psychology of religion*, 11, pp. 25-33. doi: 10.1207/S15327582IJPR1101_03.
- Goffman, E. (1963). *Stigma: Notes on the management of spoilt identity*. Englewood Cliffs, Prentice Hall.
- Greeff, M., Uys, R.L., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P. Kohi, T.W., Mullan, J., Naidoo, J.R., Cuca, Y., & Holzemer, W.L. (2009). Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: a longitudinal study. *International journal of nursing studies*, 47, pp. 475-486.
- Greeff, M. (2010). A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. Potchefstroom: NWU. (Unpublished research proposal)
- Harvey, R.D. (2001). Individual differences in the phenomenological impact of social stigma. *Journal of social psychology*, 141(2), pp. 174-189. doi: 10.1080/00224540109600545
- Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. (1998a). Psychosocial differences between urban and rural people living with HIV/AIDS. *The Journal of rural health*, 14, pp. 138-145. doi: 10.1111/j.1748-0361.1998.tb00615.x
- Heckman, T.G., Somlai, A.M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C.A. & Kelly, J.A. (1998b). Barriers to care among persons living with HIV/AIDS in urban and rural areas.

- AIDS Care: Psychological and socio-medical aspects of AIDS/HIV*, 10(3), pp. 365-375. doi: 10.1111/j.1748-0361.1998.tb00615.x
- Heijnders, M & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma reduction strategies and interventions. *Psychology, Health and Medicine*, 11(3), pp. 353-363. doi: 10.1080/13548500600595327
- Herek, G.M., Gillis, J.R. & Cogan, J.C. (2009). Internalized stigma among sexual minority adults: Insights from a social psychological perspective. *Journal of Counselling Psychology*, 65, pp. 32-43. doi: 10.1037/a0014672
- Holzemer, W.L. & Uys, L.R. (2004). Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3), pp. 165-174.
- Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6), pp. 541-551. doi: 10.1111/j.1365-2648.2007.04244.x
- Kalichman, S. (2013). Teaching tip sheet: Stigma and prejudice. Retrieved from: <http://www.apa.org/pi/aids/resources/education/stigma-prejudice.aspx>.
- Keyes, C.L.M. (2002). The mental health continuum: From languishing to flourishing in life. *Journal of health and social behavior*, 43(2), pp. 207-222. Retrieved from <http://www.jstor.org/stable/3090197?origin=JSTOR-pdf>
- Keyes, C.L.M. (2005). Mental illness and/or mental health? Investigating axioms of the complete state model of health. *Journal of consulting and clinical psychology*, 73(3), pp. 539-548. doi: 10.1037/0022-006X.73.3.539
- Keyes, C.L.M., Wissing, M., Potgieter, J.P., Temane, M., Kruger, A. & Van Rooy, S. (2008). Evaluation of mental health continuum-short form (MHC-SF) in Setswana-speaking South Africans. *Clinical psychology and psychotherapy*, 15, pp. 181-192. doi: 10.1002/cpp.572
- Kohi, T.W., Makoe, L.N., Chirwa, M., Holzemer, W.L., Phetlhu, D.R. & Uys, L.R. (2006). HIV and AIDS stigma violates human rights in five African countries. *Nursing ethics*, 13(4), pp. 405-414. doi: 10.1191/0969733006ne865oa

- Kohi, T.W, Portillo, C.J. Durrheim, K., Dlamini, P.S., Makoe, L.N., Greeff, M., ... Holzemer, W.L. (2010). Does perceived HIV stigma contribute to nurses' intent to migrate in five African countries. *Journal of the Association of Nurses in AIDS Care*, 21(2), pp. 134-143. doi:10.1016/j.jana.2009.09.004
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), pp. 606-613. doi: 10.1046/j.1525-1497.2001.016009606.x
- Mak, W.W.S., Cheung, R.Y.M., Law, R.W., Woo, J., Li, P.C.K., & Chung, R.W.Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine*, 64, pp. 1549-1559. doi: 10.1016/j.socscimed.2006.12.003
- Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Ortiz, D., Szekeres. G., & Coates, T.J. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*, 22 (Suppl 2), 67-79. doi: 10.1097/01.aids.0000327438.13291.62
- Makoe, L.N., Portillo, C.J., Uys, L.R., Dlamini, P.S., Greeff, M., Chirwa, M., ... Holzemer, W.L. (2009). The impact of taking or not taking ARV's on HIV stigma as reported by persons living with HIV infection in five African countries. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 21(11), pp. 1357-1362. Doi: 10.1080/09540120902862576
- McCoach D.B. (2010). Hierarchical linear modeling. In Hancock, G.R., & Mueller, R.O. (Eds.) *The reviewer's guide to quantitative methods in the social sciences*. New York: Routledge.
- Mkhize, N. 2004. Psychology: An African perspective. In Ratele, K., Duncan, N., Hook, D., Mkhize, N., Kiguwa, P. & Collins, A. (Eds.) *Self, community and Psychology*. Landsdowne, UCT Press.
- Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., ... Kohi, T. (2007). Urban and rural differences in HIV/AIDS stigma in five African countries. *Medical journal of AIDS research*, 6(1), pp. 17-23. doi: 10.2989/16085900709490395
- Nyblade, L.C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, health & medicine*, 11(3), pp. 335-345. doi: 10.1080/13548500600595178

- O'Brien, Y. (2012). Community-based HIV interventions. Retrieved from: <http://www.slideshare.net/Yvonneo1/community-based-hiv-interventions>.
- Ogden, J., & Nyblade, L. (2005). Common at its core: HIV-related stigma across context. Washington DC: International Center for Research on Women (ICRW). Retrieved from <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>
- Pavot, W., Diener, E., Colvin, C., & Sandvik, E. (1991). Further validation of the Satisfaction with Life Scale: evidence for the cross-method convergence of well-being measures, *Journal of Personality Assessment*, 57(1), pp. 149-161.
- Psychosocial Working Group. (2011). Forced migration online: A world of information on human displacement. *Psychosocial working group*. Retrieved from: <http://www.forcedmigration.org/psychosocial/>.
- Reif, S., Golin, C.E., & Smith, S.R. (2005). Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 17(5), pp. 558-565. doi: 10.1080/09540120412331319750
- Ryan, R.M. (2009). Self-determination theory and wellbeing. *Wellbeing in developing countries (WeD)*, *WeD research review 1 (June 2000)*. University of Bath, UK.
- Ryan, R. M., & Deci, E. L. (2001). To be happy or to be self-fulfilled: A review of research on hedonic and eudemonic well-being. In Fiske, S. (Ed.) *Annual Review of Psychology*. Palo Alto, Annual Reviews/ Inc.
- Sanjuan, P., Molero, F., Fuster, M.J. & Nouvilas, E. (2012). Coping with HIV related stigma and well-being. *Journal of Happiness Studies*, 14(2), pp. 709-722.
- Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of social aspects of HIV/AIDS*, 1(3), pp. 157-164.
- Taylor, B. (2001). HIV, stigma and health: integration of theoretical concepts and the lived experiences of individuals. *Journal of advanced nursing*, 35(5), pp. 792-798. doi: 10.1046/j.1365-2648.2001.01912.x
- Thorne, S. (2008). *Interpretive description*. Walnut Creek, Left Coast press.

- Uys, L.R., Chirwa, M.L., Kohi, T.W., Greeff, M., Naidoo, J.R., Makoe, L.N., ... Holzemer, W.L. (2009). Evaluation of a health setting-based intervention. *AIDS patient care and STDs*, 23(12), pp. 1059-1066. doi: doi:10.1089/apc.2009.0085
- Valdiserri, R.O. (2002). HIV/AIDS stigma: An impediment to public health. *American Journal of Public Health*, 92(3), pp. 341-342.
- Varni, S.E., Miller, C.T., McCuin, T. & Solomon, S.E. (2012). Disengagement and engagement coping with HIV/AIDS stigma and psychological well-being of people with HIV/AIDS. *Journal of Social and Clinical Psychology*, 31(2), pp. 123-150. doi: 10.1521/jscp.2012.31.2.123
- Williamson, J. & Robinson, M. (2006). Psychosocial interventions, or integrated programming for well-being? *Intervention*, 4(1), pp. 4-25.
- Wissing, M.P. & Van Eeden, C. (2002). Empirical clarification of the nature of psychological well-being. *South African journal of psychology*, 32(1), pp. 32-44.
- Yang, L. H. & Kleinman, A. (2008). 'Face' and the embodiment of stigma in China: The cases of schizophrenia and AIDS. *Social Science and Medicine*, 67, pp. 398-408. doi: 10.1016/j.socscimed.2008.03.011

ARTICLE 3: Health behaviour change of people living with HIV after a comprehensive community-based HIV stigma reduction intervention

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Health behaviour change of people living with HIV after a comprehensive community-based HIV stigma reduction intervention

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Abstract

HIV stigma impedes access to care and treatment and globally this fuels HIV transmission. Fear of stigmatization prevents people living with HIV (PLWH) from using opportunities to access health care and from using treatment. It has an overall impact on PLWH's quality of life and health behaviour. The core research question of this study was therefore whether a comprehensive community-based HIV stigma reduction intervention would result in changed health behaviour of PLWH. The research objective was to explore and test change-over-time in the HIV stigma experiences and health behaviour of PLWH after the intervention. An experimental quantitative single-system research design with one pre- and four repetitive post-tests, utilizing purposive sampling, was used to test change-over-time in the health behaviour of 18 PLWH. The measurements included the use of a demographic questionnaire, the Perceived AIDS Stigma Instrument for PLWA, the Revised ACTG Self-Report Adherence to Medication Measure, the Revised Self-Care Symptom Management Strategies as a measure of health behaviour and the HIV/AIDS Targeted Quality of Life Instrument. Research assistants were trained to apply the instruments in a private setting which was convenient for the participants. The results indicated that 18 PLWH voluntarily remained engaged with HIV stigma reduction measurement for a year after the intervention and that HIV stigma reduction leads to health behaviour change, less intense HIV symptoms, improved adherence to treatment, responsible disclosure management, improved relationships and improved quality of life. Recommendations include the escalation of this intervention to other cultures, provinces and urban or rural vulnerable communities. Mechanisms to keep PLWH actively involved in community-based HIV stigma reduction should be explored and should lead to community support structures for future participants in repeats of the intervention.

Key words: health behaviour; health behaviour change, HIV stigma; stigma experiences.

Résumé

La stigmatisation liée au VIH entrave l'accès aux soins et traitements, et accroît la transmission du VIH mondialement. La crainte de la stigmatisation empêche les personnes vivant avec le VIH (PVVIH) de saisir les opportunités d'accès aux soins de santé et de bénéficier des traitements. Elle affecte l'ensemble de la qualité de vie des PVVIH et leurs comportements de santé. Cette étude cherche ainsi à savoir si une intervention communautaire globale de réduction de la stigmatisation liée au VIH changerait le comportement de santé des PVVIH. L'objectif était d'étudier et tester l'évolution dans le temps des expériences de stigmatisation liée au VIH et des comportements de santé des PVVIH après l'intervention. Pour tester l'évolution dans le temps du comportement de santé de 18 PVVIH, on a utilisé une méthode de recherche expérimentale quantitative à système unique avec un test préalable, quatre tests postérieurs répétés, et un échantillonnage dirigé. Les mesures incluaient l'utilisation d'un questionnaire démographique, de l'Instrument sur la stigmatisation perçue par les PVVIH, de la Mesure révisée ACTG d'auto-rapport d'adhérence au traitement, des Stratégies révisées d'autogestion des symptômes comme mesure des comportements de santé, ainsi que de l'Instrument sur la qualité de vie orientée sur le VIH. Les assistants à la recherche ont été formés à employer ces instruments dans un contexte privé, pratique pour les participants. 18 PVVIH ont participé volontairement à la mesure de la réduction de la stigmatisation pendant un an après l'intervention et les résultats ont montré que la réduction de la stigmatisation liée au VIH entraîne un changement des comportements de santé, des symptômes du VIH moins intenses, l'amélioration de l'adhérence au traitement, une gestion responsable de la divulgation du VIH, l'amélioration des relations et de la qualité de vie. Il est recommandé d'étendre cette intervention à d'autres cultures, provinces et communautés vulnérables urbaines ou rurales. Les mécanismes pour maintenir la participation active des PVVIH à la réduction communautaire de la stigmatisation liée au VIH méritent d'être étudiés et devraient générer des structures de soutien communautaire des participants des futures interventions.

Mots-clés : *stigmatisation liée au VIH; expériences de stigmatisation ; comportement de*

1 Introduction

This study forms part of a large SANPAD project dealing with the stigma experiences of people living with HIV (PLWH) and the stigmatization by people living close to them. HIV remains a highly stigmatized illness throughout the world and the focus in this article is on stigma and the health behaviour of the PLWH. Not only is HIV complex in nature but HIV stigma impacts on the physical, psychological, social and financial dimensions of PLWH as it violates general health, basic human rights, social and economic freedom and quality of life (Chirwa et al., 2009; Dlamini et al., 2009). Holzemer et al. (2007) identify the different types of HIV stigma as internal stigma, received stigma and associated stigma. Other authors refer to self-stigma (Mak et al., 2007), perceived stigma (Link, Yang, Phelan & Collins, 2004) and secondary stigma (Ogden & Nyblade, 2005). These, in turn, have life-intrusive consequences like decreased social participation, personal and emotional frailty and diminished physical and mental health (Asiedu, 2010; Cahill & Valadez, 2013; Rensen, Bandyopadhyay, Gopal & Van Brakel, 2011), and thus also have a serious effect on the health behaviour of PLWH. The effects of HIV stigma often become an added burden to existing compromised health behaviour of PLWH, rendering them vulnerable to challenges of social participation, self-responsibility and behaviour modification as well as choices regarding their sexual partners, lifestyle and medical care (Genberg et al., 2007; Mallory et al., 2007; Taylor, 2001; Zimmerman, Olsen & Bosworth, 2000). The interplay between HIV stigma and HIV health behaviour is crucial for defeating the AIDS pandemic and restoring quality of life for PLWH (Bhagwanjee, Petersen, Akintola & George, 2008; Greeff et al., 2010).

The behaviour theory of Fishbein (2000) identifies action, target, context and timing as the four basic elements of behaviour. Applied to HIV health behaviour this would manifest as action (using), target (condom), context (vaginal sex with two partners) and timing (always/sometimes), combined with attitude and intention toward risky or healthy behaviour. Health behaviour is as dynamic and complex as any other behaviour and always has meaning and purpose (Bonell & Imrie, 2001). It sometimes resides in dimensions of character or attitude, willpower, physical/psychological/mental strengths and resilience or even peer pressure, psychosocial interaction or one's spiritual relationship with a higher being (Setswe, 2009). In

some African contexts, for instance, health or ill health is seen as a consequence of human behaviour, or something sanctioned by God or brought on by the ancestors (Pinkoane, 2005), which complicates motivation towards behaviour change.

This suggests that potential health behaviour change interventions have to be comprehensive, cover a broad spectrum of challenges and achieve fundamental shifts in attitude, belief systems and power relations (Duncan, Harrison, Toldson, Malaka & Sithole, 2005; Link & Phelan, 2001). Innovative efforts surpassing the boundaries of single disciplines, and moving into lesser known territories of transdisciplinarity, could thus assist the behavioural sciences of the day to reduce risky health behaviour and to instil 'good' health behaviour (Jordan & Bazzarre, 2002; Kelly, Murphy, Sikkema & Kalichman, 1993) in the face of HIV stigma. A number of conventional HIV stigma-related behaviour modification mechanisms and contemporary health behaviour change models in literature will be discussed below.

1.1 Conventional behaviour change mechanisms

Acceptance of HIV within the context of a lifetime illness requires the courage to manage HIV stigma and to prevent the stigma from becoming a hidden and continuous burden on the affected individual who chooses to keep the diagnosis secret (Weiss, Ramakrishna & Somma, 2006). The genuine acceptance of HIV as part of one's life is imperative as a foundation for the infected person to commit to appropriate long-term health behaviour modification (Foster & Gaskins, 2009). Many patients in the USA are now viewing and managing HIV as yet another manageable chronic disease, packaged with modified behaviour and a lifelong treatment regime like diabetes or hypertension (Holzemer, 2012). Some PLWH, however, are terrified by their HIV diagnosis and the stigma attached to it and they deny being ill and avoid treatment (Allick, 2012).

Increased information and education leads to deeper understanding of HIV and empowers people to skilfully use preventative tools like condoms and to make educated choices of sexual partners (Bonell & Imrie, 2001). Through a lack of knowledge, PLWH can become enveloped in a personal cloud of stigma, without realizing the manageability of the illness if it is treated correctly (Allick, 2012). The South African government, in managing a country with devastating

AIDS statistics, still places high priority on increased HIV information and education to reach vulnerable populations (South African National AIDS Counsel [SANAC], 2011). India's National AIDS Control Programme, NACP IV 2012–2017, also leans heavily on the eradication of HIV ignorance, social judgment and transmission ignorance (International Centre for Research on Women [ICRW], 2013). Education, information sharing, counselling and shared advice could remedy health behaviour driven by fears and unwillingness (Greeff et al., 2008). Setswe (2009) explores different ways of making information available and suggests group interaction of PLWH for sharing experiences, social and stigma pressures, risk perceptions, partner negotiations and personal concerns and motivation. A dynamic HIV workplace program of a multinational brewing company reported that although educational and promotional activities sparked a positive response for employees and their spouses in five African countries, the average uptake behaviour of HIV counselling and testing (HCT) varied between 15% and 32% (Van der Borgh et al., 2010).

HIV counselling and testing remains a key health behaviour for stemming the tide of HIV and is therefore included in the South African National Strategic Plan that envisages annual HIV testing of everyone in South Africa (SANAC, 2011). The UNAIDS 2004 report suggested the use of an associated policy of “three C’s” for HCT, namely confidentiality, counselling and consent for everybody, to maximize the uptake of HCT. An HIV workplace programme the South African mining sector seemed successful in education and HCT but demonstrated a significant gap between exposure to HCT and the uptake of treatment (Bhagwanjee et al., 2008). One of the advantages is a sense of relief in knowing one’s HIV status, which opens the subsequent potential to responsibly re-plan and modify one’s lifestyle, risky behaviour, sexual partners, condom use, abstinence, treatment and supportive friendships (Bonell & Imrie, 2001). HIV stigma and the fear of being identified, unfortunately remains a critical challenge to HIV testing, care and prevention (Florom-Smith & De Santis, 2012).

Access and Adherence to Treatment can be seen as participatory behaviour of PLWH and is as important as HCT. Barriers to making the decision and taking the action of starting treatment often is HIV stigma related (Allick, 2012). The aforementioned South African mining workplace reported perceived confidentiality violations on the part of healthcare staff, fear of having to

cope with the illness itself and fear of organizational stigmatization and discrimination as reasons for refusal of treatment (Bhagwanjee et al., 2008). A significant and stable correlation exists between perceived HIV stigma and self-reported reasons for missed medications (Dlamini et al., 2009). Non-uptake of treatment behaviour is very consequential to HIV stigma and the challenges posed by this phenomenon. Furthermore, the up-scaling of antiretroviral treatment programs into low and middle income countries with the proviso of integrated protection from HIV stigma and discrimination, prevention, treatment and care services, could also be remedial to non-participatory behaviour (UNAIDS, 2004). Dlamini et al. (2009) emphasize that HIV stigma challenges should be discussed in-depth with PLWH before they are offered ARV regimens, as people ordinarily only engage in behaviour that offers desired benefits. Florom-Smith and De Santis (2012) observe that the experience of stigma is often the reason why PLWH fail to adhere to their prescribed treatment regimens.

Responsible HIV disclosure management remains complex. One of the more important reasons for disclosure is the potential of openness and responsible negotiation of sexual partners about condom-protected sex or consensual unprotected sex or one-partner-only relationships (Bonell & Imrie, 2001). The disclosure decision should always be well-informed because disclosing PLWH have no control over reactions of other people, the subsequent disclosure by third parties or the potential consequences after any incident of disclosure (Greeff, 2013). Reasons for refusal to disclose HIV status include anxiety for the moment of telling, denial of the diagnosis, complacency with the secret, fears of unknown implications or reactions of others, fears of ridicule, blame, rejection or stigma (Greeff et al., 2008). It was also found that PLWH who disclosed to a friend had higher baseline scores on a social activity inquiry scale regarding their quality of life (Greeff et al., 2010). Other factors contributing to the complexity of disclosure are cultural sensitivity, culture-congruent communication, acceptance of the person, genuine caring and respectful interaction (Watson, 2002). Foster and Gaskins (2009) further report that PLWH did not believe that they would find any meaningful support from religious communities if they were to disclose their positive HIV status. This illustrates the anxiety attached to every disclosure of one's HIV status, as the response can never be predicted (Greeff, 2013). It seems evident that disclosure leaves the PLWH vulnerable where stigma is rife, and Sales, Ryan, Silver, Sarkisian and Cunningham (2007) report that stigmatized PLWH avoided

all medical care, even emergency treatment, for fear of disclosure of their sero-status, which they believed would lead to inferior care and hostile treatment by staff who viewed them as a hazard.

Support-seeking behaviour is a human response to adversity like stigmatization, discrimination, job insecurity, a decreased quality of life and a need for compassion, care, acceptance, openness, friendship, sharing and respect from significant others (Relf, Mallinson, Pawlowski, Dolan & Dekker, 2005). Support groups have traditionally been recognized for their value to provide emotional support, sharing experiences, reducing the burden of stigma, and exploring new ideas on how to deal with common challenges (Social Tract, 2011). Foster and Gaskins (2009) identified spiritual sharing as important supportive behaviour for PLWH. However, if stigma is prevalent, PLWH would often have reservations over whether to disclose their sero-status and from whom to seek support, if at all (Florom-Smith & De Santis, 2012).

1.2 Health behaviour change models, theories and interventions

Behaviour change interventions for HIV stigma reduction requires a design that accurately speaks to specific outcomes, needs and contexts (Funnell & Rogers, 2011). Whilst there is paucity in research findings on behaviour change from any academic discipline over the last two decades, the lack of exhaustive answers to the challenges offered by HIV stigma and the broader pandemic is emphasized (Moore & Charvat, 2007). A summary of 11 analyses on eight behaviour change interventions reported a 30% success rate only for the measured reduction of HIV-related risk behaviour over time (McCoy, Kangwende & Padian, 2010).

Many non-specific behaviour change and behaviour change communication models, techniques and interventions are documented but careful consideration is imperative in the choices among these (Mirembe, 2012). All these behaviour change models normally start with a decision making process based on the creation of urgency or need for change, then selling ideas and working towards buy-in, consulting broadly, identifying leadership and then managing a chaotic phase with possible resistance, avoidance and disintegration. The settling down stage follows after this, and introduces exciting processes of engaging participation, co-creation of a new behavioural future whilst utilizing techniques and methods that maximize participation in the

change in behaviour (Longo, 2011). Zimmerman et al. (2000) refer to the 'stages of change' model for gradual change in behaviour: the person moves from being dis-interested, unaware or unwilling to the act of activating change. The change starts with a form of pre-contemplation, followed by consideration of a change (contemplation), and then taking deliberate action to make a behaviour change as intended, as the beginning of a lifelong change (Norcross, Krebs & Prochaska, 2011). This trans-theoretical model is at the basis of a number of other behaviour change theories, like the BASNEF model with locus of control theory (Hubley, 1988), the health belief model (Stretcher & Rosenstock, 1997), motivational interviewing (Zimmerman, Olsen, & Bosworth, 2000), cognitive-behavioural therapy (Heijnders & Van der Meij, 2006) and the well-known applied twelve step programmes to change co-dependent behaviour (Zimmerman et al., 2000).

The principles and elements of all the above theories or models can guide change processes. PLWH are not powerless and can in different circumstances become effective change agents in their own skin, circumstance and culture (Gladwell, 2002). Mashadi (2012) suggests that individuals use voluntary cognitive behaviour strategies like positive goal setting, the identification of personal strengths and scheduled distraction activities to overcome negativity or depression and to direct determined new behaviour, like changed sexual practices. Various other researchers further contributed to the field of HIV stigma-related behaviour change. Corrigan (2004) suggested that changing approaches in terms of public stigma should be grouped into three categories, namely a) protesting prejudice, b) education, and c) personal contact with PLWH. Kendra, Cattaneo and Mohr (2012) and Boyd, Katz, Link and Phelan (2010) concur on matters of education and contact with PLWH. Boyd et al. (2010) also emphasize that personal contact with the stigmatized could lessen anger, blame, social distancing and fear. Kendra et al. (2012) indicate the role of education as a means of reducing HIV stigma and found that traditional lecturing was less effective than personal contact and experiential learning techniques.

An innovative approach to health behaviour change in the future could thus stem from conventional contributions but could also move beyond the borders of disciplines and cut across the conventional scope of practice and research. Critical success factors could be drawn

from all the above elements and principles and could be carefully applied to appropriate situations, assumptions, activities, resources and envisaged outcomes (Funnel & Rogers, 2011). Emerging transdisciplinarity and trans-disciplined partnerships can facilitate exciting explanatory and meaningful contributions for HIV stigma and health behaviour change (Nicolescu, 2007). The focus of such partnerships would be on collaboration and common elements that drive and change health behaviour across the full spectrum and through the lenses of different disciplines (Jordan & Bazzarre, 2002). HIV and HIV stigma-related behaviour change can benefit from a broad perspective of diversity, respectful confrontation and mutual transformation of disciplines. This will require scientifically transformed minds that would strive for synergy and collective encounters across barriers, for the greater good (Selcer, 2011).

2 Problem statement

HIV stigma and stigmatization impede access to care and treatment and it fuels HIV transmission all over the world. Fear of stigma or stigmatization prevents people from using opportunities to learn about HIV, from learning their HIV status, from utilizing health care facilities and from accessing treatment. Stigma lets people maintain potentially risky sexual relations for fear of being questioned should they change. PLWH are often fearful to disclose their HIV status and thus compromise supportive relationships and quality of life. The more PLWH are exposed to HIV stigma experiences, the more difficult it becomes to face their challenges and take responsibility to break the silence, and to modify their health habits and lifestyle choices. It seems critical to invest in HIV stigma reduction and to limit its crippling effects on the health behaviour of PLWH.

3 Research question

The core research question of this study was whether a comprehensive community-based HIV stigma reduction intervention will result in changed health behaviour in PLWH.

4 Research objective

The research objective was to explore and test change in the HIV stigma experiences and health behaviour of PLWH over time after a comprehensive community-based HIV stigma reduction intervention.

5 Research design

A quantitative experimental single system design (De Vos, Strydom, Fouche & Delport, 2005) with a pre-test and four repetitive post-test measures (01 x 02 03 04 05) at a three months interval was conducted in both an urban and a rural setting.

6 Research methodology

6.1 Sample

The sample of the study consisted of PLWH in both an urban (Potchefstroom) and a rural (Ganyesa) district of the North West Province, South Africa. Mediators (who had a trust relationship with PLWH), existing community public benefit organizations, and HIV health care clinics assisted with purposive voluntary sampling. The identified PLWH had to be over 18 years of age and conversant in Afrikaans, English or Setswana. They had to be HIV positive for at least six months prior to their inclusion. The sample of 18 PLWH was relatively small due to the therapeutic nature of the intervention in the bigger SANPAD study and the intended interactive contact between PLWH and people living close to them during the workshops.

10 PLWH were from the Potchefstroom urban district and 8 from the rural district of Ganyesa in the North West Province, South Africa. PLWH were required to sign forms confirming their informed consent for participation and for recording processes (see ethical considerations). They were included in a preparatory workshop relating to possible disclosure of their HIV status during the intervention.

Table 12: Sample distribution

PLWH						
URBAN			RURAL			
Female	Male	Total	Female	Male	Total	TOTAL
9	1	10	5	3	8	18

6.2 Intervention

The intervention for this study was adapted from the validated intervention manual by Uys et al. (2009). It was based on three tenets, namely the a) information sharing on HIV stigma and how to cope with it, b) equalising of relationships between PLWH and people living close to them through increased interaction and contact, and c) empowerment to implement an HIV stigma reduction project in their communities.

The comprehensive community-based HIV stigma reduction intervention primarily consisted of three activities. The first of these was a two-day lecture and activity-based workshop for PLWH in both urban and rural settings, which focused on their personal understanding of HIV stigma, responsible disclosure management and identification of personal strengths. The initial workshop was then followed by a series of six three-day workshops attended by all PLWH and one person from each of six groups of people living close to them, namely their spouses/partners, their children over 15 years of age, their family members, their friends, spiritual leaders and community members. The first day of these activity-based workshops for PLWH and people close to them focused on an understanding of HIV stigma and coping with it, as well as the relationships amongst them. All the workshops had two facilitators (one HIV infected and one non-HIV infected person) in each group. The second day was focused on learning how to plan a project for HIV stigma reduction in their own community. It offered each of the designated groupings an opportunity to plan their own project for community members of designated categories similar to their own, e.g. partners with partners. They had a four-week period to implement their projects and were facilitated by the researchers. This meant that six projects were running in Potchefstroom (urban setting) and six projects in Ganyesa (rural

setting) simultaneously. On the third and last day of the intervention, the different groupings personally presented their project reports to invited community members and the research team. Each project was evaluated and small prizes were presented for the most outstanding urban and rural community HIV stigma reduction projects.

6.3 Data collection

The data collection for health behaviour of PLWH included a demographic questionnaire utilized pre-intervention alongside four valid and reliable measuring instruments for the pre-test and four repetitive (three-monthly) post-test measures. These were the Perceived AIDS Stigma Instrument for PLWA (Hasi-P), Revised ACTG Self-report Adherence to Medication Measure, the Revised Self-Care Symptom Management Strategies (SSC-HIVrev) and the HIV/AIDS Targeted Quality of Life Instrument (HAT-QoL).

A *demographic questionnaire* that included personal data, like age, gender, marital status, number of children, education level and employment status, was used. Relevant data relating to general health, HIV diagnosis, CD4 count and health behaviour (clinic visits, disclosure of HIV status and adherence to treatment) were also gleaned.

The *Revised ACTG Self-Report Adherence to Medication Measure* stems from the AIDS Clinical Trials Group's instrument (ACTG-Rev) that initially consisted of 14 self-reported reasons for missing medications. Holzemer and colleagues reported on an additional factor analysis conducted to reduce the ACTG-Rev to a nine-item instrument with a one-factor solution. Two scores are calculated from the revised nine-item scale as measure of health behaviour. Respondents rate how often they have missed their ARV medications for a particular reason in the past month, on a scale of 1 (never) to 4 (often), and these are then added up. The resulting score ranges from 9 to 36, where higher scores mean the person missed more doses (Holzemer et al., 2001).

The *Perceived AIDS Stigma Instrument for PLWA (HASI-P)* is a 33-item instrument developed by Holzemer et al. (2007). This scale measures six HIV and AIDS-related stigma dimensions expected to be experienced by PLWH (verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion, workplace stigma). The instrument reflects a total

score and the means of each of the six dimensions. It was initially validated by Holzemer et al. (2007) with a sample of 1477 respondents from five African countries. A Cronbach reliability coefficient 0.94 was found.

The *Revised Self-Care Symptom Management Strategies (SSC-HIVrev)* is a measure of health behaviour described by Holzemer et al. (2001) and measures the intensity and frequency of 72 common signs and symptoms of HIV. Part 1 of the instrument features 45 HIV related physical and psychological symptoms clustered according to 11 factor scores. The initial reliability ranged between 0.76 and 0.91. Part 2 contains 19 HIV related symptoms that do not cluster into factors but offer clinical knowledge. These 64 items were used whilst the eight gynaecological symptoms for women, in part 3, were not utilized for this study. The HIV Sign and Symptom Check-List (rev.) has been used extensively in Southern Africa, with a Cronbach reliability estimate of 0.96 for the total scale (Dlamini et al., 2009).

The *HIV/AIDS Targeted Quality of Life Instrument (HAT-QoL)* as developed by Holmes and Shea (1999) is a 34-item HIV specific instrument to identify quality-of-life concerns of PLWH. The scale measures nine dimensions: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust and sexual function. The subscales are scored on a Likert scale rating from 1 (none of the time) to 5 (all the time) during the past four weeks. The final score is transformed into a linear 0-100 scale where 100 is the best score possible. The Cronbach alpha reliability coefficient was 0.86 at baseline, and 0.96 and 0.95 for two subsequent assessments, indicating excellent consistency reliability of the items (Dlamini et al., 2009; Holmes & Shea, 1999).

Research assistants were trained two weeks before the intervention as preparation to perform data collection and to facilitate the workshops. They then received the names of participants from the mediators, scheduled appointments with them and ensured transport and logistical comfort for the commencement of the intervention at the North-West University campus.

6.4 Data analysis

The Statistical Package for the Social Sciences (SPSS, version 21) for Windows was applied for data analysis. Descriptive statistics including mean, mean square error and p-values were

computed. Effect sizes calculated the practical significance of mean differences for changes across time. Hierarchical linear models were used to estimate the effect within the urban and the rural groups. This type of modelling takes into account the dependency on repeated data collection from identified people and explains the variability within and between urban-rural groups over time (McCoach, 2010).

7 Ethical considerations

Permission for this SANPAD-funded research component was obtained from the School of Nursing Science as well as from the North-West University Ethics Committee (NWU-OOO 11-09-A1) (30/03/2009-29/03/2014). The North West Provincial Department of Health granted permission for the research. Basic ethical principles like respect for human subjects, benevolence and justice were maintained (Burns & Grove, 2009). *Respect* for participants was demonstrated by offering information about the study, criteria for their inclusion, the schedule for workshops, three-monthly measuring and the option to freely withdraw from the process at any time. It was also explained that anonymity would be ensured by means of a coding system that did not link their true identity with their specific responses at any time. Only partial confidentiality could be ensured, though, since the participants worked together in groups during the workshops and would therefore know each other's identities. The participants signed a consent form if they were satisfied with the information and the intentions of the research team. *Benevolence* for participants was achieved through the sharing of knowledge on HIV stigma and coping with it, identification of personal strengths, learning about responsible disclosure management, potential enhancement of close relationships and exposure to project skills training. *Justice* for participants related to fair treatment and the management of possible risks by providing a safe environment, transport and a light lunch.

8 Findings and discussion

The urban-rural data was pooled for analysis because no significant differences were found

between the two groups over time and there neither was a significant difference in the main effect for these groups.

8.1 The demographic and background information of the 18 PLWH

This information showed of the 18 PLWH participants showed that the ages of participants ranged between 27 and 52, with an average age of 37. Only 3 participants were married at the time, 1 was widowed, 2 were divorced and 12 were never married. 3 participants had no children, 6 had one child each, 6 had two children and 2 had three children. 7 of them passed grade 10; 2 passed grade 11 and 3 passed grade 12. None of the participants achieved a degree, 1 had a diploma, 7 had a post-school certificate and 10 had no post-school education. 7 were employed, 6 lived on government grants, 7 were supported by family and one earned a living by doing piece jobs. The information from the demographic questionnaire, alongside data from the other instruments, forms the collective basis for the thematic discussion of findings. The PLWH may be described as a middle-aged group with minimal education, general lack of employment and representative of the lower socio-economic population.

8.2 Awareness of HIV and general health status

Awareness of HIV and general health status of these PLWH seemed satisfactory and they could all report on their existing participation in health care, like knowing their HIV status, their most recent CD4 count and visiting their clinics when due. 8 PLWH had a CD4 count below 500 cells per cubic millimetre of blood, which is the most recent WHO guideline for starting treatment (World Health Organization [WHO], 2013). 6 participants had CD4 counts between 500 and 800 and 1 reported a count of 1300 cells per cubic millimetre of blood. 4 participants reported no visits to a clinic, 6 went once, 8 PLWH went more than once and 2 were hospitalized during the past three months. Overall, it appeared that the PLWH were participating well in their own healthcare and although one reported poor health, 7 described their health as fair and ten said that they enjoyed good health.

8.3 ARV treatment and adherence to treatment

The ARV treatment and adherence to treatment of the group was measured by the ACTG

questionnaire and was combined with information gleaned from the demographic questionnaire. Although 3 of the 18 PLWH did not answer ARV questions in their demographic questionnaire, the ACTG gave a more comprehensive picture. Table 13 combines the information of 18 PLWH (coded between 101 and 210), with nine reasons and four frequency categories for missing dosages of their ARV medication. This measure refers to time 2, directly after the intervention took place. 8 of the 18 people said that they have never forgotten to take their medicines whilst 7 gave reasons, and frequencies of using these reasons, for missing dosages. Of these 7 PLWH, 5 reported that they missed taking their medication four times or less over the last three months. The reason most frequently offered was that it was too difficult to take medication at a specific time (see table 13). 2 of the 18 PLWH missed several dosages. One person (coded 101) sometimes missed a dose because of being unable to take it at specific times, being too busy, being away from home, oversleeping or forgetting to take it. The person coded 106 marked all nine reasons for missing dosages, with varying frequency ratings. The behaviour scores on the ACTG scale for persons 101 and 106 were 20 and 26 respectively, whilst the ideal score is 9 and the worst possible score is 36. 11 of the 18 PLWH scored a perfect adherence score of 9. Responses to the demographic questionnaire indicated that one person stopped ART once before because of a lack of regular food. 14 of the 18 PLWH reported diligent adherence to their treatment regimens with the aid of reminders like an alarm clock, cell phone, daily radio program or a caring relative that ensured that they took their ART at the correct times.

4 PLWH reported no side-effects of the ART, 4 felt bloated, 2 experienced vomiting, 2 reported a skin rash and 2 reported pain because of the ARVs. These findings, for 16 of the 18 PLWH, indicate a pattern of adherence to treatment which was strengthened by the intervention, with relatively few side-effects.

Table 13: PLWH reasons and frequency of using reasons for missing dosages of medication

ACTG self report on reasons and frequency of using these reasons for missing dosages of medication										
Reasons	Avoid	Felt too	Too many	Felt	Specific time	Too	Away from	Forgot	Slept	Behaviour
18 PLWH	Side-effects	sick	pills	depressed	impossible	busy	home			9 to 36
101	1	1	1	1	3	3	3	4	3	20
102	1	1	1	1	3	2	2	1	1	13
103	1	1	1	1	1	1	1	1	1	9
105	1	1	1	1	1	1	1	1	1	9
106	3	2	3	3	3	3	2	3	4	26
107	3	4	1	1	3	1	1	1	1	16
108	1	1	1	1	1	1	1	1	1	9
109	1	1	1	1	1	1	1	1	1	9
110	1	3	1	3	2	1	1	1	3	16
111	1	1	1	1	1	1	1	1	1	9
201	1	1	1	1	1	1	1	1	1	9
202	1	1	1	1	1	1	1	1	1	9
203	1	1	1	1	1	1	1	1	1	9
204	1	1	1	1	1	1	1	1	1	9
205	1	1	1	1	1	1	1	1	3	11
207	1	1	1	1	1	1	1	1	1	9
209	1	3	1	3	1	1	1	1	1	13
210	1	1	1	1	1	1	1	1	1	9

NB: never = 1, rarely = 2, sometimes = 3, often = 4 (behaviour score per coded participant - 9 better; 36 missed many).

8.4 Disclosure of HIV status by PLWH

In the section disclosure of HIV status by PLWH in the demographic questionnaire, 9 of the 18 PLWH indicated that they chose to disclose their HIV sero-status on the same day of their diagnosis. 3 PLWH disclosed within the first week, 4 within the first two months and the last 2 only disclosed it for the first time years after their diagnosis. In 50% of the cases, disclosure was towards a family member. Of the remaining 50% (9 participants), 4 disclosed to a partner, 4 to a friend, 1 to a neighbour and 1 did not disclose at all. Subsequent disclosures by 15 of the PLWH were mostly to family members (83.3%) and friends (61.1%). Thereafter the PLWH disclosed to spiritual leaders (50%), community members (44.4%) and neighbours (44.4%). Further subsequent disclosure was made to partners (38.9%), to children (33.3%) and to a lesser degree to colleagues (11.1%). Family was thus preferred for first disclosure. For subsequent disclosure family members were also the most preferred group, although friends were also considered, and then spiritual leaders.

8.5 Support by others towards PLWH

The category of support by others towards PLWH, as seen in table 14, shows in the demographic questionnaire by whom the PLWH were supported and how they were supported. Family members were the most preferred support system (72.2%), and thereafter a partner (38.9%), child (33.6%) or friend (33.3%). The support mechanisms of encouragement, sharing of worries and 'being checked on' were each mentioned by 3 of the PLWH. 2 of the PLWH each identified provision of money, food and care and reminders to take medication as support mechanisms. Although spiritual leaders were high on the list of preferred parties for subsequent disclosure, they were less frequently indicated as a source of support (16.7%). PLWH were mostly supported by family members, followed by some support from other PLC.

Table 14: PLWH disclosure of HIV status and their support system

Disclosure behaviour									
Disclosure; how long post HIV?	Same day (50%); 2-5 days (16.9%); 2-3 weeks (11.1%); 1-2 months (11.1%); 1-3 years (11.1%)								
	Partner	Child	Family	Friend	Spiritual	Collea-	Commun	Neighbor	Nobody
To whom:			Member		Leader	que	Member		/other
First disclosure?	22.2%		50.0%	22.2%				5.6%	5.6%
Subsequent disclosure?	38.9%	33.6%	83.3%	61.1%	50.0%	11.1%	44.4%	44.4%	No(5.6%)
Current support system?	38.9%	33.6%	72.2%	33.3%	16.7%	11.1%		22.2%	No (5.6%)
How do they support you?	5.6% no answer. Encourage me (16.9%); Give me money (11.1%); Talk/share worries (16.9%);								
	Checks on me (16.9%); Give me food (11.1%); Care/Accept me (11.1%); Remind me to take								
	my meds (11.1%)								

The change in stigma experiences of PLWH after the intervention was measured on the Perceived AIDS stigma instrument PLWA (HASI-P) for PLWH. The scale indicated internal reliability, with a Cronbach alpha value for health care neglect (HCN) of 0.62 and alpha values ranging between 0.77 and 0.85 for the other four subscales. Effect sizes were calculated for these analyses where the limited number of 18 PLWH might not have enough statistical power to indicate statistically significant differences. The information on Table 15 reflect five different subscales of HIV stigma dimensions for the PLWH. The pre-intervention scores are shown on time 1 and the comprehensive community-based HIV stigma reduction intervention occurred between times 1 and 2. Four three-monthly post-test scores on each subscale follow upon this, to test possible change-over-time. The subscale on verbal abuse (VA) is not statistically significant ($p = 0.10$) but the effect sizes between times 1 and 2, 1 and 3, 1 and 4 as well as 1

and 5 are all larger than 0.5, indicating practical significance. The mean ($\bar{X}$) scores decreased from $\bar{X} = 12.1$ at time 1 to $\bar{X} = 9.8$ at time 2 and $\bar{X} = 8.3$ at time 5. The negative self-perception (NSP) scores of the PLWH are not statistically significant ($p = 0.26$) either. Again, the effect sizes of the decrease between times 1 and 3 and times 1 and 5 indicate practical significance, with values of 0.55 and 0.49. The health care neglect (HCN) subscale indicates a statistically significant improvement in the HIV stigma experience of PLWH ($p = 0.03$). The four effect sizes ranging between 2.89 and 3.64 are indicative of practical significance as well. Although not statistically significant, the subscale of social isolation (SI) had effect sizes of between 0.71 and 0.96 and thus showed practical significance and an improvement in the experiences of social isolation by PLWH. Fear of contagion (FC) indicated statistical and practical significance ($p = 0.03$, d between 1.84 and 2.78). The results on the HASI-P show that the experiences of PLWH improved after the comprehensive community-based HIV stigma reduction intervention; if not with statistical significance, then with practical significance. The total stigma score as calculated from the different subscales, however, indicates a statistically significant ($p = 0.02$) improvement-over-time in the HIV stigma experiences of the PLWH, as well as a practical significance with all effect sizes larger than 0.50.

Table 15: PLWH experiences of dimensions of stigma over five times

Dimensions	Mean scores							Effect sizes			
	Time 1	Time 2	Time 3	Time 4	Time 5	MSE	p	1 with 2	1 with 3	1 with 4	1 with 5
VA	12.1	9.8	8.2	8.2	8.3	1.25	0.1	2.06	3.49	3.49	3.4
NSP	7.39	6.8	6.19	6.69	6.32	4.76	0.26	0.27	0.55	0.32	0.49
HCN	7.6	7.1	7.04	7.1	6.97	0.03	0.03	2.89	3.23	2.89	3.64
SI	6.7	5.75	5.51	5.51	5.42	1.78	0.38	0.71	0.89	0.89	0.96
FC	7.7	6.63	6.31	6.42	6.08	0.34	0.03	1.84	2.38	2.2	2.78
Tot	43.61	37.94	35.01	35.47	34.69	12.61	0.02	1.6	2.42	2.29	2.51

8.6 Intensity and frequency of HIV signs and symptoms experienced by PLWH

The aspect of *intensity and frequency of HIV signs and symptoms experienced by PLWH* was measured (over five times) on the Revised Self-Care Symptom Management Strategies (SSC-HIVrev) as a measure of health behaviour (Holzemer et al., 2001). The scoring sheet allows choices among *do not have the problem*; *mild*; *moderate*; and *severe* in terms of the listed signs and symptoms. Table 16 below indicates mean scores of all 18 PLWH. A low score (9) reflects

the absence of the problem (*do not have the problem*) and a high score (36) thus reflects high intensity and frequency of a sign or symptom. Five of the nine subscales reflect a statistically and practically significant decline of signs and symptoms in PLWH after the comprehensive community-based HIV stigma reduction intervention. These were fatigue ($p = 0.05$), numbness ($p = 0.01$), rectal itch ($p = 0.03$), bruising ($p = 0.02$) and gynaecological symptoms ($p = <0.01$). Three of the remaining signs and symptoms, namely fear, gastro intestinal symptoms (GI_upset) and sore throat, decreased with practical significance and effect sizes larger than 0.50. Although not statistically significant, the gastro-intestinal symptoms decreased with effect sizes of 1.07 between times 1 and 2 directly after the intervention; with effect sizes of 2.47 between times 1 and 3; with 0.82 between times 1 and 4; and with 1.66 between times 1 and 5. The subscale and symptom with the least change over time after the intervention was shortness of breath (SOB). The times 1 and 5 effect size of 0.4 might indicate some practical significance in the decrease. The gynaecological scale was included for the female participants and reflected the highest intensity and frequency mean scores of all the signs and symptoms but also the largest effect sizes of improvement on top of the statistical significance. The stigma reduction intervention seemed to have made a difference to both the intensity and severity of experienced signs and symptoms of HIV. The opportunity to share these experiences and the experience of support possibly lightened the burden for individuals.

Table 16: HIV signs and symptoms of PLWH over five times

PLWH - Stigma symptoms at five times								Effect sizes of each time with time 1			
Variables	Time 1	Time 2	Time 3	Time 4	Time 5	MSE	p	1 with 2	1 with 3	1 with 4	1 with 5
Fatigue	6.22	6.07	4.88	5.76	4.99	0.85	0.05	0.16	1.45	0.5	1.33
Fear	7.13	6.01	5.26	5.84	5.66	4.89	0.15	0.51	0.85	0.58	0.66
GI_upset	8.61	7.61	6.29	7.84	7.05	0.88	0.11	1.07	2.47	0.82	1.66
SOB	4.09	3.99	3.78	4	3.66	1.16	0.84	0.09	0.29	0.08	0.4
SoreThroat	4.26	4.67	4.12	4.41	4.02	0.05	0.23	1.83	0.63	0.67	1.07
Numbness	6.57	5.44	4.49	4.77	4.95	0.12	0.01	3.26	6	5.2	4.68
Rectal_Itch	3.96	3.34	3.07	3.12	3.13	0.29	0.03	1.15	1.65	1.56	1.54
Bruising	5.09	4.61	4.22	4.1	4.29	0.33	0.02	0.84	1.51	1.72	1.39
Gyneal	12.81	10.47	9.42	9.09	9.25	1.17	<0.01	2.16	3.13	3.44	3.29

8.7 Quality of life concerns for the PLWH

Quality of life concerns for the PLWH were identified and assessed on The HIV/AIDS-targeted Quality of Life Instrument (HAT-QoL) (Holmes & Shea, 1999). The closer a score is to 100, the

better PLWH managed their quality of life in spite of certain life concerns. The HIV mastery subscale, with a Chronbach's alpha value of 0.38, did not prove to be reliable in this population, and is therefore not discussed further. The HAT-QoL (table 17) refers to concerns during the four weeks prior to measurement and included overall functioning, life satisfaction, health worries, financial worries, medication worries, disclosure worries, provider trust and sexual functioning. There were increases from the time 1 mean score ($\bar{X} = 86.38$) to time 3, with an effect size of 0.61, indicating practically significant change at time 3 after the intervention. The life satisfaction (LS) subscale increased with an effect size of 0.48 between times 1 and 2, indicating practically significant change immediately after the intervention. The subscale for specific health worries (e.g. *can't live the way I want to* and *going to die*) showed a statistically and practically significant improvement ($p = 0.01$, d between 0.69 and 1.25) after the intervention and towards time 4.

Financial worries (FW) were the more prominent result on the HAT-QoL for the 18 PLWH. In spite of the high degree of practical significance in the improvement after the intervention, the time 1 ($\bar{X} = 32.46$) to time 5 scores ($\bar{X} = 43.22$) were far below the ideal of 100. Time 4 decreased, but time 5 showed a great improvement over pre-intervention. The effect sizes varied between 1.60 and 2.23 between times 1 and 2, and between times 1 and 5. This subscale includes worries about the lack of a fixed income, insufficient funds to pay bills and not being financially independent.

The scores on the scale for medication worries (MW) were close to 100 even before the intervention. The scores improved even further after the intervention from time 2 onwards, indicated practical significance and had effect sizes of 0.42 between time 1 and 2, of 0.73 between time 1 and 2; of 0.40 between times 1 and 4; and of 0.62 between times 1 and 5.

There was a statistically and practically significant ($p = 0.02$) improvement in the disclosure worries (DW) of PLWH after the intervention from time 1 ($\bar{X} = 77.39$) to time 5, where the score reached almost 90 ($\bar{X} = 89.54$).

The subscale for worries about the doctor (PT) included aspects like accessibility, being included in the doctor's decision making and a feeling that the doctor cares. These scores showed

practically significant improvement, with effect sizes of 0.43 between times 1 and 3 and of 0.51 between times 1 and 4. The improvement, however, could not be sustained.

The sexual functioning (SF) subscale mean score for time 1 ($\bar{X}$ = 66.09) is fairly low in comparison with the other scale, except for financial worries. The comprehensive community-based HIV stigma reduction intervention clearly made an impact and brought improvement in the sexual functioning worries of PLWH. The effect sizes of 1.94, 2.93, 3.99 and 3.05 indicate strong practically significant changes between time 1 and each of times 2, 3 and 4. The $\bar{X}$ = 84.89 at time 5 is also much improved from the $\bar{X}$ = 66.09 at time 1.

The quality of life scale indicated statistically significant improvement on health and disclosure worries. There was a practically significant increase specifically at time 2, directly after the intervention for life satisfaction (LS), financial worries (FW), medication worries (MW) and sexual functioning (SF). There were inconsistencies on these four scales at times 3 and 4 but by time 5 they were all higher than the -intervention score. The subscale *worries about the physician* (PT) decreased directly after the intervention and although it increased again at time 3 and 4 with practical significance, and it finally had a lower score at time 5 than pre-intervention.

Table 17: Quality of life concerns of PLWH over five times

PLWH - worrying factors over five times								Effect sizes of each time with time 1			
Variables	Time 1	Time 2	Time 3	Time 4	Time5	MSE	p	1 with 2	1 with 3	1 with 4	1 with 5
HATQ_Total	86.38	85.89	92.95	89.5	85.83	116.05	0.52	0.05	0.61	0.29	0.05
HATQ_LS	86.09	91.39	83.37	89.55	89.11	119.64	0.66	0.48	0.25	0.32	0.28
HATQ_HW	77.39	85.45	91.21	92.05	82.24	137.13	0.01	0.69	1.18	1.25	0.41
HATQ_FW	32.46	40.2	40.3	36.57	43.22	23.38	0.45	1.6	1.62	0.85	2.23
HATQ_MW	90.01	94.02	96.97	93.8	95.92	91.44	0.45	0.42	0.73	0.4	0.62
HATQ_DW	77.39	89.96	95.36	91.9	89.54	17.48	0.02	3.01	4.3	3.47	2.91
HATQ_PT	83.77	75.72	87.88	88.66	79.1	91.03	0.26	0.84	0.43	0.51	0.49
HATQ_SF	66.09	78.04	84.12	90.64	84.89	37.94	0.08	1.94	2.93	3.99	3.05

The research question as to whether the comprehensive community-based HIV stigma reduction intervention would make a difference to the HIV stigma experiences and health behaviour of PLWH, has thus been answered affirmatively. All the instruments that were applied, indicated either statistical or practical significance in the improvement of HIV stigma experiences and health behaviour of PLWH.

9 Conclusions

This study found no significant difference between the urban-rural results on HIV stigma experiences and health behaviour of PLWH over time. This could be ascribed to the participants all being black Setswana-speaking South Africans from the North West Province. The urban-rural data was therefore pooled for further analysis. It should be noted that the PLWH in this study had to be HIV positive for at least six months prior to the intervention and the purposive sampling suggested that they were already familiar with the health care system. The comprehensive community-based intervention aimed at measuring and reducing HIV stigma for this group, which it succeeded to do. The intervention successfully reduced their HIV stigma experiences, changed aspects of their health behaviour, reduced the intensity of their HIV signs and symptoms and improved their quality of life. By facilitating the sharing of knowledge on HIV stigma and on coping with it, the intervention afforded PLWH an opportunity to reflect on their illness. The intervention further allowed for equality in relationships amongst those who were HIV positive and those who were HIV negative, which created a situation in which they could feel better about themselves. It also gave them the opportunity to work together in self-initiated projects towards the reduction of HIV stigma in their communities.

Based on the findings in the demographic questionnaire and ACTG scale, it is concluded that the 18 PLWH were a middle-aged group with minimal post-school education, mostly unemployed and of relatively low socio-economic status. Based on the measurements directly after the intervention, their participation in health care was satisfactory, because they knew their CD4 counts and most of them did not miss dosages of medication but used the services of health care services when necessary. Most disclosed their HIV status mainly to family within the first month after the diagnosis. Family members were providing the most support. From further findings on the ACTG scale, it can be concluded that two of the 18 PLWH reflected behaviour scores indicative of risky health behaviour whilst 11 had perfect scores of nine. The reason mostly offered (five times) for missing dosages of medication was difficulty to take it at a specified time. This could be due to stigma and a lack of privacy, which made participants reluctant to take their medication at the prescribed times if their HIV-positive status would be revealed by such behaviour.

On the HASI-P, statistically or practically significant decreases were noted in the stigma experiences of PLWH on the five measured dimensions of verbal abuse, negative self-perception, health care neglect, social isolation and fear of contagion. The total score of these dimensions combined indicates a statistically significant change over time, which leads to the conclusion that the comprehensive community-based HIV stigma reduction intervention succeeded in reducing the HIV stigma experiences of PLWH.

The intensity and frequency of the HIV signs and symptoms experienced by PLWH declined over time after the intervention. This could be because HIV stigma declined after the intervention and because PLWH were able to share their experiences in general and to focus less on symptoms, as they experienced a sense of normality in the group.

It can be concluded that the intervention led to an increase in their quality of life. An unfortunate finding is the concerns of PLWH about their physician because the mean score immediately after the intervention and the last score almost a year later both decreased to lower than before the intervention. This could be due to limited resources and less availability of doctors in clinics as well as the difficulty to build a relationship with alternating doctors. Although there were inconsistencies during the measuring period, these scales were better at time 5 than at time 1 before the intervention. It can be concluded that the intervention contributed PLWH's improved quality of life.

An overall conclusion can be drawn that the comprehensive community-based HIV stigma reduction intervention was successful and potentially life-changing for PLWH. The measurement stretched over a year. The fact that participants remained in the project without receiving any remuneration speaks of an on-going engagement with HIV stigma, stigma reduction and health behaviour modification. The findings suggest that when HIV stigma reduces for PLWH, a conscious change in self-judgment and stigma experiences follows and this leads to health behaviour change, reduced signs and symptoms, better adherence to treatment, responsible disclosure management, improved relationships and improved quality of life.

10 Limitations of the study

This study was part of the comprehensive community-based stigma reduction intervention of SANPAD and possibilities for changing logistics were therefore limited. It was also limited with regard to the number of participants since the intervention is of a therapeutic nature and focused among others on personal sharing and interaction.

11 Recommendations

It is recommended that this comprehensive community-based HIV stigma reduction intervention be repeated. The findings and conclusions show that the intervention successfully reduced HIV stigma and simultaneously addressed the interplay between HIV stigma and health behaviour. It is therefore recommended that this stigma reduction intervention be included in health behaviour change efforts, and that it should be used without changing the tenets it was built on or the content and therapeutic method of presentation. The training of facilitators and field workers prior to commencement of the intervention will always be imperative. Equally important is the proper preparation of the PLWH for responsible disclosure management. The reason for such preparation and the insistence on smaller numbers of participants is that the intervention reaches sensitive areas of people's lives, where they might choose to disclose their HIV status, share painful stigma experiences and build or re-build important relationships.

This intervention should be escalated to other cultures, communities and provinces in both urban and rural areas. It should also target vulnerable communities since it can be repeated in any setting. It could be beneficial to add an intervention three to six months after the first intervention, focusing on aspects of positive health behaviour coupled with psychosocial and spiritual well-being towards an improved quality of life for PLWH. It could be very helpful for PLWH to shift the focus from themselves and their symptoms to constructive matters of concern for the community. Mechanisms to strengthen continuous active participation of PLWH in HIV stigma reduction in communities should be explored. Where HIV stigma is rife, health behaviour is compromised. There should be no end to the reduction of HIV stigma and the participation of PLWH in positive health behaviour. It is critically important that there

should be continuous support for responsible disclosure management for them and other PLWH entering the fray after repeated interventions in such a broader context. It is further recommended that this intervention be escalated to the community at large to ensure further and more innovative HIV stigma reduction and health behaviour change mechanisms.

12 References

- Allick, C. (2012, March 23). Patients living with HIV are dying in denial. *Toronto Star: Health & Wellness*. Retrieved from http://www.thestar.com/life/health_wellness/2012/03/23/patients_living_with_hiv_are_dying_in_denial.html
- Asiedu, G.B. (2010). *“Once it’s your sister, they think it’s in the bloodline”: Impact of HIV/AIDS-related stigma in Ghana* (Doctoral thesis). Retrieved from <http://krex.k-state.edu/dspace/bitstream/handle/2097/6698/GladysAsiedu2010.pdf?sequence=1>
- Bhagwanjee, A., Petersen, I., Akintola, O., & George, G. (2008). Bridging the gap between VCT and HIV/AIDS treatment uptake: perspectives from a mining-sector workplace in South Africa. *African Journal of AIDS Research*, 7(3), 271-279. doi: 10.2989/AJAR.2008.7.3.4.651
- Bonell, C., & Imrie, I. (2001). Behavioral interventions to prevent HIV infection: Rapid evolution, increasing rigour, moderate success. *British Medical Bulletin*, 58(1), 155-170. doi: 10.1093/bmb/58.1.155
- Boyd, J.E., Katz, E.P., Link, B.G., & Phelan, J.C. (2010). The relationship of multiple aspects of stigma and personal contact with someone hospitalized for mental illness, in a nationally representative sample. *Socio Psychiatric Epidemiology*, 45, 1063–1070. doi: 10.1007/s00127-009-0147-9
- Burns, N., & Grove, S.K. (2009). *The practice of nursing research: appraisal, synthesis and generation of evidence* (6th ed.). St. Louis, MO: Elsevier Saunders.
- Cahill, S., & Valadez, R. (2013). Growing older with HIV/AIDS: New public health challenges. *American Journal Public health*, 3(3), 7-15. doi: 10.2105/AJPH.2012.301161

- Chirwa, M.L., Greeff, M., Kohi, T.W., Naidoo, J.R., Makoe, L.N., Dlamini, P.S., Kaszubski, C., Cuca, Y.P., Uys, L. & Holzemer, W.L. (2009). HIV stigma and nurse job satisfaction in five African countries. *Journal of the Association of nurses in Aids care*, 20(1), 14-21.
- Corrigan, P.W. (2004). Target-specific stigma change: A strategy for impacting mental illness stigma. *Psychiatric rehabilitation journal*, 28(2), 113-121. doi: 10.2975/28.2004.113.121
- De Vos, A.S., Strydom, H., Fouche, C.B., & Deport, C.S.L. (2005). *Research at grass roots for the social sciences and human service professions* (3rd ed.). Pretoria: Van Schaik Publishers.
- Dlamini, P.S., Wantland, D., Makoe, L.N., Chirwa, M., Kohi, T.W., Greeff, M., Naidoo, J., ... Holzemer, W.L. (2009). HIV stigma and missed medications in HIV-positive people in five African countries. *Aids patient care and STDs*, 23(5), 377-387. doi:10.1089/apc.2008.0164
- Duncan, C., Harrison, M.G., Toldson, I.A., Malaka, D., & Sithole, S. (2005). Social stigma, HIV/AIDS knowledge and sexual risk: A cross-cultural analysis. *Journal of applied biobehavioral research*, 10(1), 1-26. doi: 10.1111/j.1751-9861.2005.tb00001.x
- Fishbein, M. (2000). The role of theory in HIV prevention. *Aids Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 12(3), 273-278. doi: 10.1080/09540120050042918
- Florom-Smith, A.L., & De Santis, J.P. (2012). Exploring the concept of HIV-related stigma. *Nursing Forum*, 47(3), 153-165. doi: 10.1111/j.1744-6198.2011.00235.x
- Foster, P.P., & Gaskins, S.W. (2009). Older African Americans' management of HIV/AIDS stigma. *AIDS Care: Psychological and Socio-medical aspects of HIV/AIDS*, 21(10), 1306-1312. doi: 10.1080/09540120902803141
- Funnel, S.E., & Rogers, P. J. (2011). *Purposeful program theory: effective use of theories of change and logic models*. San Francisco, CA: John Wiley & Sons.
- Genberg, B.L., Kawichai, S., Chingono, A., Senday, M., Chariyalertsak, S., Konda, K.A., & Celentano, D.D. (2007). Assessing HIV/AIDS stigma and discrimination in developing countries. *Aids and Behavior*, 12(5), 772-780. doi: 10.1007/s10461-007-9340-6
- Gladwell, M. (2002). *The tipping point: how little things can make a big difference*. New York: Hachette Book group.

- Greeff, M. (2013). Disclosure and stigma: A cultural perspective. In P. Liamputtong (Ed.), *Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective* (pp. 71-95). Netherlands: Springer.
- Greeff, M., Phetlhu, R., Makoe, L.N., Dlamini, P.S., Holzemer, W.L., Naidoo, J.R., ... Chirwa, M.L. (2008). Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative health research*, 18(3), 311-324. doi: 10.1177/1049732307311118
- Greeff, M., Uys, R.L., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P. ... Holzemer, W.L. (2010). Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: A longitudinal study. *International Journal of Nursing Studies* 47(4), 475-486. doi:10.1016/j.ijnurstu.2009.09.008
- Heijnders, M & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma reduction strategies and interventions. *Psychology, Health and Medicine*, 11(3), pp. 353-363. doi: 10.1080/13548500600595327
- Holmes, W.C., & Shea, J.A. (1999). A new HIV/AIDS-targeted quality of life (HAT-QoL) instrument: development, reliability, and validity. *Medical Care*, 36(2), 138-54.
- Holzemer, W.L., (2012, August). A 25-year program of research on living with HIV infection. 23rd *International Nursing Research Congress: Creating a legacy through nursing research, innovation and global collaboration*. Special session presented at the Sigma Theta Tau International Congress, Brisbane, Australia. Program book, p 76. Abstract retrieved from <https://stti.confex.com/stti/congrs12/webprogram/Session15034.html>
- Holzemer, N.L, Hudson, A., Kirksey, K.M., Hamilton, M.J. & Bakken, S. (2001). The revised sign and symptom check-list for HIV (SSC-HIVrev). *Journal of the Association of Nurses in AIDS Care*, 12(5), 60-70.
- Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6), 541-551.
- International Centre for Research on Women [ICRW]. (2013). A global HIV stigma reduction framework; adapted and implemented in five settings in India. Summary report. India's National AIDS Control Programme (NACP IV, 2012-2017). Retrieved from

http://www.icrw.org/files/publications/web_ICRW_STRIVE_India%20stigma%20framework_0.pdf

- Jordan, O.M.G., & Bazzarre, T. (2002). The behaviour change consortium: Setting the stage for a new century of health behaviour-change research. *Health Education Research Journal*, 17(5), 500-511.
- Kelly, J.A., Murphy, D.A., Sikkema, K.J., & Kalichman, S.C. (1993). Psychological interventions to prevent HIV infection are urgently needed: new priorities for behavioural research in the second decade of AIDS. *American Psychologist*, 48(10), 1023-1034. doi: 10.1037/0003-066X.48.10.1023
- Kendra, S.K., Cattaneo, L.B., & Mohr, J.J. (2012). Teaching abnormal psychology to improve attitudes toward mental illness and help-seeking. *Teaching of Psychology*, 39(1), 57-61. doi: 10.1177/0098628311430315
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing Stigma. *Annual Review of Sociology* 27, 363-385.
- Link, B.G., Yang, L.H., Phelan, J.C., & Collins, P.Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3), 511-541.
- Longo, R. (2011, May 22). Is Lewin's change management model still valid? HR Professionals [Web log post]. Retrieved from <http://rosariolongo.blogspot.com/2011/05/is-lewins-change-management-model-still.html>
- Mak, W.W.S., Cheung, R.Y.M., Law, R.W., Woo, J., Li, P.C.K., & Chung, R.W.Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine*, 64, 1549-1559. doi: 10.1016/j.socscimed.2006.12.003
- Mallory, O., Johnson, T.B., Neilands, S.M., Dilworth, S.F., Morin, R.H., Chesney, R., & Chesney, M.A. (2007). The role of self-efficacy in HIV treatment adherence: Validation of the HIV treatment adherence and self-efficacy scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359-370. doi: 10.1007/s10865-007-9118-3
- Mashadi, L. (2012). Applying a cognitive behavioural model to understanding stigma. *Serenity Neuroscience newsletter*, 10(2), 9-11.

- McCoach D.B. (2010). Hierarchical linear modeling. In G. R. Hancock, & R. O., Mueller, (Eds.) *The reviewer's guide to quantitative methods in the social sciences* (pp. 123-140). New York: Routledge.
- McCoy, S.I., Kangwende, R.A., & Padian, N.S. (2010). Behaviour change interventions to prevent HIV infection among women living in low and middle income countries: A systematic review. *AIDS and Behavior*, 14(3), 469-82. doi: 10.1007/s10461-009-9644-9
- Mirembe, I. (2012, September 24). It is time to give more than just information to address HIV. *Daily Monitor*. Retrieved from <http://www.monitor.co.ug/OpEd/Commentary/It-is-time-to-give-more-than-just-information-to-address-HIV/-/689364/1515272/-/k7ofvez/-/index.html>
- Moore, S.M., & Charvat, J. (2007). Promoting health behaviour change using Appreciative Inquiry: Moving from deficit models to affirmation models of care. *Family & Community Health*, 30(1), 64–74.
- Nicolescu, B. (2007). Transdisciplinarity as methodological framework for going beyond the science-religion debate. A publication of Metanexus Institute.
- Ogden, J., & Nyblade, L. (2005). *Common at its core: HIV-related stigma across context*. Washington DC: International Center for Research on Women (ICRW). Retrieved from <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>
- Pinkoane, M.B. (2005). *Incorporation of the traditional healers into the national health care delivery system* (Unpublished doctoral thesis). North-West University, Potchefstroom.
- Relf, M.V., Mallinson, K., Pawlowski, L., Dolan, K., & Dekker, D. (2005). HIV-related stigma among persons attending an urban HIV clinic. *The Journal of multicultural nursing & health*, 11(1), 14-23.
- Rensen, C., Bandyopadhyay, S., Gopal, P.K., & Van Brakel, W.H. (2011). Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 33(9), 711-719. doi:10.3109/09638288.2010.506942
- Sales, J.N., Ryan, G.W., Silver, J.S., Sarkisian, C.A., & Cunningham, W.E. (2007). Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *Journal of Urban Health*, 84(6), 814-828. doi:10.1007/s11524-007-9220-4

- South African National AIDS Council [SANAC]. (2011). *National Strategic Plan (NSP) on HIV, STIs and TB 2012-2016*: Republic of South Africa. Retrieved from <http://www.info.gov.za/view/DownloadFileAction?id=155622>
- Selcer, P. (2011) *"Patterns of Science: Developing Knowledge for a World Community at Unesco"*. Available from ProQuest Dissertations and Theses database. (UMI No. AAI3463035). Retrieved from <http://repository.upenn.edu/dissertations/AAI3463035> University of Pennsylvania, Texas.
- Setswe, G. (2009). HIV / AIDS prevention strategies. PDM Summer School, University of Stellenbosch, 16 January 2009. *Presentation*, 16p.
- Social Tract. (2011). Module on support groups. Retrieved from: <http://www.docstoc.com/docs/71295180/Social-Tract-Support-groups>
- Taylor, B. (2001). Nursing theory and concept development or analysis. HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals. *Journal of advanced nursing*, 35(5), 792-798. doi: 10.1046/j.1365-2648.2001.01912.x
- UNAIDS. (2004, June). *UNAIDS/WHO policy statement on HIV testing*. UNAIDS Global Reference Group on HIV/AIDS and Human Rights. Retrieved from http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf
- Uys, L.R., Chirwa, M.L., Kohi, T.W., Greeff, M., Naidoo, J.R., Makoe, L.N., ... Holzemer, W.L. (2009). Evaluation of a health setting-based intervention. *AIDS patient care and STDs*, 23(12), 1059-1066. doi:10.1089/apc.2009.0085
- Van Der Borgh, S.F., Schim Van Der Loeff, M.F., Clevenberg, P., Kabarega, J.P., Kamo, E., Van Cranenburgh, K., ... Rinke De Wit, T.F. (2010). Long-term voluntary counselling and testing (VCT) uptake dynamics in a multicountry HIV workplace program in sub-Saharan Africa. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22(2), 195-205. doi: 10.1080/09540120903111486
- Weiss, M.G., Ramakrishna, J., & Somma, D. (2006). Health related stigma: rethinking concepts and interventions. *Psychology, Health & Medicine*, 11(3), 277-287.
- World Health Organization [WHO]. (2013). Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. London: WHO. Retrieved from http://apps.who.int/iris/bitstream/10665/85321/1/9789241505727_eng.pdf

Zimmerman, G.L., Olsen, C.G. & Bosworth, M.F. (2000). A 'Stages of Change' approach to helping patients' change behaviour. *American Family Physician*, 61(5), 1409-1416.

SECTION D: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

1 Introduction

The conclusions that follow are based on the findings of the three research articles in section C, following the comprehensive community-based HIV stigma reduction and wellness enhancement intervention. The focus is on conclusions about a reduction in HIV stigma experiences of PLWH and stigmatisation by PLC after the intervention, psychosocial well-being of PLWH and PLC after the intervention, and lastly improved health behaviour of PLWH after the intervention. A summative conclusion is provided.

2 Conclusion

2.1 Conclusions about HIV stigma experiences of PLWH and stigmatisation by PLC after the intervention

No significant differences were found between the *urban* and *rural* groups over time in HIV stigma experiences of PLWH or stigmatisation by PLC after the intervention. The urban-rural data was thus pooled for the further analysis to evaluate the effectiveness of the intervention. The similarity in the data of the groups can be ascribed to the fact that both groups consisted of primarily Setswana-speaking persons who all resided in the North West Province, South Africa. No cultural differences were evident during the intervention in the two settings and it seemed as though social and cultural practices were similarly understood and performed.

During the pre-test measure, *stigma* was indicated by PLWH as being present on all five the indexes (verbal abuse, negative self-perception, health care neglect, social isolation by others and fear of contagion), which proves that stigma is an important reality in PLWH's lives in both urban and rural settings. The stigma experiences of PLWH decreased either statistically or practically significantly on all the indexes after the intervention, though, with the total stigma score showing a statistically significant change. The third measure (time 3), approximately three

months after the intervention, revealed changing effect sizes, showing the personal benefits derived from the intervention. It can be concluded that the comprehensive community-based HIV stigma reduction intervention successfully reduced HIV stigma experiences in PLWH. The linear correlation amongst all the HIV stigma indexes further indicates the complexity of HIV stigma and emphasises that it is important to focus on all the indexes during the intervention.

Although only three of the five indexes were used in the analysis of *stigmatization* by PLC, the three remaining indexes (symbolic, instrumental and general stigma) all showed statistically significant changes, indicating a reduction in stigmatisation by PLC after the intervention. Similar to the findings of the experiences of PLWH, large effect size scores featured at the third measure about three months after the intervention, as PLC started to internalise effects of the intervention. The symbolic enhancement is indicative of a change in PLC's moralising behaviour towards PLWH, with fewer prejudices. The instrumental index showed that PLC became less worried about protecting themselves from getting infected. This could be due to the increased contact between PLWH and PLC during the workshops and the community project. The type of prejudice-based HIV stigma intent measured by symbolic, instrumental and general stigma scales included opinions on HIV as a punishment for sleeping around, refusal of HIV-positive children in public schools and reluctance to touch someone who is HIV-infected. All these and other stigmatisation concepts and actions of the PLC reduced after the intervention, which led to the conclusion that stigmatisation by PLC could also be reduced through the intervention.

It is important to note that a change-over-time in the HIV stigma experiences of PLWH occurred simultaneously with a change-over-time in the HIV stigmatisation behaviour by PLC. These changes in stigma experiences and stigmatisation could be sustained over a one-year period after the intervention, showing that the impact on both PLWH and PLC was tangible. The preparation of PLWH at the onset of the intervention to help them understand HIV stigma, manage their disclosure responsibly and identify their strengths, seems to have been an important preparation for the rest of the workshops, which also included the PLC. Using a team of facilitators (one PLWH and one non-infected person), as well as bringing PLWH and PLC together in the same workshop and during the projects, emphasised the importance of equal relationships and the importance of contact. The facilitators were modelling equality,

acceptance and cooperation. The fact that the stigma experiences of PLWH as well as stigmatization by PLC were effectively decreased, indicates that the interactive small group activities and discussions worked well and that the content was appropriate. The increased interaction and contact amongst participants normalised togetherness, offered sharing opportunities, activated support for each other, and reduced the fear of contagion. The projects that were executed together by the PLWH and the PLC as leaders in stigma reduction in their own communities could have contributed to the phenomenon that both PLWH and PLC regained some control after having received the devastating news that HIV will always be a reality in their lives. By including the entire circle of PLC surrounding the PLWH, a more comprehensive response to HIV stigma could be ensured. The intensity and time that went into the intervention over a four-month period could have been overwhelming for PLWH, but they never mentioned this. The intervention was time-consuming and intense for participants as well as facilitators but had meaningful results in reducing HIV stigma experiences for PLWH and stigmatisation by PLC. Participants benefitted from the therapeutic nature of the intervention that offered skilled facilitators, a limited number of participants and a structured, safe environment. The comprehensive community-based HIV stigma reduction intervention contributes to filling existing gaps in the quest for successful HIV reduction interventions.

2.2 Conclusions about psychosocial well-being of PLWH and PLC after the intervention

As in the case of HIV stigma experiences by PLWH and stigmatisation by PLC, no significant differences were found in the changes-over-time in psychosocial well-being between the urban and the rural settings of both PLWH and PLC due to the intervention. The data for urban and rural participants was thus also pooled for further analysis to evaluate the effect of the intervention on the psychosocial well-being of PLWH and PLC. This could possibly be ascribed to the cultural similarity of the two groups, as both included mainly Setswana-speaking people of the North West Province, South Africa.

An unexpected result of this study, however, was the change-over-time in psychosocial well-being of the PLWH and the PLC due to the intervention. More regressive changes were noted in most of the psychosocial well-being measures of PLWH and more positive changes in those of the PLC.

Results of the *Mental Health Continuum Scale* for both the PLWH and the PLC before the intervention showed that most of the participants were already on the flourishing side of the scale, with very few on the languishing side of the scale. PLWH showed no statistically significant changes on the total scale after the intervention but there were practically significant changes in the sub-scales. They mainly remained on the flourishing side of the scale. This could possibly be because PLWH were directly confronted by the reality of their illness during the intervention and because they were in less denial. Time 5, almost a year after the intervention, showed a sudden decrease on the scale for the PLWH; possibly because they confronted the reality of their illness instead of negating it, or because they internalised uncomfortable health-related or lifestyle truths. The PLC, on the other hand, started on a lower level of flourishing in their mental health than the PLWH but demonstrated consistent practically significant improvement across the spectrum of the measurement after the intervention, with a statistically significant change in social well-being. This might be indicative of the personal gain for PLC regarding their mental health after the intervention. It could stem from a relief that they themselves were not HIV positive, a sense of relief to be interacting freely with other PLC in similar situations, developing empathy for PLWH about their HIV status, learning new skills to interact with PLWH, and experiencing support from both PLWH and the other PLC in the group during the intervention.

On the *depression scale* the PLWH showed the biggest positive statistically significant change in psychosocial well-being, moving from a mild depression severity to no depression severity. It can thus be concluded that PLWH experienced the intervention as positive, felt less isolated, felt more supported and thus no longer felt depressed. The PLC measured on the higher end of the mild depression severity at the onset of the intervention, indicating that they were more depressed than the PLWH. This could be due to their burden of having to take care of PLWH and having a variety of additional responsibility they have to face because of this situation. Although they moved to the lower end of the mild depression severity end of the scale, they remained depressed. The re-building of damaged relationships between PLWH and PLC as well as the acquisition of new skills towards assuming leadership in HIV stigma reduction in their own communities could have left both groups feeling more hopeful, more empowered and less depressed.

The *life satisfaction* of the PLWH started lower than that of the PLC. The PLWH measured on an average satisfaction with life at the onset of the intervention. After the intervention they showed a practically significant increase, possibly because they found themselves among supportive people; but this unfortunately decreased again. The HIV stigma reduction intervention clearly brought about a deepened confrontation with the reality of being HIV positive. It could have activated an awareness among PLWH of aspects of dissatisfaction with life on more levels than just the physical. The PLC, on the other hand, rated themselves fairly consistently as experiencing average life satisfaction and this even improved slightly over time, although neither with a statistical nor a practical significance. They have to keep on facing the reality that they have a PLWH that they have to take care of, as well as the additional burden of finances that they must deal with, for example. During the intervention, however, they became aware that they were not the only people that face this difficulty.

The immediate increases in the *coping self-efficacy* of PLWH directly after the intervention may have been based on the excitement of PLWH to finally be among people with whom they could share their experiences and on their increased courage and confidence. The HIV stigma reduction and wellness enhancement intervention possibly created the awareness needed to take the first steps towards coping self-efficacy. The change could not be sustained over time, however. The process of dealing with their reality and of internalising aspects of their situation would probably require more time. PLC increased in terms of both *problem focus coping* and *stop unpleasant emotions*. In some ways it offered shared examples of how to cope with the situation, as well as possible problem solving. It suggested mechanisms of how to stop unpleasant emotions in important relationships and to equalise such relationships and share more freely. The *seek support from friends and family* scale, however, decreased on a statistically significant level, most probably because they now were among supportive people and no longer had to avoid rejection by others in the community, and because they had a new support system.

A further aspect of psychosocial well-being lies in the *spiritual dimension* of people. On this scale both PLWH and PLC measured low at the onset of the intervention, with PLWH measuring lower than the PLC. In the case of PLWH, the scores declined further on a statistically significant

level for religious well-being. In the case of the PLC, the spiritual and existential well-being showed a statistically significant improvement due to the intervention; but not in the case of religious well-being, which remained low. It can thus be concluded that both PLWH and PLC suffer in terms of their spiritual well-being. This could stem from a struggle to find peace with their HIV status, or a depletion of spiritual energy because of such a struggle in the midst of a lack of support. It could also stem from self-prejudice, based on expected religious prejudices because of the stigma associated with HIV or with a lifestyle that resulted in their HIV infection. Another reason may be their concerns for the future, limited hope for going forward and a longing for spiritual attributes like connectedness and transcendence beyond pain. Issues of an existential search for meaning, procreation, family life, fulfilling relationships and healthy children could all be concerns that they experience. The intervention sharpened a spiritual consciousness as well as a consciousness of a heavily stigmatised disease with a dreaded possible outcome.

It could be concluded that the HIV stigma reduction intervention had a positive impact on the psychosocial well-being of both PLWH and PLC. There were distinct improvements at times 2, directly after the intervention, and time 3 of the mental health, depression severity, satisfaction with life, coping self-efficacy, and spiritual well-being scales. The only exception was the spiritual well-being. The intervention seems to have made a major impact on the psychosocial well-being of the PLC. Unfortunately, the PLWH did not show the same extent of improvement. The PLWH did, however, regain some control over their situation after being included together with PLC in the same intervention; by receiving information on HIV stigma and by being led to understand the stigma and how to cope with it; by receiving opportunities to build relationships; and by being equipped to develop their own leadership to face HIV stigma head-on. For PLC, the intervention created an environment of awareness and a longing for meaningful psychosocial well-being; but PLWH will need more time to change the effect of their painful experiences with being diagnosed with the illness and they will require a long-term process of internalisation. After the intervention, they could no longer deny their illness. Although changes could not be sustained over time, the comprehensive community-based HIV stigma reduction and wellness enhancement intervention succeeded in initiating various aspects of psychosocial well-being.

2.3 Conclusions on improved health behaviour of PLWH after the Intervention

It should be noted that the PLWH in this study had to be HIV positive for at least six months prior to the intervention, and the purposive sampling suggested that they were already participants in the health system and familiar with the system. However, there was no significant difference between respectively the urban and rural findings on both HIV stigma experiences and health behaviour of PLWH over time. This was possibly because the participants were all black, Setswana-speaking South Africans from the North West Province, South Africa, with similar cultural practices. The urban-rural data was therefore pooled for further analysis.

The main aim of the comprehensive community-based HIV stigma reduction intervention was to reduce HIV stigma for PLWH. Many authors refer to the impact of HIV stigma on health behaviour, though. The researchers thus used this opportunity to also evaluate possible effects on health behaviour changes over time alongside the evaluation for a reduction in HIV stigma of PLWH. The findings indicate that there was indeed improvement in health behaviour, as HIV stigma experiences declined.

The findings in the *demographic questionnaire* show that the 18 PLWH were a middle-aged group with minimal post-school education, a general lack of employment and part of the lower socio-economic population. Their participation in health care seemed satisfactory from the start, because they knew their own CD4 counts and most indicated that they did not miss any dosages of medication, and that they used the health care services when needed. A high percentage indicated that they disclosed their HIV status within the first month after the diagnosis, mainly to family members. They further indicated that family members were the ones providing the most support to them.

On the *ACTG* scale, measuring adherence to ART, only 2 of the 18 PLWH reflected behaviour scores indicative of risky health behaviour, whilst 11 had perfect scores of 9. The reason mostly offered (5 times) for missing dosages of medication was that it was difficult to take ART at a specified time. This could be due to the high stigma experienced in the community and a lack of

privacy at the specific time when the medication had to be taken, or difficulty to take the medicine without disclosing their HIV status.

The findings on the *HASI-P* scale, measuring HIV stigma experiences, showed statistically or practically significant decreases in the HIV stigma experiences of PLWH on the five measured dimensions of verbal abuse, negative self-perception, health care neglect, social isolation and fear of contagion. The total score of these dimensions combined indicates a statistically significant change-over-time, which leads to the conclusion that the comprehensive community-based HIV stigma reduction intervention succeeded in reducing the HIV stigma experiences of PLWH.

The intensity and frequency of the *HIV signs and symptoms* experienced by PLWH declined over time after the intervention. This could be due to the decline in HIV stigma experiences after the intervention and because the PLWH were part of a supportive group which gave them the opportunity for normalisation among the group, to share their experiences and to focus less on their symptoms.

The same trend is observed in the increase in the *quality of life* of PLWH after the intervention. This was indicated on eight of the nine dimensions of the scale. The one unfortunate result is the concerns of PLWH about their physician, because both the mean score immediately after the intervention and the last score almost a year later decreased to lower than the score before the intervention. This could be due to limited resources, less availability of doctors in clinics and not being able to build a relationship with alternating doctors. Although there were inconsistencies during the measuring period, these scales were higher at time 5 than at time 1, before the intervention. It can be concluded that the HIV stigma intervention contributed to a better quality of life of PLWH.

2.4 Summative conclusion of the comprehensive community-based HIV-stigma reduction intervention with PLWH and PLC

The comprehensive community-based HIV stigma reduction intervention and wellness enhancement intervention were successful in achieving the goals set to reduce HIV stigma experiences of PLWH, to reduce stigmatisation by PLC, and to enhance the psychosocial well-

being of PLWH and PLC. The change from mild depression to no depression that was reported by PLWH, is a positive finding. By facilitating the sharing of knowledge on HIV stigma and on how to cope with it, the intervention afforded PLWH an opportunity to reflect on their illness. The intervention further allowed for equality in relationships among those who were HIV positive and those who were HIV negative, giving them an opportunity to feel better about themselves. Unfortunately the improvement on the other aspects of their psychosocial well-being was short-lived and could not be sustained over time, possibly because of their deeper trauma. The improvement in their health behaviour, however, shows the impact of the HIV stigma intervention on more than just their stigma experiences.

The intervention with the workshops and HIV stigma reduction projects with their own communities seemed to have been a life-changing event for both PLWH and PLC. The four post-test measurements stretched over a year and although participants were not remunerated, they chose to remain in the process – this speaks of an on-going engagement with HIV stigma reduction, their psychosocial well-being, and improving their health behaviour. The findings suggest that when HIV stigma reduces for PLWH, a conscious change in self-judgment and HIV stigma experiences follows, which leads to health behaviour improvement, like less intense signs and symptoms, adherence to treatment, responsible disclosure management, and improved quality of life. The findings of spiritual well-being for both PLWH and PLC need further exploration, as the illness and stigma experiences seem to have taken its toll and depleted their inner capacities.

The tenets of the comprehensive community-based HIV stigma reduction and wellness enhancement intervention were well researched and implemented. The modelling of facilitators of equal partnerships in combination with HIV stigma and coping information, with the personal contact between PLWH and PLC, group interaction, relationship building between PLWH and PLC, and their own HIV stigma reduction projects in their own communities, worked well. The projects afforded them the opportunity to work together in self-initiated projects towards reducing HIV stigma and taking back some of the control that they lost during the devastation of the illness. They displayed hope and pride in the presentations of their community projects. The participating PLWH and PLC became constructive activists against HIV

stigma and stigmatisation, instead of victims or perpetrators. They became conscious of their needs to be psychosocially well and PLWH stopped their compromising health behaviour.

3 Limitations

As the study was based on a comprehensive and therapeutic approach to reducing HIV stigma and involved HIV disclosure by PLWH, it limited the number of potential PLWH and PLC that could be included in the intervention to 10 persons from each group per workshop. Large numbers could compromise the personal contact and personal sharing in small group interaction. It could also put strain on the availability of well-trained paired facilitators, who had to create a climate in which the PLWH would be willing to share their HIV status, and who had to model a working relationship between a PLWH and someone without the HI virus. The control over the sample size of specific designated groups of PLC was difficult because PLWH had to have control over whether they wanted to bring someone from a specific designated group, and whom they chose to bring. In some cases they were unable to bring someone from a specific group, if they did not have a partner or a child of the required age, for instance. They were, however, never excluded from such a workshop. It could be more practical in future to allow them freedom to nominate any people living close to them, but bearing in mind that some richness might be lost if the designated groups are mixed. The fact that the study was also part of a larger SANPAD study ruled out the possibility of changing any logistics.

4 Recommendations

Based on the literature, findings, conclusions and limitations of the present study, a number of recommendations could be made:

The successful HIV stigma reduction obtained through this specific comprehensive community-based HIV stigma reduction and wellness enhancement intervention should motivate the retention of the intervention with its existing tenets, content and method of presentation, as it

is, and the expansion thereof into many several communities. The therapeutic nature of the intervention should be respected and valued. Role modelling of affective relationships is enhanced by using a paired non-infected person and a PLWH as facilitators.

Diverse rural and urban communities should be engaged and if necessary, cultural sensitivity competencies should be built into the planning and implementation of the training of facilitators and during the workshops with PLWH and PLC.

Well formulated and descriptive guidelines for future facilitators or researchers are imperative to ensure that the current intervention is retained.

The training of facilitators prior to commencement of the intervention must always be a priority.

Earnest preparation of PLWH, before PLC are introduced into the intervention, is of utmost importance to ensure their competence in responsible HIV disclosure management and their comfortable participation in the workshops, after having identified their personal strengths. The implementation of the guidelines described by Greeff (2013) for the empowerment of PLWH in the art of responsible disclosure management, is strongly recommended. She refers to the management of experiences before and after disclosure and describes a comprehensive framework for the HIV disclosure process. She furthermore suggests 14 steps to ensure responsible disclosure management: understanding of disclosure and nondisclosure, gaining knowledge of the total context of disclosure, acknowledging specific reasons for disclosure, weighing up consequences, listing the circumstances, listing enabling factors for disclosure, listing what not to do, listing the feelings that are involved, deciding to whom to disclose, deciding how much to disclose, evaluating the knowledge level of the person you are disclosing to, determining the best time/place for disclosure and listing possible post-disclosure problems (Greeff, 2013: 89-90).

Groups have to be kept small during the intervention to ensure personal sharing and interactive processes for the equalisation of important relationships amongst PLWH and PLC. They should always be involved together. Smaller numbers of participants are important because the

intervention deals with sensitive areas, where people might choose to disclose their HIV status, share painful stigma experiences and build or re-build important relationships.

A subsequent intervention should follow about three to six months after the first workshops to ensure sustainability of the intervention. This should strengthen the initial tenets and add further competencies, like strengthening the participants' psychosocial well-being, as well as their spiritual well-being, and replenishing their personal depletion caused by HIV stigmatisation.

Long-term sustainability of change-over-time in the reduction of HIV stigma experiences and stigmatisation after such an HIV stigma reduction intervention needs to be measured in a variety of settings. The differences in measures could be affected by seasonal changes and it could be meaningful to record this more specifically in further research.

The intervention can be made less intensive by omitting certain groups of PLC (partner, child, family member, friend, spiritual leader, community member). PLC could also be chosen from among any persons living close to a PLWH and not necessarily from specific designated groups. This could be the choice of the PLWH.

It is also recommended that this HIV stigma reduction intervention be included in health behaviour change efforts.

Mechanisms should be explored to strengthen continuous active participation of PLWH and PLC in HIV stigma reduction in communities. This should include the escalation of this intervention to the community at large to ensure further and more innovative HIV stigma reduction and health behaviour change mechanisms.

5 Reference

Greeff, M. 2013. Disclosure and stigma: A cultural perspective. (*In* Liamputtong, P., *ed.* Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective. Netherlands: Springer. p. 71-95).

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
		Institution			Project Number						Year		Status			
Status: S = Submission, R = Re-Submission, P = Provisional Authorisation, A = Authorisation																
Approval date: 30 March 2009										Expiry date: 29 March 2014						

Special conditions of the approval (if any): None

General conditions:

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

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviation 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

THE NORTH-WEST UNIVERSITY AND VRIJE UNIVERSITEIT AMSTERDAM

CONSENT TO BE A RESEARCH SUBJECT

A COMPREHENSIVE COMMUNITY-BASED HIV STIGMA REDUCTION AND WELLNESS ENHANCEMENT INTERVENTION

1 PURPOSE OF THE STUDY

A team of researchers from various disciplines of the North-West University and the Vrije Universiteit, Amsterdam are conducting a study on a comprehensive community-based HIV stigma and wellness enhancement intervention in the North West province, South Africa. You are being asked to participate in this study because you are a person living with HIV or a person living and working close to a person living with HIV.

2 PROCEDURE

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

- A set of questionnaires will be completed by you prior to a workshop.
- If you are a HIV positive person an in depth interview will be conducted with you at the beginning of the research and you will be expected to join an initial two day workshop followed by six workshops with people living and working close to you.
- If you are a person living or working close to a person living with HIV you will be expected to join a two day workshop followed by a project that you will be involved in for a month that will be evaluated during a further one day session.
- After the workshops interviews will be conducted with you asking you about you experiences during the intervention.
- This will be followed by questionnaires completed by you on a three monthly basis for four times during 2011.

3 RISK/DISCOMFORTS

As people living with HIV and people living and working close to such persons the HIV status of the person will be made known to all the people in the various groups. In the workshops you will be joined by other people similar to yours. Sharing experiences could be painful and uncomfortable. Some of your privacy might be lost during the intervention, however your data will be handled as confidential as possible. Your name will never be made known and no individual identifiers used in any publications resulting from the survey. Only the team of researchers will work with your data.

4 BENEFITS

By being involved in this research project will become knowledgeable about HIV stigma, learn to cope with the situation and become empowered to be leaders in the field of HIV stigma reduction. Your participation will help the researchers to develop a comprehensive community-based approach to reduce HIV stigma.

5 COSTS

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

6 PAYMENT

You receive no payment for participation. You will receive a meal and refreshments during the workshop days and will be transported to the site.

7 QUESTIONS

You can talk to Prof Greeff (project leader) or Poncho (research assistant) if you have any further questions concerning your consent. They can be reached at 018 299 2092.

8 CONSENT

You will be given a copy of this consent to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point.

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

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

Date

Signature of the participant

Date

Signature of the person obtaining consent

APPENDIX C: GUIDELINES FOR SUBMISSION TO JOURNAL: AIDS CARE

Advice to authors on preparing a manuscript

NB: Please follow any specific instructions for authors provided by the Editor of the journal

Font: Times New Roman, 12 point. Use margins of at least 2.5 cm (1 inch).

Title: Use bold for your article title, with an initial capital letter for any proper nouns.

Authors' names: Give the names of all contributing authors on the title page exactly as you wish them to appear in the published article.

Affiliations: List the affiliation of each author (department, university, city, country).

Correspondence details: Please provide an institutional email address for the corresponding author. Full postal details are also needed by the publisher, but will not necessarily be published.

Anonymity for peer review: Ensure your identity and that of your co-authors is not revealed in the text of your article or in your manuscript files when submitting the manuscript for review. Advice on anonymizing your manuscript is available [here](#).

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Keywords: Please provide five or six keywords to help readers find your article. Advice on selecting suitable keywords is available [here](#).

Headings: Please indicate the level of the section headings in your article:

- First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.

- Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
- Third-level headings should be in italics, with an initial capital letter for any proper nouns.
- Fourth-level headings should also be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Tables and figures: Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables and figures should be supplied either at the end of the text or in a separate file as requested by the Editor. Ensure you have permission to use any figures you are reproducing from another source. Advice on artwork is available [here](#).

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If your article is accepted for publication, it will be copy-edited and typeset in the correct style for the journal.

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FURTHER GUIDELINES FOR SUBMISSION TO JOURNAL: AIDS CARE

Journal Details AIDS Care

Psychological and Socio-medical Aspects of AIDS/HIV

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Published By: Routledge

Volume Number: 23

Frequency: 12 issues per year

Print ISSN: 0954-0121

Online ISSN: 1360-0451

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- Papers will be considered providing that they have not previously been published or submitted simultaneously elsewhere for publication.

Manuscript format should be in the style of the American Psychological Association (6th edition).

- Manuscripts can be in these formats: (i) Short reports not exceeding 1500 words; (ii) Original articles of 1,500-3,000 words. We may also consider exceptional papers of up to 5,000 words. The word count does not include the abstract, references, figures and tables.

- Manuscripts should be double spaced, with ample margins of at least one inch. Footnotes to the text should be avoided wherever this is reasonably possible. All identifying information should be removed from the Manuscript Files for Review prior to submission, as detailed above.
- Abstracts should be no longer than 300 words, and form a continuous piece of text with no subheadings.
- Illustrations should not be inserted in the text but each provided as separate files and given figure numbers and title of paper and name. All photographs, graphs and diagrams should be referred to as Figures and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3).
- Captions for the figures should be provided and should make interpretation possible without reference to the text. Captions should include keys to symbols.
- Tables should be submitted as separate files and should be given Arabic numbers (e.g. Table 3). Their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words or numerals should be repeated on successive lines; 'ditto' or 'do' should not be used.

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- Description of the Journal's reference style, Quick guide
- Any consistent spelling style is acceptable. Use double quotation marks with single within if needed.
- If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

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- Proofs will be sent to the author if there is sufficient time to do so. Proofs including proofs of illustrations are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned within 3 days of receipt.

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APPENDIX D: GUIDELINES FOR SUBMISSION TO AFRICAN JOURNAL OF AIDS RESEARCH

Instructions to Authors Editorial policy: Submission of a manuscript implies that the material has not previously been published, nor is it being submitted elsewhere for publication. Submission will be taken to imply transfer of copyright of the material to the publishers NISC (Pty) Ltd.

Contributions are accepted with the understanding that the authors have the authority for publication. Material accepted for publication in the African Journal of AIDS Research (AJAR) may not be reprinted or published in translation without the express permission of the publisher NISC. Contributions must conform to the principles outlined in Ethical considerations in research publication available on the Journal's Instructions to Authors page at

<http://www.nisc.co.za/journals?id=1>. AJAR will publish research papers of 5 000 to 10 000 words. Review papers will be considered only if they make an original conceptual or theoretical contribution to the field. The entire paper must be written in English. (Also see our guide The Editorial Process for Submissions to AJAR at <http://www.nisc.co.za/journals?id=1>).

Review process: Papers submitted to AJAR will be reviewed by two appropriately qualified and experienced referees to ensure that all articles accepted for publication are methodologically and conceptually sound and make an original contribution to the field. The reviewers are instructed to rate papers using the following criteria:

- (1) the paper is well structured and the presentation is clear;
- (2) the goals of the project are readily apparent;
- (3) the methods used are appropriate to the project and appear to have been satisfactorily executed;
- (4) the results/findings and conclusions are well argued and cognisance is taken of alternative interpretations;
- (5) appropriate use is made of figures and tables (where relevant);

- (6) the paper takes into account related empirical and/or analytic work in the field; and
- (7) the paper makes an original contribution to knowledge in the area.

Submission: Manuscript submissions should be made online at the African Journal of AIDS Research ScholarOne Manuscripts site at <<http://mc.manuscriptcentral.com/raar>>. Queries regarding presentation can be addressed to the Copyeditor or Editorial Assistant. Further information on formatting and referencing style, including examples of tables and graphs, may be obtained at <http://www.nisc.co.za/journals?id=1>>. Manuscripts must adhere to the format criteria described below, and papers failing to do so will be returned to authors to be corrected before being reviewed. Submitted manuscripts should contain the following sections (each beginning on a new page): (1) Title page, with authors' names and affiliations; (2) Abstract page, with the title repeated; and (3) Body of text, ending with a full list of references.

Title page: Author names must appear only on the title page. This page should also include the author's names (full first name and surname), a full postal address for each author's affiliation, the e-mail address of the designated corresponding author. Recommended but not required are short biographical notes for the authors (highest academic degree, work experience, research interests) and/or any acknowledgements.

Abstract page: This should include the title of the paper and an abstract. The abstract is a concise statement of the scope of the work, the principal findings and the conclusions. It should not contain references. Below the abstract, up to eight additional keywords or phrases (which are not already given in the title) should be listed in alphabetical order.

Body of text: All papers should include Introduction and Conclusions sections, but given the diverse range of papers that might be published in AJAR, we do not prescribe a standard format for the middle section. In structuring the body of the paper, authors are requested to take into account the review criteria described above.

Format – Manuscripts should be in MSWord format. The headings and text should be presented in 12-point Arial font. The text should use 1.5 line spacing, with no extra line spacing, and

should not include text columns. Headings should be cased in sentence format (Example: The history of injectable contraception). Primary headings should be presented in bold, secondary headings in bold and italics, and tertiary headings in italics only. Paragraphs should not be indented but separated by a line space. Complex Tables and all Figures (graphs, photographs or scanned images) should be sent as separate files. All hyperlinks, bookmarks, cross-references, etc., should be removed. For more details, see the Format Guide for Contributors to AJAR (<http://www.nisc.co.za/journals?id=1>).

Citations – Multiple citations in the text must be separated by semicolons and cited chronologically (Example: Habib, 1998; Bwanika & Davis, 2000; Ministry of Health, 2011). If there is more than one citation with the same publication year, these should be listed alphabetically. If the author is referred to in the text the following format applies: ‘Nzioka (2001) suggests that....’ If previously printed text is quoted, the citation must include the author, year of publication, and page number. Examples: “Quote” (Ajulu, 1999, p. 63) Machel (1998, p. 66) suggests that “Quote.”

Please use ‘et al.’ correctly: if more than two authors are cited in a reference include all the authors’ names (up to six) the first time that the work is cited; thereafter, use only the first author’s name followed by et al.

References – For presenting the full list of references at the end of your manuscript, please consult our guide Referencing Style for AJAR at (<http://www.nisc.co.za/journals?id=1>), which follows the Harvard style of referencing. The list should be in alphabetical order by first author, and include all the authors of a given reference (do not use ‘et al.’ in the list); likewise, use full journal titles. URLs may be cited only for references that are not available in print (such as a webpage) or ones that link to hard-to-find sources (e.g. municipal document), and these URLs must be up-to-date at the time of submission.

Example reference list:

Brown, B. (2004) Adolescents' relationships with peers. In: Lerner, R. & Steinberg, L. (eds.) *Handbook of Adolescent Psychology*. Hoboken, New Jersey, John Wiley and Sons.

Cohen, D. (2002) HIV and education in sub-Saharan Africa: responding to the impact. *Perspectives in Education* 20(2), pp. 13–23.

Department of Education [South Africa] (2005) *Revised National Curriculum Statements*. Pretoria, South Africa, Government Printers.

Leedy, P.D. & Ormrod, J.E. (2005) *Practical Research, Planning and Design* (8th edition). New York, Pearson Educational.

National AIDS Control Council (NACC) [Kenya] (2006) *Kenya HIV/AIDS Data Booklet, 2006*. Nairobi, Republic of Kenya, NACC.

Ndlovu, N. (2001) *An empowerment group for children of sexual abuse*. PhD thesis, University of Zululand, Durban, South Africa.

Seel, R. (2000) 'An introduction to appreciative inquiry.' *Facilitator Newsletter*, Issue 28, Summer 2000. Available at: <...> [Accessed 20 May 2012].

Stein, J. (2003) 'Sorrow Makes Children of Us All': A Literature Review of the Psychosocial Impact of HIV/AIDS on Children. CSSR Working Paper No. 47, Cape Town, South Africa, CSSR.

UNAIDS (2010) *2010 UNAIDS Report on the Global AIDS Epidemic*. Geneva, UNAIDS.

Abbreviations and Acronyms – Heavy use of abbreviations particular to a subject area (Example: 'OVCs' for 'orphans and vulnerable children') should be avoided, particularly as these may amount to labelling. When an abbreviation or acronym is used for the first time, it should be followed in parentheses by the full text to which it refers; thereafter, it may be used without explanation. The only exception is the use of HIV and AIDS. The terms 'for example,' 'that is,' and 'namely' should be written in full in the text, but abbreviations for these (namely: e.g., i.e. and viz.) should be used in parenthetical text.

Footnotes/endnotes – Endnotes should be used rather than footnotes, and it is preferable to limit the use of endnotes. (Full references should appear only in the References section and never in the endnotes.)

Non-English words – These should be italicised, but not capitalised by virtue of being non-English words.

Numbers – The period (.) must be used as the decimal indicator, and ‘thousands’ must be designated by a space rather than a comma (Example:1 500 000).

Quotes – Double quote marks and regular font should be used to designate material quoted from previously printed text. Single quote marks and italic font should be used to denote informants’ quotes.

Tables and Figures – Tables and Figures should contain only information directly relevant to the content of the paper. Each Table and Figure must include a full, stand-alone caption, and each must be sequentially mentioned in the text. Highly stylised formatting should be avoided and the entire content of the Tables (columns and rows) and the Figure legends must be editable. Tables may use thin single lines but should not include cells with shading. Figures must not repeat data presented in the text or tables. Authors must ensure that their figures conform to the style of the journal. Pay particular attention to line thickness, font and figure proportions, taking into account the Journal’s printed page size. Costs of redrawing figures may be charged. Please refer to Figure Guidelines for Authors: format, style and technical considerations available from the Journal’s Instructions to Authors webpage at www.nisc.co.za/journals?id=1. For digital photographs or scanned images the resolution should be at least 300 dpi for colour or greyscale artwork and a minimum of 600 dpi for black line drawings. These can be saved (in order of preference) in PSD, JPEG, PDF or EPS format. Graphs, charts or maps can be saved in AI, PDF or EPS format. MS Office files (Word, PowerPoint, Excel) are also acceptable but DO NOT EMBED Excel graphs or PowerPoint slides in a MS Word document, rather send the original Excel or PowerPoint files. More detailed technical information is given in Figure Guidelines for Authors.

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Beginning each on a new page, your submission should contain three sections:

- 1. Title page:** Include the paper's title; authors' names; authors' affiliations and postal addresses; the designated corresponding author's e-mail address; and the date of submission to *AJAR*. Acknowledgements and brief notes on the authors are optional but recommended.
- 2. Abstract page:** Repeat the title of the article; give a concise statement of the article in an abstract that is less than 300 words; list up to eight key words or phrases not otherwise found in the title.
- 3. Body of the text and a full references list:** This would usually include an Introduction, Methods, Results or Findings, Discussion and Conclusions, as well as a full list of References. The components of the middle sections are not strictly prescribed given the different types of research published in *AJAR*.

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PAGE SET-UP

- Use 12-pt Arial font.
- Use 1.5 line spacing.
- Separate paragraphs with a line space and do not indent the start of paragraphs.
- Do not use double word spaces.
- AJAR uses British (UK) English.

AUTHOR BYLINE

- Give full first names, not single initials only.
- Omit academic titles or qualifications (e.g., MD, PhD) (rather use these in the notes on the authors).

AUTHORS' AFFILIATIONS

- Give the full postal address for each author's affiliation.
- Designate the corresponding author with an asterisk (*).
- Give the corresponding author's e-mail address.

TITLE OF THE ARTICLE

- Use the fewest possible words while being informative, accurate and interesting.
- Avoid using quotes as well as catchy or colloquial choices of words.
- Try to include an indication of geographical place.
- Do not use abbreviations.

ABSTRACT

- Write in sentence form, as a single paragraph.
- Do not exceed 300 words.

KEYWORDS

- Give up to 8 thoughtfully chosen key words or phrases that differ from the ones in the title.
- Use all lowercase (unless this is inappropriate); alphabetise them and separate by commas.

HEADINGS

- Only the first word of a heading should be uppercase (unless the word is a proper noun or acronym).
- Never use all caps for headings.
- Use the following font styles to denote the hierarchy of the headings used in the paper:

Level 1: **Regular font and bold**

Level 2: ***Italic and bold***

Level 3: *Italic and not bold*

- Do not number the headings.

LISTS

Bulleted lists: Use only simple bullets.

Numbered lists: Use this style: 1)...; 2)...; and 3)....

Other lists: In some cases (where enumeration is more-or-less irrelevant), you may choose to use one of these styles: a)...; b)...; and c).... OR (i)..., (ii)..., and (iii)....

ACRONYMS & ABBREVIATIONS

- When used for the first time, place acronyms and abbreviations in parenthesis preceded by the full text to which they refer. An exception is HIV and AIDS, which need not be spelled out, ever.
- Avoid the use of uncommon acronyms or abbreviations.

- No punctuation is required with abbreviations (e.g., use USA, not U.S.A.).
- Do not use arbitrary capitalisation for terms that are subsequently referred to with an abbreviation, but only capitalise terms that are proper nouns.

Samples:

The main strategy adopted to assess adherence is drug-readiness training (DRT).

An overview of HIV-prevention programmes in the Southern African Development Community (SADC).

- **e.g., i.e. and viz:** These abbreviations should be used only in parenthetical comments; otherwise, spell out the terms in the text, as ‘for example’, ‘that is’ and ‘namely.’ *Samples:*

Interrelated social groups may influence a woman’s decisions to obtain healthcare (e.g. her spouse, parents, in-laws).

Efforts to create demand for PMTCT services should include local health advocates, for example traditional healers, outreach personnel, and birth attendants.

NON-ENGLISH WORDS

Use italic font for non-English words, do not arbitrarily capitalise or use quote marks for virtue of words being non-English. You may or may not choose to follow the word/ phrase with an English translation, which should be given in parenthesis () if it occurs fluid with the text, or else in square brackets [] if it occurs within an informant’s quote

Samples:

He did not acknowledge his sister’s marriage due to a dispute over lobola.

In Botswana, there are different terms for so-called single (lesiela) and double (khutlwana) orphans.

They include descriptive names popularly coined for the disease, such as the Sesotho term mokakallane wa letekatse ('the disease of promiscuity').

'They went inside to burn their own muti [traditional medicine].'

NUMBERS & DATES

- Spell out numbers at the start of a sentence, as well as the numbers 1 to 10 in the narrative.
- Denote 'thousands' by using a space rather than a comma (e.g., 5 549 employees; \$2 900).
- As the decimal indicator, use a period rather than a comma (e.g., 72.5%).
- Strive to link numbers with an en-dash (–) rather than a hyphen (-) (e.g., 2007–2011; 80–89%; 15–29-year-olds).
- Use this format for dates: 6 August 1995.
- Use the percent symbol (%) with numbers, unless the number is written in words.

UNITS OF MEASUREMENT

- Report distance, volume, weight, area, etc. in metric units: km, ml, µmol, mg, kg, ha.
- Leave a space between the number and the unit of measure (e.g., 6 km).

SYMBOLS & STATISTICAL TERMS

- Use the following symbols, in sequence, for footnotes: *, **, †, ‡, §, ||, ¶
- Samples of *AJAR*'s style for some statistical terms: $p < 0.001$; p -value; $n = 297$; n (%); t -test; $\pm$ SD; 95% CI

HYPHENS vs DASHES

Be aware that there is a difference between hyphenation and short and long dashes. In general: use hyphens (-) to join words or numbers with words; use en-dashes (–) for number ranges; and use em-dashes (—) for emphasis or balance, as shown in the following samples:

Hyphenation: powerful human-rights-based arguments; long-term impacts; one-fourth; semi-urban areas; a 20-item screening instrument.

En-dash [keystroke: Ctrl+Num-]: in the age group 18–24 years; 24–49-year-olds; pp. 61–64; 2–5 days.

Em-dash [keystroke: Alt+Ctrl+Num-]: E-health — the application of information and communications technologies in the healthcare sector — is fast developing worldwide.

PARENTHESES vs SQUARE BRACKETS

- Use parentheses (round brackets) as a first choice to set off parenthetical matter.
- Use square brackets [] within parenthetical matter, in all cases: that is, always use square brackets within round brackets.

Samples:

(Family Health International [FHI], 2005). (Central Statistical Office [Zambia], 2003).

None of the sources ranked among the top-50 journals (requiring in impact factor [IF] of 0.48 and above).

- Also use square brackets to indicate an editorial comment (e.g., interjection, clarification, translation, substitute words) within all types of quotes.

Samples:

“A lack of managerial experience meant programmes were often poorly implemented, said Saloojee [professor of paediatrics]” (*Business Day*, 2006).

‘The [pre-test] counselling was good.’

‘You hear it directly from [the employees].’

‘I am caring for four grandchildren [she counts on her fingers] — no, I think they are five.’

'She was nothing like this woman in the magazine...'

[laughter].

QUOTATIONS & QUOTE MARKS

Informant quotes: In general, these are written responses to survey questions or comments taken from recordings/ transcripts of interviews or focus group discussions. Denote these quotes by using single quote marks and italic font.

Samples:

One worker revealed, *'I got worried when I heard the information [at pre-test counselling], so I came for testing.'*

'I am very proud of the workshop because we were now researchers' (11-year-old boy).

Quotes from other texts: Use double quotation marks and regular font to denote quotes taken from either another printed source, a spoken source (e.g., a lecture, parliamentary address, conference presentation), or an electronic source (e.g., webpage posting). Also, the page number must be included in the citation if the quote comes from a print source.

Samples:

Du Bruyn (2006, p. 25) writes: "Disclosure of HIV/AIDS information by South African companies in their annual reports still remains voluntary."

The school principals hoped to contribute to a "coherent and consistent response" as mandated by departmental policy (Department of Education, 2003, p. 14).

Uncommonly used words, words out of context, newly coined terms, words denoting categories, or questions from surveys: Set these off using single quote marks and regular font.

Samples:

Ethical employers would not demand ‘too much’ data. A Lesotho programme involved ‘expert patients’ in peer education.

Such inequities become more magnified when looking through a ‘gender lens.’

...a 5-point Likert scale ranging from ‘strongly disfavour’ to ‘strongly favour.’

Seventy percent answered ‘yes.’

The questionnaire also asked, ‘Are available support programmes used by employees?’

Only one open-ended question was posed: ‘How do you respond to HIV in your school?’

Punctuation with quote marks: Place periods and commas *inside* quote marks; place semicolons, colons, and superscripts *outside* quote marks.

Samples:

Micro-credit loans to ‘orphan households,’²

An additional three family members were described as ‘very sick.’

Three sub-themes emerged: ‘individuals in government,’ ‘role-modelling behaviour,’ and ‘government bureaucracy.’

Quotes within quotes: Use single quote marks within double quote marks, in all cases.

Sample:

Elizabeth Kubler Ross (1985, p. 5) wrote: “People with AIDS have to go through the ‘stages of dying.’”

“How do you write about orphans in a different way? I mean, ‘AIDS orphans are all alone and don’t have any resources.’ What else can you say?” (South African journalist, quoted in Stein, 2002).

CITATION STYLE

Form and punctuation: Do not include authors’ first names or initials. Separate different citations with a semicolon (;). Use an ampersand (&) to link the last author in a citation, whether the citation occurs in the narrative or in parenthesis, and don’t use commas before ampersands.

Order: Strings of citations should follow ascending chronological order (i.e., oldest to most recent) and then alphabetical order for citations with the same year.

Use of *et al.*: Please use ‘*et al.*’ correctly —

- Use italic font, end it with a period, and use a comma before the year.

Samples:

Walsh *et al.* (2006) (Walsh et al., 2006).

- For works with three or more authors, do not use *et al.* the first time a citation is made in the text, but list *all* the authors. Thereafter, use the first author’s name alone followed by *et al.*
- If a work has 8 or more authors, cite only the first 6 followed by *et al.*
- Never use *et al.* in the references list: always list all authors, no matter how many.

Citation samples: As mentioned, especially note *AJAR*’s use of punctuation (commas and semicolons) and ampersands [&]. Also, do not use ‘*ibid.*’ or ‘*op. cit.*’

Samples:

Results reported by Collier *et al.* (2007) in Rwanda.... Pattman & Chege (2003a) found that... (Chambers, 1983; Van Klinken, 2003; Mansuri & Rao, 2004; Ndubani *et al.*, 2004; UNAIDS, 2004

and 2006) Farmer (2004a and 2004b) (Thi, Brickley, Vihn, Colby, Sohn, Trung *et al.*, 2008) Ramkisoorn (2000, cited in Louw, Van Ede & Ferns, 2005).

REFERENCING STYLE

- Never number the list of references.
- Create the list in alphabetical order of author/s surnames, and then chronologically — from oldest to most recent — for works by the same author/s.
- Ensure that each reference in the list is complete. Especially:
- use full journal titles;
- give complete lists of authors: never use '*et al.*' in the list;
- include both the volume and number for journal articles;
- give both the place (city) and publisher of print sources;
- give the location and dates of conferences.

Reference samples: A separate pdf titled *REFERENCING STYLE for AJAR* shows the style for numerous reference formats. The journal's style is largely based on the Harvard Style. Alternately, authors are asked to consult a recent issue of the journal. Please help us by paying scrupulous attention to punctuation and font. The following samples cover only a few basic reference formats:

Journal article

Rehle, T., Shisana, O., Pillay, V., Zuma, K., Puren, A. & Parker, W. (2007) National HIV incidence measures — new insights into the South African epidemic. *South African Medical Journal* 97(3), pp. 194–199.

Book

Barnett, A. & Whiteside, A. (2006) *AIDS in the Twenty- First Century: Disease and Globalization* (2nd edition). Hampshire, UK, and New York, Palgrave Macmillan.

McLean, A. (1979) *Work Stress*. Reading, Massachusetts, Addison-Wesley.

Chapter in a book

Carlise, C. (2001) HIV and AIDS. In: Mason, T., Carlise, C.

& Whitehead, E. (eds.) *Stigma and Social Exclusion in Health Care*. London, Routledge.

Report

UNAIDS (1998) *HIV-Related Opportunistic Diseases*. Technical Update, October 1998. Geneva,

UNAIDS. King, M. (2002) *The King Report on Corporate Governance for South Africa, 2002*. Johannesburg, South Africa, The Institute of Directors.

Conference

Setswe, G. (2005) *Systematic review of behavioural interventions for reducing the risk of HIV in occupational settings*. Paper presented at the 2nd South African AIDS Conference, Durban, South Africa, 7–10 June 2005.

Newspaper article

Epstein, H. (2004) 'The fidelity fix.' *New York Times Magazine*, 13 June 2004, pp. 54–59.

The Economist (2004) 'AIDS and business,' 2 December 2004, p. 8.

URLs/electronic sources

This is a grey area: Try to include at least the following elements when you list an electronic source:

Name of author or organisation (year of publication or most recent update) 'Title of webpage.'
Title of document on website, date posted. URL of document [Date accessed].

Importantly, provide only URLs that work. Also, do not cite URLs for print sources that are not difficult to obtain (e.g., UNAIDS documents); likewise, do not short-cut the need to give a complete reference by merely citing an URL.

TABLES & FIGURES

Tables should not include shading or bold type; minimise the use of vertical lines.

Figures should adhere closely to the size, style and format of *AJAR* as explained in the document *Figure Guidelines for Authors: format, style and technical considerations*, as costs of redrawing may be charged to authors. Please, set out the captions (legends) separate to the Figures (so that they may be edited).

Make a separate file for all Figures and Tables. However, you may place Tables that are not lengthy or complex at the end of your paper.

Include a citation in the text, at least once, for each Table and Figure. Number them consecutively. It is not necessary to suggest points of insertion as the Tables and Figures will be placed properly in the layout following their first mention in the text. Thus, do not refer to Tables or Figures as 'above' or 'below' in the text.

Write captions that are informative but succinct for each

Table and Figure.

Cite sources fully if you reproduce a Figure or Table from another published or unpublished source. Ensure that you have obtained written permission from the source publisher to reproduce the material.

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- Please scan and save photographs and line art work as separate files; scan at a minimum of 300 dpi (photos) and 600 dpi (line art) and save as TIFF, JPG, EPS or PDF formats.
- Refer to an illustrative image as a Figure, accordingly numbered and with a caption.
- Copyright of special images must belong to the author or used with permission.

FOOTNOTES & ENDNOTES

- Use endnotes rather than footnotes: that is, create a
Notes section. Limit the use of endnotes.
- Use Arabic numerals as superscripts.
- In some cases it may be preferable to use a single footnote on the first page, such as to refer to a term in the title or an item in the author byline.

HYPERLINKS/BOOKMARKS/CROSS-REFERENCES Please remove these from your paper before submitting it to *AJAR*.

REFERENCING STYLE for the *African Journal of AIDS Research (AJAR)*

Please help us in the following ways when you compose the References section of your paper:

- Alphabetise the list by (first) authors' last names, and then list chronologically from the oldest to most recent reference.
- Pay scrupulous attention to punctuation and the use of italic versus regular font, as shown in these samples taken from *AJAR*.
- Give complete references. Especially: use full journal titles and include all authors (never use '*et al.*' in the references list).
- If you are unsure of what style to use for a given format, strive at least to be complete and consistent.

- Do not use a numbered list for the references.
- Remove Cross References, Bookmarks and Hyperlinks from your file. Also, do not insert Manual Line Breaks (i.e., shift+enter) or Tabs when you create your list.

Journal article

Auvert, B., Taljaard, D., Lagarde, E., Sobngwi-Tambekou, J., Sitta, R. & Puren, A. (2005) Randomized, controlled intervention trial of male circumcision for reduction of HIV-infection risk: the ANRS 1265 trial. *PLoS Medicine*

2(11), pp. 1–111.

Brown, L., Macintyre, K. & Trujillo, L. (2003) Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention* 15(1), pp. 49–69.

Glantz, L.H., Annas, G.J., Grodin, M.A. & Mariner, W.K. (1998) Research in developing countries: taking ‘benefit’ seriously. *Hastings Center Report* 28(6), pp. 38–42.

Gray, R.H., Li, X., Wawer, M.J., Gange, S.J., Serwadda, D., Sewankambo, N.K., Moore, R., Wabwire-Mangen, F., Lutalo, T., Quinn, T.C. & the Rakai Project Group (2003) Stochastic simulation of the impact of antiretroviral therapy and HIV vaccines on HIV transmission; Rakai, Uganda. *AIDS* 17(13), pp. 1941–1951.

Kegeles, S.M., Coates, T.J., Christopher, T.A. & Lazarus, J.L. (1989) Perceptions of AIDS, the continuing saga of AIDS-related stigma. *AIDS* 3(supplement 1), pp. S253–S258.

Lende, D.H. & Lachiondo, A. (In press) Embodiment and breast cancer among African-American women. *Qualitative Health Research*.

Smith, M. & Davidson, J. (2006) ‘It makes my skin crawl’: The embodiment of disgust in phobias of ‘nature.’ *Body and Society* 12(1), pp. 43–67.

Book

Barnett, A. & Whiteside, A. (2006) *AIDS in the Twenty- First Century: Disease and Globalization* (2nd edition). Hampshire, UK, and New York, Palgrave Macmillan.

Foucault, M. (1978) *The History of Sexuality, Volume 1: An Introduction*. Harmondsworth, UK, Penguin.

Greene, W.H. (2000) *Econometric Analysis* (4th edition). Upper Saddle River, New Jersey, Prentice-Hall.

Mann, J., Tarantola, D.J.M. & Netter, T.W. (eds.) (1992) *AIDS in the World*. Cambridge, Massachusetts, Harvard University Press.

Chapter in a book

Cameron, E. (2005) Just a virus, just a disease. In: Cameron, E. (ed.) *Witness to AIDS*. Cape Town, South Africa, Tafelberg.

Pryor, J.B. & Reeder, G.D. (1993) Collective and individual representations of HIV/AIDS stigma. In: Pryor, J.B. & Reeder, G.D. (eds.) *The Social Psychology of HIV Infection*. Hillsdale, New Jersey, Lawrence Erlbaum Associates.

Conference/seminar/workshop

Averitt Bridge, D., Hodder, S., Squires, K., Aberg, J., Abrams, S., Storfer, S. & Feinberg, J. (2008) *Clinicians fail to routinely provide reproductive counseling to HIV-infected women in the United States*. Program and abstracts of the 17th International AIDS Conference, Mexico City, Mexico, 3–8 August 2008. Abstract No. TUPE0911.

Brandt, R. (2008) *Maternal mental health and HIV*. Sexual and Reproductive Health and Rights Roundtable, 4th Public Health Association of South Africa Conference, Cape Town, South Africa, 2–4 June 2008.

Grégoire, L.-J. (2001) *VIH-SIDA, lute contre la pauvrete et development humain en Afrique subsaharienne: defies et enejux*. Paper presented at the ICASA Satellite Conference on HIV/AIDS, Poverty and Human Development in Sub-Saharan Africa, Ouagadougou, Burkina Faso, 5–7 December 2001.

Kelly, M. (2002) *Addressing the susceptibility of youth to HIV infection*. Paper presented at the International Policymakers Conference on HIV/AIDS, New Delhi, India, 11–12 May 2002.

Sandström, A. (2004) *Dialogue, mainstreaming and direct support*. Presentation at HIV/AIDS and Economics Workshop, Lusaka, Zambia, 23–25 February 2004.

Setswe, G. (2005) *Systematic review of behavioural interventions for reducing the risk of HIV in occupational settings*. Paper presented at the 2nd South African AIDS Conference, Durban, South Africa, 7–10 June 2005.

Report/government policy or programme plans

Department of Health [South Africa] (2007) *HIV/AIDS and STI Strategic Plan for South Africa 2007–2011*. Pretoria, South Africa, Provincial Department of Health.

Fox, S., Oyosi, S. & Parker, W. (2002) *Children, HIV/ AIDS and Communication in South Africa: A Literature Review*. Johannesburg, South Africa, Centre for AIDS Development, Research & Evaluation (CADRE).

Free State Department of Health (FSDoH) [South Africa] (2003) *Proposed Plan for the Implementation of ARVs in the Free State Province*. Bloemfontein, South Africa, FSDoH.

Government of Botswana (1999) *Short-term Plan of Action: National Gender Programme 1999–2003*. Gaborone, Botswana, Ministry of Lands and Home Affairs, Women's Affairs Department, Government Printer.

UNAIDS (2006) *2006 Report on the Global AIDS Epidemic*. Geneva, UNAIDS.

UNAIDS/Panos Institute (2001) *Young Men and HIV: Culture, Poverty and Sexual Risk*. Geneva, UNAIDS.

World Health Organization (WHO) (2003) *The 3 by 5 Progress Report*. Geneva, WHO.

World Health Organization (WHO), UNAIDS & UNICEF (2007) *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector*. Progress Report, April 2007. Geneva, WHO.

Numbered report/monograph

Gillespie, S. & Kadiyala, S. (2005) *HIV/AIDS and food and nutrition security: from evidence to action*. Food Policy Review No. 7. Washington, D.C., International Food Policy Research Institute (IFPRI).

Leclerc-Madlala, S. (2002) *Youth, HIV/AIDS and the importance of sexual culture and context*. CSSR Working Paper No. 9. Cape Town, South Africa, University of Cape Town, AIDS and Society Research Unit.

Ngwira, N., Bota, S. & Loevinsohn, M. (2001) *HIV/AIDS, agriculture and food security in Malawi: background to action*. RENEWAL Working Paper No. 1. Lilongwe, Malawi, Ministry of Agriculture and Irrigation, and The Hague, The Netherlands. Available at: http://www.ifpri.org/renewal/pdf/renewal_wp1.pdf.

RADAR (Rural AIDS and Development Action Research Programme) (2002) *Social interventions for HIV/ AIDS: intervention with micro-finance for AIDS and gender equality*. IMAGE Study, Evaluation Monograph No. 1. Johannesburg, South Africa, University of the Witwatersrand, School of Public Health.

UNAIDS (2000) *Knowledge is power: voluntary HIV counseling and testing in Uganda*. UNAIDS Best Practice Collection No. BP035. Geneva, Joint United Nations Programme on HIV/AIDS (UNAIDS).

Draft report

De Lannoy, A. (2005) *Vulnerability, care and support in and through schools: a review of school-based research*. Draft paper commissioned by the Children's Institute for the Caring Schools Project, University of Cape Town, South Africa

Guidelines/handbook/training manual

Department of Health and Human Services (DHHS) [USA] (2008) *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. Bethesda, Maryland, National Institutes of Health, Office of AIDS Research Advisory Council (OARAC).

Free State Department of Health (FSDoH) [South Africa] (2004) *Adult Antiretroviral Treatment Guidelines*. Bloemfontein, South Africa, FSDoH.

Grimwood, A. (ed.) (2004) *National Antiretroviral Treatment Guidelines*. Durban, South Africa, Health Systems Trust.

Referencing Style

National AIDS/STD Control Programme (NASCP) [Nigeria] (2005) *National Guidelines on Prevention of Mother- to-Child Transmission of HIV (PMTCT)*. Abuja, Nigeria, Federal Ministry of Health, Federal Secretariat.

Planned Parenthood Association of South Africa (PPASA) (1996) *Parent Education Programme: Training Manual for Sexuality and Reproductive Health*. Cape Town, South Africa, PPASA.

Jürgens, R. (2007) *Taking Action against HIV: Handbook for Parliamentarians No.15/2007*. Geneva, Inter-Parliamentary Union (IPU), the United Nations Development Programme (UNDP), and the Joint United Nations Programme on HIV/AIDS (UNAIDS). Available at: http://data.unaids.org/pub/Manual/2007/20071128ipu_handbook_en.pdf [Accessed 15 January 2007].

UNFPA, WHO & PATH (2005) *Condom Programming for HIV Prevention. A Manual for Service Providers*. New York, United Nations Population Fund (UNFPA). Available at: http://www.unfpa.org/upload/lib_pub_file/422_filename_condom_prog.pdf [Accessed 20 May 2008].

Newspaper or magazine article/newsletter

Barrell, H. (2002) 'Would the real AIDS dissident please declare himself.' *Mail & Guardian*, 19 April 2002.

Botswana Guardian (2006) 'Old people at risk of HIV/AIDS,' 1 December 2006, Gaborone, Botswana.

DeBeers (2008) *Women in the Workplace Newsletter*, Issue 2, April 2008.

Epstein, H. (2004) 'The fidelity fix.' *New York Times Magazine*, 13 June 2004, pp. 54–59.

Rademeyer, A. (2004) 'Jeug kort vigsfeite.' *Beeld*, 29 October 2004, p. 3.

The Economist (2004) 'AIDS and business,' 2 December 2004.

The Washington Post (2007) Interview with Thabo Mbeki, 25 September 2007.

Press release

Government of the Republic of Namibia/Ministry of Health and Social Services (2007) Press release, 17 April 2007: 'Results of the 2006 National Sentinel Survey among Pregnant Women.'

Kaiser Family Foundation (2005) Press release: 'United Nations Secretary General Kofi Annan launches Global Media AIDS Initiative.' Online at: <http://www.kff.org/newsroom/philip011504nr.cfm> [Accessed 25 August 2005].

UNAIDS/WHO (2005) Press release, 21 November 2005: 'HIV infection rates decreasing in several countries but global number of people living with HIV continues to rise.' Geneva, World Health Organization (WHO).

Lecture/spoken comments

Mbeki, T. (2001) ZK Matthews Memorial Lecture, University of Fort Hare, Alice, South Africa, 12 October 2001.

Walker, C. (2002) 'Ensuring women's land access.' Moderator's comments at the Regional Workshop on Land Issues in Africa and the Middle East, Kampala, Uganda, 29 April 2002.

Personal communications

Personal communications need not be listed in the references section, but simply mentioned in the text using the following form: (pers. comm., first name or initial and last name, affiliation, month and year).

Samples:

(pers. comm., L. Regensberg, clinical director, Aid for AIDS, South Africa, June 2007); (pers. comm., N. Nkwe, advocacy officer, Bonela, Botswana, May 2008).

Thesis/dissertation

Bali, D.N. (2003) *The role of informal carers for HIV/ AIDS patients in high prevalence sub-Saharan African countries*. Master's thesis, Department of International Health, Liverpool School of Tropical Medicine, Liverpool, United Kingdom.

McKittrick, M. (1995) *Conflict and social change in northern Namibia, 1850–1954*. PhD thesis, Department of History, Stanford University, California.

Legislation

United Nations (2006) *Resolution adopted by the General Assembly, 60/262. Political Declaration on HIV/AIDS*. New York, United Nations.

United Nations Security Council (1999) *UN Security Council Resolution 1261 (1999) on the Children and Armed Conflict*. S/RES/1261, August 1999. New York, United Nations.

Product instructions

Partec Gmbh (2006) *Protocol for CD4+ T-cell counting with the Partec CD4 Easy-Count Kit* (Partec Code No. 05-8401). Munster, Germany, Partec Gmbh.

Survey/fact sheets

All Media Products Survey (AMPS) (2000) *All Media Products Survey, December 2000*. Johannesburg, South Africa, Markinor.

Buckner, B., Singh, K. & Tate, J. (2006) *Zambia Sexual Behaviour Survey 2005*. Lusaka, Zambia, Central Statistical Office, Ministry of Health, and MEASURE Evaluation.

Gallup International (2000) *Gallup International Millennium Survey: Religion in the World at the End of the Millennium*. Online at: <http://www.gallup-international.com> [Accessed 2 December 2007].

Ghana Statistical Service (GSS), Noguchi Memorial Institute for Medical Research (NMIMR) & ORC Macro (2004) *Ghana Demographic and Health Survey 2003*. Calverton, Maryland, GSS, NMIMR and ORC Macro.

Institut National de la Statistique (INS) [Cameroon] & ORC Macro (2004) *Enquête Démographique et de Santé du Cameroun 2004*. Calverton, Maryland, INS and ORC Macro.

Ministry of Health and Social Welfare (MoHSW) [Lesotho], Bureau of Statistics (BOS) [Lesotho] & ORC Macro (2005) *Lesotho Demographic and Health Survey 2004*. Calverton, Maryland, MoHSW, BOS and ORC Macro.

ORC Macro & Ministry of Health (MoH) [Uganda] (2006) *Uganda HIV/AIDS Sero-Behavioural Survey 2004–05*. Calverton, Maryland, ORC Macro, and MoH.

Pettifor, A., Rees, H., Steffenson, A., Hlongwa-Madikizela, L., MacPhail, C., Vermaak, K. & Kleinschmidt, I. (2004) *HIV and Sexual Behaviour among Young South Africans: A National Survey of 15–24-year-olds*. Johannesburg, South Africa, University of the Witwatersrand, Reproductive Health Research Unit.

Shisana, O., Rehle, T., Simbayi, L.C., Parker, W., Zuma, K., Bhana, A., Connolly, C., Jooste, S. & Pillay, V. (2005) *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005*. Cape Town, South Africa, Human Sciences Research Council (HSRC).

UNAIDS/WHO (2004) *Epidemiological Fact Sheets on HIV/ AIDS and Sexually Transmitted Infections, 2004 Update, Ghana*. Geneva, UNAIDS.

Census

Government of the Republic of Namibia/National Planning Commission (GRN/NPC) (2004) *2001 Population and Housing Census. Oshikoto Region. Basic Analysis with Highlights*. Windhoek, Namibia, Central Bureau of Statistics.

National Population Commission [Nigeria] (2006) *2006 National Census, Provisional Figures*. Abuja, Federal Republic of Nigeria, Government Printers.

Statistics South Africa (StatsSA) (2004) *Census 2001. Primary Tables — Eastern Cape: Census 1996 and 2001 Compared*. Pretoria, South Africa, StatsSA.

Database

Actuarial Society of South Africa (ASSA) (2005) *The ASSA 2003 HIV Database*. Online at: www.assa.org.za/scripts/file_build.asp?id=100000538 [Accessed 22 January 2006].

Thomson Scientific (2007) *Glossary of Thomson Scientific Terminology*. Online at: <http://scientific.thomson.com/support/patents/patinf/terms/#I> [Accessed 6 August 2007].

Software

StataCorp (2005) *Stata Statistical Software: Release 9*. College Station, Texas, StataCorp LP.

Electronic (online) sources

AJAR's style for referencing any electronic source is a simplified, consistent presentation of the source's main elements. Try to include the following:

- Name of author or organisation (year of publication or most recent update) 'Title of webpage.' *Title of document on website* (date posted). URL of document [Date accessed].
- Where possible and relevant, provide URLs to specific documents rather than references to home or menu pages.
- Provide only URLs that work: test the URLs in your references list prior to submission.
- Give your date of access only if the source itself has no date or if its content is likely to change.

There are many grey areas in referencing electronic sources. To learn more about trends in how to do so, Google 'online style.'

Professional website or webpage

National Institute of Allergy and Infectious Diseases (NIAID) [USA] (2003) 'General Information about HIV/AIDS Treatment.' Online at: www.niad.nih.gov/daids/therapeutics/geninfo/geninfo.htm#1 [Accessed 5 June 2005].

US Department of Education (1999) 'US Department of Education Home Page.' Online at: www.ed.gov/index.html [Accessed 1 October 1999].

World Health Organization (WHO) (2007) 'HIV/AIDS country information — South Africa.' Online at: www.who.int/hiv/countries/en/index.html [Accessed 12 March 2008].

Electronic journal article

Abass, U.L., Anderson, R.M. & Mellors, J.W. (2007) Potential impact of antiretroviral chemoprophylaxis on HIV-1 transmission in a resource-limited setting. *PLoS ONE* 2(9), p. e875.

Article authored on the Web

Cherney, J.K. (2003) *Appreciative teambuilding: creating a climate for great collaboration*. Online article, 2 April 2003. Available at: http://www.teambuildinginc.com/article_ai.htm.

Electronic news article/online posting

AIDSmap (2006) 'South Africans debating HIV testing: voluntary or opt-out?' Reproduced from PLUS News, 24 May 2006. Online article: <http://www.aidsmap.com/en/news/DC93CD0F-BA12-4EB3-AEAF-DCF1939CD7F5.asp>.

Currie, I. (2006) 'About the draft Protection of Personal Information Bill.' Online posting, August 2006, Johannesburg, South Africa, University of the Witwatersrand, Mandela Institute. Available at: <http://web.wits.ac.za/Academic/CLM/Law/CentresClinicsResearch/MandelaInstitute/Privacy/Briefing.htm>.

Article from an electronic publishing source

Turesson, G. (2006) *Prevention of HIV: a field study of Tanzania nurses' culturally adopted prevention work against HIV*. Malmö University Electronic Publishing, Malmö, Sweden. Available at: http://dSPACE.mah.se:8080/browsetitle?starts_with=preschool.

Unattributed online posting

Organization of African First Ladies Against HIV/AIDS (2008) Online posting:
<http://commitments.clintonglobalinitiative.org/projects.htm?mode=view&rid=209674>
 [Accessed 1 September 2008].

Referencing Style

Online educational material

Treatment Action Campaign (TAC) (2008b) 'TAC's Treatment Literacy Materials.' TAC, Cape Town, South Africa. Online at: <http://www.tac.org.za/community/treatmentliteracy> [Accessed 10 June 2008].

Whitworth, J. (2006) 'Malaria and HIV.' *HIV InSite Knowledge Base Chapter* (2 May 2006).
 Online at: <http://hivinsite.ucsf.edu/InSite?page=kb-05&doc=kb-05-04-04>.

APPENDIX E: GUIDELINES FOR SUBMISSION TO JOURNAL OF SOCIAL ASPECTS OF HIV/AIDS

Author guidelines: SAHARA-J

The Journal publishes contributions in English and French from all fields of the social aspects of HIV/AIDS including care, support, behaviour change, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy and media.

While the emphasis is on empirical research (qualitative and quantitative), the Journal also accepts theoretical and methodological papers and review articles. These should not be longer than 8,000 to 10,000 words. We also publish short communications, letters, commentaries and book reviews.

Priority is given to articles that are relevant to Africa and the developing world and which address social issues related to HIV and AIDS. Special issues may deal with a specific topic, region or country. Submission of papers presented at the biannual International Conferences of HIV/AIDS and STI in Africa and biannual Social Aspects of HIV/AIDS Research Alliance (SAHARA) conferences are especially invited.

Authors are requested to submit their original manuscript and figures with two copies and a matching disc to the editor: Prof Karl Peltzer, Social Aspects of HIV/AIDS and Health, Human Sciences Research Council, Private Bag X41, Pretoria 0001, South Africa. Manuscripts can also be submitted by e-mail. Please create one folder (with the name of the corresponding author) for all word and figure files, and e-mail this to the editor at jsahara@hsrc.ac.za.

Submissions will be considered on the understanding that they comprise original unpublished material and are not under consideration for publication elsewhere (all authors are to sign on

submission of the article), and the study(ies) on which they have been based have been subject to appropriate ethical review.

All submissions may be subject to initial assessment by the editor or appropriate Editorial Board members to determine their suitability for consideration by the Journal.

Papers accepted for formal review will be sent anonymously to at least two independent referees. Short biographic details of not more than 10 lines should be provided at acceptance of the paper for publication.

Manuscript preparation

Manuscripts must be typewritten, double-spaced with wide margins, on one side of white paper. Good quality printouts with a font size of 12 are required. The corresponding author should be identified (include a fax number and e-mail address).

Abstract and keywords

Please supply an abstract (without subheadings) of up to 300 words, and up to six keywords.

Text

Follow this order when typing manuscripts:

- On the covering page – author(s), affiliation(s), full postal address, fax number and email address. Names and affiliations of co-authors should be clearly indicated. Please ensure that these details are printed on the cover page only, and do not appear on any other separate sheet.
- References
- Appendix
- Figure captions

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

References

All publications cited in the text should be presented in a list of references following the text of the manuscript. In the text refer to the author's name (without initials) and year of publication (e.g. 'Since Shisana and Simbayi (2002) have shown that...' or 'this is in agreement with results obtained later (Uys, 2002)'). For 2 - 6 authors all authors are to be listed at first citation, with '&' separating the last two authors, for more than six authors, use the first six authors followed by 'et al'. In subsequent citations for three or more authors use 'et al' in the text. The references should be arranged alphabetically by authors' names. The manuscript should be carefully checked to ensure that the spelling of authors' names and dates are exactly the same in the text as in the reference list.

References should be given in the following form:

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

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

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

The reference style should follow APA guidelines:

<http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>