Experiences of HIV stigma and Coping-Self-efficacy in a rural and urban context of the North West Province: a mixed methods study

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Mini-dissertation submitted in partial fulfilment of the requirements for the degree *Magister Artium in Research Psychology* at the Potchefstroom Campus of the North-West University

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“There’s a truth that is deeper than experience. It is beyond what we see, or even what we feel. It’s an order of truth that separates the profound from the merely clever, and the reality from the perception. We’re helpless, usually, in the face of knowing it; and the cost of knowing it, like the cost of knowing love, is sometimes greater than any heart would be willing to pay. It doesn’t always help us to love the world, but it does prevent us from hating the world. And the only way to know that truth is to share it, from heart to heart...”

From *Shantaram*, by Gregory David Roberts

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List of Abbreviations

AIDS = Acquired Immunodeficiency Syndrome

CSE = The Coping Self-efficacy scale

HASI-P = HIV and AIDS Stigma Instrument-PLWA

HIV = Human Immunodeficiency Virus

MIV = MenslikeImmuniteitsgebreksvirus

PLHA = People Living with HIV and AIDS

Research Outline

The following research is presented in an article format, including the following sections:

- A brief summary providing a concise description of the problem statement, objectives, methodology, results and conclusions and recommendations
- One article, entitled: ***Experiences of HIV stigma and Coping Self-efficacy in a rural and urban context of the North West Province: A mixed methods study,*** intended for submission to the journal *AIDS Care*.
- Conclusion, limitations and recommendations are included at the end of the article, providing a more comprehensive discussion than discussed in the article.
- The research is submitted in this format consistent with Rule A.7.5.7.4

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A thank you to God for the blessings and answered prayers

Author’s Contributions

This study is a part of a larger study initiated by Prof. M. Greeff as project leader and several other researchers, as well as an international collaborator from the Netherlands. Each researcher’s contribution in this study is described in the table below.

Researcher contributions

Ms A.L. Stewart	Masters’ in Research Psychology student, responsible for the literature study, data collection and writing up of the final article
Prof. Q.M. Temane	Supervisor, as well as critical reviewer of the study and the article
Prof. M. Greeff	Project leader for the larger intervention study and co-supervisor, as well as critical reviewer of the study and the article
Dr. I.P. Khumalo	Supervisor, as well as critical reviewer of the study and the article
Prof.C. Doak	International collaborator

The following statement is a declaration by the co-authors to confirm their role in the study and agree to the article format for submission as a mini-dissertation. The intended journal for publication is *AIDS Care*.

Declaration

I hereby declare that I have approved the inclusion of one article as a mini-dissertation and that my role in the study complies with what is described in the above table. I hereby give consent that this article be published as a mini-dissertation of Ms A.L. Stewart, as part of the Masters' in Research Psychology.

Signed:

Ms. A.L. Stewart

Prof. Q.M. Temane

Prof.M.Greeff

Dr. I.P. Khumalo

Prof. C.M. Doak

Summary

High levels of HIV stigma are reported for people living with HIV or AIDS (PLHA) and PLHA have to cope with this. These experiences may differ in a rural and urban setting. Obtaining a true reflection of the level of HIV stigma experienced by PLHA in a rural and urban setting and their level of coping self-efficacy, while dealing with this stigma, will be helpful in planning future intervention strategies.

The study aims to compare qualitative expressed experiences with quantitative measures of levels of HIV stigma and coping self-efficacy of PLHA in a rural and urban setting. Secondly the aim is to establish the relationship between the levels of HIV stigma experiences of PLHA and coping self-efficacy of PLHA. The study took place in the North West Province, in both a rural (n=12) and urban (n=11) setting. Participants were selected by means of purposive sampling. A convergent parallel design was used within a mixed method approach. In-depth interviews provided qualitative data. Quantitative data came from two scales, the HIV and AIDS stigma scale-PLWA (HASI-P) (Holzemer et al., 2007a) and the Coping self-efficacy scale (CSE) (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006).

The study revealed that HIV stigma does exist, and is experienced by PLHA in the North West province in both a rural and an urban setting with no significant difference. Qualitative data confirmed the results of the HIV stigma measure, and also provided a rich understanding of the differences in contexts between the two settings. Additional types of stigma found to those included in the HASI-P point to shifts in the way people and communities experience HIV stigma. Results of the CSE scale showed that PLHA from both rural and urban settings employed the three types of coping self-efficacy as described by Chesney et al. (2006), with no significant difference between the two groups.

Statistical correlations within the HASI-P revealed correlations between certain types of stigma experienced, indicating that HIV stigma is not experienced in a single dimension but can extend to more than one area of the lives of PLHA. Correlations within the CSE scale illustrate that ways PLHA cope may be related to each other

Recommendations focus on further research options, policy development and implementation in practice. The goals of the research were reached in that it was confirmed that HIV stigma and coping self-efficacy of PLHA in rural and urban settings, using qualitative and quantitative methods, does exist. The relationship between HIV stigma and coping self-efficacy of PLHA was established through the correlation of scales and through the evidence found during in-depth interviews; that HIV stigma exists and that PLHA develop coping self-efficacy to deal with it.

Keywords: HIV stigma, people living with HIV or AIDS (PLHA), coping self-efficacy, rural, urban

Opsomming

Hoë vlakke van MIV-stigma is gerapporteer deur mense wat lewe met MIV of VIGS (MLMV), en MLMV moet hierdie ervarings hanteer. Hierdie ervarings kan verskil tussen landelike en stedelike omgewings. 'n Ware weerspieëling van die vlak van MIV-stigma soos ervaar deur MLMV inlandelike en stedelike omgewing, en hulle vlak van hantering self-doeltreffendheid, terwyl hierdie stigma hanteer word, sal nuttig wees in die beplanning van toekomstige intervensiestrategieë.

Die studie het ten doel om kwalitatief geverbaliseerde ervarings te vergelyk met kwantitatiewe maatstawwe van die vlakke van MIV-stigma en hantering self-doeltreffendheid in 'n landelike en stedelike omgewing. Tweedens is die doel om die verhouding tussen die vlakke van MIV-stigma ervarings van MLMV en die hanteringself-doeltreffendheid van MLMV te bepaal. Die studie is gedoen in die Noordwesprovinsie, in beide 'n landelike (n = 12) en stedelike (n=11) omgewing. Deelnemers is deur middel van doelgerigte steekproeftrekking gekies. 'n Konvergerende parallelle ontwerp is gebruik binne 'n gemengde metode benadering. In-diepte onderhoude het die kwalitatiewe data voorsien. Kwantitatiewe data is verskaf deur twee skale, die HIV/AIDS Stigma Instrument-PLWA (HASI-P) (Holzemer et al., 2007a) en die Coping Self-Efficacy Scale (CSE) (Chesney, Neilands, Chambers, Taylor &Folkman, 2006).

Die resultate van die studie het aan die lig gebring dat MIVstigma wel bestaan en deur MLMV ervaar in die Noordwesprovinsie word in beide 'n landelike en stedelike omgewing, met geen betekenisvolle verskil nie. Kwalitatiewe data het die resultate van die MIVstigmaskaal bevestig, en 'n ryk begrip van die verskille in kontekste tussen die twee omgewings is verkry. Addisionele vorme van MIVstigma is gevind by die wat ingesluit was in die HASI-P en toon verskuiwings in die manier waarop mense, en ook gemeenskappe, MIV stigma ervaar. Resultate van die CSE het getoon dat MLMV uit beide omgewings in staat is tot die drie tipes hantering self-doeltreffendheid soos beskryf deur Chesney etal. (2006), met geen betekenisvolle verskille tussen die twee groepe nie.

Statistiese korrelasies binne die HASI-P het aangedui dat daar korrelasies tussen sekere tipes MIV stigma was, wat aandui dat MIV stigma nie in 'n enkele dimensie ervaar word nie, maar kan uitbrei na meer as een gebied van MLMV se lewens. Korrelasies binne die CSE skaal illustreer dat die maniere waarop MLMV situasies hanteer is, verband hou met mekaar.

Aanbevelings fokus op verdere navorsing en die ontwikkeling van beleid en implementering in die praktyk. Die doelwitte van die navorsing is bereik, in die sin dat dit bevestig is dat MIVstigma en die hantering self-doeltreffendheid van MLMV in landelike en stedelike instellings, soos met behulp van kwalitatiewe en kwantitatiewe metodes bepaal, wel bestaan. Die verhouding tussen MIVstigma en die hantering self-doeltreffendheid van MLMV is bepaal deur die korrelasie van skale en deur die bewyse wat gevind was tydens in-diepte onderhoude;dat MIVstigma bestaan en dat MLMV se hantering self-doeltreffendheid metodes ontwikkel om dit te hanteer.

Sleutelwoorde:

MIV stigma, mense wat leve met MIV of VIGS (MLMV), hanteringmself-doeltreffendheid, landelik, stedelik

Manuscript

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Experiences of HIV stigma and Coping Self-efficacy in a rural and urban context of the North West Province: A mixed methods study

Abstract

A true reflection of the level of HIV stigma experienced by PLHA in a rural and urban setting and their levels of coping self-efficacy would be helpful in the process of planning intervention strategies. This study compares qualitatively expressed experiences of HIV stigma to a quantitative measure of HIV stigma of people living with HIV or AIDS PLHA in both a rural and urban context. Additionally, coping self-efficacy of PLHA and its relationship to levels of HIV stigma were examined. A convergent parallel design was used within a mixed method approach. Participants from rural (n=12) and urban (n=11) settings were purposively selected. The study revealed that PLHA experienced HIV stigma and showed coping self-efficacy, in a rural and urban setting, without significant difference. Qualitative data confirmed these results and provided a rich understanding of the differences in urban and rural contexts. Correlations revealed HIV stigma is multidimensional, and coping strategies of PLHA may be related to each other. Although HIV stigma exists, PLHA develop coping self-efficacy to deal with those experiences. Further research is required, as well as the implementation of findings in the process of policy development and practice.

Keywords:

HIV stigma, people living with HIV or AIDS (PLHA), coping self-efficacy, rural, urban

Introduction

Southern Africa has the highest rate of HIV infections globally with South Africa representing 68% of the global 34 million recorded cases, as reported in the UNAIDS World AIDS Day Report 2011. According to Alonzo and Reynolds, (1995) people who are stigmatised are "a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse" (p. 304). HIV stigma and associated discrimination adversely impacts various societies globally, (*Asia*: Ickovics, White, Stasko, & Ghose, 2007, Mawar, Sahay, Pandit, & Mahajan, 2005;*France*: Perettie-Watel, Spire, Obadeia, & Moatti, 2007 and *Southern Africa*: Greeff & Phetlhu, 2007). HIV stigmatising beliefs can be attributed to many social influences, including assigning responsibility for contracting HIV, as well as viewing HIV infected individuals as tainted and contaminated (Simbayi, Kalichman, Strebel, Cloete, Nomvo, & Mqeketo, 2007).

The resulting effects of HIV stigma may negatively influence support-seeking behaviours and access to health care of those infected, as well as increasing reluctance for others to be tested (Mawar et al., 2005). According to Greeff and Phetlhu (2007), there is a relationship between the meaning a person ascribes to being stigmatized and the person's willingness to engage in health-seeking behaviour, including voluntary testing and accessing of treatment. A fear of HIV stigma is noted as the main reason among HIV positive women in sub-Saharan Africa for avoiding assistance and disclosure of HIV status (Simbayi et al., 2007). HIV stigma in South Africa can be seen to be experienced at many points of help-seeking and social living, including voluntary testing (with education and religious institutions undermining prevention efforts), disclosure (whereby youth are afraid to tell their parents due to fear of gossiping), quality of life (examples have been reported of family members hiding an HIV- positive relative who is in need of care) and even in death (negating the cause of death) (Campbell, Foulis, Maimane, & Sibiya, 2005).

Authors report differing stigma experiences for rural and urban settings. Support, for example, may differ between the two contexts due to employment and external support resources available (Naidoo et al., 2007). Lack of anonomynity was cited as a major deterrent to accessing testing sites and health care in rural areas in Alaska and New Mexico, as these communties tend to be smaller and the health providers well known (Brems, Johnson, Warner, & Roberts, 2010).

Experiences of HIV stigma may be linked to the coping self-efficacy of PLHA. In a study by Wissing et al. (2011) of coping self-efficacy as a mediator between stress and depression and psychological well-being, it was found that coping self-efficacy did mediate between symptoms of stress and depression as well as levels of psychosocial well-being. The process of coping includes primary appraisal or assessment of the stressful situation, a decision on what to do to cope, or secondary appraisal, which is influenced by self-efficacy (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006). Bandura and Adams, (1977) describe coping strategies as being affected by the level of perceived self-efficacy. Coping self-efficacy affects persistence, effort, level of apathy and choice of actions and behaviours (Bandura & Adams, 1977).

Problem Statement

HIV stigma impacts on people’s lives and health-seeking behaviour. How people cope with it differs. The level of HIV stigma experienced may also differ according to whether people live in a rural or urban setting. Having a true reflection of the level of stigma experienced by PLHA in both a rural and an urban setting, and their level of coping self-efficacy, while dealing with this stigma, will be helpful in planning future intervention strategies.

Research Objectives

To compare qualitative expressed experiences with quantitative measures of levels of HIV stigma and coping self-efficacy of PLHA in a rural and urban setting. Secondly the aim is to establish the relationship between the levels of HIV stigma experiences and coping self-efficacy of PLHA.

Research Methodology

The study conducted falls under a larger SANPAD Research Project entitled *A Comprehensive Community-based HIV Stigma Reduction and Wellness Enhancement Intervention* (reference number 09/15). The research project was interventionist in nature, including workshops in a therapeutic setting to aid the understating of HIV stigma and ultimately the reduction of HIV stigma experienced by PLHA, people living close to them and the community at large. The larger study included a test battery, in-depth interviews and the workshops. The focus of this study is on PLHA experiences of HIV stigma and coping-self-efficacy in a rural and urban setting, the data of which could be gathered from the larger SANPAD Research Project.

Literature Review

The literature review for the purpose of this article included articles gathered from electronic resources, such as EBSCO Host, Google Scholar and Science Direct.

Stigma was described by Erving Goffman in 1963 as a discrediting socially constructed identification which forms a basis for later exclusion from a social group (Eba, 2008). The three aspects of stigma that Goffman identified (blemishes of personal character, stained social identity and physical deformity or defects) are characteristic of HIV and AIDS stigma, as cited by Simbayi et al. (2007). Parker and Aggleton (2003), in reaction to Goffman, emphasize a need to move beyond stigma as something “highly individualized” (pg 16) and focus on social processes such as discrimination, culture, power and difference, strategic deployement of stigma and the politics of exclusion. Incorporating an ecological approach, Ickovics, White, Stasko, and Ghose (2007), in the same manner as Parker and Aggleton (2003), state that there is a lack of attention given to other domains such as family, institutions and policy or structures. Ickovics et al (2007) present an “influence matrix” (p. 2) showing how the individual is embedded in various contexts such as family and community. With a focus on HIV stigma in Africa, Deacon, Prosalendis, and Stephney (2005) propose a “blaming model of stigma”, whereby a sense of control is gained by blaming outgroups as being at risk. Deacon et al. (2005) define stigma as “ideology that identifies and links the presence of a biological disease agent (or any physical signs of disease) to negatively defined behaviours or groups in society.” (p. ix). The Siyam’kela Project report includes a definition of stigma as a social label affecting how a person views himself and how society views the person (Siyam'kela, 2003). The project exposed general indicator findings, such as perceptions about HIV and AIDS as well as external stigma (avoidance and rejection for example) and internal stigma (social withdrawal and perceptions of self for example) (Siyam'kela, 2003).

This study is grounded in the Holzemer et al. (2007b) model that describes stigma as a process that begins with triggers of stigma, leading to stigmatising behaviours, then types of stigma having specific stigma outcomes. The process is placed within the context of a person’s environment, the health-care setting and various agents. Holzemer et al. (2007b) refer to internal stigma as one of the types of stigma identified along with received and associated stigma.

Internal stigma refers to a person's own negative perceptions about themselves, received stigma refers to behaviours toward a person living with HIV or AIDS that is stigmatising, and associated stigma refers to stigmatising behaviours received by those associated with someone living with HIV or AIDS (Holzemer et al., 2007b). Studies on how HIV stigma is experienced by PLHA in South Africa (in both rural and urban communities) have yielded results in line with the Holzemer et al. (2007b) model whereby received, internal and associated stigma have been experienced (Holzemer et al., 2007b). In the North West Province PLHA and nurses involved in their care experienced nine dimensions of received stigma with gossiping as the most reported, four dimensions of internal stigma, with social withdrawal as most reported and aspects of associated stigma of nurses and their family members (Greeff & Phetlhu, 2007).

In examining differences in HIV stigma experiences between rural and urban contexts Naidoo et al. (2007) reported higher incidences of received and internal stigma among urban participants than among rural participants in their study of stigma across five African countries, and attributed these differences to social networks and differences in literacy levels between the two contexts. The results of the study by Naidoo et al. (2007) differ from those of Brems, Johnson, Warner and Roberts (2010) and their study of experiences of HIV-related stigma in rural Alaskan and New Mexico communities in that, for various reasons, incidences of HIV related stigma were higher among rural participants. In a report by directors of NGOs in Africa it was noted that among rural communities with lower education rates HIV stigma was higher (Benotsch et al., 2008). Both Naidoo et al. (2007) and Brems et al. (2010) state that the size of the communites is relevant, that larger rural communities may not differ significantly from urban communities in terms of how HIV stigma is experienced.

How HIV stigma is experienced by PLHA and how they cope with these experiences may impact on their quality of life (Mokoae, et al., 2008).When an environmental stress occurs, an individual first appraises the situation for potential risks or gains, appraises the possible actions to take and finally executes those actions (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Self-judgment of the ability to cope with a situation is referred to by Bandura (1982) as perceived self-efficacy, a form of personal control that in the context of chronic illness may impact on quality of life (Arnold, et al., 2005). Self-efficacy can influence the judgment or second appraisal of an individual as to which type of coping to elect (Chesney et al., 2006). Engaging in certain behaviours and activities may reinforce a person's coping self-efficacy, and a person may avoid behaviours that do not increase coping self-efficacy (Kang, Deren, Andia, Colón, & Robles, 2004). Two psychological strategies, according to Medley, Kennedy, Lunyolo, and Sweat (2009) when coping with a chronic illness, such as HIV, are problem-focused coping and emotion-focused coping. Problem-focused coping includes enacting changes; either to self or environment to reduce stress, and emotion-based coping is how the individual perceives the stress, not necessarily enacting changes. Emotion-based coping may include self-acceptance, an important part of coming to terms with being HIV positive as well as when and who to disclose to (Medley, Kennedy, Lunyolo, & Sweat, 2009).

Both strategies were observed in the study of Makoae et al. (2008) where rationalisation, seeing self as being OK, turning to God, hoping and humour were listed under emotion-based coping and joining a group, disclosing, going for counselling, and helping others under problem-focused coping. Chesney et al. (2006) include "problem-focused coping" as one dimension of coping, adding "stop unpleasant thoughts and emotions" and "get support from friends and family". Typically these categories of coping are influenced by psychosocial factors such as social support (Nannis, Patterson, & Semple, 1997). The dimension of seeking social support, as described in Chesney et.al (2006), is relevant to the South African context which is collectivist in social orientation, and where HIV stigma largely occurs in a social/interpersonal context. This third dimension involves both problem and emotion focussed coping but is independent as it is a definite set of skills (Chesney, et.al., 2006)

The Coping Self Efficacy scale of Chesney et al. (2006) formed part of the test battery in the larger SANPAD study, from which this study gathered its data. The scale furthers the stress and coping theory (regulation of distress and management of issues underlying it) by assessing the link between the theory and secondary appraisal. The inclusion of the scale was apt in lieu of the nature of the larger HIV stigma reduction study in that the scale was developed in order to assess coping self-efficacy in people coping with chronic illness (Chesney et. al. 2006). Chesney et. al. (2006) note that it is important to assess coping self-efficacy using instruments tailored to the sphere of activity. Validation of the instrument included data analysed gathered for HIV-seropositive men with a depressed mood. This study is therefore conceptualised in line with coping self-efficacy as described by Chesney et.al. (2006).

Research Design

Data were gathered as part of a greater intervention study aimed at stigma reduction within communities. The intervention included educational material and group participation to help PLHA understand the context of stigma and to share experiences. The workshop, over a period of five months extended to people living close to PLHA and to community and spiritual members. This study focused on the experiences of PLHA

A convergent parallel design (Creswell & Plano Clark, 2011) was used within a mixed method approach. Qualitative data were gathered using the interpretive description approach (Thorne, 2008) and quantitative data were collected using a survey design (Creswell, 2009).

Method

The study comprised three stages: Qualitative data gathering through in-depth interviews, quantitative data gathering through measurements and a comparison of qualitative and quantitative results.

Sample.

The study took place in the North West Province, from both a rural (Ganyesa, n=12) and urban (Ikageng, n=11) setting. A purposive voluntary sampling method (Bowling, 2002) was used. The participants were identified through local wellness centres and NGOs and were invited to be a part of the intervention. The inclusion criteria for participants were: must be a person living with HIV or AIDS for at least six months; must speak, write and understand Setswana, English and/or Afrikaans; must be 18 years or older; must be prepared to disclose his/her status; and must be willing to give consent to be interviewed and recorded. There was no specific gender inclusion criterion. In the rural group nine (9) were female and three (3) were male and in the urban group, ten (10) were female and there was one (1) male participant. Based on the therapeutic nature of the intervention from which the participants were selected the sample size was kept small (Thorne, 2008)

Phase one: Qualitative Data Gathering.

Qualitative data collection took place in the form of in-depth interviews that explored the PLHA's experiences of HIV stigma. In-depth interviews as described in de Vos, Strydom, Fouché and Delport (2005) were conducted and recorded using a digital recorder. Two open-ended questions were asked, "Tell me about your experience of stigma as a person living with HIV" and "How did you experience this interview today?" These questions were presented to experts and pilot-tested (Botma, Greeff, Mulaudzi & Wright, 2010) to assess the applicability to this study and the depth of answers expected. Communication techniques such as paraphrasing, clarifying and reflecting were utilised (Okun, 1997). Training on in-depth interviewing was conducted prior to the study by the project leader. Field notes from the interviewer were also recorded (de Vos, Strydom, Fouché & Delport, 2005). The same procedure was followed in both the rural and the urban setting. The interviews were, in all cases conducted in English with the option of using an interpreter in order to ensure comfort of the participant and richness of data.

Data Analysis of Qualitative Data.

The recorded interviews were translated and transcribed verbatim (Nieuwenhuis, 2007). Content analysis (Botma, Greeff, Malaudzi & Wright, 2010) of the rural and urban data was done separately in order to identify any differences between the two areas, using the technique of open coding from Tesch (Creswell, 2009). A co-coder was used and consensus on the themes achieved after further discussions.

Trustworthiness of Qualitative Data Collection and Analysis.

The four epistemological standards in the model proposed by Lincoln and Guba (1985) as cited in Botma et al. (2010) were adhered to, viz. truth value, applicability, consistency and neutrality. Truth value was maintained by prolonged engagement during the in-depth interviews as well as reflexivity during field notes recorded by the interviewer. Those conducting the interviews were trained by the project leader in interviewing techniques. Triangulation of methods, sources and investigators took place. Peer discussions occurred continuously through meetings with supervisors, adding to credibility.Applicability was upheld by the sample choice and a dense description of methodology. Consistency was ensured through the availability of an audit trail, as well as using a co-coder during data analysis. Neutrality was maintained by the mentioned triangulation and audit trail.

Phase 2: Quantitative Data Gathering.

Participants completed the HIV/AIDS Stigma Instrument-PLWA (HASI-P) (Holzemer et al., 2007a) and the Coping Self-efficacy Scale (Chesney et al., 2006) at the Potchefstroom Campus of the North-West University, after the in-depth interviews had been conducted. Trained bilingual fieldworkers administered the measuring instruments on a one-on-one basis with the participants.

The HIV/AIDS Stigma Instrument – PLWA (HASI-P) (Holzemer et al., 2007a).This is a 33-item scale which measures six dimensions of HIV stigma of the individual (Holzemer et al., 2007a). The instrument was validated by Holzemer et al. (2007a) in five African countries, including South Africa. The six dimensions include verbal abuse (8 items: α=0.90), negative self-perception (5 items: α=0.90), health care neglect (7 items: α=0.83), social isolation (5 items: α=0.89), fear of contagion (6 items: α= 0.80) and workplace stigma (2 items: α=0.76) (Holzemer et al., 2007a). Negative self-perception was classified as internal stigma and the other five dimensions are forms of received stigma.

The Coping Self-efficacy Scale (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006).The Coping Self-efficacy Scale is a 26-item scale that measures an individual's evaluation of their coping self-efficacy, assessing three types of coping; problem-focused coping, stop unpleasant thoughts and emotions and get support from friends and family. Chesney et al. (2006) validated the scale, finding that the three types of coping categorised, problem-focused coping (α=0.91), stop unpleasant thoughts and emotions (α=0.91) and get support from friends and family (α=0.80),showed strong internal reliability and consistency.

Data Analysis of Quantitative Data.

Data were analysed using the SPSS V20 software to evaluate levels of stigma and coping self-efficacy for each of the subscales represented by the mean scores (¯) of the rural and urban groups. The p-values for the subscales were calculated to show any significant differences (p=0.05). The T-tests were conducted to test the significance of the differences of means of the rural and urban group. Correlations within and between the HIV/AIDS Stigma Instrument – PLWA (HASI-P) (Holzemer et al., 2007a) and the Coping Self-efficacy Scale (Chesney et al., 2006) were also conducted.

Validity and Reliability.

In order to improve validity to the small number of participants used, a mixed method approach was applied. The combination of two quantitative scales with the qualitative in-depth interviews makes for contextual validity (Creswell, 2009). Internal validity was maintained by conducting data collection in two settings within the North West Province of South Africa. Training by the project leader on how to survey using the scales was conducted prior to data collection. All the participants from both the rural and urban contexts completed the Stigma Instrument – PLWA

(HASI-P) and the Coping Self-efficacy Scale, in similar conditions; away from their homes and on a one-on-one basis. The scales included in this study have been validated in research on the particular measures (Holzemer et al., 2007a; Chesney et al, 2006).

Phase 3: Comparison of Qualitative and Quantitative Results.

Firstly, descriptive statistics (e.g. means) for all study measures were calculated. Secondly, t-tests were calculated to show differences of the means of the study measures between the rural and urban areas. Finally, correlations of the dimensions of the main measures of the study were calculated to show the relationship in line with the objective of the study.

Ethical Considerations.

Ethical approval was granted by the North-West University, as well as permission obtained from the Department of Health and local health authorities to conduct the study. Precautions to minimize risks to participants included a written signed consent form, the use of participant codes to ensure confidentiality, and the provision of psychological help if distress was experienced by the participant (Brinkmmann & Kvale, 2008). Training was provided for both the qualitative in-depth interviews, as well as how to conduct the quantitative questionnaires. The process of the research was made clear to the participants as well as the fact that they may withdraw at any time if they wish (Patton, 2002). It was also made clear in the consent form what the benefits were to both the researcher and to the participants (Patton, 2002). During the interviews permission to record was obtained before the interview began. Although there was a slight risk of loss of confidentiality by being in the interview itself, participants were reassured that their codes, and not their names, would be included in the transcripts. The expected length of the in-depth interview and conducting the two scales was indicated in the consent form, as well as the surveys. The interviews and scales were conducted outside the area where the participants were living, in order to minimise discomfort and lack of confidentiality. Participants were not paid to take part.

Results and Discussion

Levels of HIV Stigma and Verbalised Experiences of HIV Stigma

(Insert Table 1 here)

Table 1 displays the subscales of the HASI-P and their itemised descriptors, comparative mean scores (¯) per subscale for the rural and urban groups, as well as the p-value (p<0.05) indicating significant differences between the two groups. Included alongside the results of the HASI-P are confirmatory categories of the itemised descriptors as found during the in-depth interviews and their accompanying quotations, as well as those itemised descriptors not confirmed. The subscales have been grouped under "Received Stigma" (verbal abuse, healthcare neglect, social isolation, fear of contagion and workplace stigma) or "Internal Stigma" (negative self-perception). Richer descriptions than the itemised descriptors were found for both the rural and urban groups, and will be discussed in Table 2.

Verbal abuse, an eight item subscale, showed no significant difference (p=0.29) between the rural (¯= 11.17) and urban (¯ = 13.18) groups. Three of the eight items were confirmed by the rural group ("insulted", "blamed" and "no future"). Not found during the in-depth interviews for the rural group were the categories "scolded", "punishment from God", "mocked", "labelled" and "offensive songs". The urban group confirmed six of the eight items for verbal abuse, including “scolded”, “insulted”, “blamed”, “no future”, “labelled” and “mocked”. Not found during the in-depth interviews from the urban group were the items “punishment from God” and “offensive songs”. Verbal abuse in the urban setting, according to the in-depth interviews, is experienced differently and more extensively than in the rural setting, highlighting differences in community structures.

Healthcare neglect is a seven item subscale, of which both rural (¯=7.58) and urban (¯=7.63) groups indicated having had experiences, with no significant difference (p=0.92) between the two groups. Although participants had responded on the seven items of the subscale, they were not confirmed by either group during the in-depth interviews, indicating a difference in the items mentioned in the scale to that experienced by PLHA.

Social isolation, a 5 item subscale, showed no significant difference (p=0.93) between the rural (¯=6.75) and urban (¯=6.63) groups. Four of the five items were confirmed by the rural group, (“not visiting”, “end relationship”, “stopped being friends” and “avoided”) with the item “not chatting” not found during the in-depth interviews. The urban group confirmed three of the five items (“not visiting”, “stopped being friends” and “avoided”) with “end relationship” and “not chatting” not confirmed. The items of the subscale, and the experiences revealed during the in-depth interviews showed similarity in both settings, confirming that social isolation is a form of HIV stigma generally experienced by PLHA in the North West province.

The experience of *fear of contagion* was evident in both rural (¯=7.75) and urban (¯=7.63) settings with no significant difference (p=0.94). The in-depth interviews from the rural group confirmed four of the six items of the subscale (“sharing eating utensils”, “sharing cups”, “not touch someone’s child” and “made to eat alone”). Not confirmed during the interviews for the rural group was “asked to leave because of coughing” and “stopped eating with others”. The urban group confirmed three of the six items, “sharing eating utensils”, “sharing cups” and “stopped eating with others”. Not included in the confirmatory categories for the urban group were “not touch someone’s child”, “asked to leave because of coughing” and “made to eat alone”. The categories confirmed by the in-depth interviews of the two groups indicate that although *fear of contagion* is experienced in both settings, how it is experienced differs. This may be due to differences in the way a community functions, including social interactions, such as eating and village involvement in interacting with children.

Workplace stigma is a two item scale which indicated no significant difference (p=0.37) between the rural (¯=2.01) and urban (¯=2.04) groups. The items were not confirmed by the in-depth interviews (“tried to get me fired” and “denied opportunities”). Only one participant from the rural and urban group was employed. Quite notably, employment as such was a problem as most of the participants themselves were unemployed, thus interpretation of the item must be done carefully. That stigma was indicated in the scale shows that, despite the small number of employed respondents, stigma in the workplace had been experienced and a much larger study is needed to explore how it was experienced in the two settings.

Negative self-perception, under internal stigma, is a 5-item subscale that showed no significant difference (p=0.85) between the rural (¯=7.25) and urban (¯=7.54) groups. Both the rural and urban groups confirmed the items “not deserve to live”, “worthless” and “feel ashamed”. The rural group did not confirm “trouble to family” and “not a person” while the urban group only indicated one item (trouble to family) as not confirmed. The situations were thus very similar for the two settings and the sets of data showed great similarity.

Additional Categories to the Existing Quantitative Measure Found During In-depth Interviews

(Insert Table2 here)

Qualitative data from the in-depth interviews highlighted themes not reflected in the subscales of the HASI-P. These themes may add richness to the subscales of verbal abuse, social isolation and fear of contagion, as well as a possible new subscale, non-verbal abuse. For internal stigma, indicated as negative self-perception, three themes were observed during the in-depth interviews: negative self-perception, fear of disclosure and isolation of self (See Table 2). Quotes enrich the categories observed.

Types of received stigma not reflected by what was measured under the subscale *verbal abuse* included “gossiping” *"But they didn’t talk so loud. They just look and talking, talking, talking, talking that you have an HIV positive”*, “pestering” *"They ask me these funny questions...Why are you coughing like this?”,* “disclosing without consent” *"I feel so angered because I think it is my secret to know that I have got HIV positive."* and “disbelief about status” *"The pastors, I tell them, and they say, You are lying.".* Forms of *social isolation* found included “rejection” *"Go outside of my house."* and “not getting support” *“When my days were dark she wasn’t there for me”.*

Additional categories of *fear of contagion,* included “limit physical contact” *"Refusing to touch me",* “not sharing sleeping quarters” *"You sleep maybe they want you outside. They do not want you to use their blanket in house.",* “won’t share ablutions” *"They can’t wash with the same, in the same bathroom. They can’t use your soap. They can’t use your waslap (face cloth)",* “won’t share home” *"You will infect everybody in the home",* and “not eating the food you prepared" *"When you cook food, they can't eat that food ".* The additional theme *non-verbal abuse* included "gesturing"*"they scratch each other"* and "facial expressions" *"You know, you can see people with their eyes."* These additional types of stigma reflect a possible disparity between what is currently being measured through the use of the HASI-P and what is currently being experienced. It is noted that the sample size of this study was small and continual studies are needed to enrich the current descriptions of HIV stigma. It is also noted that having the themes above mentioned in in-depth interviews even in a small sample means that there is stigma being experienced in these forms in these two settings and further study is encouraged.

Three categories found during the in-depth interviews may enrich the forms of internal stigma in the measure. *Negative self-perception* included the category "self-labelling through associations of symptoms and treatment of other PLHA" *"The way they treated them, you know. So I thought it would happen to me." Fear of disclosure* included "fear of received stigma*" "You "It was because I feared that when people would know, they would point me with fingers."* and "afraid of affecting loved ones" *"I was thinking they will be heartbroken."* The category *self-isolation* included "withdrawal" *"You become, stay indoors. No mixing with people."* ,"lonely" *"I think that. Maybe I will be alone because of my problem"* and "feel different" *"I feel like a, not a South African, maybe like I'm from Norway."* The category "withdrawal" was particularly evident during the in-depth interviews showing a need for a larger study to review the current scale. The additional forms of stigma point to a greater understanding of the contexts of how HIV stigma is experienced by PLHA. There are, thus, shifts in the types of stigma experienced (received and internal) that could enrich the current subscales of the HASI-P measure, and are new subscales could be included.

Levels of Coping Self-efficacy and Verbalised Coping Self-efficacy

(Insert Table 3 here)

Table 3 displays the subscales of the coping self-efficacy scale, the mean scores (¯ of the rural and urban groups and the p-values ($p<0.05$) for each subscale. Included are categories of coping self-efficacy that emerged during the in-depth interviews and their accompanying quotations, confirming the description of each subscale as drawn from Chesney et.al. (2006) and Mokoae, et al., 2008. The confirmatory categories of coping self-efficacy have been ordered to show similarities and differences between the two groups by placing unique categories per group under a line.

There was no significant difference ($p=0.66$) in the dimension *problem-focused coping*, between the rural (¯=83.25) and urban (¯=86.91) groups. Both groups included six of the same categories of coping for the subscale ("disclose", "acquiring knowledge", "attention to health", "helping others", "get help" and "stand up for self") as found during the in-depth interviews. Additionally the rural group included "resist urge to act hastily". The urban group included two more categories "accept what cannot be changed" and "actively not withdrawing". Thus the high scores for the measure of *problem-focused coping* were confirmed by the categories of coping self-efficacy found during the in-depth interviews. The categories of *problem-focused coping* as found during the in-depth interviews also confirmed that there was great similarity between the rural and urban groups but that there is a possibility that the urban group tends towards more proactive problem-focussed coping.

Statistically, there was no significant difference ($p=0.79$) between the rural (¯=65.85) and urban (¯=67.77) scores for the subscale *stop unpleasant thoughts and emotions*. The confirmatory categories were the same for both groups, including “acceptance of HIV”, “self-acceptance”, “turn to God”, “rationalising”, and “knowing status is power”. The statistics and categories therefore show that there is great similarity between the two groups.

Get support from friends and family showed no significant difference (p=0.92) between rural (¯=33.47) and urban (¯=32.88) groups. Both groups showed self-efficacy in getting support from “friends” and “family”, as confirmed by the in-depth interviews and added “from health-care services”. The urban group also gained support “from religious institutions” and “support groups”, which suggests that there is higher self-efficacy to access more areas of support in the urban setting than in the rural community, or that there are more social support structures available.

Correlations Within and Between the HASI-P and CSE Scales

(Insert Table 4 here)

Correlations of all the quantitative study measures are presented in the Table 4. Correlations were deemed significant at the 0.01 and 0.05 levels. The data from the rural and urban sets were pooled as there were no statistically significant differences between the means of the subscales of either of the scales. Correlations found within a scale generally show internal validity.

Correlations within the HASI-P (Holzemer et al., 2007a) showed a significant link between *verbal abuse* and *social isolation* (r=0.67); *health care neglect* and *fear of contagion* (r=0.53); and *fear of contagion* and *social isolation* (r=0.59). These internal correlations indicate relationships between types of HIV stigma, showing that HIV stigma is experienced in more than one dimension. For example PLHA who experience verbal abuse and fear of contagion may tend to towards social isolation.

Within the coping self-efficacy scale (Chesney et al., 2006) there were high correlations between *problem-focused coping* and *stop unpleasant emotions and thoughts* (r=0.83); and *problem-focused coping* and *get support from friends and family* (r=0.76). This shows that as a person gains self-efficacy in problem-focussed coping this positively correlates to other ways of coping. Stopping unpleasant thoughts and emotion and getting support from friends and family are more likely to reflect higher self-efficacy in a person who employs problem focussed coping.

Correlations between the HASI-P and CSE scale showed significant correlations between *verbal abuse* and *problem-focused coping* (r=0.47); and *workplace stigma* and *get support from friends and family* (r=0.46). The correlations show the relationship between experiences of HIV stigma and the coping self-efficacy of PLHA and confirm the "stress and coping" model described in Chesney et al. (2006). A person who experiences verbal abuse may moderately be driven to social isolation but may also be mildly driven to employ problem focussed coping strategies.

As mentioned previously workplace stigma is a problematic item as those employed in the sample were too few to represent the sample. It has been noted in the above results that there are at times discrepancies between what the stigma scale measured and what was experienced in the in-depth interviews. It may be that those participants who did complete the section on the scale for workplace stigma did so significantly enough to show that it is experienced and that when it is there is a mild tendency to seek support from friends and family.

Conclusion

HIV stigma does exist, and is experienced by PLHA in the North West Province in both a rural and an urban setting. The quantitative measure (HASI-P) indicates that the six dimensions of HIV stigma, as described by Holzemer et al. (2007b), are evident in both rural and urban settings, with no significant difference. Qualitative data confirmed the results of the HIV stigma measure, as well as highlighting a few differences in contexts between the two settings, particularly in how verbal abuse is experienced. Additional types of stigma found to those included in the HASI-P point to shifts in the way people are stigmatised, and show a need for continual review of current scales and seeking understanding.

The results of the CSE scale show that PLHA from both rural and urban settings employed the three types of coping self-efficacy as described by Chesney et. al. (2006), with no significant difference between the two groups. There were a few variations in ways of coping in the qualitative data, which showed a slight difference in the way PLHA in rural and urban settings employed *problem-focused coping*, and the urban group having more extended ways of *getting support*.

Statistical correlations within the HASI-P revealed that there were correlations between certain types of stigma experienced, indicating that HIV stigma is not experienced in a single dimension but can extend to more than one area of the lives of PLHA. Correlations within the CSE scale illustrate that coping self-efficacy in one strategy may mean that coping self-efficacy will be evident in another. Correlations between the two scales demonstrate that as PLHA experience certain types of stigma, they display self-efficacy in certain ways of coping. This shows that although HIV stigma exists, PLHA develop coping self-efficacy to deal with those experiences.

The goals of the research were achieved in that it was confirmed that HIV stigma and coping self-efficacy of PLHA in rural and urban settings do exist and that there is no significant difference between the two groups. The relationship between HIV stigma and coping self-efficacy of PLHA was established through the correlation of scales and through the evidence found during in-depth interviews; that HIV stigma exists and that PLHA employ various ways of coping to deal with it.

Limitations

A limitation of this study is that the sample size was small; however, as explained, the sample was kept small due to the therapeutic nature of the intervention study from which this data were collected. In order to counteract this limitation a mixed methods study was employed, combining two measures and including qualitative data from in-depth interviews. The in-depth interviews and the quantitative measures were conducted in English, which may elicit limited spontaneous responses from non-English speakers. To compensate for this, an interpreter was utilised when necessary.

Recommendations

Further research

- Continual studies on HIV stigma and coping self-efficacy of PLHA are necessary as this study shows there may be ongoing shifts in the community dynamic, how PLHA are stigmatised, and how they cope.
- The stigma scale (HASI-P) could be revised and the subscales *verbal abuse*, *social isolation* and *fear of contagion* could be enriched with items found during the in-depth interviews. Internal stigma could include three possible subscales, *negative self-perception*, *fear of disclosure* and *isolation of self*. Revision could also include the removal of those descriptors not found in the qualitative data (in-depth interviews) such as the types of *health-care neglect* and *workplace stigma*. This would make for a more valid depiction of the state of HIV stigma at present.
- A coping self-efficacy scale could be developed, specifically for coping with stigmatised illnesses, such as HIV or AIDS, based on more qualitative data (in-depth interviews and focus groups) gained from a larger sample.

Policy development

- Knowledge gained of the types of HIV stigma and ways of coping found in this study could enrich current community intervention programmes that attempt to reduce HIV stigma and increase coping strategies for PLHA.
- Policy guidelines on reducing HIV stigma could be formulated and used in public, health and education domains to help educate and protect PLHA.

Practice

- In the health-care domain, once a person is diagnosed with HIV or AIDS, there could be a system of referral to workshops or support groups on HIV stigma and ways of coping, in order to increase PLHA quality of life.

Table 1. A comparison of stigma measures and qualitative data

Received Stigma	**Means**			**Confirming categories and quotations**			
Verbal abuse	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Scolded Insulted Blamed No future Punishment from God Labelled Mocked Offensive songs	11.17	13.18	0.29	Insulted Blamed No future	*"I don't want that smell."* *"You make my child become sick because of you are not all right. You are positive."* *"Have you bought a coffin yet?"*	Scolded Insulted Blamed No future Labelled Mocked	*"I told you don't do that. Don't do that. Don't go around with boys."* *"I am better than you because you don't wash."* *"As if you wanted to be sick",* *"That one is going to die."* *"You are cheap; you are a slut or a prostitute."* *"Look at her, she is ill and positive...what, what, wh and laugh then."*
				Not found during interviews Scolded Punishment from God Labelled Mocked Offensive songs		**Not found during interviews** Punishment from God Offensive songs	
Health care neglect	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Denied care Refused treatment Discharged, still needing care Shuttled around Waited till last to be helped Left in soiled bed Pain ignored	7. 58	7. 63	0.92		No comments confirmed the items as listed under health care neglect		No comments confirmed the items as listed under health care neglect
Social isolation	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Not visiting End relationships Not chatting Stopped being friends Avoided	6.75	6.63	0.93	Not visiting End relationships Stopped being friends Avoided	*"Not coming to me because of my status".* *"He says he can't stay with a person living with HIV."* *"My friend can't go at the school with me to talk, to eating."* *"Separating when they hear you are HIV positive."*	Not visiting Stopped being friends Avoided	*"When they heard I am sick, they stopped to come"* *"Start to hate me and don't want to go with me"* *"They ignore me, it's like they don't know me."*
				Not found during interviews Not chatting		**Not found during interviews** End relationships Not chatting	

Table 1. A comparison of stigma measures and qualitative data (continued)

Fear of contagion	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Eating utensils Sharing cups Not touch someone's child Stopped eating with others Asked to leave due to coughing Made to eat alone	7.75	7.63	0.94	Eating utensils Sharing cups Not touch someone's child Made to eat alone	*"Which dishes can we eat with them? They say like that to us"* *"They don't want to drink with the same cup."* *"You make my child become sick because of you are not all right. You are positive"* *"They didn't want to eat with me"*	Eating utensils Sharing cups Stopped eating with others	*"They do not want to eat in the dish when you use it"* *"If you are in a party, they will never share the glass with you."* *"They don't want to eat with me. I was feel so sad and then I become so afraid to go with my friends and go and sit with them"*
				Not found during interviews		**Not found during interviews**	
				Stopped eating with others Asked to leave due to coughing		Not touch someone's child Asked to leave due to coughing Made to eat alone	
Workplace stigma	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Tried to get me fired Denied opportunities	2.01	2.04	0.37		No comments confirmed the items as listed under Workplace stigma		No comments confirmed the items as listed under Workplace stigma
Internal Stigma	**Means**			**Confirming categories and quotations**			
Negative self-perception	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Not deserve to live Worthless Feel ashamed Trouble to family Not a person	7.25	7.54	0.85	Not deserve to live Worthless Feel ashamed	*"I feel like committing suicide,"* *"...at last you can see that you are not, you don't have good enough"* *"Yes, I feel ashamed"*	Not deserve to live Worthless Feel ashamed Not a person	*"I even thought of committing suicide."* *"I feel small. I feel very small."* *"Everything I did, everywhere I went, I felt ashamed to hear a person saying, "Look at her. She is positive."* *"I feel that they are classifying me as a non-living person"*
				Not found during interviews Trouble to family Not a person		**Not found during interviews** Trouble to family	

Table 2: Additional categories to the existing quantitative measure from in-depth interviews

Additional types of Received stigma		**Additional types of Internal stigma**	
Verbal abuse		**Negative self- perception**	
Gossiping	*"But they didn’t talk so loud. They just look and talking, talking, talking, talking that you have an HIV positive"*	Self labelling through associations of symptoms and treatment of other PLHA	*The way they treated them, you know. So I thought it would happen to me."*
Pestering	*"They ask me these funny questions. “Why are you coughing like this?”*	**Fear of disclosure**	
Disclosing without consent	*"I feel so angered because I think it is my secret to know that I have got HIV positive."*	Fear of received stigma	*“It was because I feared that when people would know, they would point me with fingers.”*
Disbelief about status	*"The pastors, I tell them, and they say, You are lying."*	Afraid of affecting loved ones	*“I was thinking they will be heartbroken."*
Social isolation		**Isolation of self**	
Rejection	*"Go outside of my house."*	Withdrawal	*“You become, stay indoors. No mixing with people."*
Not getting support	*“When my days were dark she wasn’t there for me”*	Feel different	*“I feel like a, not a South African. Maybe like I’m from Norway.”*
Fear of contagion		Lonely	*"I think that. Maybe I will be alone because of my problem"*
Limit physical contact	*"Refusing to touch me."*		
Not sharing sleeping quarters	*"You sleep maybe they want you outside. They do not want you to use their blanket in house."*		
Won’t share ablutions	*"They can’t wash with the same, in the same bathroom. They can’t use your soap. They can’t use your waslap (face cloth)"*		
Won’t share home	*"You will infect everybody in the home"*		
Not eating the food you prepared	*"When you cook food, they can’t eat that food "*		
Non verbal abuse			
Gesturing	*"They scratch each other"*		
Facial expressions	*“You know, you can see people with their eyes.”*		

Table 3. Coping self-efficacy measures and confirming qualitative data

Types of coping	**Means**			**Confirming categories and quotations**			
Problem-focused coping	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Analyse the problem and employ strategies that make th perceived problem less challenging	83.25	86.91	0.66	Disclose	*"Like when you are sick and you go to the doctor, and the doctor gives you the medicine and you become healthy. (talking to others)"*	Disclose	*"Living with a secret is not safe. It is heavy. If I continue to hide it, it will cause stress on me."*
				Acquiring knowledge	*"I see in the TV about this and at the books I see. I read."*	Acquiring knowledge	*And then I'll follow the experience of the counsellors. And the experience of the doctors.*
				Attention to health	*"But when you eat your treatment and you become healthy, and when you eat the right food, you exercise and protect, there is no one can see you are positive."*	Attention to health	*"I must look after myself. Eat healthy food. Sleep enough. No drinking,"*
				Helping others	*"That she must know it's not only her,"*	Helping others	*"Okay and maybe after that I motivate them who are ill."*
				Get help	*"But there was one lady at the clinic. She says, When you have a problem you must call me."*	Get help	*"Then looked for a support group all for myself,"*
				Stand up for self	*"I told him: I don't like that "*	Stand up for self	*"I confront the person, then I'm alright"*.
				Resist urge to act hastily	*"I go to my room and thinking before I can talk to them"*	Accept what cannot be changed	*"But I tell myself I cannot change that thing."*
						Actively not withdrawing	*"I am living as a normal person."*
Stop unpleasant emotions and thoughts	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Altering emotional response	65.85	67.77	0.79	Acceptance of HIV	*"When I accept I am HIV positive, I had power, you know, power than before."*	Acceptance of HIV	*"HIV is my friend."*
				Self acceptance	*"No one can accept you before you accept you."*	Self acceptance	*"So that is why I walk tall. I am brave."*
				Turn to God	*"God thanks for this one. You send this stuff to come and tell me a story"*	Turn to God	*"The Lord saved my life "*
				Rationalising	*"Not you for the first time, many people have that sick."*	Rationalising	*"As I read magazines that were showing different types of HIV transmission"*.
				Knowing status is power	*"I am happy. I am proud because I know my status"*	Knowing status is power	*"I'm better because I know my status."*

Table 3. Coping self-efficacy measures and confirming qualitative data (continued)

Get support from friends and family	**Rural**	**Urban**	**P-value**	**Rural**		**Urban**	
Belief in ability to seek help from others to cope with problems	33.45	32.88	0.92	Friend Family From health care services	*"And also the friends that love me."* *"She also encourage me, this is not the end of the world. (aunt)"* *"I feel fine because when I go to the hospital he counse me"*	Friend Family From health care services	*“When I am sick, there is one friend who really stands with me.”* *"And close relatives supported me".* *"Inside I greet that sister in the ward …Just like that, believe me, encouraged me.*
						From religious institutions Support groups	*"He hugged me and even the congregation was happy to see me."* *"So that now I'm feeling better because I go to support groups at the clinic."*

Table 4. Correlation between HASI-P and CSE Scale

Subscales	1	2	3	4	5	6	7	8	9
HASI_Verbal abuse	1.00								
HASI_Negative perception of self	0.21	1.00							
HASI_Health care neglect	0.27	-0.15	1.00						
HASI_Social isolation	0.67**	0.05	0.29	1.00					
HASI_Fear of contagion	0.39	0.16	.53**	.59**	1.00				
HASI_Workplace stigma	-0.15	0.41	-0.11	-0.12	-0.11	1.00			
CSE_Problem focused coping	0.47*	0.12	-0.18	0.37	0.35	-0.19	1.00		
CSE_Stop unpleasant emotions and thoughts	0.44	-0.24	-0.20	-0.75	-0.38	0.00	.83*	1.00	
CSE_Get support from friends and family	0.17	-0.10	-0.19	0.15	0.25	.46*	.76**	0.71	1.00

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

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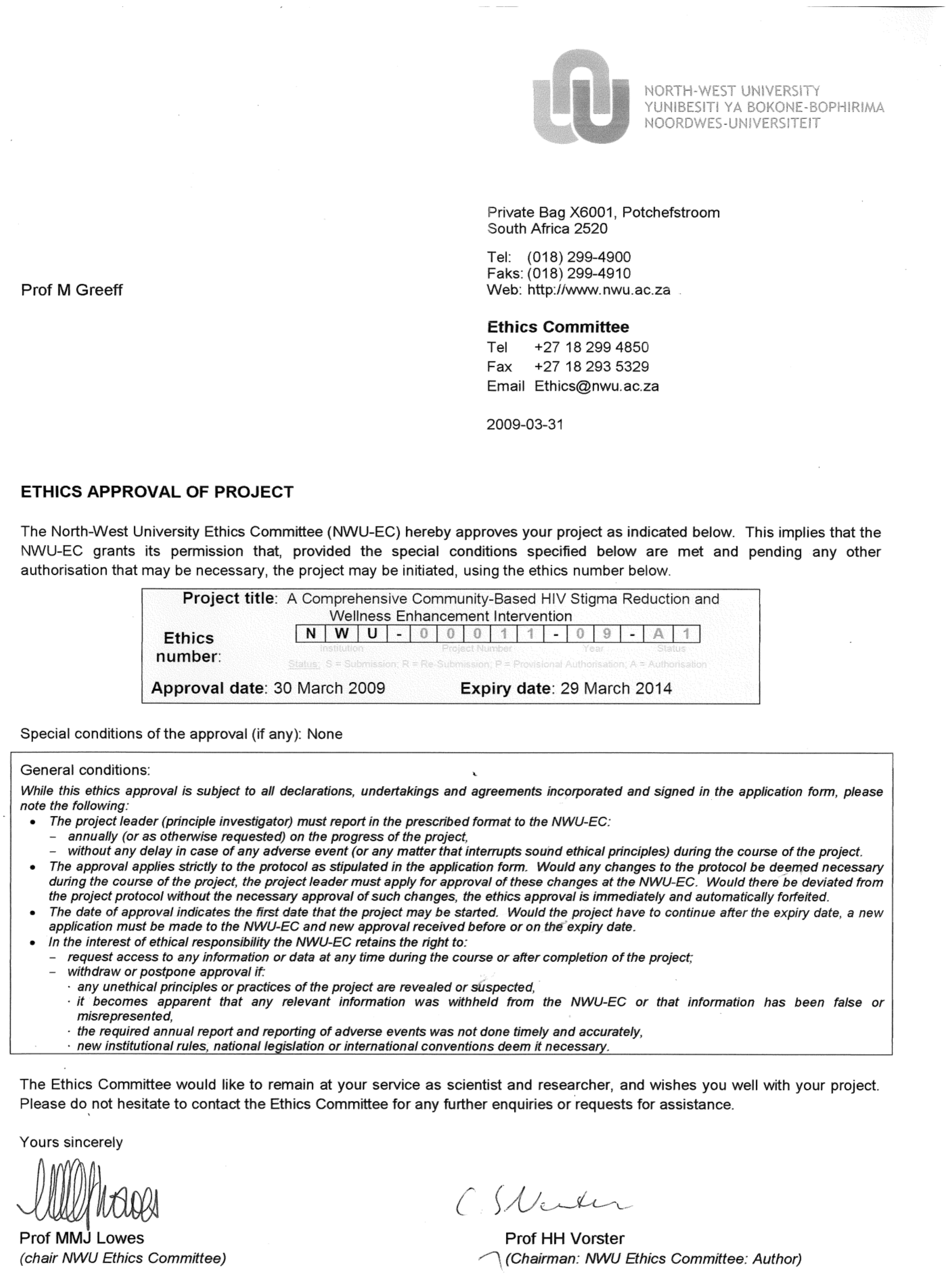
Appendix A: Ethical approval



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Prof M Greeff

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 deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.*
- *In the interest of ethical responsibility the NWU-EC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the project are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,*
    - *the required annual report and reporting of adverse events was not done timely and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*

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

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

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

Appendix B: Informed consent

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

__________________ __________________________

Date **Signature of the participant**

_________________ __________________________

Date **Signature of the person obtaining consent**

Appendix C: Example of in-depth interview

Moderator And that's what we would like to find out. If you, as XXX, have had experiences where people treat you maybe differently. Like as if you've got this label. Or mark or something on you and they see you and then they might treat you in another way.

Respondent Okay. I understand now.

Moderator Okay

Respondent For the first time when I was pregnant, my nurse said to me I must take a blood test. So he gives me the advice, so I go and then when he took my blood, he said I am HIV positive. I am all right with that. I say I am all right because I see in the TV about this and at the books I see. I read, and when I am working at the Rustenburg, we talk about Love Life. You see, so I say, "I am all right." (They say) "So let's sit down and talk about this." I will say, "No, I am all right."

But I am not all right. When I am coming at home, I am confused a little bit. "What I will say to my boyfriend or my parents or my family?" I don't know what to start, you see. But when the time is running, I think the first one I must tell is my mother. And I tell my mother, "Mother, I have something to tell you, but I doubt." She says, "Talk, I will listen. I will not tell anybody." I say, "Mother, I am pregnant. But I took the blood test, so they say I am HIV positive."

(She said) so, it's not you who are wrong. There are too many people who are HIV positive. So when they tell you are positive, don't like I'm dying uh, uh. My mother advised me that. After that, I go to my uncle's daughter. I tell her, "I have something to tell you but I don't know where to start." She says "I know I was at the hospital at Klerksdorp, and they told me I am HIV positive." I say, "And me also," you see. She gives me the advice and me also we talk about that.

Moderator Okay

Respondent So after that, now I am free, you see. After that, I go to my boyfriend: "I want to tell you something, but not here. I want to go with you at the clinic." (He said) "Why go to the clinic? Tell me now." Okay, I will think before I will tell you." For the first time I think, when I tell my boyfriend, he will leave me. What about the baby? You see that things. But there was one lady at the clinic. She says, "When you have a problem you must call me. I will come to you and tell you what to do what to begin." They give me also the advice.

Appendix D: Example of Field notes

Participant 101

Observational notes

101 is very animated, very excited to talk, very enthusiastic and very chatty. I'm not too sure if this covers up any real feelings or not but I had the feeling she is being open and honest.

Methodological notes

In this interview the participant led most of the conversation and I found it was easy to reflect and to paraphrase and to get more information, because she was so willing to speak.

Personal notes

I am not too sure how much is true emotion, I found it was an easy interview to get a lot of information, I do have some doubts, that there are places I could have gone deeper.

Appendix E: HIV/AIDS Stigma Instrument – PLWA (HASI-P)

HIV/AIDS Stigma Instrument – PLWA (HASI-P)©

I'm going to read a list of events that may have happened to you during the past three months. After I read each item, please tell me how often it happened to you <u>because of your HIV status</u>:

In the past 3 months, how often did the following events happen <u>because of your HIV status</u>?	Never	Once or twice	Several times	Most of the time
1. I was told to use my own eating utensils.	☐	☐	☐	☐
2. I was asked not to touch someone's child.	☐	☐	☐	☐
3. I was made to drink last from the cup.	☐	☐	☐	☐
4. Someone mocked me when I passed by.	☐	☐	☐	☐
5. I stopped eating with other people.	☐	☐	☐	☐
6. I was asked to leave because I was coughing.	☐	☐	☐	☐
7. Someone stopped being my friend.	☐	☐	☐	☐
8. A friend would not chat with me.	☐	☐	☐	☐
9. I was called bad names.	☐	☐	☐	☐
10. People sang offensive songs when I passed by.	☐	☐	☐	☐
11. I was told that I have no future.	☐	☐	☐	☐
12. Someone scolded me.	☐	☐	☐	☐
13. I was told that God is punishing me.	☐	☐	☐	☐
14. I was made to eat alone.	☐	☐	☐	☐
15. Someone insulted me.	☐	☐	☐	☐
16. People avoided me.	☐	☐	☐	☐
17. People cut down visiting me.	☐	☐	☐	☐

18. People ended their relationships with me.	☐	☐	☐	☐
19. I was blamed for my HIV status.	☐	☐	☐	☐
20. Someone tried to get me fired from my job.	☐	☐	☐	☐
21. My employer denied me opportunities.	☐	☐	☐	☐
The next set of questions is about your experiences <u>in the hospital or clinic</u>.				
In the past 3 months, how often did the following events happen <u>because of your HIV status</u>?	Never	Once or twice	Several times	Most of the time
22. I was denied health care.	☐	☐	☐	☐
23. I was refused treatment because I was told I was going to die anyway.	☐	☐	☐	☐
24. I was discharged from the hospital while still needing care.	☐	☐	☐	☐
25. I was shuttled around instead of being helped by a nurse.	☐	☐	☐	☐
26. At the hospital/clinic, I was made to wait until last.	☐	☐	☐	☐
27. At the hospital, I was left in a soiled bed.	☐	☐	☐	☐
28. In the hospital or clinic, my pain was ignored.	☐	☐	☐	☐
These questions are about some of <u>your thoughts or feelings</u>.				
How often have you thought or felt this way during the past 3 months <u>because of your HIV status?</u>	Never	Once or twice	Several times	Most of the time
29. I felt that I did not deserve to live.	☐	☐	☐	☐
30. I felt ashamed of having this disease.	☐	☐	☐	☐
31. I felt completely worthless.	☐	☐	☐	☐
32. I felt that I brought a lot of trouble to my family.	☐	☐	☐	☐
33. I felt that I am no longer a person.	☐	☐	☐	☐

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Appendix F: Coping Self-Efficacy Scale (CSE)

Coping Self-Efficacy Scale (CSE) (Chesney et al., 2006)

When things aren't going well for you, or when you're having problems, how confident or certain are you that you can do the following:

Cannot do at all					**Moderately certain can do**					**Certain can do**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

For each of the following items, write a number from 0 - 10, using the scale above.

When things aren't going well for you, how confident are you that you can:

1. Keep from getting down in the dumps. ______ 99
2. Talk positively to yourself. ______ 99
3. Sort out what can be changed, and what can not be changed. ______ 99
4. Get emotional support from friends and family. ______ 99
5. Find solutions to your most difficult problems. ______ 99

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6. Break an upsetting problem down into smaller parts. ______ 99
7. Leave options open when things get stressful. ______ 99
8. Make a plan of action and follow it when confronted with a problem. ______ 99
9. Develop new hobbies or recreations. ______ 99
10. Take your mind off unpleasant thoughts. ______ 99

11. Look for something good in a negative situation. ______ 99

12. Keep from feeling sad. ______ 99

13. See things from the other person's point of view during a heated argument. ______ 99

14. Try other solutions to your problems if your first solutions don’t work. ______ 99

15. Stop yourself from being upset by unpleasant thoughts. ______ 99

16. Make new friends. ______ 99

17. Get friends to help you with the things you need. ______ 99

18. Do something positive for yourself when you are feeling discouraged. ______ 99

19. Make unpleasant thoughts go away. ______ 99

20. Think about one part of the problem at a time. ______ 99

21. Visualize a pleasant activity or place. ______ 99

22. Keep yourself from feeling lonely. ______ 99

23. Pray or meditate. ______ 99

24. Get emotional support from community organizations or resources. ______ 99

25. Stand your ground and fight for what you want. ______ 99

26. Resist the impulse to act hastily when under pressure. ______ 99