

A COMMUNITY-BASED HIV STIGMA REDUCTION INTERVENTION FOR PEOPLE LIVING WITH HIV AND THEIR PARTNERS

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ABSTRACT

The diagnosis of HIV impacts the lives and the relationships of both people living with HIV (PLWH) and their partners. The researchers aimed to describe the influence of a community-based HIV stigma reduction intervention on PLWH and their partners by means of a case study as well as their lived experiences during and after the

intervention in both an urban and a rural setting in the North West Province, South Africa. A qualitative holistic multiple case study design and interpretive description approach through in-depth interviews was used. Purposive voluntary sampling was used for the PLWH and snowball sampling for their partners. The case record included multiple sources. Document analysis and open coding were used for analysis. No real differences were noted between the urban and rural groups and the data was then pooled. Participants expressed experiences that were evident of a successful intervention. Follow-up interventions with PLWH and partners are suggested.

Keywords: community-based, HIV stigma, intervention, partners

INTRODUCTION AND BACKGROUND INFORMATION

This study was part of a larger comprehensive community-based HIV-stigma reduction intervention project involving people living with HIV or AIDS (PLWH) and different groups of persons living close to them such as partners, children, family, friends, spiritual leaders and community members, in both an urban and a rural setting. The aim of the larger study was to describe the influence of this HIV-stigma reduction intervention, as well as the lived experiences during and after the intervention. Due to the sensitive nature of the intervention, PLWH were first prepared in a two-day workshop to understand HIV stigma and how to manage disclosure in a responsible manner before they were included in the workshops with the different mentioned groups. PLWH agreed to participate even though they did not necessarily have representatives in all the different groups. They felt that they could benefit from being present with groups that they did not have in their lives. The PLWH having representatives felt comfortable sharing the experience with them. This manuscript focuses and reports specifically on PLWH and their partners as one of the specified groups. Partner in this study refers to a person who is closely related and associated with the PLWH, such as a spouse or boyfriend/girlfriend, married or unmarried.

While stigma definitions vary, generally they indicate an attribute that discredits or devalues individuals (Brown *et al.*, 2003:49). The most used construct of stigma, conceived by Goffman (1963:3) and built on by Alonzo and Reynolds (1995:304), defines stigma as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. The latter definition remains the definition of choice for this study. Stigma can also be a social construct in which a person's characteristics are identified as 'different' and highly undesirable, further separating them from the community (Siyam'kela, 2003:13).

By end 2013 people living with HIV or AIDs were estimated at 35 million globally, with 24.7 million living in sub-Saharan Africa (UNAIDS, 2014:1) and an estimated 5.26 million in South Africa (Statistics SA, 2013:4). Although HIV treatment has reduced AIDS to a chronic condition, increased unwanted disclosure of the illness has forced

PLWH to confront more stigma and isolation (Masquillier *et al.*, 2015:214). As a socio-economic-psychological phenomenon, stigma experiences are painful and difficult for PLWH and the people living close to them, and who are often also stigmatised through association. This could also include their health care providers (Greeff *et al.*, 2010:476). HIV remains one of the most stigmatised medical conditions worldwide, resulting in silence, secrecy and denial (Apinundecha *et al.*, 2007:1157). Consequently, stigma is a major barrier to HIV and AIDS care, as well as for primary and secondary prevention. HIV-related stigma affects the whole family, impacting family identity, relationships and coping behaviours (Li *et al.*, 2008:434). Varaz-Diaz *et al.* (2005:169) as well as Pulerwitz and Bongaarts (2014:311) found that stigma led to the mentioned reluctance to access health care services, as well as a loss of social support, persecution, isolation, job loss. Stigma further reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV infection and reduces the quality of life of PLWH (Sowell & Phillips, 2010:396). Greeff *et al.* (2010:475) indicate that perceived HIV stigma has a constant and significant negative impact on life satisfaction for PLWH. Stigma thus has a powerful impact on all levels of society, resulting in excluding behaviours such as isolation, division and breaking down communities and undermining equal human rights. Accordingly, there are individual, collective and communal levels of involvement needed to reduce stigma (Siyam'kela, 2003:8; Li *et al.*, 2008:434).

Several models and frameworks describing stigma have been formulated over the years. At the time the conceptual model of Holzemer *et al.* (2007:541,546) was developed, delineating the context and the process of HIV and AIDS stigma, the Siyam'kela (2003:6) project pioneered the development of stigma indicators. This article uses the Holzemer model as grounding theory. It holds that stigma occurs within the contextual factors of the environment, the healthcare system and the agent. Within this context stigma is seen as a process of four elements, namely, stigma triggers, stigma behaviours, types of stigma and stigma outcomes. There are three types: received, internal and associated stigma. Consequently the outcomes of stigma are general health, violence, poor quality of life and reduced access to care (Holzemer *et al.*, 2007:547, 550).

In the literature reference is made to these mentioned types but use different terms. *Received stigma* refers to all types of stigmatising behaviour, including avoidance and rejection (Holzemer *et al.*, 2007:547) and is similar to Weiss's (1993:1273) etic view and Siyam'kela's (2003:14) external stigma. *Internal stigma* (Holzemer *et al.*, 2007:547) includes thoughts and behaviours stemming from the person's own negative self-perceptions based on their HIV status, similar to Weiss's (1993:1273) emic view of stigma. *Associated stigma* comes from association with someone living with, working with or otherwise connected with PLWH (Holzemer *et al.*, 2007:547). Salter *et al.* (2010:559) refer to it as secondary stigma.

PLWH often fear stigmatisation from their partners (Turan *et al.*, 2011:1118) and disclosing to them because of the possibility of further stigmatisation, rejection or discrimination, which results in non-disclosure and risky behaviour (Turan *et al.*, 2011:1118). Yet, as mentioned, earlier partners are also stigmatised by association (Greeff *et al.*, 2008:107). Few studies and interventions focus on HIV stigma reduction for PLWH and their partners. Only a small number of studies have been published in this area (Sengupta *et al.*, 2010:119). Noteworthy is the work of Manyedi (2007:3, 39) who examined the strategies widows employed to overcome and cope with stigma after their partners died of AIDS. She developed a programme to empower such women. Valerian *et al.* (2002:415) studied the impact of perceived HIV-related stigma on the relationship after the HIV-positive party finds out about the sero-positive diagnosis and discloses it to the partner. Interventions and programmes either directly address HIV-related stigma, while others are designed to empower PLWH to overcome stigma and to act against stigma discrimination (Masquillier *et al.*, 2015:224; Siyam'kela, 2003:12; Sallar & Somda, 2011:279; Taylor 2001:1; Wu *et al.*, 2008:513; Zeelen *et al.*, 2010:382).

Several more general HIV stigma reduction programmes and interventions have been published. These interventions aim to share information and increase understanding of HIV stigma, human rights, advocacy, gender, violence, the workplace, disclosure, dealing with HIV stigma, relationships and communication with others, strengthening the position or coping of the PLWH, as well as how health care professionals should respond to stigma (Greeff, 2009:2). Brown *et al.* (2003:49, 52–53) in their systematic review identified four types of interventions, namely, information-based approaches, skills building, counselling approaches, and contact with the affected group. Uys *et al.* (2009:1060) added contact with the affected group, increased knowledge of stigma and empowerment through HIV stigma reduction projects. Their findings found an increased understanding and knowledge of HIV stigma and discrimination, enhanced relationships and a significant increase in voluntary testing by nurses (Uys *et al.*, 2009:1064). Overall, stigma reduction interventions appear to work in the short term and on a small scale, but this is inadequate in relation to time and resources invested (Greeff, 2009:3; Pulerwitz & Bongaarts, 2014:311).

Authors also differ as to whether HIV stigma is highest in urban or in rural settings. Naidoo *et al.* (2007:23) found that urban groups described more incidents of stigmatisation and discrimination, possibly because they could express themselves more fluently than the rural groups. In contrast, Bunn *et al.* (2008:285) found that HIV-related stigma was relatively more frequent in rural areas. This is manifested in significantly lower life satisfaction, little social support from family and friends, reduced access to health care, elevated levels of loneliness, and increased community stigma (Heckman *et al.*, 2008:138). Regardless, the impact of the epidemic is already being felt on all sectors of society, from urban industries to rural villages (Connolly *et al.* in Greeff *et al.*, 2007:312).

The following research question arose: Can a community-based HIV stigma reduction intervention have an influence on stigma experiences of PLWH and their partners in an urban and a rural setting?

STATEMENT OF THE RESEARCH PROBLEM

A positive diagnosis of HIV impacts the lives and the relationships of both PLWH and their partners. This could be a result of the PLWH being stigmatised by either the community or the partner, but the partner also experiences associated stigma. The literature was also not clear whether stigma differs in urban and rural settings. A limited amount of research has been performed on interventions to reduce HIV stigma in PLWH and their partners. This forms the focus of this study.

OBJECTIVES

This research aimed to describe the influence of a community-based HIV stigma reduction intervention on PLWH and their partners by means of a case study as well as the lived experiences of these two groups during and after the intervention in both an urban and a rural setting of the North West Province, South Africa.

DEFINITIONS OF KEYWORDS

Community-based refers to an intervention that includes community members, the communities' social norms, forces and structures. A community is characterised by people, with common ties, who interact socially, who are diverse and who reside in a common place (Prinsloo, 2015:84).

Although published in 1995, the definition of **HIV stigma** of Alonzo and Reynolds (1995:304) remains the definition of choice, referring to it as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people. HIV stigma is further described as a phenomenon that can lead to the labelling of people as being HIV-positive (Siyam'kela, 2003).

An **intervention** is a treatment, therapy, procedure, or action implemented to manage a well-defined problem (Burns & Grove, 2005:28, 29). In this study the term intervention refers to the community-based HIV-stigma reduction intervention that was conducted with PLWH and their partners in both an urban and a rural setting.

Partners refer to persons who are closely related and associated with PLWH and could be a spouse or boyfriend/girlfriend of a married or unmarried PLWH.

RESEARCH METHODOLOGY

Research design and setting

A qualitative holistic multiple case study design (Yin, 2009:59) was used to describe the influence on PLWH and their partners, while the interpretive description approach (Thorne, 2008:50) was used for the lived experience during and after the intervention. The Ganyesa rural group and the Potchefstroom urban groups were each handled as a separate case. In both chosen settings the people spoke mostly Setswana and their lifestyles characterised by poverty and high unemployment rates (SA Statistics, 2016a; SA Statistics, 2016b) evidenced in other studies done in these settings.

Research method

Two phases characterise the research method through which this study was conducted.

Phase 1: A Holistic multiple case study of the community-based HIV stigma reduction intervention with PLWH and their partners

Sample

The population in this phase of the study was made up of two groups of people: PLWH and their partners living in the greater Potchefstroom district (urban) and in the Ganyesa district (rural) of the North West Province, South Africa. Due to the highly sensitive nature of the study, great care was taken with the inclusion of the PLWH. They were recruited through mediators with trust relationships with them from local healthcare facilities and non-governmental organisations. For PLWH, purposive voluntary sampling (Thorne, 2008:90) was conducted. The following inclusion criteria were used: diagnosed with HIV for at least 6 months; above 18 years of age; able to communicate in Afrikaans or English or Setswana; willing to share their status should they feel comfortable; willing to attend the intervention workshop; open and willing to share their experience in an in-depth interview and willing to be recorded on a digital recorder. Although not all PLWH had partners, they discussed this matter and was given a choice as how to handle this. They chose to include all PLWH who wanted to attend even if they did not have a partner. Nine (9) took part in this workshop for PLWH and their partners. Five (4 females, 1 male) PLWH from the greater Potchefstroom urban district and four (2 females, 2 males) from the Ganyesa rural district decided to attend (n=9).

For partners of PLWH, snowball sampling (Burns & Grove, 2009:356) was used to identify the partners of the PLWH. Each PLWH was invited to bring a partner if they were actively involved in a relationship. The following inclusion criteria were used: a

person living or sharing life with a PLWH or being married to them; above 18 years of age; able to communicate in Afrikaans or English or Setswana; willing to attend the workshop; open and willing to share their experience in an in-depth interview; willing to be recorded on a digital recorder. It was not important to know the status of the partners. Few of the PLWH, however, were in relationships at the time, but the groups felt that this would be a valuable experience and should continue. Two (2) partners (males) from the greater Potchefstroom urban district were included and two (2) partners (female) from the Ganyesa district (n=4). Partners were asked whether they would have a problem if PLWH who were not at present involved in a relationship were included in the study.

The HIV stigma reduction intervention

See figure 1 for a brief outlay of the intervention. Prior to the intervention all PLWH attended a workshop on their own about understanding HIV stigma, to manage disclosure in a responsible manner and to identify their personal strengths. This workshop and follow-up workshops were presented by two facilitators, a non-infected and an infected person, trained beforehand to present the workshop. The underlying tenets of the intervention were: 1) to increase knowledge of HIV stigma and coping with it; 2) equalising the relationship between PLWH and their partners; and 3) to empower them to handle HIV stigma through a HIV stigma reduction community project with other partners. The intervention included a three-day workshop followed by a one month HIV stigma reduction community project planned and executed by the PLWH and their partners for other partners in their community. The three-day workshop was presented by means of focused presentations, followed by activity-based group discussions involving both PLWH and partners at the same time. Day one focused on sharing information on understanding HIV stigma and how to cope with it; day two on building a bridge between the knowledge and understanding they have gained and how to use it constructively in planning an HIV-stigma reduction community project with other partners in the community. During the month that the project was executed, the researcher and research assistant formed a supportive network, acted as facilitators and monitored their progress. The third day of the workshop took place after the month-long project to evaluate the implementation of the project with other partners in their community. On this third day a project report was presented by the participants to invited stakeholders from the community and the researchers. The researchers and stakeholders evaluated the project presentation.

Data collection

The case record consisted of: the training manual and presentations; naive sketches that each participant wrote at the end of each workshop by completing two statements: ‘I experienced the first/second/third day of the workshop as ...’ and ‘I feel ...’; field notes that were written during and at the end of every workshop day by the facilitators; as well as the written project report and its evaluation.

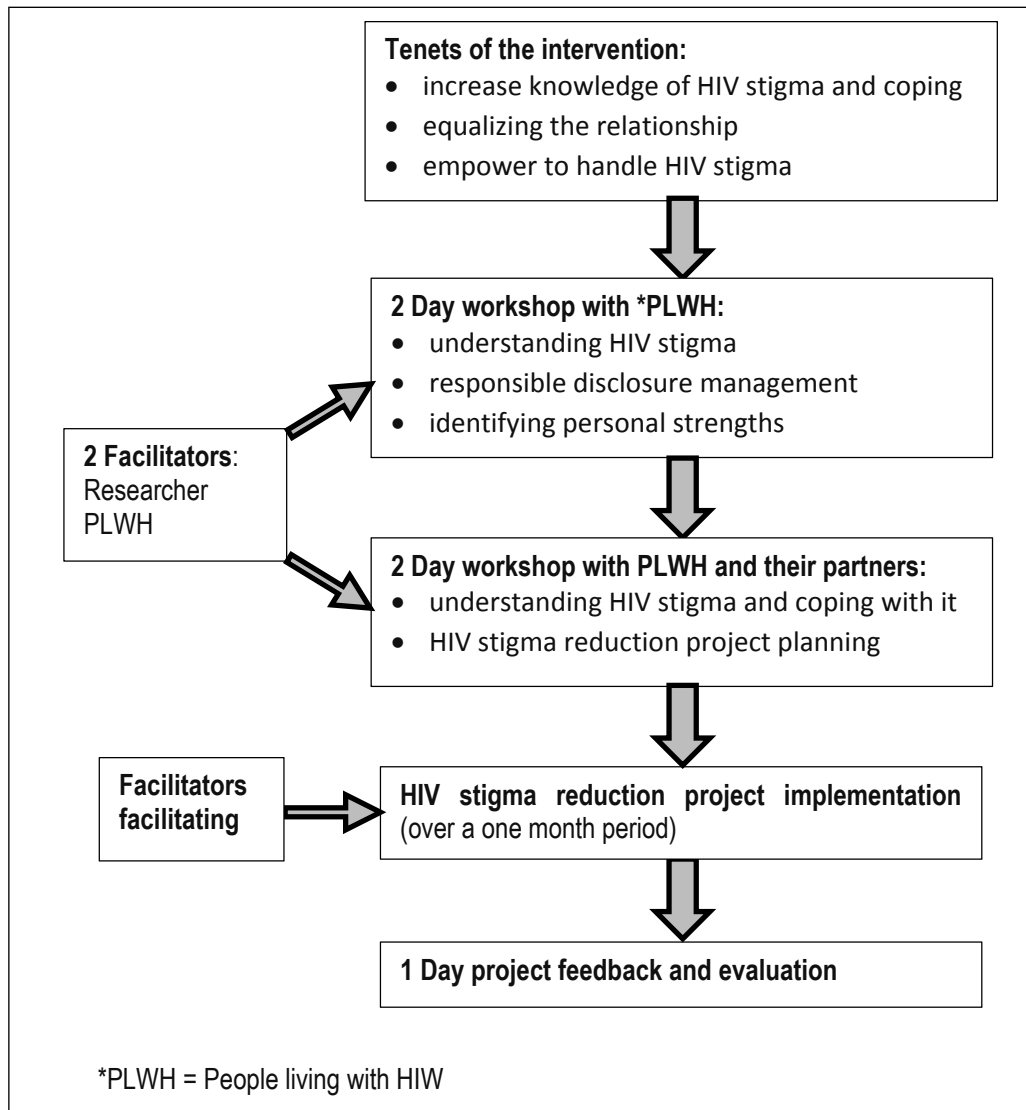


Figure 1: HIV stigma reduction intervention for PLWH and their partners

Data analysis

Data obtained from the case record was analysed using document analysis and looking for pattern matching, explanation building and cross-case synthesis (Yin, 2009:136).

Phase 2: Qualitative interpretive exploration and description of the lived experience of PLWH and their partners during and after the community-based HIV stigma reduction intervention

Sample

The same participants described under phase one were used for phase two.

Data collection

In this phase data were collected by means of in-depth interviews with both PLWH and their partners. The open-ended questions were discussed beforehand with experts on qualitative research as well as experts on HIV stigma. These questions were adjusted and evaluated in practice. For the PLWH, the question was: ‘How did you experience the workshop and project with your partner and others in the group?’ For the partners: ‘How did you experience the workshop and project with your partner and others in the group?’ Appointments were made with participants beforehand and the initial informed consent was confirmed, as well as that interviews could be recorded. The interviews took place in the setting most convenient and private for the participants. Communication techniques as mentioned by Okun (cited in Botma *et al.* (2010:226)), for example, reflection, summarisation, probing, were utilised. Participants were informed about the use of a digital recorder and that confidentiality and anonymity would be maintained throughout the process. Methodological, theoretical and personal field notes were recorded after each interview (Botma *et al.*, 2010:217).

Data analysis

The interviews were transcribed and manually analysed using the open coding technique of Tesch (1990), as discussed by Creswell (2009:186). The researcher got a sense of the whole, listed the topics as codes and turned them into categories and themes. An independent co-coder was used to analyse the data using a work protocol. A confidentiality agreement was signed. Consensus discussions were conducted to come to an agreement about the coding, categories and final themes.

Ethical considerations

Ethical approval was obtained from the Research Committee of the School of Nursing Science, as well as from the Health Research Ethics Committee of the North West University, Potchefstroom Campus (NWU-00011-09-A1). Permission to undertake this programme was also obtained from the Department of Health of the North West Province, as well as the local Department of Health. A relationship with the community existed due to several previous community engagement projects. Participants were approached through health care settings, as well as non-governmental organisations (NGOs). Nurses and health care workers were trained and used as mediators to link the research assistant and researchers with the prospective participants. A private, interruption-free and comfortable venue for the intervention was arranged for both the urban and the rural settings. During the first contact with prospective participants, the research assistant explained the objectives of the research, ensured that they knew what was expected of them and what kind of data would be collected, as well as that they were able to withdraw at any stage. The researchers were available to answer any uncertainties. Informed consent was obtained by the research assistant as an independent person from each participant after having had an opportunity to discuss it with anyone they wished to. Appointments were confirmed a day before the intervention. Transport to venues was available for participants, as well as a light meal. A token of appreciation was given to them after the intervention. The data is stored in a safe place with hard copies being locked away and the electronic data protected by password. The data will be kept for five years.

Trustworthiness

The researcher ensured rigour, using the model of Lincoln and Guba (Krefting, 1991:214). Truth value was assured by prolonged engagement during the intervention and interviews with participants. The researcher was part of a multidisciplinary research team. She consistently reflected on her experiences during the research through writing field notes and having discussions with study leaders. Triangulation of sources and investigators increased credibility. Saturation of data and a dense description of the research allowed for applicability. There is an audit trail and the possibility for a step-wise replication of the research is possible. A co-coder participated in data analysis. This ensured consistency. Neutrality was ensured through the audit trail, triangulation of sources and investigations and reflexivity.

FINDINGS AND DISCUSSION

The results of this study focus on the detailed description of the intervention, as well as the findings from the in-depth interviews. As no real differences were noticed during the analysis between urban and rural groups, the data was pooled.

Phase 1: Findings from the holistic multiple case study

The findings focus on the data obtained from the mentioned case record.

Day one of the intervention

The purpose of this day was to get PLWH and their partners understand HIV stigma, how to cope with it, and to build on and improve their relationships. The naïve sketches of day one indicated their experiences.

People living with HIV or AIDS (urban and rural groups)

It was found that PLWH did gain knowledge about HIV stigma. They saw strength within themselves, felt proud and felt empowered to reach out to others. PLWH mentioned a mind shift filled with hope and happiness. They felt that it was easier to accept their illness and stigma. They felt gratitude towards God and felt a sense of belonging.

Partners of PLWH (urban and rural groups)

The partners mentioned that they too gained knowledge and mentioned a change in their attitude towards PLWH. It empowered them to cope better and encouraged them to seek help. They realised the importance of taking responsibility for their health. They experienced a mind shift and felt encouraged to act to reduce stigma in their communities. They felt that the intervention added value to their lives.

Day two of the intervention

The second day focused on building a bridge between the knowledge of HIV stigma and the coping skills they gained the previous day and putting it into action by first being taught how to plan a project and then planning an HIV stigma reduction project with other partners in the community by activating their own leadership in social change. They would then implement their planned projects over the next month. It was important to facilitate their own initiatives. From the naïve sketches it was found that participants experienced the onset of this day as difficult because it was a new experience to them, but later felt empowered by knowing on how to constructively act against HIV stigma in the community by constructing a HIV stigma reduction project. Each group (urban and rural) planned their own project with partners in their community. They wanted to repair relationships. The participants expressed self-confidence and pride about being able to do it. They felt that they could now be leaders in the community to reduce HIV stigma.

The urban group community project

The urban group named their project 'Remove the Label'. Their aim was to build a community who would understand stigma and talk freely about it. They utilised a classroom after hours at a nearby school. They invited people they knew were in similar situations as they were in. During the meeting they used a psycho-drama play to demonstrate how HIV stigma happens. They hoped to achieve a better understanding of stigma and to stop the labelling of others. The event was managed by five (5) PLWH and two (2) partners. Sixteen (16) community members attended the event. The attendees expressed their gratitude and could express their observation of stigmatisation in the community.

The rural group community project

The rural group worked on a door-to-door project they named 'Coming Together and Working Together'. Their aim was to change the community's attitudes towards stigma, unite partners and encourage them to live freely together through improved communication. The four PLWH and two partners visited seven houses and reached five other partners. The partners were excited to talk about stigmatisation within their own homes and used the opportunity to express their own experiences of stigmatisation.

Day three of the intervention

Day three focused on the report-back by the participants regarding the execution of the two mentioned projects that were their own initiative. The projects were evaluated by the researchers and invited stakeholders from the community.

The urban group presented their project and reflected on the importance of the project. It was, however, initially difficult to recruit community members to attend. However, they reported that persistence and perseverance led to their success. Participants expressed their intention to continue with HIV stigma reduction projects in the community until they are satisfied that the people understand HIV stigma and change attitudes.

The rural group reported back that they also found planning the project challenging, but were proud when they achieved their goal. The presentation was anxiety provoking as it was the first time they had to do something like this. The participants felt proud about their project and more comfortable and encouraged about achieving their goal. Participants were strengthened by the workshop that motivated them to go ahead. They felt the door-to-door project was easy to do because visiting people in their own homes provided privacy.

Phase 2: Findings from the in-depth interviews

The purpose of the in-depth interviews with PLWH and their partners was to get a more in-depth understanding of their lived experiences after having been part of the workshops and their own HIV stigma reduction project with community members. The themes found during analysis of first the PLWH followed by their partners will be discussed with references to enriching quotes from the in-depth interviews. See table 1 for a summary of the findings.

Table 1: Summary of findings

Themes	Subthemes
Findings of PLWH	
Gained knowledge about HIV stigma and how to cope with it	Stigma a powerful social weapon Feeling better about themselves
Painful experiences of HIV stigma	Painful if you tell a trusted person that turns you down Ashamed Isolate self Feel neglected
Promoted support and human dignity	Learnt what support is Learnt how to be supportive Safe environment where learnt to disclose free of rejection Leaving the group was painful Support gave them strength and freedom
Improved self-image and self-acceptance	Regained their self-image Still have meaningful lives Experienced self-acceptance
Initially difficult but empowered people to establish change and experience meaning	Initial fear to disclose Planning the project was difficult Did experience the feeling of success Happy because gained knowledge Broke through internal personal prisons Felt freedom
Being empowered helped to reduced stigma in the community	Empowered to help reduce stigma Started to dream Reached out into the community Motivated to educate the community
Findings of Partners	
Gained knowledge about HIV stigma and became leaders to empower others	Gained knowledge about stigma Pride with their success Moved from fear to action to pride A life-changing experience

Awareness of painful experience of PLWH when stigmatised	Partners felt the pain of PLWH Felt empowered through the knowledge they gained Felt determined to act against HIV stigma
Became united and exchanged loneliness for support	Partners united with PLWH to reduce stigma Support took the place of loneliness The ability to support other people
Became empowered to disclose their own status without fear and shame	Seeing their partners disclose empowered them to disclose Changed from being ashamed to able to talk
Acceptance of self and joy that the community is willing to learn	Learnt self-acceptance Joy to see willingness to change

Findings from the interviews with PLWH

Six themes were identified from the findings of interviews with PLWH.

Theme one: Gained knowledge about HIV stigma and how to cope with it

PLWH learned that stigma is ‘a powerful social weapon that discriminates’ and comes in different ways: ‘Like a sign or just gossiping or labelling another person.’ Sowell and Phillips (2010:399) also found that the sharing of information can address the feelings of stigmatisation by PLWH. During the intervention the participants started to feel better about themselves and started sharing: ‘When I heard that I have HIV, I didn’t feel well. I felt bad and I didn’t want to mix with people. At the workshop they told me more things to disclose and I see that I’m still person and strong to do more things.’

Theme two: Painful experiences of HIV stigma

PLWH could share their painful experiences with stigmatisation: ‘[I]t’s so painful when you tell someone you trusted and he turns you down’; ‘I felt ashamed’; ‘[B]eing with people and isolate yourself from other’; ‘[Y]ou feel neglected’. Colombini *et al.* (2014) reported similar findings where PLWH mainly experienced painful anticipated stigma from their partners.

Theme three: Promoted support and human dignity

The PLWHs learned what support is: ‘All these people in the project respect each other, they hug each other and don’t laugh at each other.’ They also learned how to be supportive towards others: ‘It’s nice to talk to PLWH that feels in the dark about it and I am able to give them advice that HIV doesn’t mean the end of the world.’ They experienced the intervention as a safe environment where they learned to disclose free

of rejection: ‘We didn’t judge each other, and there was openness, it felt like a blanket that keeps you warm, we all sharing the same problem.’ Leaving the workshop was painful because ‘if I go home I feel the pain again’. The support gave them strength and freedom: ‘I have some wings and flying out away, I’ve been brave that I can disclose it.’ Studies (Masquillier *et al.*, 2015:222; Russell *et al.*, 2016:69) have shown that inclusion into a support group can create a sense of belonging and reduce stigma experienced.

Theme four: Improved self-image and self-acceptance

Russell *et al.* (2016:69) found that it is the supportive group dynamic between PLWH that can improve their self-esteem and confidence. In this study the PLWH also regained their self-image: ‘I’m strong to do more things’, and realised that they can have meaningful lives: ‘[G]ot hope in that sense you feel you accepted yourself and you can live long.’ They experienced more self-acceptance: ‘I learned to accept myself.’

Theme five: Initially difficult but empowered people to establish change and experience meaning

Although not specifically asked to disclose, PLWH felt an initial fear to disclose: ‘I was so afraid. So scared to talk but after ... the workshop (teaching us how to disclose) ... I’m not afraid to talk about it.’ They verbalised that planning the project was difficult: ‘It was so difficult to find the partners because they were always blaming their partners’, but they did experience success: ‘[W]e teach the people about HIV stigma, people stay and ask us questions.’ They felt happy because they gained knowledge: ‘[T]hey taught us something we didn’t know, how you can speak about this disease. It gave me strength to talk freely.’ The intervention empowered them to break through internal personal prisons: ‘I have a painful heart, staying alone and not want to stay with the person. The workshop taught me things and me myself I was free because I can tell anybody’; ‘I felt free, and my heart opened up.’ Apinundecha *et al.*, (2007:1163) showed similar findings through empowering participants to design, plan and then implement a community project.

Theme six: Being empowered helped to reduce stigma in the community

PLWH verbalised that they were empowered to help reduce stigma in the community: ‘My experience is to go far teaching people about that stigma and to go other places teaching the people about this.’ They started to dream: ‘I want to open a house for the poor and stigmatised.’ Some PLWH reached out on their own into the community: ‘I go to the clinic to talk to people I spoke over the radio about HIV stigma I got calls from different people about partners I was going to the prison after they were calling me to go and visit them.’ Brown *et al.* (2003:65–66) support such an educational approach targeting the community as a whole. PLWH felt motivated to educate the

community: 'It is important to me, if we reach more people, stigma will reduce in the community, people will rush to the clinics, they will not fear to go to the clinics because of stigma.'

Findings from the in-depth-interviews with partners identified five themes.

Five themes were identified from the findings of interviews with partners of PLWH.

Theme one: Gained knowledge about HIV stigma and became leaders to empower others

The partners mentioned that they gained knowledge about stigma and expressed pride with their success: 'I was very proud that I got that knowledge to teach the community.' They mentioned that they moved from fear, to action, and then to pride regarding their achievements: 'It was nerve-wrecking to teach people in their homes. Yet I was happy to see this and if we had more of this, we as people with HIV will really end up with peace in the world.' Sallar and Somda (2011:304) found that individuals can influence the behaviour change of a community through sharing knowledge on HIV. Partners found it a life-changing experience: '[I] felt like I was now in the light.' Partners felt empowered through the knowledge they gained and felt determined to act against HIV stigma: 'I can take everything that I have learnt and go out there and tell people to stop stigmatizing people with HIV.'

Theme two: Awareness of the painful experience of PLWH when stigmatised

The partners felt the pain of PLWH: 'I was feeling just like them (PLWH). It was painful. This pain when they spoke about the way people mistreated them.' A Chinese stigma reduction study by Wu *et al.* (2008:519) also shared the painful experiences of stigma through games, role plays and testimonies that lead to a drastic behaviour change to be more respectful towards PLWH.

Theme three: Became united and exchanged loneliness for support

Partners expressed that they became united with PLWH in the aim to reduce HIV stigma: 'I experienced that we got together, the community as well as PLWH, and we got to teach them about stigma and that PLWH are just like any other person who is living with any other illness.' Support from others in the project took the place of loneliness: 'It was the support I got from the people I did the project with. They had the courage to stand in front of the community and say that they were HIV positive.' A Ugandan study (Atuyambe *et al.*, 2014) found that most partners gave encouragement

and support when a PLWH disclosed their status. The partners also felt the ability to support other people: ‘People with this illness also came out because they were scared and they had no one to talk to.’

Theme four: Became empowered to disclose their own status without fear and shame

Seeing their HIV positive partners disclose their status empowered those partners who had not done so yet to disclose their own positive status without fear and shame: ‘That as a person living positively you shouldn’t fear saying that you are ill and hide it from people; I used to be ashamed and leave the room, but now I am able to talk to them and tell them that we can live with AIDS and take our medication.’ This is particularly significant as fear of stigmatisation is one of the main reasons why people do not disclose (Colombini *et al.*, 2014; Obermeyer *et al.*, 2011:1015), but Salter *et al.* (2010:568) found that disclosure leads to a more healthy life with the love and support of family.

Theme five: Acceptance of self and joy that the community is willing to learn

They indicated that they have learned self-acceptance: ‘It taught me to accept myself.’ They experienced joy to see willingness in the community to change: ‘I felt so happy to see the community willing to learn and accepting this.’ A community willing to change can improve their health and relationships (Mall *et al.*, 2013:200).

CONCLUSIONS

No real differences were found between rural and urban communities in either the case study or the in-depth descriptions of PLWH and partners. The findings of both the case study and the in-depth interviews (based on what the participants reported) validate the fact that the intervention was successful. Both PLWH and partners expressed that they had initially limited understanding of the meaning of HIV stigma and that they gained knowledge about stigma and coping with HIV stigma. During the intervention both groups became aware of the painful experiences that stigma causes PLWH. The partners became aware how they hurt PLWH when they stigmatise, and realised that they needed to change their attitudes. In general a better relationship was established between PLWH and partners, but also in the group as a whole. Sharing these experiences during the intervention united PLWH and partners, increased their knowledge on HIV stigma and coping, enhanced relationships between them, established support among members and decreased their feelings of loneliness. Hope, dignity and pride of PLWH were restored and partners felt they could cope better and teach others about accepting PLWH. It even gave partners more freedom to disclose their own status. Both PLWH and partners experienced the planning of the project as difficult, but learned that when they work together with persistence and perseverance it can be achieved. Leadership was activated

within themselves. They experienced pride and joy when they saw the change their actions sparked in the community. They expressed a feeling of being empowered to reduce HIV stigma in their community.

RECOMMENDATIONS

The content and method used to implement the programme seem to be effective and need not be changed. The fact that this group was mainly Setswana-speaking could explain why no differences between urban and rural groups were noted. It could, however, be meaningful to add some cultural discussions. This study has the potential to be used for long-term monitoring studies of HIV stigma reduction interventions and to evaluate change over time in PLWH and their partners, as well as other groups. This intervention could be included in educational programmes offered in health care settings or NGOs to nurses, health care workers and volunteers to get more people trained in HIV stigma reduction programmes.

LIMITATIONS OF THE STUDY

A limitation of the study could be the sample size of partners that could have been bigger, however, not all the PLWH in this study had a partner and the sample size could not be increased because this intervention was part of bigger intervention study involving other people living close to PLWH. The sample size could not be determined beforehand.

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REFERENCES

- Alonzo, A. & Reynolds, N. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine*, 41(3):303–315.
- Apinundecha, C., Laohasiriwong, W., Cameron, M.P. & Lim, S. 2007. A community participation intervention to reduce HIV/AIDS stigma, Nakhon Ratchasima province, northeast Thailand. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, 19(9):1157–1165.
- Atuyambe, L.M., Ssegujja, E., Ssali, S., Tumwine, C., Nekesa, N., Nannungi, A. *et al.* 2014. HIV/AIDS status disclosure increases support, behavioural change and, HIV prevention in the long term: A case for an Urban Clinic, Kampala, Uganda. *BMC Health Services Research*, 14(1):1–11. Available at <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-276> (accessed 14 April 2016).

- Botma, Y., Greeff, M., Mulaudzi, M. & Wright, S. 2010. *Research in health sciences*. Cape Town: Heinemann.
- 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.
- Bunn, J.Y., Solomon, S.E., Varni, M.A., Miller, C.T., Forehand, R.L. & Ashikaga, T. 2008. Urban-rural differences in motivation to control prejudice toward people with HIV/AIDS: The impact of perceived identifiability in the community. *The Journal of Rural Health*, 24(3):285–291.
- Colombini, M., Mutemwa, R., Kivunaga, J., Stackpool Moore, L. & Mayhew, S. 2014. Experiences of stigma among women living with HIV attending sexual and reproductive health services in Kenya: A qualitative study. *BMC Health Services Research*, 14(1):1–9. doi: 10.1186/1472-6963-14-412. Available at <http://bmchealthservres.biomedcentral.com/nwulib.nwu.ac.za/articles/10.1186/1472-6963-14-412#?> (accessed 14 April 2016).
- Creswell, J.W. 2009. *Research design*. London: SAGE.
- Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, N.J.: Prentice-Hall.
- Greeff, M. 2009. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. SANPAD research proposal, 15 September 2009. Reference number 09/15. Unpublished.
- Greeff, M., Phetlhu, D.R., Makoae, L.N., Dlamini, P.S., Holzemer, W., Naidoo, J., Kohi, T.W., Uys, L. & Chirwa, M.L. 2007. Disclosure of HIV/AIDS status: Experiences and perceptions of persons living with HIV/AIDS and nurses in five African countries. *Qualitative Health Research*, 18(3):311–324.
- Greeff, M., Uys, L.R., Holzemer, W.L., Makoae, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J.R. & Phetlhu, D.R. 2008. Experience of HIV/AIDS stigma of PLWA and nurses involved in their care from five African countries. *Africa Journal of Nursing and Midwifery*, 10(1):78–108.
- Greeff, M., Uys, L.R., Wantland, D., Makoae, 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*, 47:475–486.
- Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. 2008. Psychosocial differences between urban and rural people living with HIV/AIDS. *The Journal of Rural Health*, 14(2):138–145.
- Holzemer, W.L., Uys, L.R., Makoae, 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.
- Li, L., Wu, Z., Wu, S., Manhong, J., Lieber, E. & Lu, Y. 2008. Impacts of HIV/AIDS stigma on family identity and interactions in China. *Families, Systems & Health*, 26:431–422.
- Mall, S., Middelkoop, K., Mark, D., Wood, R. & Bekker, L. 2013. Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa. *AIDS Care*, 25(2):194–201.
- Manyedi, M.E. 2007. Coping with stigma by women whose partners died of AIDS. PhD thesis, North West University (NWU), Potchefstroom, South Africa

- Masquillier, C., Wouters, E., Mortelmans, D. & le Roux Booyesen, F. 2015. The impact of community support initiatives on the stigma experienced by people living with HIV/AIDS in South Africa. *AIDS and Behavior*, 19:214–222.
- Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoae, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *African Journal of AIDS Research*, 6(1):17–23.
- Obermeyer, C.M., Bajjal, P. & Pegurri, E. 2011. Facilitating HIV disclosure across diverse settings: A review. *American Journal of Public Health*, 101(6):1011–1023.
- Prinsloo, C.D. 2015. A mixed method study of a community-based HIV stigma reduction ‘hub’ network. PhD thesis, North West University (NWU), Potchefstroom, South Africa.
- Pulerwitz, J. & Bongaarts, J. 2014. Tackling stigma: Fundamental to an AIDS-free future. *The Lancet. Global Health*, 2(6):311–312.
- Russell, S., Zalwango, F., Namukwaya, S., Katongole, J., Muhumuza, R., Nalugya, R. & Seeley, J. 2016. Antiretroviral therapy and changing patterns of HIV stigmatisation in Entebbe, Uganda. *Sociology of Health & Illness*, 38(1):58–72. doi: 10.1111/1467-9566.12341.
- Sallar, A.M. & Somda, D.A. 2011. Homosexuality and HIV in Africa: An essay on using entertainment education as a vehicle for stigma reduction. *Sexuality & Culture*, 15:279–309.
- Salter, M.L., Go, V.F., Nguyen Le, M., Gregowski, A., Ha, T.V., Rudolph, A., ... Quan, V.M. 2010. 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.
- Sengupta, S., Strauss, R.P., Miles, M.S., Roman-Isler, M., Banks, B. & Corbie-Smith, G. 2010. A Conceptual model exploring the relationship between HIV stigma and implementing HIV clinical trials in rural communities of North Carolina. *North Carolina Medical Journal*, 71(2):113–122.
- Siyam’kela. 2003. Siyam’kela measuring HIV/AIDS related stigma: A report on the fieldwork leading to the development HIV/AIDS stigma indicators and guidelines. Policy Project, South Africa: Centre for the Study of AIDS. University of Pretoria; United States Agency for International Development; Chief Directorate: HIV, AIDS, TB, Department of Health. Available at <http://www.csa.za.org> (accessed 13 November 2013).
- Sowell, R.L. & Phillips, K.D. 2010. Understanding and responding to HIV/AIDS stigma and disclosure: An international challenge for mental health nurses. *Issues in Mental Health Nursing*, 31:394–402.
- Statistics S.A. 2013. Midyear population estimates. Available at <http://www.statssa.gov.za/publications/statsdownload.asp?PPN=P0302&SCH=5500> (accessed 22 September 2014).
- SA Statistics. 2016a. Kagisano Molopo: Census 2011. Available at http://www.statssa.gov.za/?page_id=993&id=kagisanomolopo-municipality (accessed 31 March 2016).
- SA Statistics. 2016b. Tlokwe City Council: Census 2011. Available at http://www.statssa.gov.za/?page_id=993&id=tlokwe-city-council-municipality (accessed 31 March 2016).
- Taylor, C. 2001. *Scaling up for social development*. Sussex: ILEIA. *United Nations Development Programme (2000) Human Development Report 2000*. New York, NY: UNDP.
- Thorne, S. 2008. *Interpretive description*. Walnut Creek, CA: Left Coast Press.
- Turan, J.M., Bukusi, E.A., Onono, M., Holzemer, W.L., Miller, S. & Cohen, C.R. 2011. HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS study. *AIDS and Behavior*, 15:1111–1120.

- UNAIDS. 2014. Global AIDS epidemic facts and figures. Available at <http://www.unaids.org/en/resources/presscentre/factsheets> (accessed 22 September 2014).
- Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoae, L., Dlamini, P., Durrheim, K., Cuca, Y. & Holzemer, W.L. 2009. Evaluation of a health setting-based stigma intervention in five African countries. *AIDS Patient Care and STDs*, 23(12):1059–1066.
- Valerian, J., Derlega, B.A., Winstead, K.G., Julianne, S. & William, N. 2002. Perceived HIV-related stigma & disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology*, 7(4):415–432.
- Weiss, R.A. 1993. How does HIV cause AIDS? *Science Magazine*, 260(5112):1273–1279.
- Wu, S., Wu, Z., Ling, L., Coa, H., Yan, Z. & Li, J. 2008. A brief HIV stigma reduction intervention for service providers in China. *AIDS Patient Care and STDs*, 22(6):513–520.
- Yin, R.K. 2009. *Case study research*. 4th Edition. London: SAGE.
- Zeelen, J., Wijbenga, H., Vintges, M. & De Jong, G. 2010. Beyond silence and rumour: Storytelling as an educational tool to reduce the stigma around HIV/AIDS in South Africa. *Health Education*, 110(5):382–398.