AJNM-2014-030 A COMMUNITY-BASED HIV STIGMA-REDUCTION INTERvENTION FOR PEOPLE LIVING WITH HIV AND THEIR PARTNERS

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 effect of a community-based HIV stigma reduction intervention on PLWH and their partners. In addition, the research aimed to explore and describe 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. A qualitative holistic multiple case study design and interpretive description approach through in-depth interviews was used to implement and evaluate the intervention. Purposive voluntary sampling was conducted to access PLWH and snowball sampling for their partners. The case record included multiple sources. Document analysis and open coding was used for analysis of case records and open coding for in-depth interviews. No real differences were noted between the urban and rural groups. In both the case study and the expressed experiences it was evident that the intervention was successful. 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 comprehensive community-based intervention on HIV-stigma reduction involving children, family, partners, friends, spiritual leaders and community members, as persons living close to people living with HIV or AIDS (PLWH). The overall aim was on HIV-stigma reduction and the lived experiences during and after the intervention. This study focused specifically on the partners of PLWH. Consequently partner refers to a person that is closely related and associated with PLWH such as a spouse or boyfriend/girlfriend, both married or unmarried.

By end 2013 people living with HIV or AIDs were estimated 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.*, 2014). HIV remains one of the most stigmatised medical conditions worldwide, resulting in silence, secrecy and denial. As a socio-economic-psychological phenomenon stigma experiences are painful and difficult for PLWH and the people living close to them who are often also stigmatised through association (Apinundecha *et al.*, 2007:1157). Greeff *et al.* (2010:476) mentions that AIDS-stigma not only affects PLWH but also people living close to them and their health care providers. Consequently, stigma is a major barrier to HIV and AIDS care, as well as for primary and secondary prevention. Varaz-Diaz *et al.* (2005:169) as well as Pulerwitz and Bongaarts (2014:311) found that stigma led to a loss of social support, persecution, isolation, job loss and accessing healthcare services. Stigma also reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV infection and reduce the quality of life of PLWH (Sowell & Phillips, 2010:396). Greeff *et al.* (2010:475) indicates that perceived HIV stigma has a constant and significant negative impact on life satisfaction for PLWH. HIV-related stigma affects the whole family, impacting family identity, relationships and coping behaviours (Li *et al.*, 2008:434). Stigma 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).

While stigma definitions vary, generally it indicates an attribute that discredits or devalues individuals (Brown *et al.*, 2003:49). The most used construct of stigma, conceived by Goffman (1963:3) and build on by Alonzo and Reynolds (1995:304), define stigma as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. 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).

Severalmodels 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 ground 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 types but using different terms. *Received stigma* refers to all types of stigmatizing 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.

This article focuses on HIV stigma of PLWH and their partners. PLWH often fear stigmatisation from their partners (Turan *et al.*, 2011:1118), yet their partners are also stigmatised by association (Greeff *et al.*, 2008:107). PLWH also fear disclosing to their sexual partners, because of the possibility of further stigmatisation, rejection or discrimination, which results in non-disclosure and risky behaviour (Turan *et al.*, 2011:1118). Few studies and interventions focus on stigma reduction and wellness enhancement for PLWH and their partners and only a small number of these studies have been published (Sengupta *et al*., 2010:119). Noteworthy is the work of Manyedi (2007:3, 39) who examined the strategies AIDS widows employed to overcome and cope with stigma. He 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.*, 2014; Siyam’kela, 2003:12; Sallar & Somda, 2011:279; Taylor 2001:1; Wu *et al*., 2008:513; Zeelen *et al.*, 2010:382).

Authors further 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 contras 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).

Several HIV stigma reduction programmes, workshops and interventions have been published. Accordingly most 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) identified four types of interventions, namely: information-based approaches; skills building; counselling approaches and contact with the affected group. In a health care setting Uys *et al.* (2009:1060) added on increas contact with the affected group, increased knowledge of stigma and empowerment through HIV stigma reduction projects. Their findings indicated 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 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).

The following research questions arose: In what way can a community-based HIV stigma reduction intervention reduce stigma in PLWH and their partners in an urban and a rural setting; and what are the experiences of PLWH and their partners during and after of a community-based HIV stigma reduction in an urban or a rural setting?

Statement of the research problem

It is clear that 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 their partner, or the partner experiencing associated stigma. A limited amount of research has been performed on interventions to reduce HIV stigma in PLWH and their partners and this matter subsequently forms the focus of this study. This is significant because the partners of PLWH are supposed to be their primary source of support but in some cases contribute the most stigmatisation.

objectives

This research aimed to describe the effect of a community-based HIV stigma reduction intervention on PLWH and their partners by means of a case study method as well as to explore and describe 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

A community is a group of people who share some type of bond, who interact with each other, and who function collectively regarding common concerns (Clark, 1999:5). **Community-based** consequently refers to an intervention that includes community members, the communities’ social norms, forces and structures.

Stigma is defined by Alonzo and Reynolds (1995:503) as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people. **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 and wellness enhancement intervention that was conducted with PLWH and their partners in both an urban and a rural setting.

**Partners** refer to persons that 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) and interpretive description approach (Thorne, 2008:50) was used. The study was conducted in an urban area, Potchefstroom, and a rural area, Ganyesa, in the North West Province, South Africa. In both settings the people speak mostly Setswana. The lifestyle in both settings are characterised by poverty and high unemployment rates.

## Research method

Two phases characterize 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. 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 25 years of age; able to communicate in Afrikaans or English and Setswana; open and willing to share their experience in an in-depth interview and willing to be recorded on a digital recorder. Ten (9 females, 1 male) PLWH from the greater Potchefstroom urban district and eight (5 females, 3 males), from the Ganyesa rural district were identified, (n=18).

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 and Setswana; open and willing to share their experience in an in-depth interview; willing to be recorded on a digital recorder. Few of the PLWH however, were in relationships at the time. Two (2) partners from the greater Potchefstroom urban district were included (2 males) and two (2) female partners from the Ganyesa district (n=4).

### The HIV stigma reduction intervention

Prior to the intervention all PLWH attended a workshop on their own about understanding HIV stigma, identifying their personal strengths and to manage disclosure in a responsible manner. The workshop was 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) equalizing 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 workshop was presented by means of focused presentations, followed by activity-based group discussions involving both PLWH and partners at the same time. The intervention included a three-day workshop and a one month HIV stigma reductioncommunity project by the PLWH and their partners for other partners in their community. Day one focused on sharing information on understanding HIV stigma and how to cope with it. The second day focused 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. This was followed by one month to conduct the project in the community. During this month the researcher and research assistant acted as facilitators. 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. 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.

The case study method was used to collect data during the five weeks intervention. The case record consisted of: the training manual and presentations; naive sketches that each participant wrote at the end of each workshop day. Two statements had to be completed: “I experienced the first day of the workshop as …” and “I feel …” Field notes were written during and at the end of every workshop day by the facilitators. The written project report and its evaluation also formed part of the case record.

### 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 was 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, 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. 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) e.g. reflection, summarization, probing etc. were utilised. Participants were informed about the use of a digital recorder and that partial confidentiality and anonymity would be maintained throughout the process. Field notes were recorded noting the things the researcher heard, saw, felt, experienced and thought during the 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. 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 Ethics Committee of the North-West University, Potchefstroom Campus, NWU-00011-09-A1. Permission to undertake this programme was obtained from the Department of Health of the North West Province. A relationship with the community existed due to several community engagement projects. Participants were approached through health care settings, as well as Non-Governmental Organizations (NGO’s). Nurses and health care workers were used as mediators to link the research assistant and researcher 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 know 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. Informed consent was obtained from each participant. Transport to venues was available for participants, as well as a light meal. Appointments were confirmed a day before the intervention.

# 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 is 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 case study 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. Specific mention is made in cases where differences were noted.

# Phase 1: Findings from the Holistic Multiple Case study

The findings focus first on PLWH and then partners’ experiences during the workshops and projects and are enriched by quotes of the participants.

## Day one of the intervention

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

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

From naive sketches it was found that PLWH gained knowledge about HIV stigma. They saw strength within themselves and felt empowered to reach out to others: “I can teach other people about that stigma... without fear”. PLWH mentioned a mind shift filled with hope and happiness: “I was in the darkness now I am in the lightness” and they felt that it was easier to accept their illness and stigma: “[It] is not the end of the world or life”. They felt gratitude: “I thank God” and they were proud of themselves. They felt a sense of belonging: “like being one of them”.

## *Partners of PLWH (urban and rural groups)*

The partners mentioned that they gained knowledge and mentioned a change in their attitude: “I learned things that I did not know, care, sympathy and love”. It empowered them to cope better: “how to promote your living style to a better one” and encouraged them to seek help: “... there are some people we can seek for help and support” and to take responsibility for their health: “To take care of ourselves and others around us”. They experienced a new mind shift: “[it’s] enlightening to my life” and felt encouraged to act: “To open our mind so that we can spread the message to the community” to then teach other people “to accept themselves”. They felt that the intervention added value to their life: “...something valuable that will benefit me in the future”.

## Day two of the intervention

The second day focused on building a bridge between knowledge of HIV stigma and coping skills. Furthermore it focused on how to use this knowledge constructively in a visible HIV stigma reduction project with other PLWH and their partners in the community through activating their own leadership in social change. Participants experienced this day as difficult: “It was so difficult today... it is not easy” but felt empowered by the knowledge to act against HIV stigma in order to encourage others: “to support their partners” but also wanted to repair relationships: “I am going to be able to unite partners... spread the message to the community.” The participants expressed specific feelings of self-confidence: “I believe I am smart” and pride: “I am happy to begin doing something, making the project work”. They felt that they could be leaders in the community to reduce HIV stigma: “I see that I can be a leader and have my partner in this workshop”.

## Day three of the intervention

Day three focused on the report-back by the participants regarding the execution of the project, as well as the evaluation by the researchers and invited stakeholders from the community.

## *The urban group*

The urban group presented their project, “Remove the Label”, in a classroom at a local school, in Ikageng, Potchefstroom. Their aim was to build a community of partners who will talk freely about HIV stigma. They used psycho-dramas to demonstrated different types of stigmatisation to increase understanding, to stop labelling of others and to accept and support their own HIV positive partners. The event was managed by two partners and three PLWH. Sixteen (16) people were reached: Five partners, nine community members and two councillors. The attendees expressed their gratitude, but could also express their own experiences of stigmatisation.

Report back by the participants recognised the importance of the project “Our community is in need to know more information” but experienced it difficult to recruit partners, to arrange transport, to work with passive group members and to invite people on time. However they reported that persistence and perseverance led to their success: “not easy but if you want something you can do it.” Initially they found it difficult to talk in front of others, but gained confidence: “now I am not afraid of the people or others in the community.” Participants expressed their intention to continue with projects in the community until they are satisfied that the people understand HIV stigma and change attitudes.

## *The rural group*

The rural group worked on a door-to-door project: “Coming Together and Working Together”, in one ward in Ganyesa. Their aim was to change the community’s attitudes towards stigma, unite partners and encourage them to live freely together through improved communication. The two partners, supported by two PLWH, reached five other partners after managing to visit seven houses. The partners were excited about the talk within their own homes and used the opportunity to express their own experiences of stigmatisation.

Report back by the participants found planning the project challenging, but where proud when they achieved their goal: “When we started to plan it was difficult but at the end we achieved what we wanted”. They were nervous about presenting to the research team: “because it was the first time doing a presentation, so I had to stay focused in future and learn more on how to do these things”. The participant felt proud about their project, 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. During the project evaluation the participants expressed their intention to continue the project until they are satisfied that the people understand stigma and have changed their attitudes.

# Phase 2: Findings from the In-depth Interviews:

The purpose of the in-depth interviews with PLWH and their partners was to get an in-depth understanding of their lived experiences after having been part of the workshops and the community HIV stigma reduction project with other partners. 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.

## 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 during the intervention*

PLWH verbalized gaining knowledge about HIV stigma and how to cope with it. They 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”. During the intervention the participants started to feel better about themselves: “When I hear that I have HIV, I didn’t feel well, I feel bad and I don’t want to stay with the people but at the workshop they tell more things to disclose and I see that I’m still person and strong to do more things”.

## *Theme two: PLWH could share their painful experiences of HIV stigma*

PLWH shared painful experiences of stigmatisation: “…it’s so painful when you tell someone you trusted and he turns you down”; “I felt ashamed”; “…they start to point fingers and gossip”; “being with people and isolate yourself from other”; “…you feel neglected”.

## *Theme three: The intervention and project 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: “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 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”.

## *Theme four: Improved self-image and self-acceptance*

The PLWH regained their self-image: “I’m strong to do more things” and realized that they can have meaningful lives: “got 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: The intervention and project was initially difficult but empowered people to establish change and experience meaning*

PLWH felt an initial fear to disclose: “…I was so afraid of, so scared to talk but after... the workshop...I’m not afraid to talk about it”. They verbalized 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: “we teach the people about HIV stigma, people stay and ask us questions.” They felt happy because they gained knowledge: “they teach us something we didn’t know, how you can speak about this disease, now it gave us 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 and the workshop teach me more things and me myself I was free because I can tell anybody”; “I felt free, and my heart opened up”.

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

PLWH verbalized 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’s 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”. 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 this led them to become leaders to empower others*

The participants 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”. Participants mentioned that they moved from fear, to action, and then to pride regarding their achievements: “we had to teach people in their homes it was nerve-wrecking. I was happy to see that because if we had more of this, we will really end up with peace in the world as people with HIV.” They found it a life-changing experience: “...felt like I was now in the light and it was the first hearing about stigma”

## *Theme two: Became aware 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 is that when they spoke and each one stood up and talked about the way people mistreated them”. They 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 three: Partners became united with PLWH 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 because they had the courage to stand in front of the community and say that they were HIV positive” and “I thought I was alone so now I experienced that when I go in the community I shouldn’t be afraid to talk to people about HIV”. They 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 so now they had her to run to”.

## *Theme four: Partners became empowered to disclose their own status without fear and shame*

Seeing their HIV positive partners disclose their status empowered them 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” and “Sometimes when I was around others and they talked about people with AIDS 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”.

## *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”.

Conclusions

No 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 realized 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 amongst members and decreased their feelings of loneliness.

Hope, dignity and pride of PLWH was 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 seems 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 NGO’s 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. 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 study involving other people living close to PLWH. The sample size thus could not be determined beforehand.

Acknowledgements

SANPAD for the bursary and financial support received to conduct the research as part of a bigger comprehensive community-based HIV-stigma reduction and wellness enhancement intervention study.

Mrs. Molaudzi as research assistant and all the participants.

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.

Anglewicz, P. & Chintsanya, J. 2011. Disclosure of HIV status between spouses in rural Malawi. *AIDS care: psychological and socio-medical aspects of AIDS/HIV,* 23(8):998-1005.

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.

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.

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. *African 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.

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

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.

Manyedi, M.E. 2007. Coping with stigma by women whose partners died of AIDS. Potchefstroom: North-West University (NWU). (Thesis – PhD.).

Masquillier, C., Wouters, E., Mortelmans, D. & le Roux Booysen, F. 2014. The Impact of Community Support Initiatives on the Stigma Experienced by People Living with HIV/AIDS in South Africa. *AIDS And Behavior*, (Published online) <http://eds.a.ebscohost.com.nwulib.nwu.ac.za/eds/command/detail?sid=982b2546-60bb-4eda-a371-8ff28702a155%40sessionmgr4001&vid=2&hid=4103> Date of access” 15 Sep. 2014

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., Baijal, P., & Pegurri, E. 2011. Facilitating HIV disclosure across diverse settings: A review. *American journal of public health*, 101(6):1-22.

Pulerwitz, J. & Bongaarts, J. 2014. Tackling stigma: fundamental to an AIDS-free future. *The Lancet. Global Health*, 2(6):e311-e312.

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. <http://www.csa.za.org> Date of access 13 Nov. 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. <http://www.statssa.gov.za/publications/statsdownload.asp?PPN=P0302&SCH=5500> Date of access 22 Sep 2014.

Taylor, C. 2001. Scaling up for Social Development. Sussex: ILEIA. United Nations Development Programme (2000) Human Development Report 2000. New York: UNDP.

Thorne, S. 2008. Interpretive description. California: 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. <http://www.unaids.org/en/resources/presscentre/factsheets> Date of access 22 Sep 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):1059-66.

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. & LiI, J. 2008. A brief HIV stigma reduction intervention for service providers in China. *AIDS patient care and STD’S*, 22(6):513-518. doi: 10.1089/apc.2007.0198

Yin, R.K. 2009. Case study Research. 4th ed. 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.