

**Psychological well-being of HIV-affected children and their experience of a  
community based HIV stigma reduction and wellness enhancement  
intervention**

Tshadinyana Merriam Phetoe

20212380

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(NWU: Potchefstroom Campus)

Honours Degree: Psychology

(University of the Witwatersrand: Johannesburg)

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Supervisor: Prof I. P. Khumalo

Co-supervisor: Prof. Dr. M. Greeff

Assistant Supervisor: Prof. Dr. Q. M. Temane

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## **A Soul from a Prostitute**

A child of a prostitute, my new name it is  
That I inherited from this cruel community  
And the fact remains- my mother  
I don't care what people say 'cause she and I are one another  
"My Mother" I call her, from January to December it remains every year  
Half baked, the community sings in my ears  
The unwanted, unplanned child; a child of a prostitute  
And the attitude I get here makes me wanna vomit  
And I am sick of it  
I am sick and switched off, I'm full!!  
All these witch-crafted, diabolic words from you  
Makes me think I stink  
Maybe it's because I am a child of a prostitute  
She was not blind-folded  
And as responsible I know her  
She was trying to put food on the table  
Easy, people- I am trying to tell the other side of the story  
I'm aint gonna kill myself because you are calling me names  
Well I laugh at you all because you are all the same  
And it makes me go insane.

By: Regina - A child affected with HIV, 2010

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## **List of Abbreviations**

HIV = Human Immunodeficiency Virus

AIDS = Acquired Immune Deficiency Syndrome

PLHA =People Living with HIV or AIDS

MIV = MenslikeImmuneiteitsgebreksvirus

## **Research Outline**

The research is presented in an article format and the following are included:

1. A brief summary. The summary provides a brief description of the study that was undertaken.
2. One article will follow with the title of: '*Psychological well-being of HIV-affected children and their experience of a community based HIV stigma reduction and wellness enhancement intervention*'. The focus of the article is on children affected by associated HIV stigma in both an urban and rural settings. The article is intended to be submitted to the journal of *Social Science & Medicine*.
3. Conclusion, Limitations and Recommendations. In this section a comprehensive discussion of the overall conclusions, limitations of the study will be discussed and detailed recommendations presented.

## Acknowledgements

To the HIV-affected children who took part in this study, I appreciate each and every one of you. Thank you for all your contributions towards this project.

To my study leader Prof Khumalo, thank you for being such a good mentor, supportive friend and a brave *cheerer* when times are tough.

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To Prof Temane and the Research Team thank you for your guidance, advice and moral support.

To my baby girl Reotshepile, thank you for being part of this uplifting journey, your timing could have never been more perfect.

To my parents, Alpheus and Junior, thank you for your support, patience and to provide for me, even in days whereby I only had my studies in my pocket.

To the rest of the family, thank you for your motivation and support.

To Tsumbedzo Mukange, I appreciate you being there for me when I needed you. Thank you.

To my loved ones and friends, thank you for being there for me, even in the most inconvenient times.

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Gratitude is also given Mrs Poncho Molale for research support given throughout this study.

I thank My God the almighty, to whom all the glory belong- What a mighty God He is...

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### Authors' Contributions

The larger study was initiated by Prof. Greeff as project leader and several other researchers and a collaborative researcher from the Netherlands. Each researcher's contribution in this study is described in the table below.

Ms. T.M Phetoe	Masters Research Psychology student, responsible for implementing the research process and writing the text on <i>Psychological well-being of HIV-affected children and their experiences of the community based HIV stigma reduction and wellness enhancement intervention.</i>
Prof. Dr I.P. Khumalo	Study leader, member of the research team, critical reviewer of the study and the article.
Prof.Dr. M. Greeff	Co-study leader, project leader and critical reviewer of the study and the article.
Prof. Dr. Q.M. Temane	Assistant Study leader, research team member and critical reviewer of the study and the article.
Prof.Dr. H. Strydom	Research team member and critical reviewer of the article.

The following statement is a declaration by co-authors to confirm their role in the study and agree to its nature of being an article format for submission as a mini-dissertation.

## **Declaration**

I hereby declare that I have approved the inclusion of one (1) article mentioned above in this mini-dissertation and my role in this study complies with what is described above. I hereby give consent that this article may be published as part of the degree Magister Artium Research Psychology as mini-dissertation of Tshadinyana Merriam Phetoe.

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Ms. T.M. Phetoe

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Prof Dr. I.P. Khumalo

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Prof. Dr. M. Greeff

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Prof. Dr. Q.M. Temane

## Summary

The HIV epidemic does not only affect people living with HIV or AIDS but has a large impact on the children. They are being stigmatised by association. There is paucity in research on HIV stigma interventions. In addition, existing interventions aimed at reducing HIV stigma are not community based and very few are aimed at HIV-affected children. The purpose of this study was to assess the change on psychological well-being of HIV-affected children after a *Community based HIV Stigma Reduction and Wellness Enhancement Intervention*, and to explore and describe their experiences thereof. This study formed part of a larger *Community based HIV Stigma Reduction and Wellness Enhancement Intervention* project.

A mixed method convergent parallel design involving quantitative and qualitative data collection, analyses and integration of findings was applied. The sample was drawn from populations in the greater Potchefstroom urban area and rural Ganyesa in the North West Province. The children as participants in this study were children of PLHA in the larger study and were recruited using snowball sampling (n=11) and were between the ages 15 and 21 years. The quantitative component utilised a one group pre-test-repetitive-post-test design which was analysed by using IBM SPSS (ver. 20) by comparing t-test scores and F-ratios in ANOVA. The qualitative component of the study employed a holistic multiple case study approach and qualitative interpretive description and data were analysed by using thematic content and document analyses.

The results indicated no significant difference between the urban and the rural groups in the subscales and total scores of mental well-being. The results of the total scores projected that the participants' mental health was in the region of moderately mentally healthy. The in-depth interviews confirmed the three dimensions of the subscales indicating that they have

verbalised similar experiences to the itemised subscales of emotional, social and psychological well-being. The intervention was a meaningful experience to the children. They gained knowledge about HIV stigma and how to cope with it; as well how to build relationships amongst themselves and with the PLHA. They gained a better understanding of their parents suffering from HIV and other PLHA as well as support of one another being in this difficult situation. Conducting the project led to them becoming empowered to act as leaders in HIV stigma reduction. The results of the in-depth interviews showed that the children gained a greater awareness of the process of the stigma and experienced a general increase in their knowledge throughout the workshop and the project. They formed meaningful relationships with other children and deepened their relationships with their parents and other PLHA. The children were empowered through these interventions to advocate against HIV stigma despite the challenges they faced. They gained confidence and experienced personal growth through their participation in the project.

It is recommended that the findings of the study be applied in education to raise awareness of HIV stigma among psychology students and for training of practicing psychologists on their role in reducing HIV stigma and enhancing well-being of the PLHA and those living close to them. It could also be meaningful if the intervention were to be used for practice purposes where support is given to the newly diagnosed PLHA and those associated with them. Further research can be done to test sustainability of the intervention in a different context and with a bigger sample.

**Keywords:** HIV; AIDS; Community based; Intervention; Stigma; Children; Psychological Well-being; Urban; Rural.

## Opsomming

Die MIV epidemie beïnvloed nie slegs die persone wat daarmee gediagnoseer is nie, maar oefen beslis ook 'n groot invloed op die kinders van diesulkes uit. Die kinders ervaar onder ander stigmatisering as gevolg van assosiasie. Weinig navorsing is in verband met relevante intervensies gedoen en daarbenewens is die navorsing wat wel gemik is op die verligting van stigmatisering nie gemeenskapgebaseerd nie. Baie min is gedoen ter wille van die MIV geaffekteerde kinders sodat hulle verligting van stigmatisering kan ervaar. Die doel van hierdie studie was om moontlike verandering van die psigologiese welstand van gestigmatiseerde kinders te verken en te evalueer nadat hulle deel was van 'n gemeenskapgebaseerde intervensie toepassing wat gemik was op die verligting van MIV verwante stigma vermindering en welstand verbetering. Hierdie studie het deel gevorm van 'n groter gemeenskapgebaseerde MIV stigma vermindering en welstand verbetering intervensie.

Die metode van navorsing het bestaan uit 'n konvergente parallelle onderwerp wat kwantitatiewe sowel as kwalitatiewe data versameling, ontledings en integrasie van bevindings ingesluit het. Die steekproef is geneem uit die groter bevolking van die stedelike gebied van Potchefstroom en uit die landelike Ganyesa gebied, albei in die Noordwes-Provinsie. Die kinders wat aan hierdie deelgeneem het, was kinders van PLHA wat in die groter studie deelgeneem het en is deur sneeubal steekproefneming gewerf (n=11) en met ouderdomme tussen 15-21 jaar. In die kwantitatiewe komponent is gebruik gemaak van 'n enkelgroep voor-toets-herhalende-na-toets ontwerp en die ontleding is gedoen met behulp van IBMSPPSS (ver 20) wat die vergelyking met t-toets-tellings en F- verhoudings in ANOVA in gesluit het. In die kwalitatiewe komponent is gebruik gemaak van 'n holistiese veelvuldige gevalstudie benadering en kwalitatiewe interpretatiewe beskrywing. Die ontleding is gedoen deur middel van tematiese inhoud en dokumentering.

Die resultate het getoon dat daar geen beduidende verskille in die sub-skale en totale metings vir geestelike welsyn tussen die stedelike groep en die landelike groep voorkom nie. Die resultante van die totale tellings het aangetoon dat die deelnemers se psigologiese welstand as magtig gesond beskou word. Die in-diepte onderhoude het die drie dimensies sub-skale bevestig en oorkomste in die verwoording van persoonlike en individuele ervaring uitgewys op van die items vir emosionele, sosiale en psigologiese welstand. Die intervensie was 'n betekenisvolle en waardevolle gebeurtenis vir die deelnemers. Hulle het kennis opgedoen in verband met die prosesse van MIV stigma en maniere om die te hanteer. Hulle het insig verwerf met betrekking tot die ophou van onderlinge verhoudings en 'n verhouding met die geïnfekteerde persone. Hulle kon 'n beter begrip vorm vir hulle ouers as lyers en as slagoffers van MIV en hulle het persoonlike groei ervaar, 'n toename in selfvertroue en kon beter verhoudings met ander betrokkenes sluit. 'n Belangrike voordeel van deelname aan die projek was dat dit daartoe aan leiding gegee dat deelnemers beter toegerus is om in hulle leefwêreld as kampvegters vir die vermindering en verligting van MIV-verwante stigma op te tree.

Daar word voorgestel dat daar in die onderrigprogramme van sielkunde studente en praktiserende sielkundiges meer aandag gegee word aan die bewusmaking sowel as die bestaan, werking en bekamping van stigmatisering. Soortgelyke intervensies kan in die sielkunde praktyk ook plaasvind ter ondersteuning van die gestigmatiseerde persone. Verder navorsing kan ook gedoen word om die volhoubaarheid van intervensies na te speur, veral met 'n meer omvangryke steekproef en 'n verskeidenheid van benaderings in 'n ander konteks.

**Sluitel Woorde:** MIV; VIGS; Gemeenskapgebaseerde; Intervensie; Stigma; Kinders; sielkundige welstand; Welstand; Stedelike; Landlike

**Manuscript for Examination**

**Title: Psychological well-being of HIV-affected children and their experience of a community based HIV stigma reduction and wellness enhancement intervention**

**Journal: Social Science & Medicine**

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## **Manuscript**

### **Psychological well-being of HIV-affected children and their experience of a community based HIV stigma reduction and wellness enhancement intervention**

Tshadinyana M. Phetoe

School for Psychosocial Behavioural Sciences, NWU, South Africa

Itumeleng P. Khumalo

Optentia Research Programme, Vaal Triangle campus, NWU, South Africa

\*Minrie Greeff

Africa Unit for Trans-disciplinary Health Research, NWU, South Africa

& Q. Michael Temane

School for Psychosocial Behavioural Sciences, North-West University, South Africa

\* Corresponding author. E-mail address: [Minrie.Greeff@nwu.ac.za](mailto:Minrie.Greeff@nwu.ac.za)

## Abstract

The impact of the HIV epidemic not only affects people living with HIV or AIDS but has a large impact on their children due to them being stigmatised by association. There is paucity in research on HIV stigma interventions. Existing interventions aimed at reducing HIV stigma are not community based and very few are aimed at HIV-affected children. The purpose of this study was to assess the change in psychological well-being of HIV-affected children after a *Community based HIV Stigma Reduction and Wellness Enhancement Intervention* and to explore and describe their experiences thereof. A mixed method convergent parallel design was applied. The quantitative component utilised a one-group pre-test- repetitive post-test design and the qualitative component a descriptive holistic multiple case study approach and qualitative interpretive description. Data were collected between August 2010 and September 2011. The sample (n=11) consisted of urban and rural children (aged between 15 and 21 years) of PLHA residing in the North West Province, South Africa and were recruited by using snowball sampling. The results indicated no significant difference between the urban and the rural groups in the subscales and total scores of mental well-being. The in-depth interviews confirmed the three dimensions of the subscales indicating verbalised experiences of emotional, social and psychological well-being. The intervention was a meaningful experience to the children. They gained knowledge about HIV stigma and how to cope with it and how to build meaningful relationships. They gained a better understanding of their parents suffering. The projects activated their leadership and they were empowered to advocate against HIV stigma. The results of the in-depth interviews showed that the children gained greater awareness of the process of stigma and experienced a general increase in their knowledge. The study has implications for teaching, practice and research purposes.

**Keywords:** HIV; AIDS; Community based; Intervention; Stigma; Children; Psychological Well-being; Urban; Rural.

## **Background and Problem Statement**

Various research findings (e.g. UNAIDS, 2010; Scott & Harrison, 2009) attest to the widespread and problematic nature of human immunodeficiency virus (HIV) as an epidemic in sub-Saharan Africa. It is estimated that 33.3 million people are infected with HIV globally (UNAIDS, 2010). The sub-Saharan Africa region accounts for 67.5% of the total global infections. South Africa alone accounts for 16.5% of global infections and 1.8 million new infections were reported in 2009 (UNAIDS, 2010). Over a thousand AIDS-related deaths are reported each day in South Africa. According to Scott and Harrison (2009) trends of HIV infection in South Africa show an increase among the age-groups of 30-39 and 40-44 year olds. People in these age-groups are in their child-rearing stage of life. The consequence of this is an increase of the number of children who have at least one parent living with HIV.

It is also expected that as more people have access to anti-retroviral (ARV) treatment and live longer, the number of AIDS-related deaths would decrease (Walensky, Wood & Weinstein, 2008). In South Africa, by September 2009, ARV treatment was already offered to 90% of people who were tested and found to be in need of it (Scott & Harrison, 2009). This positive development renders HIV a chronic illness. However, the quality of life of those living with HIV, and people living and working close to the infected, particularly their children, is negatively affected. This is partly due to HIV-related stigma that is experienced by virtue of living with HIV and AIDS, or being associated with people living with HIV and AIDS (Holzemer & Uys, 2004). People living with HIV and AIDS (PLHA), their families and HIV and AIDS health workers are subjected to prejudice, discrimination, abuse, and hostility due to HIV stigma (Holzemer & Uys, 2004).

The expression of the word stigma was coined by the Greeks referring to a mark that was cut or burned into the body of a person with blemished character - a criminal, traitor, or

slave (Harvey, 2001). Several authors since have defined the word stigma. Goffman (1963) first defined stigma as a 'spoiled social identity' by which the bearer is considered to deviate from the norm and what is considered acceptable. He further explained stigma as a "...phenomenon whereby an individual with an attribute is deeply discredited by his/her society and is rejected as a result of the attribute" (Goffman, 1963, p.3). Skinner and Mfecane (2004) refer to HIV-related stigma as a complex social process that is perpetuated by existing discrimination against societal groups that are already vulnerable to HIV infection. Parker and Aggleton (2003) mention 'structural violence' which they describe as societal forces shaped by racism, sexism, poverty, political violence and other forms of social inequities embedded in the "historical and economic processes that script the distribution and outcome of HIV/AIDS." The definition of choice for this study is by Alonzo and Reynolds (1995, p.304) describing it as 'a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons'. This definition is adjusted from the initial one by Goffman (1963).

Stigma is always closely associated with and is followed by discrimination, whereby discrimination is an act of stigma (Eba, 2007). Factors related to perceptions of HIV and AIDS include views on sexual morality and HIV infection, poor HIV and AIDS health services and poverty influences stigma (Campbell, Nair, Maimane & Nicholson , 2007; Eba, 2007; Holzemer et al., 2007, Kalichman & Simbayi, 2003). It may result in poor quality of life, poor health and reduced access to care and even violence against those infected and affected (Holzemer et al., 2007). Poor health as an outcome of stigma is not only restricted to physical health, but also includes mental health. Holzemer et al. (2007) argue that HIV and AIDS stigma can result in factors such as social exclusion, rejection, high stress due to stigma and economic pressures, which may lead to stress-related mental illness. A longitudinal study

by Greeff et al. (2010) found HIV stigma to be negatively associated with life satisfaction among PLHA.

According to Holzemer et al. (2007) there are three types of stigma, namely, received, internal and associated stigma. Received stigma refers to any form of stigmatising behaviour towards a person living with HIV or AIDS. Internal stigma includes negative thoughts and behaviour based on a person's perceptions about himself/herself with regard to him/her being infected with HIV or AIDS. Associated stigma refers to stigmatising behaviour towards a person who is associated, in any form, with a person living with HIV (Holzemer et al. 2007). Ogden and Nyblade (2005) refer to associated stigma as secondary stigma. It is the latter type of stigma that is the focus of this study as it relates to children. Received and associated stigma expands on earlier concepts of etic and emic stigma by Weiss et al. (1992). The conceptual model of HIV/AIDS stigma of Holzemer et al. (2007) is the chosen theoretical model for this study because it offers a comprehensive approach to the process of stigma and has been applied in an African context. The mentioned model considers HIV stigma as a process which occurs within the context of environment, health care system and different agents or people. The process of stigma includes its triggers, stigmatising behaviours, types and outcomes (Holzemer et al., 2007). The model proposes dynamic relationships and processes in which stigma can exist and be influenced by other factors in the society (Holzemer et al., 2007).

The model of stigma by Holzemer et al. (2007) brings to light how stigma affects people living close to PLHA, for example children. They experience stigma by virtue of being related to PLHA. They may therefore also suffer other negative outcomes associated with stigma similar to their parents or adult PLHA family or relatives (Harms, Jack, Ssebannya, & Kizza, 2010; Holzemer et al., 2007; Wood, Chase & Aggleton, 2006). In a

Ugandan study, it was found that children who have lost their parents to HIV and AIDS continued to experience stigma. Harms et al. (2010) termed this type of stigma 'Okulangira' which refers to the derogatory manner in which AIDS orphaned child would be reminded about his/her inferior position in the society.

In addition to experiences associated to stigma, HIV-affected children also experience other difficulties associated to adjustment of parental HIV diagnosis. HIV-affected children are more inclined to experience depression, problem behaviours, family life stressors, emotional distress and difficulty in goal setting and HIV related stigma (Lee, Lester, & Rotheram-Borus, 2002, Rotheram-Borus, Lester & Stein, 2006; Lee & Rotheram-Borus, 2002). Literature supports this notion further by recognising that HIV-affected children, like any other groups of vulnerable children, are likely to experience high levels of stress and to be at risk for long-term negative developmental outcomes (Coldstream, 2008; Harris, 1991; Rotheram-Borus et al, 2006). Rotheram-Borus et al. (2006) found that adolescent children of people infected with HIV were more likely to experience high levels of depression, tendency of substance abuse, negative expectations of adulthood and high sexual risk behaviour. In the same study, emotional distress was associated with parental diagnosis, and high levels of stress were positively associated with HIV related stigma (Rotheram-Borus et al., 2006).

There had been a significant number of studies that reported on the positive outcomes or characteristics of vulnerable children (Malindi & Theron, 2010; Theron, 2012; Theron, Cameron, Didkowsky, Lau, Liebenberg & Ungar, 2011; Ungar, Theron & Didkowsky, 2011). These studies provide empirical evidence that children facing considerable levels of risks, such as HIV-affected children, are able to do well developmentally, despite their challenges. However, literature shows that these positive attributes are influenced by a number of social factors (Rotheram-Borus et al., 2006; Theron et al., 2011; Ungar et al., 2011) that are

transactional in nature (Dutra et al., 2000; Ungar et al., 2011). Factors associated with adjustment to parental diagnosis among HIV- affected adolescents tend to improve over time with positive parent-child bonding. Rotheram-Borus et al. (2006) found that the positive parent-child bonding acts as a buffer against the negative impact of stressful life situations and parental HIV diagnosis among adolescents. Similarly Dutra et al. (2000) found that the parent-child relationship emerged as the only significant predictor of child resiliency amongst other family characteristics examined. These studies and their empirical evidence support for delivery of family-focused coping skills interventions that provide long-term benefits to HIV- affected children.

A literature review study by Brown, Trujillo & Macintyre (2003) revealed that although several HIV stigma reduction interventions have been developed and tested worldwide, they seem to work on a small scale and had a short-term duration of impact. Holzemer and Uys (2004) were of the views that almost all the research conducted in the area of stigma and AIDS interventions lacked thorough scientific analysis. The findings by Eba (2007) also demonstrated that a need exists for studies with well-developed designs that report on the subject particularly in an African context. The presently available HIV stigma interventions are limited in scope and tend to focus on information and skills building, PLHA tolerance and target at specific community groups. Examples include *Common at its core: HIV related stigma across contexts* (Ogden & Nyblade, 2005), *Understanding and challenging HIV/AIDS stigma: toolkit for action* (Kidd & Clay, 2003), *HIV/AIDS resource pack* (Siyam'kela, 2003), *HIV/AIDS anti stigma training guide for traditional and opinion leaders* (Christian council of Ghana, UND), *Guidelines for reducing stigma and discrimination* (SANASO, 2005) and *Health setting-based stigma intervention* (Uys et al., 2009). Therefore, no intervention could be found that adopts a comprehensive approach that deals with different aspects of stigma at multiple social levels or at a community base. There

is a need to move beyond information and education and to integrate necessary elements for effective response to HIV stigma (Eba, 2007). According to Sayce (1998) the inclusion of children of PLHA in such intervention programmes would improve belonging, promote open debate about different discrimination and address power relations issues (Sayce, 1998). Uys et al. (2009) developed an HIV stigma intervention based on the Holzemer et al. (2007) conceptual model of stigma and combined information sharing, increasing contact with affected and improving coping through empowerment as its basic tenants. Although the intervention yielded positive outcomes within health settings in African context, its sustainability was not tested and applicability within community based settings was not confirmed (Uys et al., 2009). Accordingly the implementation of stigma-reduction strategies should pay attention to the causes of stigma, underlying drivers of stigma, multiple levels and layers of stigma and engaging multiple target groups and potential change agents (Eba, 2007).

However, it has been observed that the African context where HIV infections are estimated at 67% is generally neglected. Available literature focuses on AIDS orphans versus HIV-affected children whose HIV-infected parents are still alive. There is a need for an HIV stigma reduction intervention study with PLHA and their children with a thorough scientific analysis. Moreover, a shift towards a focus on well-being, rather than pathogenic aspects, is needed. The current study sought to focus on children affected by associated stigma in both an urban and a rural setting whose parents are PLHA and alive. The study formed part of a larger SANPAD funded *Community based HIV Stigma Reduction and Wellness Enhancement Intervention* project.

## Research Objective

The purpose of this study was to assess the change in psychological well-being of HIV-affected children after an intervention, and to explore and describe their experiences of the *Community based HIV Stigma Reduction and Wellness Enhancement Intervention*.

## Methodology

### Design

The present study employed a mixed method convergent parallel design (cf. Creswell & Plano Clark, 2011), involving quantitative and qualitative data collection, analyses and integration of findings. The quantitative component of the study utilised a one-group pretest-repetitive –post-test design (cf. Barbie, 2010) whereas the qualitative component employed a descriptive holistic multiple case study approach (cf. Yin, 2009) and qualitative interpretive description (cf. Thorne, 2008). See *Figure 1* for an illustration.

<Insert Figure 1 here>

### Method

**Participants.** The sample was drawn from populations in the greater Potchefstroom urban area and rural Ganyesa in the North West Province. PLHA taking part in the larger studies were recruited through health care centres and NGOs to identify PLHA in their settings. The children as participants in this study were recruited by using snowball sampling, whereby the PLHA involved in the larger study were requested to invite their children that suited the criteria to participate in the study. The inclusion criteria were: must have a parent in the intervention that has been HIV infected for at least six months; must be 15 years or older; must speak, write and understand Setswana, English and/or Afrikaans; parents must give consent and children give assent to be interviewed and recorded. The total sample

consisted of 11 children (urban =4; rural =7), aged between 15 and 21, of whom three were male participants (one in the urban group and two in the rural group) and eight female participants (rural =5, urban =3). The relatively small sample size allowed for optimal participation of PLHA and their children in the intervention and enhancement of the envisaged benefits.

### **Data gathering.**

*Structure of the intervention.* The intervention of the larger study was adapted from a validated intervention manual of Uys et al. (2009). The larger study focused on several workshops with PLHA including their partners, children, family members, friends, community members and spiritual leaders. The present study focused only on the intervention with the HIV-affected children. The PLHA and their children were brought to the university for the workshop, where privacy and comfort were ensured. Transport was provided. Arrangements were confirmed with them prior to the workshop.

The intervention aimed to reduce HIV stigma and enhance well-being among PLHA and their HIV-affected children. The intervention was based upon the following tenants: increased knowledge; equalising relationships between PLHA and their children, and empowerment to deal with HIV stigma through enhancing leadership as well as their well-being. The intervention consisted of a three-day workshop and a community project. Trained non-infected and infected persons facilitated the workshops. During the first two days of the workshop, attention was given to HIV stigma awareness and coping and project development. By the end of day two of the workshop, the group had designed an HIV stigma reduction project focusing on children in the community. This community project was implemented and evaluated within four weeks after the intervention. The third day of the workshops

consisted of the project presentation and evaluation. The intervention was conducted in both an urban and a rural setting.

***Quantitative Measures.*** The HIV-affected children were brought to the university for the administration of the pre- and two post-tests with the latter three months apart. Privacy and comfort were ensured. Trained research assistants were used to administer the quantitative questionnaire with each participant, individually. The administration of measures at the pre-test and two post-test points took place in a controlled research context.

*Mental Health Continuum (MHC-SF: Keyes, 2002; 2006).* The MHC-SF was administered for pre-tests and post-tests. This is a self-report instrument that uses a five point Likert scale. The MHC-SF measures the degree of Emotional well-being (three items), Social well-being (five items) and Psychological well-being (six items). Empirical evidence to attest to the scales validity and reliability for use among Setswana speaking population in South Africa was found by Keyes et al. (2008). The theoretically intended factor-structure consisting of emotional, psychological and social well-being was found. In that study, the scale obtained Chronbach's alpha of 0.74 (Keyes et al., 2008).

***Qualitative Measures.***

*The case study.* A holistic multiple case study design (Yin, 2009) was used to describe the qualitative data of the intervention. The case records consisted of a detailed description of the *Community based Stigma Reduction and Wellness Enhancement Intervention* manuals and lectures, naïve sketches, researchers' field notes, a detailed description of the community project, and the evaluation thereof. Naïve sketches were completed at the end of each of the three days of the workshop and consisted of two open-ended questions: "*I have experienced this day of the workshop as...*", and "*I feel...*" Each participant was given a chance to share their naïve sketches with the rest of the group, if he/she was willing. Field notes were

recorded by the research team at the end of each of the three days of the workshop. The field notes included the researcher's observational, personal and theoretical notes (Botma, Greeff, Mulaudzi & Wright, 2010). The activities of the project were documented in detail in the form of a project report. These activities included planning, execution and feedback of the project. The children presented their report on the third day of the workshop to the research team and selected stake holders of the community based on the execution of project, team spirit, successes and presentation of the report.

*In-depth interviews.* Individual in-depth interviews were conducted with each participant (Babbie, 2010). Privacy and comfort were ensured. Appointments with participants were made for a specific time. The field notes by the researcher at the end of each interview recorded any additional information that may not have been disclosed by participants (cf. Botma et al., 2010). Questions were developed and presented to experts, and pilot tested. The participants were asked an open-ended question: "*How did you experience the workshop and the project with people living with HIV and other children in the group?*" The following communication techniques as outlined by (Botma, et al., 2010), were used to facilitate the interview: minimal verbal response, paraphrasing: clarification, reflection, encouragement, comments, reflective summary and probing. A digital audio recorder was used to record the interview.

### **Data analysis.**

*Quantitative analysis.* Firstly the MHC-SF and subscales were compared for urban and rural groups using the independent t-test statistic. Based on consistent descriptive statistics of the two groups, the samples were combined to form one sample of 11 participants. Further analyses were then performed on the total sample. Secondly, descriptive statistics namely mean scores, standard deviation, range, skewness and kurtosis values were

computed as indices of score distribution and dispersion (cf. Pallant, 2007) for the MHC-SF at item, subscale and total score levels. Thirdly repeated measures utilising ANOVA were performed to examine the change in levels of mental health of the sample before the intervention (T<sub>1</sub>), shortly after the intervention (T<sub>2</sub>) and three months thereafter (T<sub>3</sub>). The significance of the difference was determined by a *p* value score below 0.05.

**Qualitative analysis.** The qualitative data were analysed by using thematic content analysis (cf. Braun & Clarke, 2006) as well as document analysis (Yin, 2009) for pattern matching, logical models, time series analysis and cross-case synthesis.

### **Rigour**

In the current study rigour was ensured by observing issues of trustworthiness as outlined by Guba's model (Botma et al., 2010; Krefting, 1991). The epistemological standards observed in this study included truth value, applicability, consistency and neutrality (Krefting, 1991).

**Truth value.** This was ensured through prolonged engagement with participants during the intervention and interviews; reflexivity through use of field notes and discussions with study leaders; triangulation of methods, sources and investigators; using a co-coder during analysis; and having senior researchers involved through study guidance.

**Applicability.** To ensure applicability of the findings the participants were sampled by using snowball sampling. A dense description of the research process provided for the reader to be able to verify transferability of the findings to their own settings.

**Consistency.** An audit trail and stepwise replication of the study was made possible through the dense description of methodology. Triangulation as discussed as well as the co-coder enhanced dependability were included.

**Neutrality.** Issues regarding confirmability of the study were addressed by triangulation, reflexivity as well as the possibility of an audit trail.

### **Ethical Aspects**

Ethical approval was granted by the Ethics Committee of the Faculty of Health Sciences of the North-West University (reference number: 09/15, expiry date: 29 March 2014) and the South African Department of Health. Informed consent was obtained from all participants. Information communicated included, aims of the research project, expectations from prospective participants, use of data for research purposes, withdrawal from the project, termination of study participation, confidentiality, risk factors, accountability, and inquiries.

### **Results of the Study and Discussions**

The results of the study focus on the results of the quantitative mental health measures of the pooled urban-rural data, as well as the combined quantitative mental health measures and the qualitative in-depth interviews. A dense description of the intervention is provided through a case study. The findings of the experiences of the HIV-affected children of the workshop and the project are described and enriched with quotes.

#### **Quantitative Mental Health Measures**

The means of the urban and rural subscales and total score of the MHC-SF at baseline (time 1) were calculated and the significance difference calculated. The results showed no significant differences between the two groups for the subscales: EWB [t(9)=1.53,  $p=.160$ ], SWB [t(9)=0.93,  $p=.379$ ] and PWB [t(9)=0.51,  $p=.626$ ]; and the total score [t (9) =0.24,  $p=.815$ ]. Based on these results, data were pooled as reflected in Table 1.

**<Insert Table 1 here>**

Table 1 displays the descriptive statistics of the total sample (n=11) of participants on the MHC-SF at item and subscale levels and the total at base point (time 1). The sample obtained a mean score of 42.45 for the total scale score within the range of 0 to 59.00. Item-level scores could possibly have ranged between 0.00 and 5.00. The present sample's mean scores at item level ranged between 1.64 (item 4) and 4.09 (item 12). The distribution of means scores according to skewness and kurtosis values indicated mean values clustering more to the right and more of a flat dispersion (cf. Pallant, 2007). Except for item 12 (skewness=-2.30; kurtosis=5.81) the rest of the items obtained values within expected normal range.

<Insert Table 2 here>

Table 2 displays the three subscales of the MHC-SF and their itemised description, comparative mean and standard deviation score over a period of three measures, the f-ratio, *df* and *p*- values ( $p < 0.05$ ) indicating significance in differences between the three measures over time. Included in the last three columns of the table are the results of the MHC-SF confirmatory categories of the itemised descriptions found during the in-depth interviews and accompanying quotations. The subscales consist of “*emotional well-being*”, “*social well-being*” and “*psychological well-being*”.

**Emotional well-being.** A three item subscale showed no significant difference [ $F(2)=0.89$ ,  $p=.420$ ] over time across the three measures ( $\bar{x} =7.91$ ,  $\bar{x} =9.18$  and  $\bar{x} =6.50$ ). Although not significant the scores indicated an increase of emotional well-being at time two directly after the intervention and a decrease during time three. All three items (“happy”, “interested in life” and “satisfied”) were confirmed by enriching quotes from the qualitative in-depth interviews among both urban and rural groups indicating the presence of emotional well-being.

**Social well-being.** A five item subscale showed no significant difference [ $F(2)=0.78$ ,  $p=.469$ ] over time across the three measures ( $\bar{x} =14.73$ ,  $\bar{x} =13.36$  and  $\bar{x} =11.20$ ). Although not significant the scores indicated a decrease of social well-being at time two directly after the intervention and a further decrease during time three. All five items (“Social contribution”, “Social integration”, “Social actualisation”, “Social acceptance” and “Social coherence”) were confirmed by enriching quotes from the qualitative in-depth interviews among both urban and rural groups indicating the presence of social well-being.

**Psychological well-being.** A six item subscale showed no significant difference [ $F(2)=0.25$ ,  $p=.779$ ] over time across three measures ( $\bar{x} =20.64$ ,  $\bar{x} =21.82$  and  $\bar{x} =19.40$ ). Although not significant the scores indicated an increase in social well-being at time two directly after the intervention and a decrease during time three. All Six items (“Self acceptance”, “Environmental mastery”, “Positive relations with others”, “Personal growth”, “Autonomy” and “Purpose in life) were confirmed by enriching amongst both urban and rural groups indicating the presence of psychological well-being. The scores indicated an increase in psychological well-being after the intervention and a decrease during time three.

**Total score:** The total score of the 14-item scaled showed no significant difference [ $F(2)=0.56$ ,  $p=.562$ ] over time across three measures ( $\bar{x} =42.45$ ,  $\bar{x} =43.91$  and  $\bar{x} =37.40$ ). Although not significant the scores indicated an increase in mental health during time two after the intervention and a decrease during time three. The total score thus indicated that the participants ranged from moderately mentally healthy to flourishing.

### **Description of the Case Study**

The intervention is reflected in a rich description of the various analysed sources of the case record. The qualitative analysis showed similar results between the urban and rural groups and thus were pooled. Special mention will be made where differences are noted.

**Day one of the intervention.** The first day focused on getting HIV-affected children to understand stigma and to cope better with it, and to build on an improved relationship between the affected children and their infected parents. The findings revealed that children had gained knowledge and understanding of HIV stigma and coping with stigma “*The workshop gave me more knowledge about HIV and Stigma. It helped me a lot about every detail that I didn’t understand about HIV and stigma.*” they felt more enlightened “*I experience lot of things that I haven’t known about...*” and “*I was having lack of knowledge about the stigma. I was thinking that my village was having the lot of things.*” The children felt happy to have gained this knowledge “*A happy day because I got the information about stigma and HIV/AIDS that I never knew about, that makes me happy.*” and felt it is important to share this new information with others “*So as myself I will pass what I have learn to other people.*”

The children shared that initially they were uncomfortable about meeting new people, however, this changed by the end of day one of the intervention. “*The first day was a bit scary because I knew no one.*”; “*very happy and more confident.*” and “*...sad because I am shy and I was welcomed.*” Their uneasiness of interacting with others was replaced by feelings of excitement and gratitude. They had formed meaningful interactions with people and had initiated positive relations among each other “*I am blessed to have met such good people with such attitude.*”; “*...excited and loved. Honoured and respected.*” and “*I know people now from the workshop now.*” The findings showed that by the end of day one of the workshop the children felt well-equipped to relate better with PLHA and their community “*I know how to treat and cope with people who are infected as I am affected too.*” and “*It helped me with the situations in our community.*” There was a sense of pride and satisfaction in their renewed ability to interact with PLHA “*...proud about the first step I took of handling people with HIV and AIDS.*” They felt that the new knowledge gave them a new

point of view about people who were infected with HIV or AIDS *“My perception on how I viewed stigma changed for the better. I even intend to give more support and contribute to helping others.”*

**Day two of the intervention.** During the second day, the focus of the intervention was on closing a gap between knowledge and understanding gained regarding HIV stigma and coping through activating leadership in social change. This was achieved by enabling the children to use this knowledge constructively to raise HIV stigma awareness in the community through a community project. During day two, the children planned community projects focusing on making other HIV-affected children aware of HIV stigma. The findings revealed that children experienced the second day as difficult and intense *“Today is a very powerful, busy and difficult day...”*; *“... we talk and talk the whole day.”* and *“...was very difficult and tiring”*. It was evident that children gained more knowledge: *“Today I learned more things than yesterday.”*; *“I think we will have much experience than yesterday.”* and *“I have learned more about workshop than yesterday.”* Generally, the children shared feelings of excitement about this new knowledge they had gained to activate change: *“I learned a lot, surely I will change other people’s views.”* and *“I experienced a lot of things than yesterday... I feel happy.”* The children also elicited feelings of excitement and optimism about the project they had planned on the day: *“...great experience due to a very good working team and exciting plans that we are determined to implement.”*; *“I feel happy because intervention is very, very important and I feel to do project.”* and *“Good today about planning a project and I think it goes well.”*

**The Projects.** The two projects implemented by urban and rural children were targeted at other children in their own communities.

The urban group implemented their project at a school in Potchefstroom. The name of the project was '*Stop Stigma Bullying*'. The aim was to raise awareness and fight against HIV stigma by creating a stigma free environment for HIV-affected children; and encourage school children to show love and support for others infected and affected by HIV; by decreasing the level of stigma bullying and increasing school attendance of HIV-affected children. The project involved '*HIV stigma talks*', a candle light ceremony, an HIV stigma play and a march and raising greater awareness through stickers, posters and banners about HIV stigma. The stigma talks targeted Grade 7 to 12 learners, with the rest of the activities targeting the whole school. The project managed to reach about 980 learners during a 4 day period. Urban children won the first price for urban groups of the larger project.

The children in the rural community formed a support group '*Stigma Ambassadors*' with the aim of making other children aware of HIV stigma and how to cope with it; to motivate them towards stigma reduction and to support those affected by stigma. The support group focused on teaching others about HIV to live positively in a stigma free environment. The children in the rural community reached out to ten other HIV-affected children in their village.

Both projects were launched and completed successfully, and had reached all their objectives within the set timeframe. The groups in both settings presented efforts of hard work, dedication and team work for the completion of the project. The teams were independent and well-organised.

**Day three of the intervention.** The third day of the intervention focused on giving the children the opportunity to present their projects to the research team and important stakeholders from the community and for it to be evaluated as well as to receive feedback. In general the children were content with the outcomes of their projects "*I feel glad that the*

*project went well.*” and had enjoyed implementing them: *“I enjoyed the project very much.”* They also shared a sense of relief on the completion of their projects: *“We are finished and finally I no longer have to have sleepless nights.”* Nonetheless, children from the rural community had also expressed their doubts and frustrations of being part of the project: *“I was thinking that our project will never go on and the people will never support us.”* They experienced support from other children who had joined their support group: *“They are so supportive and they are so patient of doing the project with us”*. The urban children on the other hand, have experienced challenges with the project but worked together to overcome them: *“It was difficult at the beginning but my group members were there to support me.”* They, however, experienced a sense of empowerment through gaining knowledge: *“The project taught me so many things in a small period of time.”*; leadership: *“I am a leader...”*; sense of determination: *“Whatever you set your mind onto, you can do it no matter how hard it is.”*; tolerance: *“I had to commit myself and learn to understand different people and their own selves.”*; and sharing with others: *“I learned that in life you have to share what you have with others that doesn’t have it.”* They were more appreciative of each other and had formed positive relations among themselves: *“I love you all. I thank God for having to meet such people with their great personalities.”* From the findings it is evident that sharing information with others was deemed meaningful to the children: *“This project was nice and I experienced more and to teach others about this project”* and *“They promised to teach their friends about stigma...”* They believed that they were able to change others’ perspective through sharing knowledge and teaching them: *“What we have taught really changed their perspectives as though they want to teach others”*.

## **Results of the in-depth interviews**

The analysis of the in-depth interviews gave a deeper understanding of the children's experiences of the workshop and the project. Seven themes were identified: forming positive relations with other children; achieving the project in spite of challenges; children advocating against HIV stigma; a greater awareness of the process of stigma; deepening relationships between children and PLHA; increased knowledge; and gaining confidence and personal growth through participation. The experiences of the urban and rural groups showed no significant differences and the results were thus pooled. Special mention will be made where differences occurred. Quotes and reference to applicable literature will enrich the discussion.

### **Theme one: Forming positive relations with other children in the intervention.**

The children mentioned how they had established positive relations among themselves. They expressed these experiences referring to gaining social support; sense of belonging; initial shyness to trusting others; being sensitive towards others; supporting each other; and resolving conflict. The children shared their experiences of being with other HIV-affected children as gaining social support: *“Knowing other children and understanding how they feel, of being affected by HIV and getting to know their situations at home...”* Being with other HIV-affected children elicited feelings of sense of belonging: *“When we were together as children and we were making plans at the [school].* When meeting each other for the first time, some children experienced some anxieties of meeting with new people, therefore came across as being shy. However, this changed and had formed trusting relations amongst themselves: *“At first when I met the children... I was like “I’m the only one who is young here. What I’m I going to do with them? How am I going to approach them? ...I think on the third day, by the time that we got to know each other and we talked when we had our breaks.”* Through interacting with others the children learned being sensitive with others: *“We had to be very sensitive when dealing with others if (XXX) doesn’t want to go to a*

meeting or something, I have to beg. 'Come on, (XXX). Hurry.'"; supporting each other: "Some people felt tired at times and wanted to pull out from the group, yes but we tried and we built the group." and resolving conflict: "It was difficult. We had a lot of fights and some bad words. But in the end, we managed to settle down and talk about it."

**Theme two: Achieving the project in spite of challenges.** The children noted that though they experienced challenges they succeeded with their projects: "...Yes because we were under pressure to make and submit a project. We did make it". They managed to create an environment where they could freely talk about HIV and HIV stigma: "...I experienced in a way that some learners were afraid to talk to other people. They told us that it's better to talk to a stranger than to a person you know. Some of the learners, talked to us...". They got other children involved in stigma reduction: "Our community has not been aware of what they have been doing, so then they will now go and tell others within the community and spread the word about stigma."; Worked as a team to overcome challenges: "We were working as a team working hard. We told ourselves that we are going to achieve the project." They benefited from the workshop: "I benefited quite a lot from the project and I was also able to teach other people and spread information to others." The children showed persistence in order to succeed with their project: "I think that we were strong enough. For us to make it, we were strong enough." They had lobbied and gained support from community for their project: "We didn't struggle to find people to participate because the community is full of young people, so we were able to gather them up quickly and train them". They shared a sense of pride in completing the project: "Then in the project, it was difficult because we were given a little time to work on the project. But we did it. For us to win was amazing because we did finish the project. So we felt great about it."

The findings support available literature on resilience of vulnerable children (Malindi & Theron, 2010; Theron, 2012; Theron et al., 2011; Ungar et al., 2011). These studies confirm that children facing considerable levels of risks, such as these HIV-affected children, are able to do well developmentally, despite their challenges.

**Theme three: Children Advocating against HIV stigma.** The children shared their experiences of advocating against stigma in their communities: information, encouraging others not to stigmatise, acceptance of PLHA, reducing stigma in order to enhance well-being of PLHA and HIV stigma advocacy to reduce the spread of HIV.

The children shared information of HIV stigma with others as a form of advocacy: *“I was happy but I was telling myself... Maybe people haven’t seen what is stigma. Let me spread out the message.”* They had also encouraged others to act against stigma: *“I am happy because I got to encourage children that they should not stigmatize against people because I learnt that the children stigmatized people...”* The children advocated for acceptance of PLHA: *“These people should be taught that people with HIV are people too. They should have that spirit of community and acceptance.”* They believed that reducing stigma would enhance well-being of PLHA: *“It would really help because people wouldn't have to hide the fact that they have HIV and they would be free.”* and reduce spread of HIV: *“...that would in-turn reduce the spread of HIV, because people would be more aware and know what they should and shouldn't do”* and *“If this person isn't accepted and isn't given the support then they start to be weak and not even care about themselves and they start not to eat and not even go to the clinic because what's the point, no one accepts me or supports me I'm just all alone”*.

These findings support those found by Uys et al. (2009) where participants in a similar intervention implemented in five African countries were empowered and showed advocacy against stigma within their health care facilities.

**Theme four: Greater awareness of the process of stigmatisation of PLHA and other children.** The children became aware of others' experiences in the community and of HIV stigma by the community: *"I felt hurt by what these kids were doing because I also taught myself about what stigma was and that how it affected people emotionally and physically because of other people."* The most common experience was negation against those living with HIV or AIDS: *"The people with HIV have their own rooms which means they are being segregated from other people..."* Some children shared their experiences of stereotyping as a form of stigma: *"My friends told me that there's a teacher is infected with this [HIV or AIDS] and I was surprised, like wow, because of how she looked you understand?..."* The children experienced gossiping as another form of stigma *"That when I stigmatize a person it is like a group of people are sitting and talking about you, they are stigmatising and you hear rumours about yourself."* They also shared that PLHA are named and shamed by their communities: *"... that there are some people in the community who aren't treated well, some people in the community say very bad things about people living with HIV. This makes people living with the disease ashamed"*. However, the experiences of stigma experience are more attributed to children in the rural community. The urban children did not explicitly share their personal experiences of stigma in their communities. One child had also mentioned that she had not personally experienced stigma. *"...People never stigmatized me, but that is also because I didn't know the status of the person I am staying with."*

The awareness of the process of stigma experiences by the children supports the findings by Greeff et al. (2010), whereby rejection, labelling, negating and gossiping were some of the experiences of stigma by PLHA in the study. The differences between the urban and rural group's experiences of stigma are supported by Sliep, Poggenpoel & Gmeiner (2001) and Duffy (2005). However, this finding is contrary to Naidoo et al. (2007), whereby HIV stigma was reported more among urban participants than their rural counterparts.

**Theme Five: Deepening relationships between children and PLHA.** When interacting with PLHA during the intervention the children experienced positive interactions with them and had learned to embrace the PLHA: “...*We have to embrace them and treat them just like any other person.*” Some children had to overcome fear and started accepting PLHA: “...*At first I was scared because I do not know how to react to people with HIV. I didn't know that they were all going to disclose their HIV status. For me, it was just “wow.” There are a lot of these people out there who can disclose their HIV status and we as people can accept people...*” The children had also learned to treat PLHA with humility and compassion: “... *I have a parent at home who is infected and it's not my parent so it taught me to accept them and love them and be able to touch them and we can even share a glass and not say no I can't use that glass because you'll infect me*” . The enhanced relationships between children and PLHA support those of Rotheram-Borus (2006) where parent-child relationship improved through participation in an intervention. Moreover, parent-child relationships were found to be important to children in dealing with stressful life situations (Rotheram-Borus, 2006; Dutra et al., 2000).

**Theme six: Increased knowledge during the intervention.** Gaining knowledge refers to the children's experiences of learning throughout the intervention. The children gained knowledge through the workshop and their projects: “*The workshop was fine. It was*

*an eye opener for me...”; “The workshop was fine for me because I thought that in the workshop I felt that we were doing something differently like working with hands. Only to find out that we were going to sit and talk in the workshop.”; “For me I got to learn a lot of things from the workshop because I was then able to go back to school and share with everyone about what I had learnt at the workshop...” and “... [Refers to the project] It was kind of part where I had to learn...” This finding partly supports that of Uys et al. (2009) confirming that the manual used in the workshops increased understanding and knowledge of stigma.*

### **Theme seven: Gaining confidence and personal growth through participation.**

Through the intervention, the children seemed to have flourished intra- personally through gaining confidence and personal growth. They have shared this experience referring to gaining confidence: “...*I was quite a shy person and I couldn't speak in front of an audience. So, after I attended the workshop that's when I started to feel free*”; self-acceptance: “*I learnt ... how to accept yourself when others stigmatize you*” and giving back to the community “*I felt proud. I was about time since I left school and I did something good for the community*”. This finding is contrary those of Uys et al. (2009), whereby no change in self-esteem and self-efficacy was associated with taking part in a similar intervention.

## **Conclusions**

The results indicated no significant differences between the urban and the rural groups in the subscales and total scores of mental well-being over time across three measures. The results of the total scores projected that the participants’ mental health was in the region of moderately mentally healthy. This finding is supported by Keyes (2006), indicating that most adolescents fit into the region of moderately mentally healthy and may experience 10% loss of flourishing overtime. The in-depth interviews, enriched by quotes, confirmed the three

aspects of the subscales indicating they have verbalised similar experiences to the itemised subscales of mental well-being.

The findings from the case study showed that the intervention was a meaningful experience to the children. They gained knowledge about HIV stigma and how to cope with it, as well as how to build relationships amongst themselves and with the PLHA. They gained a better understanding of their parents suffering from HIV and other PLHA as well as support of one another being in this difficult situation. Conducting the project led to them becoming empowered to act as leaders in stigma reduction. These findings by Uys et al. (2009) reported that the intervention had led to understanding and mutual support between the participants and the PLHA.

The results of the in-depth interviews showed that the children gained a greater awareness of the process of stigma and experienced a general increase in their knowledge throughout the workshop and the project. They formed meaningful relationships with other children and deepened their relationships with their parents and other PLHA. The children were empowered through the intervention to advocate against HIV stigma despite the challenges they had faced. They gained confidence and experienced personal growth through their participation in the project. The findings are supported by Uys et al. (2009), indicating the intervention to be a meaningful experience, was action-orientated and stimulated leadership in advocating against HIV stigma.

### **Limitations**

This study used a relatively small sample, thus limiting the validity of the quantitative results. However, the small sample size was justified by the nature of intervention and the use of mixed methods approach. These findings are limited to HIV-affected children in Potchefstroom and Ganyesa, North West Province.

## **Recommendations**

### **Education**

It could be meaningful to include the findings of this study in the curriculum of the psychology students to make them aware of the impact of HIV stigma. It is suggested that workshops be done with practicing psychologists on the contribution they could make to reduce stigma and enhance the well-being of the PLHA and those living close to them.

### **Practice**

It is recommended that psychologists are made aware of how this type of intervention on a community level can build the relationship between PLHA and children. It could also be of value if psychologists in a work as part of a trans-disciplinary health team work to reduce HIV stigma by using the principles learned from this intervention, while at the same time enhancing wellness of those affected, particularly children. Newly diagnosed PLHA could be facilitated to bring their children for workshops where they work at improving their relationship and gaining a better understanding about the illness and the impact of stigma. It would also be meaningful to measure the HIV-affected children's level of mental health on a consistent basis to monitor their psychological well-being and apply early preventative measures should it be found that the child's well-being is being affected by associated stigma.

### **Research**

For further research, it would be meaningful to test the sustainability of the intervention by applying it to a larger group or in a different context. The evaluation of a follow-up intervention to sustain the value gained during the initial intervention could be meaningful.

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**Table 1: Baseline descriptive statistics of mental health (n=11)**

Variable	Range		Mean	SD	Skewness	Kurtosis
	Min	Max				
EWB	1.00	13.00	7.91	4.09	-.39	-1.11
SWB	8.00	23.00	14.73	4.65	.00	-.50
PWB	5.00	29.00	20.64	6.62	-1.37	2.31
MHC_Total	0	59.00	42.45	10.35	-.10	-.76
MHCSF1	0	5	2.64	1.80	-.46	-1.45
MHCSF2	0	5	3.27	1.62	-.71	-.15
MHCSF3	0	5	2.00	1.90	.43	-1.62
MHCSF4	0	4	1.64	1.75	.55	-1.69
MHCSF5	0	5	3.18	1.72	-.63	-.76
MHCSF6	0	5	3.09	1.81	-.53	-1.24
MHCSF7	0	5	3.00	1.73	-.57	-1.11
MHCSF8	0	5	3.00	1.95	-.59	-1.25
MHCSF9	0	5	3.36	1.50	-1.20	1.25
MHCSF10	0	5	2.73	1.79	-.14	-1.62
MHCSF11	0	5	3.82	1.72	-1.39	.97
MHCSF12	0	5	4.09	1.51	-2.30	5.81
MHCSF13	0	5	3.18	1.72	-.63	-.76
MHCSF14	0	5	3.45	1.75	-1.00	-.16

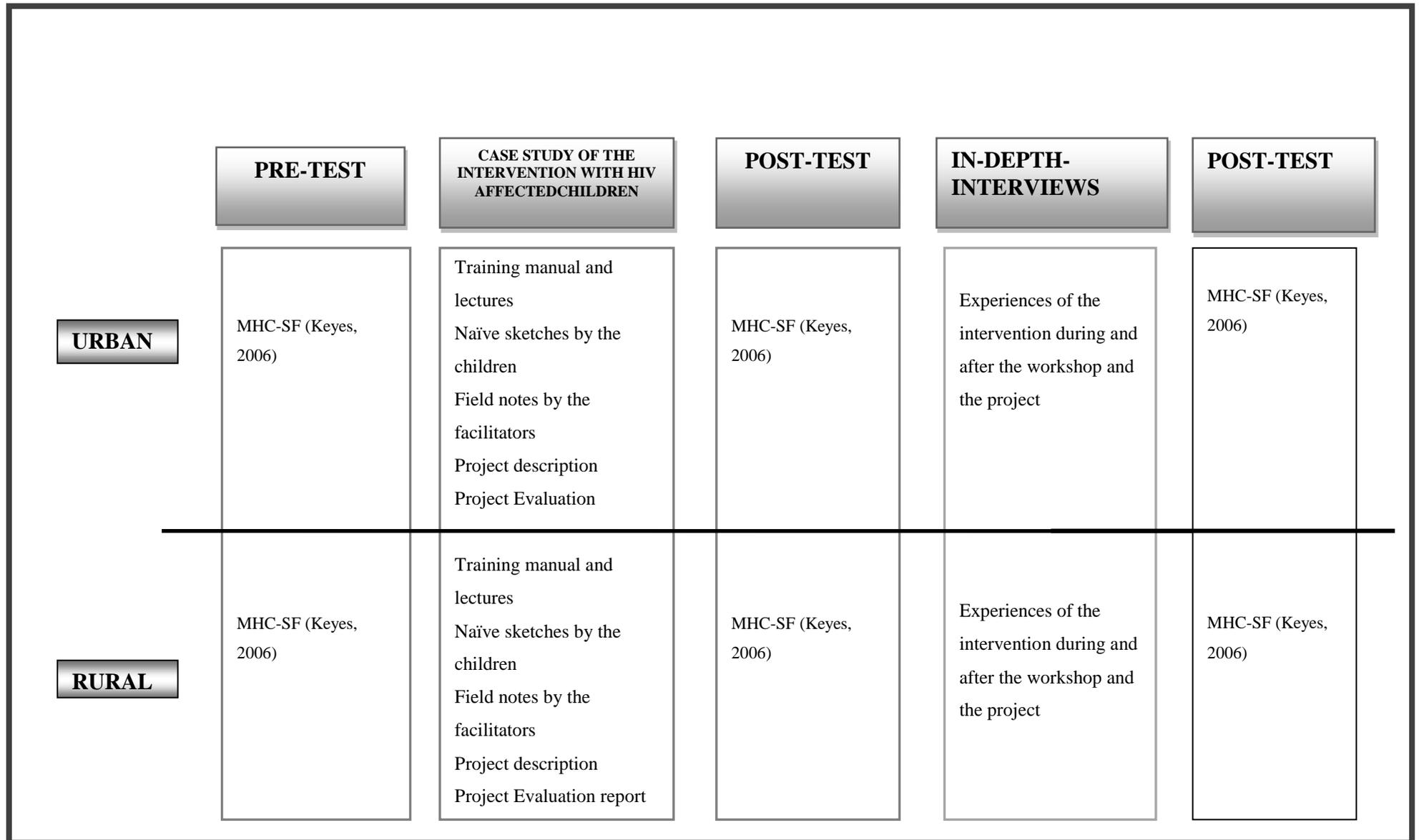
**Table 2: A comparison of mental health measures and qualitative data from in-depth interviews**

MHC Types	Time 1		Time 2		Time 3		(1/2/3) ANOVA			Confirming Quotes		
	Mean	SD	Mean	SD	Mean	SD	f ratio	df	p			
<b>Emotional well-being:</b>	7.91	4.09	9.18	4.60	6.50	5.08	.89	2	.420	<b>Matched Items</b>	<b>Urban</b>	<b>Rural</b>
Happy										Happy	“I was happy.”	“I felt happy.”
Interested in life										Interest in life	“It was fine and interesting.”	“It was very interesting.”
Satisfied										Satisfied	“We had fun with each other.”	“I was really fulfilled.”
<b>Social well-being:</b>	14.73	4.65	13.36	7.61	11.20	6.96	.78	2	.469	<b>Matched Items</b>	<b>Urban</b>	<b>Rural</b>
Social contribution										Social contribution	“It was about time since I left school and I did something good for the community.”	“I was then able to go back to school and share with everyone about what I had learnt at the workshop...”
Social integration										Social integration	“I had to socialize with them and I had to know them.”	“...in our community the spirit of co-operation is there.”
Social actualization										Social actualization	“it was really nice to do something nice for the children”	“I was just teaching them about stigma ”
Social acceptance										Social acceptance	“...you should not judge a book by its own cover.”	“...my friend who has HIV I must treat her well and I must not go around and

											Social coherence	“We were accepting each other for who and what we are.”	stigmatize them...” “People who are living with HIV and Aids are people just like us.”
<b>Psychological well-being :</b>	20.64.	6.62	21.82	7.60	19.40	9.11	.25	2	.779		Self-acceptance	“I had to learn and forgive myself”	“I could not believe that I stigmatized against a person.”
Self-acceptance										Environmental mastery	“At some points, I told myself, “Now you need to focus and learn. Now is the time to have fun.”	“I taught others how people with HIV”	
Environmental mastery										Positive relations with others	“We ate together. We had fun, made jokes, danced and all that.”	“A person is a person through other people”.	
Positive relations with others										Personal growth	“ It played a very role in my life important whereby I understand lots about people and they’re being	“I was quite a shy person ... So, after I attended the workshop that’s when I started to feel free”	
Personal Growth										Autonomy	“We told ourselves that we are	“I was able to stand in front of them, and give them the information”	
Autonomy													
Purpose in life													

										Purpose in life	going to achieve the project” “We told ourselves that we have to make this work.”	“I felt as if I was a teacher...” and “I can be able to help others.”
Total	42.45	10.35	43.91	16.96	37.40	14.98	.59	2	.562			

**Figure 1: Mixed method convergent parallel design of the intervention with children affected by associated HIV stigma**



## **Conclusions, Limitations and Recommendations**

### **Conclusions**

The results indicated no significant differences between the urban and the rural group in the subscales and total scores of mental well-being over time across three measures. The results of the total scores projected that the participants' mental health was in the region of moderately mentally healthy. This finding is supported by Keyes (2006), indicating that most adolescents fit into the region of moderately mentally healthy and may experience 10% loss of flourishing overtime. The in-depth interviews, enriched by quotes, confirmed the three aspects of the subscales indicating they have verbalised similar experiences to the itemised subscales of mental well-being.

The findings from the case study showed that the intervention was a meaningful experience to the children. They gained knowledge about HIV stigma and how to cope with it as well as how to build relationships amongst themselves and with the PLHA. They gained a better understanding of their parents suffering from HIV and other PLHA as well as support of one another being in this difficult situation. Conducting the project led to them becoming empowered to act as leaders in stigma reduction. These findings by Uys et al. (2009) reported that the intervention had led to understanding and mutual support between the participants and the PLHA.

The results of the in-depth interviews showed that the children gained a greater awareness of the process of stigma and experienced a general increase in their knowledge throughout the workshop and the project. They formed meaningful relationships with other children and deepened their relationships with their parents and other PLHA. The children were empowered through the intervention to advocate against HIV stigma despite the challenges. They gained confidence and experienced personal growth through their

participation in the project. The findings are supported by Uys et al. (2009), indicating the intervention to be a meaningful experience, was action-orientated and stimulated leadership in advocating against HIV stigma

### **Limitations**

This study used a relatively small sample, thus limiting the validity of the quantitative results. However, the small sample size was justified by the nature of intervention and the use of mixed methods approach. These findings are limited to HIV-affected children in Potchefstroom and Ganyesa, North West Province.

### **Recommendations**

#### **Education.**

- It is recommended that the findings be used in the curriculum of the psychology students to make them aware of the impact of HIV stigma on the PLHA, people associated with them and the community at large.
- It is suggested that workshops be done with practicing psychologists on their contribution to change in the emotional well-being of the traumatised child due to associated HIV stigma.

#### **Practice.**

- It could be meaningful to make psychologists aware of how an intervention on a community level can build the relationship between PLHA and their children and work towards HIV stigma reduction and enhancement of well-being.
- It could be useful if psychologists in the community work as members of a trans-disciplinary health team in a consented effort to reduce HIV stigma through using the

principles learned from this intervention and to enhance wellness of those affected, particularly children.

- Newly diagnosed PLHA could be facilitated to bring their children for workshops where they work at improving their relationship, gaining a better understanding about the illness the impact of stigma.
- It would also be meaningful to measure the HIV-affected children's level of mental health on a consistent basis to monitor their psychological well-being and do early preventative measures should it be found that the child's well-being is being affected by associated stigma. Confirming measured findings with conversations could be valuable.

#### **Research.**

- For further research, it would be meaningful to test the sustainability of the intervention by applying it to a larger group or in a different context.
- It is also suggested to include measuring perceptions of HIV stigma across time to confirm the interventions sustainability in reducing associated stigma.
- Further research can also include measuring coping abilities across time to enhance the evaluation of the intervention.
- The evaluation of the follow up intervention to sustain the value gained during the initial intervention to sustain the value gained during the initial intervention could be meaningful.

## Appendix A: Ethical Approval



NORTH-WEST UNIVERSITY  
YUNIBESITHI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom  
South Africa 2520

Tel: (018) 299-4900  
Faks: (018) 299-4910  
Web: <http://www.nwu.ac.za>

Prof M Greeff

### Ethics Committee

Tel +27 18 299 4850  
Fax +27 18 293 5329  
Email [Ethics@nwu.ac.za](mailto:Ethics@nwu.ac.za)

2009-03-31

### ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: A Comprehensive Community-Based HIV Stigma Reduction and Wellness Enhancement Intervention																																														
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>0</td><td>1</td><td>1</td><td>-</td><td>0</td><td>9</td><td>-</td><td>A</td><td>1</td></tr><tr><td colspan="3">Institution</td><td colspan="6">Project Number</td><td colspan="2">Year</td><td colspan="4">Status</td></tr><tr><td colspan="15">Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</td></tr></table>	N	W	U	-	0	0	0	1	1	-	0	9	-	A	1	Institution			Project Number						Year		Status				Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation														
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Approval date: 30 March 2009	Expiry date: 29 March 2014																																													

Special conditions of the approval (if any): None

#### General conditions:

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

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

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

Yours sincerely

Prof MMJ Lowes  
(chair NWU Ethics Committee)

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

## **Appendix B: Informed Consent**

**THE NORTH-WEST UNIVERSITY AND VRIJE UNIVERSITEIT AMSTERDAM**

**CONSENT TO BE A RESEARCH SUBJECT**

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

### **1 PURPOSE OF THE STUDY**

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

### **2 PROCEDURE**

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

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

### **3 RISK/DISCOMFORTS**

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

### **4 BENEFITS**

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

### **5 COSTS**

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

### **6 PAYMENT**

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

### **7 QUESTIONS**

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

### **8 CONSENT**

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

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

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

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

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature of the participant**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature of the person obtaining consent**

SANPAD informed consent 4 June 2010.doc

## **Appendix C: Section of an In-depth Interview**

Moderator: The knowledge that you received at the workshop you immediately stretched it at home, how to stop stigmatising and change their mindsets. You also taught your aunts and family members, you said there are boys who are naughty who label people and you told them to stop labelling and you even went all the way to family members in Klerksdorp and educated them about the knowledge you had gained of stigma. How was it like when you teaching your aunts, your brothers who you say are naughty?

Respondent: At first I had my doubts about them but then I decided to tell them because they didn't know and they would be able to teach others and they are talkers so I knew that they would teach others that when a person is like this then we should treat them in such a way and not call them names. After, I was really fulfilled because I have done something.

Moderator: So when you were educating them how did it feel to be able to teach your family and even strangers and going to Klerksdorp and teaching now?

Respondent: I felt that one day there will be a person maybe even me or a person I was teaching who might be HIV positive and other might not know how to treat that person. So in a way I was happy because I told myself “okay, so I'm teaching these people so one day I might not be there and they would treat the person in the right way. because some parents, when their children when tell them that they are HIV positive they chase you away so I was doing it so that they now knew and would be able accept someday that okay my child is so and so and give them that support.

Moderator: I hear that you feel strongly about people being excepted and that they should be supported and you believe that it's best to teach people in advance so that if ever that time comes then they are a step ahead with the skill of knowing how the person should

be treated. Why do you see this as being important, the accepting of people and giving them support?

Respondent: If this person isn't accepted and isn't given the support then they start to be weak and not even care about themselves and they start not to eat and not even go to the clinic because what's the point, no one accepts me or supports me I'm just all alone. They start losing that understanding of what they should do and what they shouldn't do. Some even commit suicide. that they were HIV positive and we shouted at them and they killed themselves. Just because a person is HIV positive it doesn't mean they can't do things for themselves just yet, they can still be able to go to work.

Moderator: So I hear that you firmly believe that a person living positively with HIV must be accepted and supported so that the person must be strong and that person must become very healthy to prevent the fact that they are being rejected they can actually die and you believe that families do not understand that this person can still support them. Is that what you're saying?

## **Appendix D: Section of a Field Note**

### **Group: Children, Rural**

**Methodology Notes.** The workshops started at 9h00 and 8h30 for days one and two respectively. The participants were always punctual. There were seven children and four PLHA's present during both workshop days. Two facilitators took turns in facilitating different sessions of the workshops. The facilitators and co-facilitator also assisted each other during sessions. The workshops were conducted in both English and Setswana. This is because some participants found it somewhat difficult to grasp some of the concepts discussed during workshops.

**Observational Notes.** During the first sessions of day one, the group looked anxious of the workshop, other members and the setting. It was not easy for all members of the group to befriend each other. Some of the children did not know what to expect from the workshops. This could have probably added to the anxiety. It was particularly difficult for the PLHA's to work together with children, especially during the first day of the workshop. Some of the PLHA's did not want to form smaller groups with children. Two of the PLHA ladies wanted to always sit together throughout the sessions. One of them eventually agreed to sit and form a smaller group with the children; however there was conflict between her and one of the children in the group. The facilitator intervened by reminding the entire group about group rules.

Some of the children during day one of the workshop did not understand the concept of stigma. However, by the end of the first four sessions, they understood the concept of stigma and its processes and model. It was also difficult for the group to grasp other academic terms. However, the group was very eager to learn as most of the concepts (for e.g. stigma) were very new to them. Most of the members were very reserved and did not participate

fully. Most of the time the facilitator and co-facilitator had to ask questions to participants, individually so to get them involved in the discussions. However, all participants contributed meaningfully to the discussions. It was also difficult during day one for the participant to share their experiences of stigma.

## **Appendix E: A Naïve Sketch**

I have experienced the project as:

A lot of hunger due to that our recruited members were very cooperative and eager to learn more. They were even fulfilled at the end of the project. What we have taught really changed their perspectives as though they want to teach others. I have just noticed that sharing views with people that can relate to is very great.

I feel:

I feel glad that the project went well. Touched due to the views that we shared. Motivated I taught something that affected or related well to them.