

**DEVELOPING AND EVALUATING A COMMUNITY-BASED HIV/AIDS
STIGMA REDUCTION INTERVENTION IN ONGENGA CONSTITUENCY OF
OHANGWENA REGION, NAMIBIA**

By

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**Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in
Nursing Science at the School of Nursing, Faculty of Health Sciences, University of
KwaZulu-Natal, Durban, South –Africa**

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June 2012

DECLARATION

I, Penehafo Angula, declare that the research reported in this thesis, except where otherwise indicated is my original work. This thesis has not been submitted for any other degree or examination at any other university.

Signed

Date

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Date

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Co-supervisor

Date

Dr J Frohlich

DEDICATION

This work is dedicated to my late uncle Salties Nghiningishiwa Kanghono and all my relatives who have passed on in the Era of HIV/AIDS. May their souls rest in eternal peace!

This study is also dedicated to all the people who are infected or affected by HIV/AIDS and experience stigma in one way or another.

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ABSTRACT

Background: Namibia has been affected by the HIV/AIDS pandemic with infected and affected persons experience stigma at different levels. As there were no local stigma reduction intervention tools, this study aimed to develop, implement and evaluate tools at different levels in a rural Namibian community.

Methods: An intervention research with a quasi-experimental non-equivalent control group pre-and post-test sample plan was used, with both qualitative and quantitative approaches. Four groups of participants participated: People Living with HIV/AIDS (PLWHA), their family members, community leaders and health care workers (n=224).

The LINMODEL community participation and Frohlich Model informed the participant selection, and the Diffusion of Innovations theory provided the framework for justifying the use of targeted intervention tools in specific groups. Seven communities and a clinic were divided into the control (n=107) and intervention (n=117) arms. The study consisted of pre- and post-intervention questionnaires for both arms, intervention training workshops for the PLWHA and community leaders, and in-depth interviews for the community and opinion leaders.

The post-intervention results showed that stigma decreased significantly in social isolation (p=0.017), workplace stigma (p=0.008) and negative self perception (p=0.006) in the PLWHA intervention arm. Verbal abuse (p=0.07) has slightly decreased but there was no statistically significant difference between the two study arms. Fear of contagion (p=0.12) has slightly increased after intervention in both arms. All mean scores (PLWHA) for the control arm increased significantly after the intervention. Regarding the family and

community leaders results, only the household stigma score ($p=0.01$) decreased significantly in the intervention arm. Health care workers reported increased stigma after intervention, stigma against PLWHA ($p=0.04$) and associated stigma towards health care providers ($p=0.005$).

Discussion: A comparison of the results in both arms indicated that the intervention was effective in reducing stigma in the intervention arm in three groups (group 4 excluded) with varying degrees of success. Stigma scores were significantly decreased in PLWHA from the intervention arm. The intervention was effective although it did not decrease all stigma scores significantly. This may require more time for the issues addressed in the intervention workshops to diffuse through the different groups.

LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy/Treatment
ARVs	Antiretroviral drugs
CAA	Catholic AIDS Action
CACOC	Constituency AIDS Coordination Committee
CBR	Community-based Rehabilitation
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DHS	Demographic and Health Survey
ECCC	Education, community involvement, contacts, continuous counselling approach
F&C-SI	Family and Community Stigma Instrument
GCP	Good clinical practice
HASI-N	HIV/AIDS Stigma Instrument-Nurse
HASI-P	HIV/AIDS Stigma Instrument-PLWA
HBM	Health Belief Model
HIV	Human Immuno-deficiency Virus
MDG	Millennium Development Goals
MEDLINE	Medical Literature Analysis and Retrieval System Online
MNSC	Master of Nursing Science
MOHSS	Ministry of Health and Social Services
MRLGH	Ministry of Regional & Local Government, Housing & Rural Development
NCSS	Number Cruncher Statistical System
NGO	Non -governmental organization
PASW	Predictive Analytics Software
PLWHA	People Living With HIV/AIDS

PMTCT	Prevention of Mother-to-Child Transmission
RACOC	Regional AIDS Coordination Committee
RAU	Rand Afrikaans University
R/N	Registered Nurse
SADC	Southern Africa Development Community
SAFAIDS	Southern Africa HIV/AIDS Information Dissemination Service
SMA	Social Marketing
SPSS	Statistical Package for the Social Sciences
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infections
TB	Tuberculosis
TPB	Theory of Planned Behavior
TRA	Theory of Reasoned Action
UKZN	University of Kwazulu-Natal
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNAM	University of Namibia
USAID	United States Agency for International Development
USA	United States of America
UNGASS	United Nations General Assembly Special Session
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

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A LETTER FROM THE STATISTICIAN

Re: Penehafo Angula (student number: 209506891)

Thank you for the opportunity to write this letter for the mentioned PhD nursing candidate.

This is to certify that I gave statistical advice and assisted Mrs Angula with data analysis in her project entitled “Developing and evaluating a community-based HIV/AIDS stigma reduction intervention in Ongenga constituency of Ohangwena Region, Namibia”

Yours sincerely,

.....

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14 November 2011

To whom it may concern

PhD Thesis Editing: Penehafo Angola

Mrs Angola received funding from the Columbia University-South Africa Fogarty AIDS International Training and Research Programme to undertake her research. This programme is administered through CAPRISA where I am employed as the training coordinator. In this capacity I provide support to the trainees including editing, and have therefore assisted Mrs Angola with the editing of her PhD thesis. She provided me with the document in Word which I edited using track changes to enable her, as the author, to make the final decisions. We also met on a number of occasions to discuss her work. My assistance included addressing issues relating to the structure of the chapters, the logic and flow of the content, grammar, duplications, assumptions and missing information.

I have been working in public health research for 18 years and have a Masters of Social Science in Geographic & Environmental Science, with a thesis on spatial epidemiology (Medical Geography). I have a Post Graduate Diploma in Public Health and have edited over 50 manuscripts and documents this year.

Your sincerely

Carrin Martin
Training Coordinator



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CHAPTER 1

ORIENTATION TO STUDY

1.1 INTRODUCTION

Although Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are manageable chronic conditions (Teague, 2007), stigma attached to being HIV positive continues to persist in many African countries, including Namibia. Despite much being known about the disease and how to prevent being infected stigma and discrimination continue to plague those who are positive, hindering an effective response to the epidemic. Rural communities are often the most affected due to a lack of programs, resources and tools to address it. Although studies have been conducted in Namibia to explore stigma, there have been few African stigma reduction interventions to combat stigma (Mufune 2003, Thomas, 2007, Keulder 2007, Nghifikwa 2011).

Within communities, stigma and discrimination are experienced at different levels by People living with HIV/AIDS (PLWHA), such as externally within families, community, in health care settings, in the workplace, and internally through a lack of confidence and poor sense of self worth. External stigma is experienced such as verbal abuse, social isolation and being denied services, including health care and participation in community projects. There is an urgent need to address stigma to prevent new HIV infections, improve treatment adherence, increase efficacy of prevention of mother-to-child transmission (PMTCT) and improve the lives of people who are living with HIV that they do not delay seeking medical services.

As there were no Namibian stigma reduction intervention tools, this study aimed to develop, implement and evaluate two training manuals at different levels in a rural

community. A quasi-experimental, pre and post-test design intervention, consisting of four community groups in the intervention arm and three in the non-equivalent control group arm was conducted. The groups were PLWHA, their family members, community/opinion leaders and health care workers. The purpose of the group selection was to understand stigma from different contexts and provide them with information on how to recognize and reduce stigma. To get insight into the experiences of community leaders on HIV/AIDS stigma in Ongenga Constituency, the qualitative approach was implemented. Diffusion of Innovations was the theoretical bases for the study, which used opinion leaders and support group members to influence change in people attitudes and behaviours to PLWHA. Two models guiding community participation in research underpinned the study to motivate community involvement in a stigma reduction intervention. The post-intervention survey was implemented to establish whether the intervention was effective to reduce some stigma scores such as social isolation, workplace stigma, negative self perception and household stigma and community opinions to PLWHA.

Many people return to their rural communities in Namibia once the complications with AIDS begin to manifest and their health deteriorates. The need for support and appropriate care from all levels during this time is essential, and is hindered by stigma and discrimination which affects the infected persons' quality of life. Developing intervention tools to reduce stigma in Namibia will provide an additional tool for the Ministry of Health and Social Services (MOHSS) and those involved in combating the disease.

1.2 BACKGROUND

HIV and AIDS have affected Namibia in the same way that they have impacted on many other southern African countries, despite its small and dispersed population. Namibia has a population of 2.3 million and a HIV prevalence rate of 18.8%, based on the national HIV surveillance survey conducted among pregnant women attending antenatal clinics (MOHSS, 2010). The country faces the same challenges as its neighbours, and not only needs to understand its local epidemic, but to address the public health issues associated with it, such as stigma and discrimination. These issues continue to affect the uptake of testing and treatment opportunities, which are provided by the public health service, in spite of the wealth of information now available about how the disease is transmitted, prevented and treated.

According to former South African President, Nelson Mandela, at the 2002 International AIDS Conference in Barcelona “Many people suffering from AIDS are not killed by the disease itself but are killed by the discrimination surrounding everybody who has HIV/AIDS. That is why leaders must do everything in their power to fight and to win the struggle against stigma” (New York Amsterdam News, 2002). The late Jonathan Mann, the then director of the World Health Organization (WHO) Global Programme on AIDS, cited in Parker et al.(2002) “identified three phases of the HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial. He noted that the third phase is as central to the global AIDS challenge as the disease itself”. Stigma and discrimination remain among the poorly understood aspects of the epidemic and in 2000 Peter Piot, Executive Director of UNAIDS, “identified stigma as a continuing challenge” (Parker et al. 2002). Overcoming stigma is therefore an important

part of public health professionals' responsibilities, and needs to be investigated by researchers and academics to find appropriate interventions.

A study conducted by the UNAIDS Secretariat (2008-2009) on the progress made regarding accessibility to justice and stigma reduction and discrimination in 56 countries found that little has been achieved. Although 90% of the countries activity plans included stigma and discrimination in their programmes, fewer than 50% of the countries had budgeted for them. The study further found that countries rarely included comprehensive package programmes for stigma reduction in their national strategic plans (UNAIDS, 2010). It was further reported that key-human rights programmes, which were identified were not implemented. Findings from people living with HIV stigma revealed that it manifests in many ways, and illustrated the need to reduce it as part of national response (UNAIDS, 2010).

People living with HIV/AIDS experience stigma and discrimination in different ways, which hinders effective HIV responses (UNAIDS, 2010). For example, the UNAIDS report (2010) revealed that more than 30% PLWHA in China were subjected to verbal abuse, 9% have been physically harassed, 14% were refused employment and 12% were denied health care. In Paraguay, PLWHA were excluded from social gatherings, in Rwanda more than 50% of PLWHA reported that they were verbally insulted, 65% lost their jobs or income and 88% were denied access to family planning services. The report further indicated that in the United Kingdom, 17% of PLWHA reported having been denied health care. Studies from five African countries, Lesotho, Malawi, South-Africa, Swaziland and Tanzania, reported stigma against PLWHA such as verbal and physical abuse, denial of access to certain public services, as well as exclusion from community

development projects. Abuse against PLWHA was perpetrated by family members, colleagues, employers and health care workers (Dlamini et al., 2007).

Providing interventions to combat discrimination and stigma need to be tailored to the needs of the society to which they are targeted to ensure that they are culturally appropriate. This means that, although interventions have been developed in many countries to address these issues, they need to be tested in the target communities to ensure that they will be effective. According to United Nations General Assembly Special Session (UNGASS), several countries submitted progress reports on how to combat HIV/AIDS, many of which highlighted stigma and discrimination. Some countries reported that involvement of PLWHA in their national AIDS plan could be meaningful (UNAIDS, 2010).

1.2.1 HIV/AIDS stigma and discrimination in Namibia

Namibia is situated in the south western part of Africa and is one of the most sparsely populated countries in this region with a population of 2, 3 million (Bureau of African Affairs, 2010). It shares borders with Angola at the north, Zambia at north east, Botswana and Zimbabwe at the east, South Africa at the south and with the Atlantic Ocean on the west (Appendix 9: Namibian map). Namibia has been severely affected by the HIV/AIDS pandemic, with the first case been diagnosed in 1986. Minister Kamwi, Minister of Health and Social Services, addressed students at the University of Namibia (UNAM) during their HIV/AIDS awareness week on the 19th April 2011 and reported that according to the Ministry of Health and Social Services' (MOHSS) HIV Sentinel Surveillance report, the HIV prevalence in Namibia was 17,8% in 2008 (MOHSS, 2008b), and had increased to 18.8% in 2010 (MOHSS, 2010). In 2008, the number PLWHA in Namibia was recorded

as 230 000, deaths related to HIV/AIDS were recorded as 17 000 and HIV/AIDS orphans (0-17years of age) were recorded as 70 000 (UNAM, 2008). According to the Ministry of Health report (MOHSS, 2010) 5 800 new infections were registered in 2008-2009, which accounts for 16 HIV infections per day. Based on these figures, the Minister of Health made a call to UNAM students to help combat stigma and discrimination as well as to influence people to change their behaviour in order to decrease new infections. It has been documented that stigma and discrimination are contributing factors to the epidemic, although not substantiated by research (MOHSS, 2006).

The Government of Namibia, and particular the MOHSS, have introduced antiretroviral therapy (ART) program in public health facilities in 2003. While it is reported that 84 455 people require antiretroviral therapy (ART), treatment has been provided to 75 681 patients as reported in Press Statement AIDS Plus Millennium Development Goals (UNAIDS, 2010). According to UNAIDS Global report on AIDS epidemic (2010), Namibia is among the four countries in Sub-Saharan Africa (Botswana, Namibia, South Africa and Swaziland), which achieved ART coverage of greater than 80% by December 2009 (UNAIDS, 2010). However, studies have shown that many people could benefit from the treatment if it were not for the stigma attached to the disease (Mwondela-Katukula in Health and Development Networks, 2006). There is therefore a need to develop interventions in different contexts in Namibia to address stigma and discrimination.

Namibia is divided into 13 regions, which are further subdivided into 107 constituencies. Ongenga Constituency of Ohangwena Region in northern Namibia is affected by the HIV epidemic as in other parts of the country, which makes its inhabitants vulnerable to stigma

and discrimination, although there has been no research to confirm this statement. Ongenga Constituency (Figure 1.1) consists of 70 scattered villages with a population of approximately 21 474 people (MOHSS, 2008a), who have access to three health clinics, which provide services to people living within 10 km of each village, as well as a few outreach points, which health care workers visit to provide services periodically.

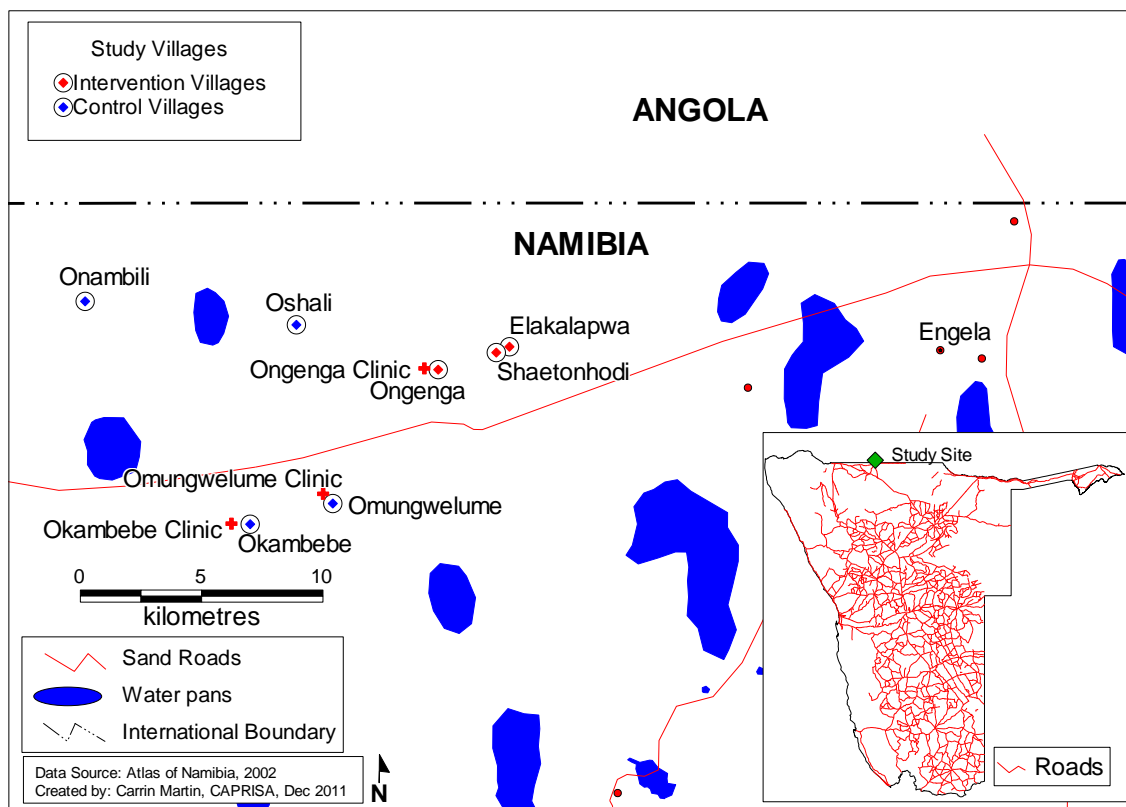


Figure 1.1 Ongenga Constituency Map

Source: Atlas of Namibia, 2002. Directorate of Environmental Affairs, Ministry of Environment and Tourism. Windhoek, Namibia

Among the three health clinics in the Ongenga Constituency (Okambebe, Omungwelume and Ongenga) only Ongenga Clinic provides antiretroviral drugs (ARVs) to PLWHA and conducts HIV voluntary counselling and testing on a monthly basis. There is one community counsellor at the ARV clinic, and due to the heavy workload and time constraints it is difficult to provide counselling to affected and infected people to address

stigma (Source: Registered Nurse at Ongenga Clinic). Stigma therefore remains a challenge, preventing people from accessing appropriate treatment and services, and resulting in increased morbidity and mortality rates. Overcoming stigma is going to be essential for the long term survival of this rural community.

Namibia has been affected by the HIV/AIDS pandemic both economically and socially, and as a result, people who are infected and affected experience stigma as well as discrimination at different levels. The recent study conducted by Nghifikwa (2011) with ten PLWHA at an ARV clinic at Oshakati Hospital in the Oshana Region, in Namibia revealed that while they experience stigma from their families and communities, they experienced less stigma from health care workers in public health settings. The author indicated two possible reasons for this outcome: 1) fear by the study participants to say bad things about nurses and doctors as their interviews were conducted at the clinic or 2) health care workers treat them well due to the experience they have gained in dealing with HIV/AIDS patients (Nghifikwa, 2011).

Smith and Morrison (2006), Mufune (2003) and Thomas (2007) reported that in some Namibian communities, HIV/AIDS is associated with shameful acts such as “carelessness” and “immorality”, and PLWHA are marked as “sick” and “harmful” people. Persons infected with HIV are often stigmatised in their community and health care settings due to the perceived association of HIV infection with immoral behaviour. As HIV is also associated with witchcraft to avoid the stigma of being presumed immoral, PLWHA in the early stage of disease seek medical attention from the traditional healers (Mufune, 2003, Smith and Morrison, 2006, Thomas, 2007).

A study conducted in four Namibian regions, with eight focus groups of PLWHA, tried to establish a link between witchcraft and HIV/AIDS. The author reported that only one respondent agreed with this theory (Keulder, 2007). According to Keulder (2007), although HIV/AIDS-related stigma is still a problem in Namibia, compared to ten years ago there has been a decline. He further claimed that apart from negative consequences, stigma has also had positive consequences such as the formation of counselling and support group networks. A report indicated that ART has been an effective measure in combating HIV/AIDS-related stigma as it reduces the visible physical effects of the disease. Other researchers have reported that PLWHA who are on ART experience more stigma than those who have not been initiated on treatment as a result of regular visits to the health care facility to collect their medication (Jackson, 2002, Nattabi et al., 2011).

Furthermore, Keulder's (2007) findings showed there is less HIV/AIDS stigma among PLWHA who are members of a support group. He suggested that future HIV/AIDS stigma studies in Namibia should also include PLWHA who are not members of a support group and those not living with HIV/AIDS. As guided by Keulder's (2007) recommendations, this study included non-support group members such as families, community leaders and health care workers as participants. Although respondents in Keulder's (2007) study reported less HIV/AIDS stigma, they also indicated that they still experience stigma within their families, friends and communities. The author did not indicate study sample size, and it is therefore difficult to quantify these findings (Keulder, 2007). The same study reported less stigma of association among families of PLWHA who were more prone to empathy and understanding. Keulder further emphasized the need to study HIV/AIDS stigma in different contexts (Keulder, 2007). Despite the evident

needed to reduce HIV/AIDS stigma in Namibia, Keulder did not make recommendations for a stigma reduction intervention.

According to Namibian Demographic and Health Survey (DHS) (MOHSS, 2008a) in the Ohangwena Region, which includes the Ongenga Constituency, the unemployment rate for women was 67% and 78% for men, with people depending on crop production and live stock for food security. Those 60 years of age or older receive a monthly social grant of N\$500 (R500) from the government. Many households depend on the grant as an important income due to the low employment rate in this region. As a result of low income, PLWHA do not always have money to go to health facilities, and when their families cannot provide them with funds, they feel discriminated against. Food shortage is also a problem in some households and PLWHA who are on ARVs need to eat before taking their medications to limit the side effects. In households affected by poverty and food shortages some members may not support the PLWHA receiving additional food which may contribute to discrimination of the PLWHA.

Namibian rural areas are less developed than the urban areas and have lower employment opportunities which results in internal migration and people moving to urban areas seeking jobs opportunities and better living conditions. This migratory pattern contributes to the spread of HIV as people leave their partners and spouses in the rural areas and stay away for months (Lurie, 2004). When they are away from their homes some indulge in new sexual relationships and do not use any protection making them vulnerable to HIV infection (Edwards, 2004). According to the DHS report (2006/2007) men are generally at higher risk of indulging in unprotected sexual intercourse than women. Although people migrate to urban areas they maintain their links with their rural community and household

to which they return when they get ill. Research has found that stigma is higher in rural than in urban areas due to the lack of correct information on HIV transmission (Ribo et al., 2004, Uys et al., 2007). Therefore the need for community-wide programs in rural areas to reduce stigma associated with HIV/AIDS is imperative.

The literature review did not reveal any HIV/AIDS stigma reduction interventions that have been conducted and/or documented in Namibia either in health care or community settings. The few studies that were done on HIV/AIDS stigma in Namibia are more exploratory, descriptive and explanatory in nature and have not tested stigma reduction interventions, resulting in a knowledge gap in this area (Mufune, 2003, Smith and Morrison, 2006, Keulder, 2007, Thomas, 2007, Nghifikwa, 2011). This study was designed to address this knowledge gap by developing, implementing and evaluating a stigma reduction intervention in rural Namibia at the family and community level. The Ongenga Constituency was selected for the study as the researcher is able to communicate fluently (write and speak) in the local language of Oshiwambo, and was able to develop the tools to evaluate a stigma reduction intervention in the language of the local population.

1.3 PROBLEM STATEMENT

HIV/AIDS related stigma remains a problem in Namibia, and although a large body of information is available about the virus and means of HIV transmission, knowledge and understanding of HIV appears to be low in rural communities. Stigma not only affects PLWHA but their families and communities, as it is to their families in the rural areas that PLWHA return when they need care. Stigma not only affects the psychological well-being

of the PLWHA, but their access to employment, health care, community acceptance and their participation in community activities. In some instances, people associated with infected persons are also stigmatized, socially isolated and victimized.

The Ongenga Constituency in northern Namibia is typical of many rural communities, which are affected by the disease, with high prevalence rates and stigmatization of infected and affected persons. From observation and informal discussions with the local communities, many families have members living with HIV, or have lost their loved ones. Where the parents have died due to AIDS related illnesses the child-headed families sometimes depend on receiving food and clothing from friends, neighbours, church as well as from relatives, which further contributes to stigma and discrimination of people who are infected and affected by HIV (Kuhanen et al., 2008). In a study conducted by Mchombu (2009) in Ohangwena Region, northern Namibia, orphans may experience stigmatization, abuse, human rights violation such as name calling, denial of access to education and shelter, or being forced to engage in unprotected sex.

According to Angula (2008) in a qualitative study conducted in Windhoek (Khomas Region), Namibia, PLWHA experienced stigma and discrimination in their own families and have been thrown out of the house after disclosing their seropositive HIV status. It is evident that HIV/AIDS stigma is a problem in Namibia and needs to be addressed. No tools have been developed or evaluated in Namibia which can be implemented to address stigma. The absence of any strategies to reduce HIV/AIDS stigma informed the following research questions:

- What are the types, level and extent of HIV/AIDS stigma in the Ongenga Constituency?

- What is the intervention needed to reduce HIV/AIDS stigma in the community?
- Does HIV/AIDS stigma change after a stigma reduction intervention and if so how?
- What are the views of participants on HIV/AIDS stigma after the intervention?
- How effective is the intervention in reducing stigma in the community?

1.4 RESEARCH HYPOTHESIS

People living with HIV/AIDS in a community that is participating in a stigma reduction intervention will report significantly less stigma post-intervention.

1.5 STUDY AIMS AND OBJECTIVES

The aim of this study was to measure the level of HIV/AIDS stigma in the rural Ongenga Constituency in Namibia and to develop, implement and evaluate the effectiveness of a stigma reduction intervention. The study had the following objectives:

- To determine the current views, opinions and level of HIV/AIDS stigma in a rural community.
- To develop a community-based HIV/AIDS stigma reduction intervention.
- To implement a community-based HIV/AIDS stigma reduction intervention, with a control and an intervention arm in a rural community.
- To determine the views on HIV/AIDS stigma after the intervention.
- To evaluate the outcome by comparing the quantitative findings from both control and intervention arms of the study.

1.6 SIGNIFICANCE OF THE STUDY

The literature review did not reveal any HIV/AIDS stigma reduction intervention that has been conducted and/or documented in Namibia. To address this gap the intent of this study was to:

1. Determine the levels of stigma in a rural community, which is likely to be similar throughout Namibia.
2. Develop, implement and assess the effectiveness of a community-based stigma reduction intervention.
3. Determine the appropriateness of such an intervention by comparing it with a control arm who did not participate in the intervention.
4. Develop a set of tools for a HIV/AIDS stigma reduction intervention that can be modified for the specific context and serve as a baseline for future HIV/AIDS stigma reduction interventions in rural Namibia.
5. This study added to the new knowledge regarding HIV/AIDS stigma reduction in the community, it is unique and the first one to be conducted and documented in Namibia.

1.7 PARADIGMATIC FRAMEWORK

According to Thomas Kuhn (1970) a paradigm view is the underlying assumptions and intellectual structures upon which research and practice is based. As a world view, a paradigm is guided by a set of beliefs and feelings about the world and how it should be understood as well as studied. The beliefs and feelings include ontology (the nature of reality), epistemology (the nature of knowing and construction of knowledge) and methodology (the process of research) (Kuhn, 1970). These assumptions and structures are

important as they guide researcher in conducting their study scientifically. This study is based on both positivism and interpretivism (constructivism) paradigms, which are detailed in the next chapter.

1.7.1 Ontology

Ontology is the study of the nature of being in general and its inclusion was necessary to provide multiple realities on stigma. The researcher had previously conducted a study with PLWHA in Windhoek (Khomas Region) where she identified stigma as an obstacle that prevents people to live positively with the disease (Angula, 2008). A literature review did not reveal any quantitative information on the level and extent of stigma in Namibia. Before developing and introducing a stigma reduction intervention, it was necessary to determine the level and extent of stigma in the study population, requiring a quantitative approach. Stigma is experienced by PLWHA, their families and associates, and to obtain a full understanding of its extent, it was necessary to include those affected by stigma, community leaders who can influence public opinion, and those who should provide equitable quality of care to all in need. To accommodate the different individuals and social groups infected and affected by HIV/AIDS and those persons stigmatizing the infected and affected a mixed method (quantitative and qualitative approach) was applied to ensure that the relevant questions were asked and explored to guide the development of a stigma reduction intervention

1.7.2 Epistemology

Epistemology is the study of the nature, origin and limits of human knowledge and was included to ensure the use of an appropriate research technique. The premise for this study was the Diffusion of Innovations theory, which contends that change in social systems can

occur by disseminating an innovative idea, practice, product or service. In this study, the intent of Diffusion of Innovations theory was to communicate knowledge to those who will benefit from it either by changing their behaviour or expectations (Sharma and Kanekar, 2008, Murray, 2009). Several authors on this theory recommend the importance of involving community and opinion leaders as influential people who can accelerate the rate of diffusion in changing social systems (Valente and Davis, 1999, Dearing, 2004, Murray, 2009). In this study, mixed methods design was used to reduce stigma in the families, community and opinion leaders, resulting in the inclusion of a constituency councillor, teachers, local pastors, PLWHA support group leaders, local health care workers, villages' headmen, as well as church groups of Ongenga Constituency.

This study was also guided by two models of community participation in research: 1) Frohlich model (2001) 'Managing community participation in clinical health research' and 2) LIN MODEL (Apinundecha et al., 2007) 'Community participation intervention to reduce HIV/AIDS stigma'. Diffusion theory and the models of Frohlich and Apinundecha et al., are discussed in Chapter Two.

1.7.3 Methodology

In this study both quantitative and qualitative methods (mixed method) were used. A quantitative approach was used to determine the level of stigma. To obtain the lived experience and insight into HIV/AIDS stigma, and how to reduce stigma, a qualitative approach was considered more appropriate.

1.8 DEFINITIONS OF TERMS

The main concepts relevant to this study are defined:

Stigma: Any negative attitude, behavior or acts towards persons who are HIV positive and/or their families or associates, that serve to devalue, discredit, discount or discriminate against them on the basis of their HIV positive status (Greeff et al., 2008a).

Discrimination: It is a consequence of stigma and occurs when there is no objective justification, which results into unfairly and unjust treatment to people who are perceived to belong to a particular group (Mahajan et al., 2008).

Indicators of stigma: Stigma can be external, internal, or associated. In this study, external stigma refers to what others do and/or act to discriminate, blame, insult or name call those who are HIV positive. External stigma includes isolation, avoidance, rejection, discrimination, moral judgment, verbal, emotional and physical abuse. Internal stigma refers to negative perception of self, fear of judgment and self blaming as a result of HIV positive status. Stigma of association refers to stigma either to families/associates or to caregivers of PLWHA (Naidoo et al., 2007).

Diffusion: The spreading of something more widely from one society to another. In this study it refers to a process whereby the new idea (stigma reduction) is communicated through certain channels including opinion leaders over time within a social systems (Rogers, 2003).

Innovation: The introduction of new ideas about reducing Community-based HIV/AIDS stigma through intervention (Rogers, 2003).

Family: Household members and relatives who care and support PLWHA, whether they live with them or not.

Community members: People who live in the same geographical area (constituency) with PLWHA with whom they have something in common. They share services such as health facilities, church, open markets, schools and basic services such as water points (Naidoo and Wills, 2010).

Community leaders/opinion leaders: Informal and formal leaders (eg. Village headmen, teachers and pastors) in the community who have a certain influence over other people (Valente and Davis, 1999). In this study community leaders and opinion leaders are used synergistically.

Rural community: People who live in a rural area (Naidoo et al., 2007), Ongenga Constituency of Ohangwena Region.

Support groups: Groups of people who are usually HIV positive in the community who support PLWHA in different ways. These support groups have centres at which they gather for emotional or other support.

Intervention: Activities that are implemented in the intervention arm aimed at reducing stigma such as training workshops for PLWHA, workshop for community leaders, inclusion of PLWHA living in the Ongenga Constituency and community involvement (Joubert et al., 2007).

Intervention arm: The group of participants who received the stigma reduction intervention package (Joubert et al., 2007).

Control arm: The group of participants who received health education instead of the stigma reduction intervention package (Joubert et al., 2007).

1.9 ETHICAL CONSIDERATIONS

To ensure human subject protection, the following seven ethical principles for clinical research as recommended by Emanuel et al. (2004) were included: collaborative partnership, social value, scientific validity, fair selection of study population, favourable risk-benefit ratio, ethical approval, informed consent, and respect for recruited participants and study communities (Emanuel et al., 2004).

1.9.1 Collaborative partnership

The results of this study will benefit Namibian communities in general and the MOHSS in particular. The partners included in this study consisted of PLWHA organisations, their members, families, community leaders and health care workers, all of who are either affected by stigma, or are in a position to change the current levels of discrimination.

At the end of this trial, the study results will be provided to the MOHSS to ensure their use for health improvements and benefits. A simplified study report would be compiled in the local language (Oshiwambo) of the study area to provide to community members who do not understand English. This study was based on the community participation intervention to reduce stigma model (LINMODEL) that was tested in northeast Thailand and was found to be effective (Apinundecha et al., 2007). To strengthen the collaborative partnerships the Preparatory Process described in the Frohlich Model (2001) was implemented.

1.9.2 Social value

As the literature did not reveal any studies conducted or documented on HIV/AIDS stigma reduction interventions in Namibia, if proven to be effective this study will serve as the baseline for future stigma reduction interventions in Namibia. The stigma reduction package will be integrated into the teaching modules of the Community Health Sciences, University of Namibia, to educate the students about an intervention process and tools to enable them to address stigma and discrimination in their profession. While training within the Ongenga Constituency was undertaken specifically for this study, it is anticipated that those who received the training will continue to address stigma and discrimination after the final intervention assessment, which will continue to benefit the region. The intervention tools will be available, to be implemented and amended according to the specific language of that community.

1.9.3 Scientific validity

The community entry process was applied prior to conduct the study, which lent itself to community ownership and building the collaborative partnerships. Although the control group did not receive a stigma reduction package they received health education that would help them inform health decision making. Should the stigma reduction intervention prove to be beneficial, the control arm will also receive the stigma reduction intervention, which including training in stigma reduction, contact approach and community involvement. As the HIV prevalence in Namibia is high (18%) (MOHSS, 2010) the evaluation of a HIV stigma reduction intervention was scientifically valid for this community. Irrespective of results of this study participants in both the intervention and control arms would have benefited through the health information they received.

To ensure scientific rigor the following research principles were adhered to: confidentiality, anonymity, informed consent, voluntary participation, and respect for privacy.

Confidentiality: This research necessitated obtaining information from PLWHA which was done through their support group leaders. Personal or sensitive information provided by them during the intervention was not disclosed to anyone, nor was it attributed to specific persons in its reporting. The matter of confidentiality was raised at the start of intervention workshops with all the participants, and all participants were requested to respect the shared information.

Anonymity: No names were recorded on the participants' questionnaires and interview scripts, and codes were used to identify individuals. Neither the codes nor the names of individuals were used in quoting their comments or discussions. The training workshops participants' names and contact details were recorded to facilitate follow-up for technical support purposes, this information only being accessed by the researcher.

Informed consent: An informed consent statement was read and explained to participants and those who agreed to participate were asked to sign the informed consent document. In the case of illiterate participants, verbal consent was obtained in the presence of a literate and impartial witness (Appendix 4: Consent form).

Voluntary participation: Participation in this study was voluntary, and participants were informed that they were free to withdraw at any stage without being punished, compromised or denied future health related service.

1.9.4 Fair selection of study population

Once the Ongenga Constituency had been identified as the ideal study group, representation was made to the Minister of Health to conduct the study in that constituency. The relevant community structures were approached for their approval, and the four study groups and research process were discussed. With their consent and guidance, the four study groups (PLWHA, family members, community leaders and health care workers) were identified and the method of participant selection agreed upon. Volunteers were invited to participate in the study without incentives to ensure there would be no bias in their responses.

1.9.5 Favourable risk-benefit ratio

Through a stigma reduction intervention this study attempted to reduce community-based HIV/AIDS stigma in a rural community. The risks associated with the study were minimal while the benefits would be considerable should the intervention prove to be beneficial. It could be argued that PLWHA who participated in the intervention workshop lost their anonymity as a result of disclosing their HIV status to the researcher. However they were reassured that their information would remain confidential and would not be linked to any identifiable names in the study report. There was no physical harm to participants as no bio-medical procedures took place. If proven to be beneficial the study could result in improved health, physical or social wellbeing of the PLWHA as well as their acceptance, less stigmatization, more individuals going for VCT, improved adherence to ART, more support for PMTCT and decreased HIV infections.

1.9.6 Research approval

Permission and approval was obtained from the following organizations before the study was implemented:

1. The Humanities & Social Sciences Research Ethics Committee at University of KwaZulu-Natal (UKZN) (Appendix 1);
2. The National Ethics Research Committee at the Ministry of Health and Social Services (MOHSS), in Namibia (Appendix 2);
3. The Ongenga Constituency Councillor (Appendix 3);
4. All the study participants gave individual consent before any study procedure was conducted (Appendix 4).

1.10 CHAPTER LAYOUT:

The layout of this thesis is as follows:

Chapter 1: Orientation to the study.

Chapter 2: Literature review.

Chapter 3: Research Methodology.

Chapter 4: Community-based HIV/AIDS stigma reduction intervention.

Chapter 5: Data analysis and study results.

Chapter 6: Discussion, recommendations and conclusion.

1.11 CONCLUSION

This chapter presents the background of HIV/AIDS stigma in general and for Namibia in particular. The problem statement was clear and a gap to reduce HIV stigma in Namibia

through a stigma reduction intervention was identified. The study aim, objectives and hypothesis were formulated and research questions developed. Paradigmatic framework and assumptions, which included ontology, epistemology and methodology, are explained. The main concepts relevant to this study are defined. Ethical considerations to ensure human subject protection was discussed and explained. The Chapter layout of the thesis was provided.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of a literature review is to establish what other researchers have done in the area of interest, and to identify methods that can be applied to the study under consideration. This process identifies the gaps in knowledge as well as areas researched, instruments used, conclusions reached, recommendations made and theories included. This literature review includes information from different computerized data bases such as Health Source: Nursing/Academic, MEDLINE-PUBMED, MEDLINE-EBSCO as well as SCHOLAR GOOGLE. The literature review was extended to relevant text books and theses from the library, but was limited to English documents only.

This literature review focused on five components:

1. HIV/AIDS stigma: definition, its causes and effects on individuals, families, communities and on caregivers as well as types of stigma.
2. Stigma measurement and reduction theories, tools, strategies and interventions: identifying how stigma can be measured as well as what options are available to combat or address it.
3. Diffusion of Innovations Theory: focusing on transferring new ideas to influence change in social systems.
4. Models of community participation in research: as this is a community project involving opinion leaders, People living with HIV/AIDS, their families and community members, these will guide how attitudinal and behavioral changes will be affected. The two models consist of:
 - a. “Managing community participation in clinical research” (Frohlich, 2001)

b. “Community participation intervention to reduce HIV/AIDS stigma”

(Apinundecha et al, 2007)

5. The mix method approach: how qualitative and quantitative research methods can be used to measure changes in attitude and behaviour to stigma.

2.2 HIV/AIDS STIGMA

According to Herek (1990) the term stigma was first reported in 1907 in a psychiatric text book, where a psychopathology known as Stigmata of Degeneration was described. It originated from the Greeks and is referred to bodily signs, which were designed to expose something bad or unusual as an indication of the moral status for that person (Herek, 1990 in VandenBos). The signs were worn or burnt onto the persons’ bodies as their ‘social identity’ to be seen by others. Persons who wore them were avoided publicly as they were regarded as traitors, criminals or ritually polluted people (Goffman, 1963). According to Erving Goffman (1963:3), the sociologist who developed the theory of association between stigma and diseases, stigma is an “undesirable or discrediting attribute” that an individual possesses, thereby reducing his status in the eyes of the society (Goffman, 1963). Furthermore, Goffman reported three types of stigma, which are: abominations of the body, blemishes of individual character (e.g. mental disorder, imprisonment, addiction, alcoholism, homosexuality etc.), as well as tribal stigma of race, nation and religion. All three types indicate that the person possesses an undesired differentness and as a result, the person could be discriminated against by others.

Goffman (1963) reported that tribal stigma, which is linked to race, nation and religion, can be transmitted to the other members of the same group such as family. The literature

reported that HIV/AIDS stigma is linked to racial discrimination. According to Parker et al. (2002) racial and ethnicity stigma and discrimination do contribute to HIV/AIDS stigma. The literature revealed that HIV/AIDS epidemic has been characterized by racist assumptions such as “AIDS is an African disease” and “AIDS is brought by White men” (Parker et al., 2002). It is documented that stigma is being used to produce social inequality between groups based on class, gender, race, ethnicity or sexuality. The authors further recommended that there is a need to understand stigma as a political and social process to help reconsidering the responses to HIV/AIDS stigma (Parker et al., 2002).

Following Goffman’s definition, the term changed over time and as a result some literature defined it as holding negative thoughts or feelings against other people due to being regarded as “different” from the rest of the group. Others defined it as a process, which occurs in a particular culture or setting. According to the United States Agency for International Development (USAID) the person who is stigmatized is seen as someone who possesses a spoiled or polluted identity (USAID, 2006).

Stigma can be a result of a particular characteristic such as sexual promiscuity as it is often associated with unacceptable behaviour. It can result from a negative attitude towards behaviour of a certain group. In the case of HIV/AIDS, it is associated with homosexuals, prostitutes and immoral behaviours. Similarly, literature documented that PLWHA are vulnerable to stigma due to the connotations linked to the most widespread transmission modes such as homosexuality, drug addiction, prostitution, multiple sexual affairs, adultery and/or sex before marriage. Those are regarded as immoral behaviours in society, thereby lead to stigma and this perception leads to stigmatization, which refers to a complex process that contains cognitive, emotional and behavioural aspects towards

individuals who are regarded as “different” (Brown et al., 2003, Bos et al., 2008). Several Western studies (Bos et al., 2008), documented that stigma is influenced by a number of factors such as fear of contagion, social rejection, the nature of the disease and its association to death, perceptions of responsibility related to HIV infection, as well as its association with norm-violating behaviour.

HIV/AIDS is the latest stigmatized health condition, having followed Leprosy, Sexually Transmitted Diseases (STD), Tuberculosis (TB), Epilepsy and mental illness (Brown et al., 2001). HIV/AIDS stigma is present in almost all countries, although it is most evident in the developing ones. It may also come from different levels of society, either from family, community or from people in positions of leadership. Stigma blocks HIV infection reduction efforts, care and support for PLWHA as they are scared to reveal their status. It delays their seeking health care services and leads to poor treatment adherence as PLWHA on ART experience stigma due to lack of privacy in delivery of ARVs which increases the risk of drug resistance (Nattabi et al., 2011). It is well documented that the success of HIV prevention and treatment depends on the reduction of HIV/AIDS stigma (Jackson, 2002, UNAM, 2008).

Stigma can be viewed differently depending on the viewer’s perspective and can be either an ‘emic’ or ‘etic’ view. The ‘emic’ view refers to personal perspective (insider’s views) while ‘etic’ refers to others’ perspective (outsider’s views). These views determine whether stigma is classified as either external (inflicted by another) or internal (self-inflicted) both of which can be felt, perceived or enacted. Felt stigma is referring to real or imagined fear of how others will react towards the person who has negative attribute and/or “undesirable disease” (in this case HIV/AIDS) (German and Erin, 2003, Brown et

al., 2003). Perceived stigma refers to the views of others on a certain group labelling them with undesirable characteristics or behaviour such as HIV being a result of infidelity or promiscuity. Enacted stigma refers to the experiences of being discriminated against, for example persons who are refused employment on the basis of their HIV status (German and Erin, 2003, Brown et al., 2003). Literature has revealed that there are some institutions/organizations that refuse to employ people who tested HIV positive. There are reports of companies, which dismissed employees on the basis of their HIV status. Moreover, some companies withhold promotions for HIV positive employees. This discrimination based on HIV status is confirmed by the study done in five African countries where cases of PLWHA who were dismissed from work, refused loans and denied health care as a result of their HIV positive status were reported (Holzemer et al., 2007a).

Naidoo and colleagues (2007) have reported on the following three types of HIV/AIDS stigma, external, internal, and associated:

1. **External stigma** refers to *received and enacted*. These are outsider's views (etic) towards PLWHA. This type of stigma refers to any experience behaviors, attitude or discrimination acts towards PLWHA. Received stigma includes acts such as rejecting, labeling, gossiping, abusing, neglecting, avoiding and negating. Research documented that 'avoiding' as received stigma is more common in rural areas while gossiping was found more common among families and neighbours. Participants in this study reported that verbal abuse, avoiding, rejecting and name calling are the most common form of external stigma either in the families or in the community.
2. **Internal stigma** refers to personal views (emic), which include the *felt and perceived* stigma. These refer to individuals who devalue themselves due to their

HIV positive status and their perception of others' attitudes towards them. It can also include individuals' perceptions on their personal knowledge about being HIV positive (an individual stigmatizing oneself). Felt stigma can prevent a person from seeking medical or other assistance and can lead to self isolation from the society. Internal stigma prevents individuals from disclosing their HIV status due to fear of rejection. Furthermore, an individual who is HIV positive can withdraw from a loving relationship to prevent discrimination (Naidoo et al., 2007, Greeff et al., 2008a).

3. **Associated** refers to stigma towards people who are close to PLWHA, such as families, friends and their care givers. These groups are being stigmatized due to their relationship with PLWHA (Naidoo et al., 2007, Greeff et al., 2008a). Following literature review the researcher had concentrated on measuring the level of these recently supported three types of stigma.

The impact of HIV/AIDS stigma on individuals, families and communities is well documented in the literature as a global problem, although its level varies from country to country (Brown et al., 2003, Holzemer et al., 2007a, Bos et al., 2008). Namibia is no exception, the recent study conducted with ten PLWHA at the ARV clinic at Oshakati Hospital, Namibia, in 2010, revealed that stigma and discrimination still remains a problem in the families and communities. According to Nghifikwa (2011) some PLWHA reported that they are being stigmatized and discriminated by their families and communities, by being avoided, verbally abused, called names, laughed at, judged and labelled by others as the transmitters of HIV. They also reported internal stigma in the form of self negative perception, therefore feeling guilty, have low self esteem and fear of becoming ill any time due to being HIV positive. However, Nghifikwa reported low

stigma in health care settings as participants indicated that health care workers treat them well and show sympathy (Nghifikwa, 2011).

The impact of stigma is also well documented by several authors such as Jackson (2002), Brown et al. (2003), Castro and Farmer (2005) and Thomas (2006) and Rutledge et al.(2009). It prevents people from going for VCT, and anti retroviral therapy (ART) adherence and PLWHA do not seek medical help timely. As a result of stigma, men do not accompany their partners for Prevention of Mother-To-Child-Transmission of HIV (PMTCT) services due to fear of asked to be tested for HIV, as it was reported by Angula (2008). Addressing stigma will help to reduce new HIV infections, improve support for PLWHA, decrease discrimination against PLWHA, increase efficacy of PMTCT and adherence to antiretroviral therapy (ART) (Angula, 2008).

Stigma is experienced at a number of levels in different environments, including household, institutional, workplaces, and at health care facilities. In some instances, people are not employed due to their HIV positive status (UNAM, 2008) and insurance companies refuse to insure those who are seropositive as it was indicated by Ngavetene, in New Era of 5/03/2008 (Sasman, 2008). Literature reports religious leaders (pastors) who preach that HIV is a 'curse' and 'punishment' from God (Nyblade et al., 2003, Ncama, 2004, UNAM, 2008). PLWHA can be isolated physically or emotionally, and in some cases they isolate themselves to the extent that they no longer access services and important support systems (Nyblade and MacQuarrie, 2006, Angula, 2008, UNAM, 2008, UNAIDS, 2011).

Women are particularly stigmatized, as HIV/AIDS stigma is gender-related and they are blamed or mistakenly perceived as being the main transmitters of sexual transmitted infections (STI) including HIV. For example, where heterosexual transmission is significant, sex workers are blamed for the epidemic (Parker et al., 2002, Nyblade et al., 2003, UNAM, 2008, Rutledge et al., 2008). A recent study conducted in three Namibian regions reported that women are blamed for the spread of HIV. They are not free to speak of their HIV status to their partners or families for fear of rejection, divorce, violence and death (Health and Development Networks, 2006). However, men are also sometimes blamed for transmitting HIV in heterosexual relationship, due to their preferences for multiple sexual partners.

According to Ncama (2004) stigma and discrimination were present in community/ home based care organizations as it was reported by a Malawian study. Moreover, stigma was reported from health facilities (Ncama, 2004). Research has also found that some physicians refuse to treat patients on the basis of their HIV status (Holzemer et al., 2007a, Rutledge et al., 2008). In some communities PLWHA are denied access to the daily necessities or basic services such as water, food, shelter, security or even access to health care and education (Nyblade et al., 2008a).

Victim blaming has been a powerful enacted stigma since the 1980s and explains the lack of solidarity in providing proper care for PLWHA in many communities. Stigma operates within families, workplaces, communities, institutions, in the media and in government policies (Castro and Farmer, 2005, Nyblade et al., 2008a). Furthermore, literature reported that there are some religious people who help to create the perception that people who are infected have “sinned” and they deserve their “punishment” from God (Ncama,

2004). There was a case of a pastor in Windhoek, Namibia, who told an audience via radio that “HIV/AIDS is a curse from God and a punishment for man's iniquities.” This perception increases the HIV/AIDS stigma in the communities (UNAM, 2008, Rutledge et al., 2008).

Stigma has been identified as the main deterrent of disclosure of HIV status (USAID, 2006, Makoae et al., 2008, Greeff et al., 2008a) with the literature reports both negative and positive consequences of disclosure either publicly or to family and friends. According to Bos et al. (2008) disclosing an HIV status publicly is extremely difficult, particularly in developing countries where PLWHA reported that they fear being judged and rejected by their spouses and family members.

However, according to Greeff and colleagues (2008a) in their five African countries study on disclosing HIV status, disclosure can have positive results such as self-understanding, healing, authenticity in relationships, empowerment, as well as a welcome relief from the burdens of secrecy and rumours. In the multinational study on coping with stigma that was conducted in Lesotho, Malawi, South Africa, Swaziland, and Tanzania, participants reported that they felt relieved after disclosing their HIV positive status (Makoae et al., 2008). The literature also emphasized that HIV disclosure has a therapeutic effect on PLWHA as it helps them to access social support (Greeff et al., 2008a). Researchers further reported that HIV positive AIDS educators experienced good support from peers and families when they disclosed their status publicly. They reported that after disclosing, PLWHA felt psychological release and had no regrets. Bos et al. (2008) further suggested that HIV positive people who prefer to disclose their status publicly should be counselled and guided accordingly, before they do it (Bos et al., 2008). Furthermore, Makoae et al.

(2008) reported that disclosure is regarded as a coping strategy by some PLWHA, in spite of which, it remains the most challenging action to take.

Contrary to those positive findings, there are reports of violence after HIV positive persons disclosed their status publicly, for example, the case of an AIDS activist Gugu Dlamini, who was stoned to death by her neighbours in her township near Durban (SA) (Brown et al., 2003). Similarly, there are cases of PLWHA who have been thrown out of their homes by family members as a result of their HIV positive status, while some are abandoned and rejected by their partners (Angula, 2008). Other negative consequences of disclosing are being dismissed from work and losing their income, less access to promotion at work as well as being denied leadership positions. Some PLWHA reported being unable to access life cover and funeral insurance due to their HIV status, and, that those who are close to them might be stigmatized as well (Greeff et al., 2008a).

Stigma not only affects PLWHA, but their health care providers, caregivers, families, relatives and friends experience stigma of association (UNAM, 2008). Despite this, only few interventions/studies have been conducted to reduce stigma, particularly in Southern Africa Development Community (SADC) countries. The study was conducted recently in the five African countries of Lesotho, Malawi, South Africa, Swaziland, and Tanzania to pilot testing stigma reduction in public health facilities, but excluded families and communities (Holzemer et al., 2007a). While, stigma and discrimination have been documented in the Caribbean as well as in other parts of the world, only a few stigma reduction interventions have been conducted. Bos et al. (2008) suggested a context specific needs assessment for effectiveness of HIV/ AIDS stigma reduction intervention strategies.

The literature presents several strategies, which could be used to reduce HIV/AIDS stigma in different contexts. For example, a study that was conducted by Apinundecha, Laohasiriwong, Cameron, and Lim in Nakhon Ratchasima Province, northeast Thailand, reported that education strategy combined with community participation is very effective in reducing stigma at community level (Apinundecha et al., 2007). The community participation approach in stigma reduction is also supported by Somma and Bond (2006) who indicated that programs that are theoretically sound are most likely to succeed, that interventions to reduce stigma should be guided by lessons learned elsewhere but, based on local strengths and resources (Somma and Bond, 2006).

The literature recommends the involvement of both infected and affected people as well as communities in stigma reduction interventions, to enable them to become empowered in the process that families and communities who live next to affected people have a role to play in stigma reduction as do influential people as well as leaders (Somma and Bond, 2006, Apinundecha et al., 2007). The community participation approach was therefore used to develop, implement and evaluate stigma reduction interventions in a rural Namibian community in this study.

Progress has been made in stigma reduction in the health care sector, but there are still gaps on how to reduce stigma at community level. Nyblade, Thu Hong, Van Anh, Ogden, Jain, Stangl et al. (2008) in their Viet Nam study on participatory interventions to reduce HIV-related stigma found that there is a need to address its immediate actionable drivers such as lack of awareness and knowledge of stigma, fear of acquiring HIV through everyday contact with PLWHA and discriminatory acts linking people to improper as well as immoral behaviour. They recommend participatory methods in stigma reduction

interventions where, community members are involved and develop a sense of ownership over the project or program. Participatory methods such as games, role plays and group discussions create a non-judgmental environment that allows participants to explore their personal values and behaviours. At the same time, these methods help to improve participants' knowledge and awareness on HIV/AIDS (Nyblade et al., 2008b).

Nyblade and colleagues (2008b) indicated that participants who were exposed to intervention activities reported less fear of getting HIV through every-day contact with PLWHA, such as sharing meals or shaking hands. After the interventions, participants had more knowledge about how HIV is transmitted, were more confident about interacting with PLWHA, which contributed to stigma reduction. PLWHA who participated in that study reported less discrimination after interventions, that community members cared for them and communicated with them openly after the interventions. However, it was found that intervention activities did not reduce stigma related to blaming PLWHA for contracting the disease particularly the sex workers and injected drug users. All these studies agreed that greater exposure to interventions is needed to significantly reduce stigma related to judgmental acts (Nyblade et al., 2008b).

Several stigma reduction programs have been developed and implemented, but only a few have been evaluated. There is a need to test and evaluate stigma reduction strategies and interventions in other settings such as in community, family, schools and workplaces. Very few studies on stigma reduction had been conducted in the SADC countries, and a limited number of have been tested (Holzemer et al., 2007a). Brown and colleagues (2003) reviewed 22 studies which tested stigma reduction interventions in developed and developing countries. This review only concentrated on the experimental and/or quasi-

experimental studies, most of which (13 out of 22) were conducted in the United States of America (USA). Three were conducted in other developed countries and only six were done in Africa. The review found that a combination of strategies rather than one is useful in stigma reduction interventions and these findings can serve as baseline for stigma reduction interventions in other settings (Brown et al., 2003).

2.3 MEASURING STIGMA

A literature search did not reveal any quantitative HIV/AIDS stigma study done in Namibia, despite its HIV prevalence. However, there is a Namibian baseline instrument with a few questions on stigma, which was developed by John Hopkins University Centre for Communication Programs in collaboration with University of Namibia (UNAM), and was used in households' survey in Namibia.

HIV/AIDS stigma measurement instruments were developed and tested two HIV/AIDS stigma instruments for use in health settings in five African countries, one for nurses and the other one for people living with HIV/AIDS. The two instruments are: HIV/AIDS Stigma Instrument-PLWA (HASI-P) (Holzemer et al., 2007b) and the HIV/AIDS Stigma Instrument-Nurse (HASI-N) (Uys et al., 2009). The items on these instruments were developed based on a stigma literature review, tools to measure stigma and on validation from a sample of 1,477 PLWHA from five African countries. Several discussions were held with HIV/AIDS health care workers and PLWHA before their development and evaluation in health settings. However, in the absence of other instruments, the HASI-P can be used in any settings aiming to measure stigma among. The HASI-P was validated with a sample of PLWHA, the scale's alpha reliabilities were examined and the concurrent

validity was explored by correlating stigma scores with symptom frequency, Quality of Life, Life Satisfaction and Overall Functioning. The Cronbach alpha reliability of that instrument estimate was > 0.70 , which is acceptable (Holzemer et al., 2007b p.1006).

“The results showed that stigma factor scores were significantly correlated with symptom frequency the mean score for six factors was 0.158. The Pearson product moment correlations between stigma factor scores were significantly and negatively correlated with Quality of Life; the mean correlation for stigma with Life Satisfaction was -0.195 and with Overall Functioning was -0.148. Stigma factor scores were more negatively correlated with the Life Satisfaction Quality of Life measure than with Symptom Frequency and Overall Functioning. This demonstrates that stigma has a significantly negative relationship with Life Satisfaction and modestly supports the concurrent validity of the new scale”.

Similarly, HASI-N was validated with nurses from all five African countries and consisted of two factors, one for nurses stigmatizing patients and the other for nurses being stigmatized by other people. This instrument has a Cronbach alpha of 0.90, which shows reliability. Concurrent validity was tested by comparing the level of stigma with job satisfaction and Quality of Life. A significant negative correlation was found between stigma and job satisfaction (Uys et al., 2009). Both instruments have used four-level Likert scale (never, once or twice, several times and most of the time). According to the authors these instruments are not copyrighted and may be used freely (Uys et al., 2009).

Another study was conducted to test quantitative measures for HIV/AIDS stigma in Tanzania and focused on the following four key domains (Nyblade and MacQuarrie, 2006):

1. Fear of casual transmission and refusal of contact with PLWHA
2. Value- and morality-related-attitudes such as blame, judgment and shame
3. Enacted stigma (discrimination)
4. Disclosure

The Tanzanian study reported that the first domain was prone to bias as respondents may choose to provide the more socially acceptable responses rather than the correct ones, and questions could also be misinterpreted. Although this remains a problem, it is recommended for community level interventions by researchers. The second domain lacks tested indicators and therefore needs more exploration. The third and fourth domains could not be used in general surveys where the HIV status is unknown, but they are useful in the sample of PLWHA (Nyblade and MacQuarrie, 2006) and given the limitations for these domains, they are open for further testing in different contexts.

These key domains mentioned above were tested again in Tanzania by Nyblade et al. (2008b) who observed that the interventions made people more aware of enacted stigma. They reported that there was no visible change after the interventions at a community level, which could be as a result of insufficient coverage and length of intervention (Nyblade et al., 2008b). While it was found that these quantitative measures are reliable, valid and appropriate for evaluation purposes, they might require some modifications to suit different situations and settings (Nyblade et al., 2008b), and it is therefore necessary to retest these domains.

Other aspects of stigma, such as anti-discrimination laws and policies, were not included in the report of that study. Nyblade et al. (2008b) concluded that there were challenges and gaps in measuring stigma, and that a comprehensive and standard set of indicators that

are feasible in limited resources setting needs to be developed (Nyblade et al., 2008b). Nyblade et al. (2008b) evaluated the indicators that were developed in 2006 for measuring HIV/AIDS stigma reduction in Tanzania and concluded that the following four aspects need to be considered for stigma reduction strategies and interventions:

1. Addressing or overcoming stigma requires personal change.
2. Start with focusing stigma reduction on small, manageable geographical area.
3. Add a specific anti-stigma component in training.
4. Training community opinion leaders is essential in stigma reduction.

2.4 STIGMA REDUCTION STRATEGIES

A number of stigma reduction strategies have been developed, many as a result over concern for the impact of discrimination on HIV positive people. The tools were developed and tested in Asia and Africa. They addressed four areas of stigma as outlined in Section 2.3 namely fear of contagion and contact with infected people, value and morality related attitudes, enacted stigma as well as disclosure related discrimination. The literature documented several strategies such as being suitable to reduce stigma at different levels of interventions namely, information based, skills building, counselling approaches and contact with affected groups (e.g. intrapersonal, interpersonal, and community level) (Brown et al., 2003). These interventions strategies could serve as a baseline for other researchers in any context where stigma reduction should be addressed.

Multi-interventions or multi-channel approaches are recommended, as they are found to be more effective than using a single approach. These approaches need to be tested in different settings to enable clear evidences on the effectiveness of each approach to be

presented (Brown et al., 2003, Heijnders and Van der Meij, 2006, Nyblade et al., 2008a). Heijnders and Van der Meij (2006) identified interventions and strategies that could be useful to reduce HIV/AIDS stigma at different levels in social frameworks. They explained that “strategy is a plan designed to achieve a particular goal and can include different interventions which are explained as the interference to prevent something or to change the results,” (Heijnders and Van der Meij, 2006: 356) intervention can be used as a research approach. Intervention research is defined by De Vos, Strydom, Fouche and Delpont (2009) as studies carried out with the purpose of creating and testing innovative ideas, human services, either to prevent problems or to maintain quality of life. It could be used in different disciplines such as education, nursing, public health and psychology (De Vos et al., 2009). The five strategies levels outlined by Heijnders and Van der Meij are intra-personal, interpersonal, organizational/institutional, community and government/structural, and are detailed below.

2.4.1 Intra-personal

At this level, people experience internal stigma such as feeling guilty and blaming themselves for having the disease. Strategies such as counselling, empowerment, treatment, self-help, cognitive behaviour therapy, advocacy, and support groups can be implemented, the primary focus being behaviour change, for example, to discourage negative self-perception. This change could be achieved by addressing their self-concept, improving self-esteem, providing coping skills and empowerment support (Heijnders and Van der Meij, 2006).

2.4.2 Interpersonal

The interpersonal strategies and interventions aim to modify the affected person's environment, to establish a good relationship between the patient and other people such as family members, co-workers as well as friends. The strategies that can be implemented are care and support, Community-based Rehabilitation (CBR) and Home care teams. The focus for this level is on educating caregivers, families, volunteers and communities (Heijnders and Van der Meij, 2006). Research has indicated that involving people who either live with or next to the affected groups will increase change behaviour on stigma in their families and communities (Somma and Bond, 2006).

2.4.3 Organizational/institutional

The aim of interventions at this level is to modify health and stigma related aspects in organizations. Research has reported that stigma and discrimination acts in health settings include breaches of confidentiality and unkind treatment. The strategies include training programs, developing new policies and institutional changes. Other interventions that target workplace and faith based organization are also recommended at this level (Siyam'kela, 2003 cited in Heijnders and Van der Meij, 2006).

2.4.4 Community

At this level, strategies and interventions aim to increase knowledge about specific health condition (e.g. smoking, obesity or HIV/AIDS and related stigma) within a community. The strategies at this level are aimed at developing community skills in dealing with stigma and consist of education, contact with affected groups, advocacy and protest. Education, combined with other strategies, is often implemented as the first step of stigma reduction and research reports positive results of this strategy (Heijnders and Van der

Meij, 2006). A study that was conducted in northeast Thailand (Apinundecha et al., 2007) found that there is a negative correlation between community stigma towards PLWHA and HIV/AIDS knowledge, indicating that the higher the knowledge on HIV/AIDS, the lower the levels of stigma. While literature on education strategy shows positive effect in stigma reduction, there are no clear evidences as to whether it changes attitudes. It is, therefore, recommended that this strategy be used in combination with other approaches, such as contact with the affected people (Heijnders and Van der Meij, 2006). This can have some shortcomings and disadvantages, for example, people can be forced to disclose their private information, which can have negative consequences. It is recommended that affected people should be well trained and prepared when this strategy is used for stigma reduction intervention (Boevink, 2002 cited in Heijnders and Van der Meij, 2006).

The northeast Thailand study by Apinundecha et al. (2007) also recommended the use of community participation in stigma reduction intervention at community level. They contend that community participation in stigma reduction is the most effective way to promote ownership and sustainability, with its focus on the interaction between researcher, the researched and their involvement in the intervention activities. That strategy was tested by Apinundecha and colleagues (2007) and the results showed a clear difference between the implementation and the control villages, with a substantial stigma reduction in the implementation villages (Apinundecha et al., 2007).

2.4.5 Governmental/structural

The strategies and interventions at this level aim to protect the rights of the affected people using legal and policy interventions as well as Rights-based strategies. Although no

evaluation on these policy interventions were found in the literature, it was indicated that they are widely implemented (Heijnders and Van der Meij, 2006, Mahendra et al., 2007). While the effectiveness of some of these strategies was not evaluated, those that were evaluated showed that a combination of counselling, education and contact with affected people was very effective in stigma reduction (Heijnders and Van der Meij, 2006). The literature concluded that stigma reduction needs collective approaches from affected groups and the general public. Equally, HIV infected people should play an active role and the programs should be more PLWHA-centred. All these approaches need broad interventions from governmental levels (Heijnders and Van der Meij, 2006).

2.5 THEORETICAL FRAMEWORK

A number of theories have been developed such as Theory of Reasoned Action (TRA), Theory of Planned Behaviour (TPB) and Health Belief Model (HBM) to understand changes in behaviour and social systems. TRA and TPB are useful in predicting deliberate behaviour and/or individuals' intention to perform it, while HBM attempts to predict and explain health behaviours focuses on the attitudes and beliefs of individuals. However, the theory most suited to this study is the Diffusion of Innovations Theory, the main goal being to bring about change in social systems by focusing on the individuals as agents of change to transfer knowledge and influence behaviour (Sharma and Kanekar, 2008, Murray, 2009).

2.5.1 Diffusion of Innovations Theory

This theory was developed by Evert M. Rogers (1962) (Murray, 2009) and its focus is on disseminating innovative ideas, practices, products or services as perceived by an

individual or a group. Diffusion is defined as “the process by which an innovation is communicated through certain channels over time among the members of a social system” (Rogers, 2003). The idea is being communicated between those with knowledge of the innovation and those who have to adopt it (Sharma and Kanekar, 2008, Murray, 2009).

The Diffusion of Innovations Theory had been applied in different programs by more than one discipline as it was found successful in immunization campaigns and family planning. Researchers have found that social contacts, interactions and interpersonal communication are important influence on adoption to new behaviours. According to several authors, such as Rogers (2003), and Clarke (2009), the uptake of an innovation could be an optional decision by an individual, collective that is made by members of the social system, or authority-based, whereby it is made by few individuals who are in the position or have power to influence people.

As it was mentioned in the definition, the process of diffusion has four key components, namely: 1) innovation, 2) communication channels, 3) time (decision process) and 4) social systems (Murray, 2009). In order for the model to be effective, the four components need to be in place, each of which will be discussed below.

2.5.1.1 Innovation

‘Innovation’ comes from an old Latin word ‘to renew or change’ something and is defined by Rogers (2003: 11) as an “idea, practice or object that is perceived as new by an individual or other unit of adoption.” It influences the spread of a new idea but results in a change in what is done or how it is done so that the status quo before the innovation was introduced changes the status around the innovation. It can be to the benefit or detriment

of a society, it may not always have the desired effect, hence the need to evaluate its effectiveness after an intervention (Sharma and Kanekar, 2008, Murray, 2009). In the context of this study, the innovation is the transfer of knowledge to reduce HIV/AIDS stigma in a rural community.

Innovation has five characteristics that influence an individual's decision to either accept and adopt or reject it, namely its relative advantage, compatibility, level of complexity or simplicity, trialability and observability of its outcomes. These are detailed below and it is recommended that they should be taken into account when the introduction of new ideas is being planned (Sanson-Fisher, 2004):

- i. **Relative advantage:** the degree of potential benefits, which clients or participants will get from an innovation, influences its rate of adoption. If the proposed change is not regarded as necessary by the recipients, uptake of the innovation may not happen. 'The greater the perceived relative advantage, the more rapid its rate of adoption is likely to be' (Robinson, 2009).
- ii. **Compatibility:** how the innovation will address the issue or the problem, whether it is compatible with their habits, values and norms, is it easy or hard to use.
- iii. **Complexity or simplicity:** is "a measure of the degree to which an innovation is perceived as difficult to understand and to use" (Sanson-Fisher, 2004:55) People are more likely to adopt change if the procedure is simple and well defined, as its complexity may also affect the duration of uptake.
- iv. **Trialability:** the acceptability of the innovation and its potential outcomes, and the degree to which it can be experimented, tested and implemented with limited resources.

- v. **Observability:** “The easier it is for individuals to see the results of innovation, the more likely they are to adopt it” (Robinson, 2009: 2).

2.5.1.2 Communication channels

The second component in diffusion research is communication channels, which are essential in information sharing such as mass media, attendance of workshops, visits from interest groups, and video or audiotapes (Sanson-Fisher, 2004). Murray (2009) identified the mass media and interpersonal contact as the two most effective means, with the former being more effective at the knowledge stage, and the latter being effective for persuasion and on a professional level. Face-to-face interpersonal communication is recommended as an effective way of convey the message as it gives the innovator a chance to explain the reasons for change or for new idea. The audiences will also have a chance to ask questions and give their views. Researchers caution that interpersonal channel's influence can either speed up or slow down the diffusion process (Valente and Davis, 1999, Dearing, 2004, Murray, 2009).

2.5.1.3 Time

The third component is time, with respect to the sequence of events, with diffusion requiring a planned change over time that could be adopted through innovation-decision process steps, which are presented below (Valente and Davis, 1999, Sharma and Kanekar, 2008).

- i. **Knowledge:** gaining knowledge about the innovation, its functions, costs and benefits, and possible positive and negative consequences
- ii. **Persuasion:** forming a favorable attitude to the innovation by persuading people of its relevance and effectiveness

- iii. **Decision:** a decision is made to commit to either accept or reject its adoption
- iv. **Implementation:** implementing the innovation within the designated group of people
- v. **Confirmation:** reinforcing the decision to implement the innovation based on positive outcomes.

The knowledge about an innovation causes an attitude that leads to individuals or groups deciding to take action, which results in behaviour change. The steps of innovation decision process are presented in Fig 2.1.

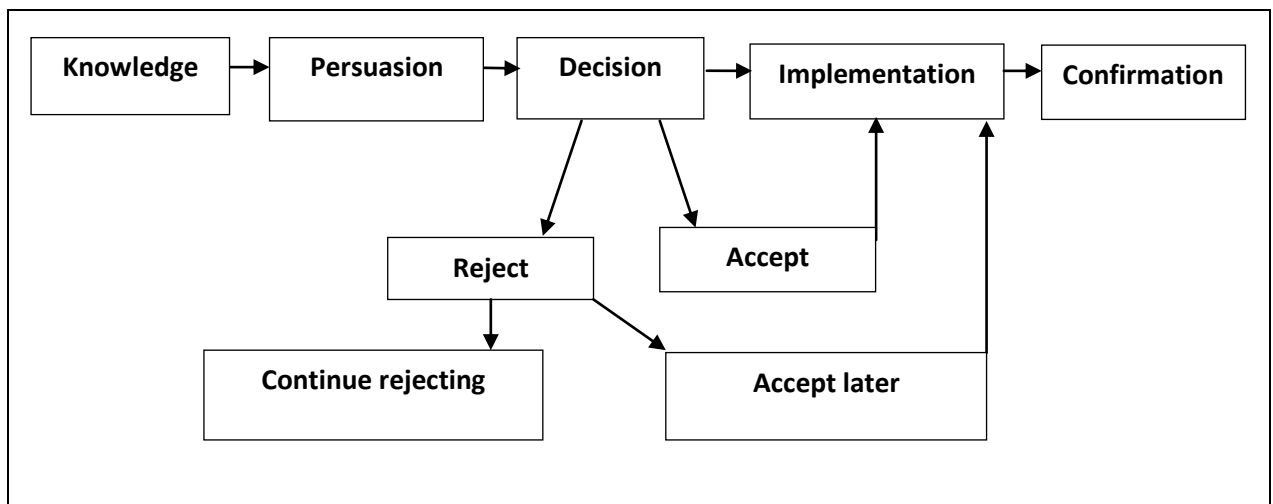


Figure 2.1 Steps of innovation decision-process (adapted from Rogers, 2003).

2.5.1.4 Social systems

The fourth component in diffusion research is social systems, which includes opinion leaders and organizations that can make a collective or authority-based decision. Research has indicated that not all individuals have an equal influence over other people, and that opinion leaders are influential in spreading either positive or negative information about an innovation. A number of authors recommended using opinion-leaders as people who can influence their community members to take up new ideas (Valente and Davis, 1999,

Dearing, 2004) and accelerate the rate of diffusion. However, their credibility depends on how they are selected (Valente and Davis, 1999, Murray, 2009). In addition to opinion-leaders, there are also change agents and change aides who can have positive influence on innovation decisions due to their competence, credibility, and trustworthiness (Clarke, 2009b).

2.5.2 Assumptions and expected outcomes

The Diffusion of Innovations Theory is based on the assumption that if change takes place in a small group (an intervention arm) the peer influence will help to diffuse the innovation to other members of the group. The expected outcomes for this study were that once community-based HIV/AIDS stigma has been overcome, people would go for voluntary counselling and testing (VCT) for HIV without the fear of being stigmatised. Furthermore, ART adherence would improve, men would accompany their partners to PMTCT services, and new HIV infections would decrease. To achieve these expected outcomes intervention research with community participation is essential, in reference to which two models guiding it are reviewed.

2.6 MODELS OF COMMUNITY PARTICIPATION IN RESEARCH

Two models guiding community participation in research were investigated as it is essential to understand the motivational factors and to identify a process to direct the research. According to Kagee and Swartz (cited in Joubert et al., 2007) community participation is defined as the active involvement of people or their representatives in research projects activities. It attempts to minimize the gap between the researched and the researchers, to distribute power fairly between the two groups. It further emphasizes

community empowerment through their active involvement in research, which would enable them to have a say in issues which affect their health and concerns. However, the authors acknowledged that community participation in research is not easy (Kagee and Swartz cited in Joubert et al., 2007).

The literature review included two models that guide community participation in research which are:

- 1) “Model to manage community participation in health clinical research” (Frohlich, 2001). This model aims to facilitate quality community participation in health related research.
- 2) “LINMODEL of community participation intervention to reduce HIV/AIDS stigma”, highlights the steps which could be followed in developing an intervention for stigma reduction. (Apinundecha et al., 2007). The two models were used to complement each other.

2.6.1 A model to manage community participation in clinical health research

According to Frohlich (2001) although community participation in research is well documented in the literature, little is published on how to manage it in clinical health research. The author developed a model to manage community participation in clinical health research and indicated factors that motivate people to participate, such as recognising people’s rights and duty to participate, raising health awareness and expectations as well as acknowledging health care institutions’ inability to cater for all health related needs (Frohlich, 2001). From this model only the Preparatory Process component has been applied in this study.

For optimal community participation, a preparatory process is necessary, which include the five activities of awareness, willingness, knowledge, preparedness/readiness and integration, which are discussed below (Frohlich, 2001).

- 1. Awareness:** to prepare community members for their involvement in research, awareness about the planned activities is essential so that they can have knowledge about or a perception of the new ideas as well as what is expected from them.
- 2. Willingness:** after community members are made aware of the planned research in their area, the next activity is to determine their willingness to support the study either by participating or by collaborating with the researcher. Participatory approaches facilitate the willingness to engage with researchers, it ensures community engagement, community and individuals' readiness and preparedness to participate in research.
- 3. Knowledge:** during this phase the researcher needs to gather knowledge about the context where the research will be conducted. Equally it is essential for all the stakeholders in the project and community representatives to learn about the proposed research and decide upon structures to be followed and ensure community participation.
- 4. Preparedness/readiness:** researchers collaborate with empowered community representatives and individuals to assess whether community members are prepared and ready to participate in the proposed research project. The collaboration between the researched community and researchers influence the impacts on community ownership and successful enrolment of and recruitment for study participants.
- 5. Integration:** 'integration' originated from Latin word 'integer' which means 'whole or entire' and it refers to combining parts so that they work together or form a whole (Oxford dictionary). To ensure sustainability of new ideas and ownership of

participatory management strategy good clinical practice (GCP) and sound ethical standards are adhered to (Frohlich, 2001).

The five activities of the Frohlich Preparatory Process applied to this study are described in Table 2.1.

**Table 2.1 The Preparatory Process to prepare the community for research
(Adapted from Frohlich 2001)**

Steps in Community Preparatory Process	Activities to prepare constituency for stigma reduction intervention
Awareness	Consultation meetings with community representatives and support group leadership.
Willingness to participate	Informal discussion with community members prior to the study. Hold meetings with community members and inform them of the planned research in their constituency.
Knowledge	Information sharing with stakeholders and community representatives. Discuss ethical considerations prior to study implementation, during study and on completion of study through study results dissemination.
Preparedness	Conduct informal assessment of community preparedness prior to study implementation. Ongoing dialogue with community members throughout research process that will facilitate collaborative partnerships.
Integration	Integrate ethical principles with community representatives to ensure ethical and scientific validity of the study. HIV/AIDS stigma reduction to be integrated in local HIV/AIDS programme for sustainability.

2.6.2 LINMODEL

The second model that was reviewed is LINMODEL of community participation intervention to reduce HIV/AIDS stigma that was developed by Apinundecha et al. (2007)

for northeast Thailand study. This model consists of eight stages which are detailed below and presented in Figure 2.3

- i. **Leader engagement:** community leaders should be engaged at beginning and preparation stage as they are the change agents within their communities.
- ii. **Information for decisions and actions:** participants are able to understand the HIV/AIDS situation in their community and the benefits associated with reducing stigma.
- iii. **Negotiable planning:** all stake holders should be involved in discussing alternatives courses of action and implementation plans.
- iv. **Management of community resources:** a number of participants have to be selected to mobilize and manage community resources, both internal and external.
- v. **Operating activities:** these included youth volunteers to access information on HIV/AIDS from the internet, disseminating information to the community, having an activity of Dharma (interactions between PLWHA and community members) to release suffering and encourages participation and understanding between PLWHA and community members.
- vi. **Development for sustainability:** the core volunteers look for sustainable strategies to continue the project once the developers have left.
- vii. **Evaluation:** to evaluate the intervention process as well as the outcome.
- viii. **Forum for learning and sharing experiences:** considering the benefits from the intervention (Apinundecha et al., 2007).

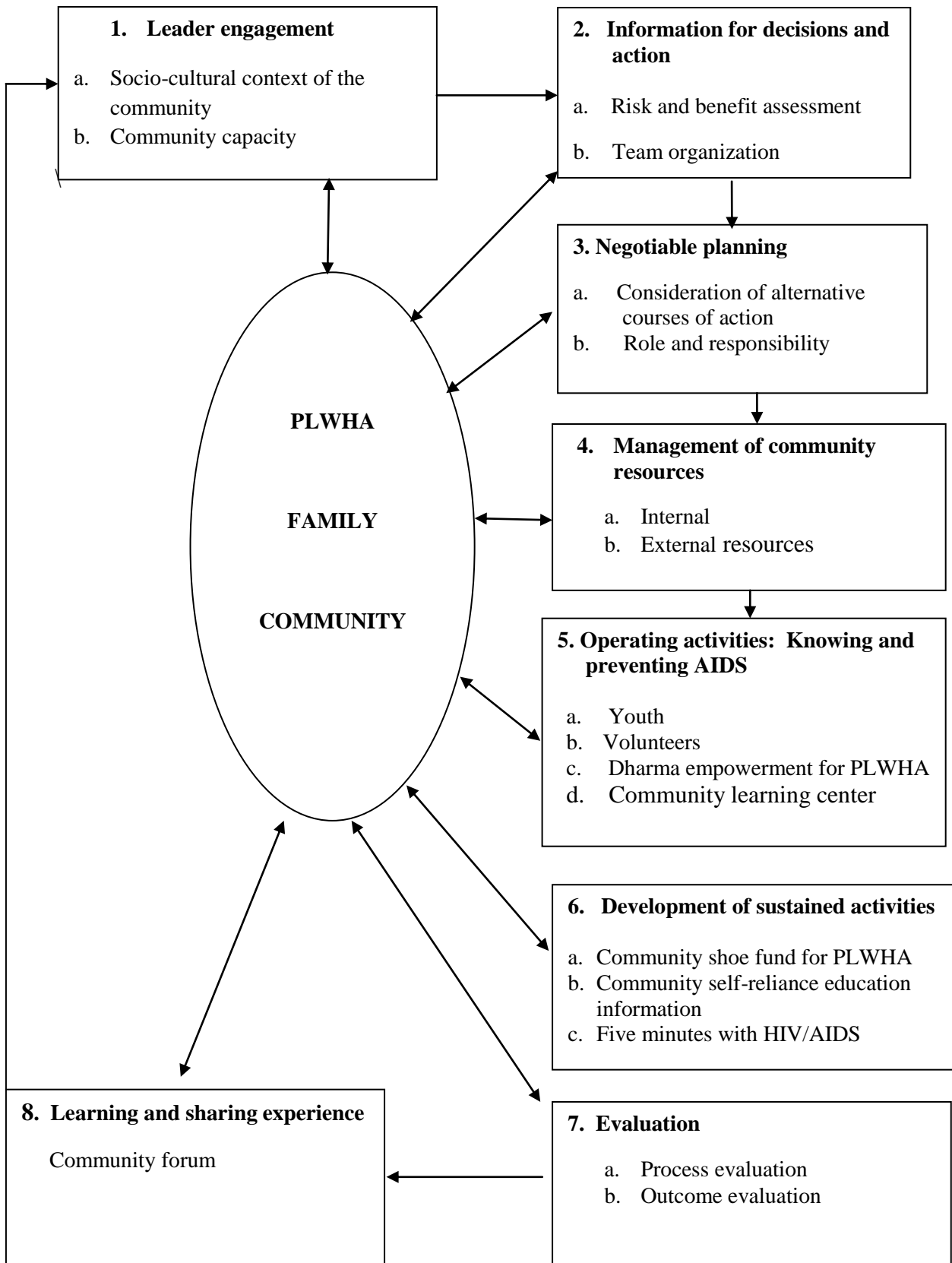


Figure 2.2 LINMODEL: A community participation intervention to reduce HIV/AIDS stigma (Apinundecha et al., 2007: 1160)

In the northeast Thailand study where this model was developed, community members and study participants were involved at all eight stages, and the study reported successful outcomes. The results demonstrated a clear difference between the implementation and the control villages, with significant stigma reduction being evident in implementation villages (Apinundecha et al., 2007).

This LINMODEL is related to the Diffusion of Innovations Theory as both encourage the use of leaders as change agents who act as linkers between the community and change agency. The LINMODEL has Stage 2 of Information for Decisions and Actions where participants are assisted with understanding their situation and changing their perceptions. This is related to the innovation decision process in the Diffusion Model, where participants acquire knowledge of the new idea that leads to action of either to accept or reject it. It was with this link that the LINMODEL was regarded suitable for this study, although a few of these stages are not feasible in some contexts, particularly where financial resources are limited.

Apinundecha and colleagues (2007) used a participatory action research, where the researched people were involved at all stages, and a quasi-experimental 'non-equivalent pre-test-post-test control group design' to evaluate the effectiveness of their intervention was applied. Their approach could be applied in other contexts where an intervention for HIV/AIDS stigma reduction is implemented, although other designs would also be applicable.

The two models provide guidance in community participation in research. The Frohlich model provides guiding principles for how community participation in clinical research can be managed, and outlined the activities in the preparatory processes. The LINMODEL

outlines the eight stages of an intervention model to reduce stigma and the stages that need to be taken, while the Frohlich Model identifies how the community participation process should be managed.

As community participation in research is essential, people's experiences and knowledge should be measured and known, but their views and opinions should also be heard. This could only be achieved through implementing mixed methods of quantitative and qualitative approaches. The next section therefore has details these approaches and motivates their paradigm relevance to this study.

2.7 CONCLUSION

This chapter defined the concept of stigma and presented the literature review on HIV/AIDS stigma, definitions, causes and effects on PLWHA, families, as well as on caregivers. HIV/AIDS stigma and its link with other discrimination such as racial, gender and sexuality were highlighted and the causes, explored, particularly the belief about its link with immoral behaviour such as prostitution, multiple sexual affairs and adultery. Stigma is an obstacle to HIV/AIDS response as it hinders prevention and it prevents disclosure. The different types of stigma, namely external, internal and associated were explained, and examples were given on how it affects individuals, families, caregivers and communities.

How to measuring stigma and a number of instruments to measure it were reviewed, including the recently developed HASI-P and HASI-N from a five African countries study and their use as a baseline tool for future researchers as they are not copyrighted

and may be used freely. A Namibian baseline survey instrument with a section of HIV/AIDS stigma was also reviewed. Several authors have developed strategies and interventions that may be used to reduce stigma and they were explained in this chapter. The key domains for measuring stigma such as fear, value and moral related attitudes, enacted stigma and those related to disclosure were discussed. The literature located several strategies and interventions that could be used to reduce stigma and it was indicated that multi-interventions and multi-strategies are favoured rather than a single approach. Strategies such as information based, skills building, counselling approaches, contacts with affected and infected groups are emphasised, and may be used at different levels such as interpersonal, institutional or community. Community participation approach is highly recommended in stigma reduction.

Theories were reviewed and the Diffusion of Innovations theory was selected as the suitable one for this study to bringing about changes in people attitudes and behaviour to PLWHA. The use of opinion leaders as influential people in changing groups was highlighted in the literature. The two models that guiding community participation in research were discussed namely Frohlich Model and LINMODEL of Apinundecha et al. and their link to this study was discussed. Finally the mixed methods in research approach were explained and the reasons for their use in this study outlined. Having provided the theoretical framework for this research by identifying the community participation models and Diffusion of Innovations theory, a mixed method approach was used to guide the study, with an outline being presented in Chapter 3.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This study measured the level of stigma and effectiveness of an intervention to reduce stigma associated with HIV/AIDS and consisted of questionnaires, in-depth interviews, which resulted in both qualitative and quantitative data as well as intervention workshops. The community intervention was implemented through a multi-phased quasi-experimental, non-equivalent control group pre- and post-test design. This study used a multi-level sampling approach on four groups of participants, who are people living with HIV/AIDS (PLWHA), their families, community members and opinion leaders as well as health care workers. Both descriptive and statistical analyses were performed to determine the significant levels of the findings by comparing the quantitative results from both control and intervention arms of the study.

As outlined in Chapter 1, HIV/AIDS stigma is a social and health problem globally. It affects almost every country in the world with Namibia being among those hardest hit by HIV and not immune to stigma. The people who are living with HIV/AIDS are being discriminated against as a result of their positive status. Their families also experience associated stigma due to their relationship with people living with HIV/AIDS. This prevents the success in the fight of HIV/AIDS prevention. It is well documented that stigma interferes with care and support for PLWHA either from the caregivers or from their families and friends. It was, therefore, necessary to intervene to address this problem in a rural Namibian community. HIV/AIDS stigma needs to be addressed from all angles of society and to take this idea to the community intervention research was the appropriate method. Through this intervention, the researcher was able to collaborate with the infected

and affected people of Ongenga Constituency. The researcher conducted intervention workshops with selected participants who were actively involved in activities aimed to reduce stigma at family and community levels. This chapter presents the methods used in this study, including the research design and population, sample size, data collection instruments and methods, data management and analysis.

3.2 THE USE OF MIXED METHODS IN RESEARCH

The choice of research approach depends on the questions and the phenomenon under study, therefore this section explains the rationale behind using mixed methods. The use of mixed methods in research has been the subject of much debate about whether they only refer to studies that include both quantitative and qualitative approaches, or whether they include different data collection techniques in one design. The aim of using mixed methods is to include a number of techniques to learn more about the topic under investigation (Alexander et al., 2008 cited in Gilbert, 2008).

A mixed-method approach is appropriate when different facets of the same phenomenon are examined (Clarke, 2009a) or when a researcher wants to address a range of questions to obtain a broader picture (O'Cathain et al., 2007). In this study, the same phenomenon (HIV/AIDS stigma) was examined and measured at different phases, with a range of questions needing to be addressed to obtain an in-depth understanding of it.

Mixed methods have varying assumptions, as they draw on a number of paradigms, three of which will be explored for this study, namely **positivism, critical rationalists and interpretivism**. These paradigms differ in their assumptions about ontology (nature of

reality), epistemology (what we should do or can do in social research) and methodology (research technique) (Alexander et al., 2008 cited in Gilbert, 2008: 138)

The positivism paradigm's ontological assumption is that there is a truth (reality) that needs to be studied and understood, and that an objective reality can only be gained directly from respondents. According to the positivism paradigm, reality can only be observed and experienced by using senses, and it assumes that an ordered universe is made up of discrete and observable events. This order can only be represented by generalizations about the relationship between concepts (Blaikie, 2000). In this study, it is assumed that the truth about stigma can be obtained from study participants who are PLWHA, their families, community leaders and health care workers. Positivism views this information as only being obtained by using quantitative approach.

The positivists believe that the purpose of doing research is to develop and test models and theories, as they seek to test hypotheses. They argue further that qualitative data are not representative and cannot be generalised as they are generally drawn from a small number of cases (Alexander et al., 2008 cited in Gilbert, 2008: 138). Their epistemological view is that researcher and participants are independent entities. They assume that knowledge can only be produced by using human senses, and that can only be obtained by doing experiments or comparative analysis. They believe that trained humans are able to produce “objective” data, and that to get the data, the observer has to interact with the observed things/subjects. Positivists base their statements on objective observation and reality, and argued that researchers should put their preconceptions aside when doing experiment or collecting data, and use only objective methods (Blaikie, 2000). According to this method’s view, researcher and participants will not influence each other. The researcher has to be objective when collecting quantitative data, while participants will give their

own views without being influenced by the researcher when completing and/or answering questionnaire (Sale and Brazil, 2004).

This positivism paradigm was criticized by the **critical rationalists** who reject the use of senses as the secure foundation for scientific theory. The rationalists argued that data collection occurs against the background of certain expectations of what exist and how it behaves (Blaikie, 2000). While the positivists are concerned about establishing fundamental patterns or relationships in social life, the critical rationalists argue that those patterns are not understandable on their own, that the motives that lead to those patterns also need to be studied (Blaikie, 2000). Therefore, qualitative methods can be used to complement quantitative methods with secondary data to provide a supporting role. It is against this argument that the need for the involvement of opinion leaders and influential people in in-depth interviews to obtain insight on the level and extent of HIV/AIDS stigma is emphasized. They are able to give information about their personal experiences and the reality of HIV/AIDS stigma either in the families or in their community (Sale and Brazil, 2004).

According to Sale and Brazil (2004), qualitative methods are based on the paradigm of **interpretivism**, which contends that multiple and changing social realities exist. Researchers therefore, conduct their studies in natural contexts to reach the best understanding of the problem. Cresswell (2009) further recommended that participants' internal and subjective experiences are equally important, as study participants present the reality of the problem although, researchers are the ones who analyze and write about it (Cresswell, 2009). According to the interpretivist paradigm', social reality is regarded as the product of negotiations of the meanings for actions and situations by social actors

(Blaikie, 2000). They seek explanations and understanding, and further argue that quantitative data alone cannot produce a full understanding of a phenomenon. Therefore, mixed methods are needed to give a study an overall strength that is greater than either qualitative or quantitative research (Cresswell, 2009).

The interpretivists' epistemological view is that the researcher, who is an investigator, and the study participants, are interactively linked to each other, the study findings being mutually created by both researcher and the researched (subjects/participants). Above all, social scientific knowledge is derived from every-day concepts and meanings and through qualitative methods the voices of participants will be heard (De Vos et al., 2009).

These differences between the positivists and interpretivists paradigms lead to researchers to start with different positions based on their own assumptions and rationales. When using mixed methods, researchers take either a **pragmatic or a dialectical approach**, as this combination leads to a fuller understanding of the social world (Alexander et al., 2008 cited in Gilbert, 2008, Cresswell, 2009).

According to Creswell (2009: 210), there are six mixed methods strategies, namely: sequential explanatory strategy, sequential exploratory strategy, sequential transformative strategy, concurrent triangulation strategy, concurrent embedded strategy and concurrent transformative strategy. The selection of which one to use depends on the phenomenon that is measured and on how often it will be measured. Researchers can apply any of those types depending on their research questions (Alexander et al., 2008). In whatever strategy is chosen both quantitative and qualitative methods could be used to collect data to obtain a clear and in-depth understanding on the phenomenon concurrently. It is however also

possible to use the concurrent embedded strategy, which may have one dominant form of data collection with a limited use of the other, or where elements of the same data are analysed in both formats. The diagram of concurrent embedded design is shown in

Figure 3.1

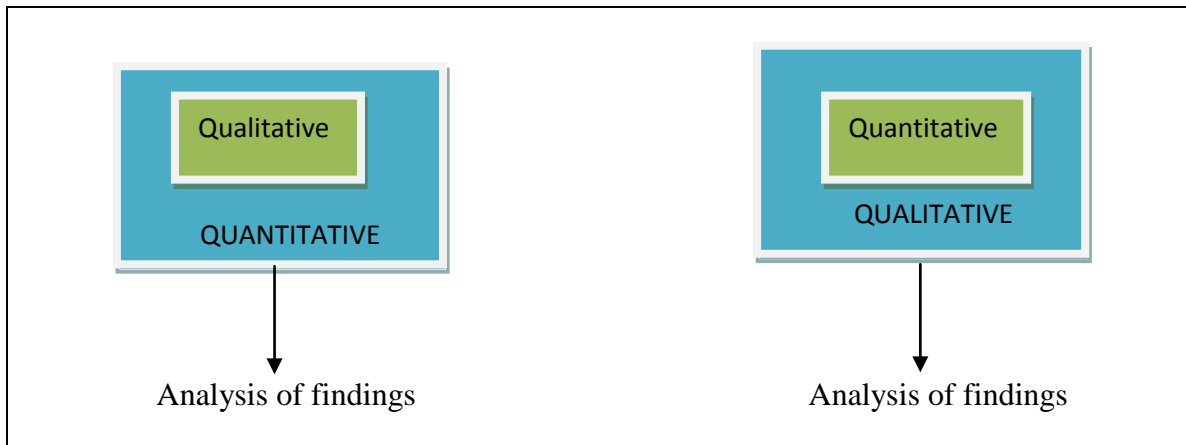


Figure 3.1 Concurrent embedded design (Creswell 2009: 210)

The use of this method provides quantitative results about what has been done, and is supported by qualitative themes that give substance to the analysis and enable more comprehensive implementation. As a result the researcher can have rich and more informative data, which could contribute extensively to new knowledge.

3.3 RESEARCH DESIGN

A quasi-experimental, non-equivalent control group pre-and post-test sampling plan was used, requiring pre- and post-tests for a treated and comparison group although they are not created through random assignment. This design resembles an experimental study but it lacks the key ingredient that is random assignment (Trochim, 2006). Research has

proven that randomization of individuals is more efficient statistically as well as the frequently preferred approach (Sylvan and Green, 1997). However, literature has also reported that random assignment of individuals to intervention and control groups has limited applicability in certain conditions such as when intervention involves systems or structural changes. When random assignment of individuals is not possible, alternative designs should be considered. The nature of the intervention, its outcomes, and objectives for evaluation should dictate the choice of the design, that was why mixed methods design was chosen for this study (Bawden and Sonenstein, undated).

In this study, a quasi-experimental sample plan was used due to the impracticalities and impossibility of individual randomization. The nature of intervention and objectives for evaluation played a role in the choice for this design as randomization to treatment (intervention workshops) could not be assigned to individuals but only to groups. Literature revealed that this design has its limitations such as threats to internal validity, but it has advantages as well. For example, it minimizes the threats to external validity, allows natural experimental findings to be generalized and is also efficient in longitudinal study, which involves longer time periods for follow-up in different environments (Trochim, 2006). This study had a follow-up component, where evaluation was conducted after six months to evaluate the effectiveness of the intervention.

Bawden and Sonenstein (undated, cited 4/10/2011) proposed that quasi-experimental designs are sometimes necessary particularly when social programs are evaluated and under certain conditions when they are preferable to experimental designs with random assignment to intervention and control groups. There are certain programs where the random assignment of clients or participants is simply not appropriate, for example when

an intervention is implemented to improve the services. Bawden and Sonenstein (undated) claimed that while the impact of intervention being measured may have effects on participants, it is the system which is being tested. It is, therefore, unlikely that the system could operate in one way for the intervention group and another way for the control. For these types of interventions, quasi-experimental design may be the only option (Bawden and Sonenstein, undated). In this study a quasi-experimental design was judged appropriate because evaluation was done on the intervention effectiveness rather than on participants.

Following the literature review, the researcher established that randomization of participants to intervention was impossible as a result the community was separated geographically into two sites where one served as a control and the other as an intervention arm. A draw was done prior to an intervention to assign community sites to either control or intervention arm. Both arms have participated in baseline assessment and separation of the community was done thereafter. The baseline survey results helped the researcher to compare and to evaluate the effectiveness of the intervention. Community separation helped to minimize the likelihood of participants from different arms to meet, and minimized threats to internal validity such as treatment diffusion to control villages. Literature reported that community separation shares several advantages with individual randomization such as avoiding bias, achieving balance of predictive factors and providing basis of statistical tests (Sylvan and Green, 1997). Wherever individual randomization is impossible, community separation would be the second choice.

Finally, quasi-experimental, non-equivalent control group pre- and post-test design was judged as the most suitable method for this study due to the following reasons:

- It was feasible for intervention delivery
- The nature of the intervention could not be done on individuals, it was only possible for groups
- It was suitable for the use of site-specific resources to decrease costs
- It has greater generalization
- There was a need to avoid contamination between the two community study arms (intervention and control).

3.4 STUDY OVERVIEW

A three-phased approach was used consisting of Preparation, Implementation and Evaluation, starting in January 2009 and ending in July 2011 (Figure 3.2).

Phase 1: Preparation

The preparation phase included a literature review to identify stigma measurement tools and training manuals. A number of research instruments and training guides were found and those that were considered appropriate were studied for their suitability and adaptability. This resulted in two standard stigma measurement instruments being adapted and a new one being developed, and the Kidd & Clay (2003) “Understanding and Challenging HIV/AIDS Stigma” Toolkit for Action that was used in Ethiopia, Tanzania and Zambia as well as Kidd et al. (2007) a Cambodian version, being adapted for the training manuals. The three HIV/AIDS stigma instruments were pre tested as was the training manual for PLWHA and changes made before the full study was implemented.

Phase 2: Implementation

Multi-approaches which consisted of surveys on stigma and discrimination, in-depth interviews, followed by intensive workshops on stigma reduction for the intervention arm were implemented in Phase 2. Two training manuals were used to train the support group members and community leaders. The training manuals were based on a Toolkit for action by Kidd and Clay (2003) and Kidd et al. (2007). The control arm was provided with general health education.

Phase 3: Evaluation

The results of the surveys and the in-depth interviews, both pre- and post-intervention were analysed in phase 3. The intention was firstly to establish the levels of stigma and discrimination, and secondly to determine whether the intervention was successful in changing the communities attitudes and reducing stigma to PLWHA. The control and intervention groups were first evaluated separately, after which a comparison between the two arms was done.

While the intention was to retain the same participants throughout the study, from the baseline to the final survey, this was not always possible. This resulted in people taking part in the baseline but not the final survey, or missing the baseline and completing the final survey. The survey forms were handed to the support group leaders or representatives with comprehensive instructions and the request to distribute them to their members. Although it was well explained to support group leaders that people who participated at baseline, should be the same persons to complete the final survey, it was observed during data analysis that it was not the case, as new participants were recruited for evaluation and many old ones were lost. It became apparent at the end of the study

that while the ideal would be to include only those who had participated throughout the study, it was decided to include those who had not to provide greater insight into either the extent of stigma and discrimination, or to determine whether information about reducing it had been diffused to members of the community following the interventions. The results will therefore be divided into the following categories in both arms jointly (baseline) and then separately (evaluation), but the post-intervention groups only will be presented separately.

The results of the study and discussion of the group findings will be presented in Chapter 5 in the order as listed below.

1. Baseline surveys: (n=224)
 - a. Group1: PLWHA,
 - b. Group2: Family members,
 - c. Group3: Community leaders
 - d. Group 4: Health care workers
2. Baseline and evaluation surveys comparisons: (n=74)
 - a. Group1: PLWHA from intervention arm versus PLWHA from control arm;
 - b. Group 2&3: Family members and community leaders from intervention arm versus family members and community leaders from control arm
 - c. Group 4: Health care workers pre-intervention versus post-intervention
3. Post-intervention groups only: (n=129)
 - a. Group 1: PLWHA intervention arm, followed by Group1: PLWHA control arm
 - b. Group 2&3: Family members and community leaders intervention arm, followed by Group 2&3: Family members and community leaders control arm;

c. No health care workers for this category

4. Qualitative results:

- a. Baseline survey: (n=10) Groups 1, 3 and 4: PLWHA, Community leaders and health care workers from both intervention and control arms, jointly.
- b. Evaluation survey: (n=17) Group 1 & 3: PLWHA and community leaders from intervention arm only (jointly).

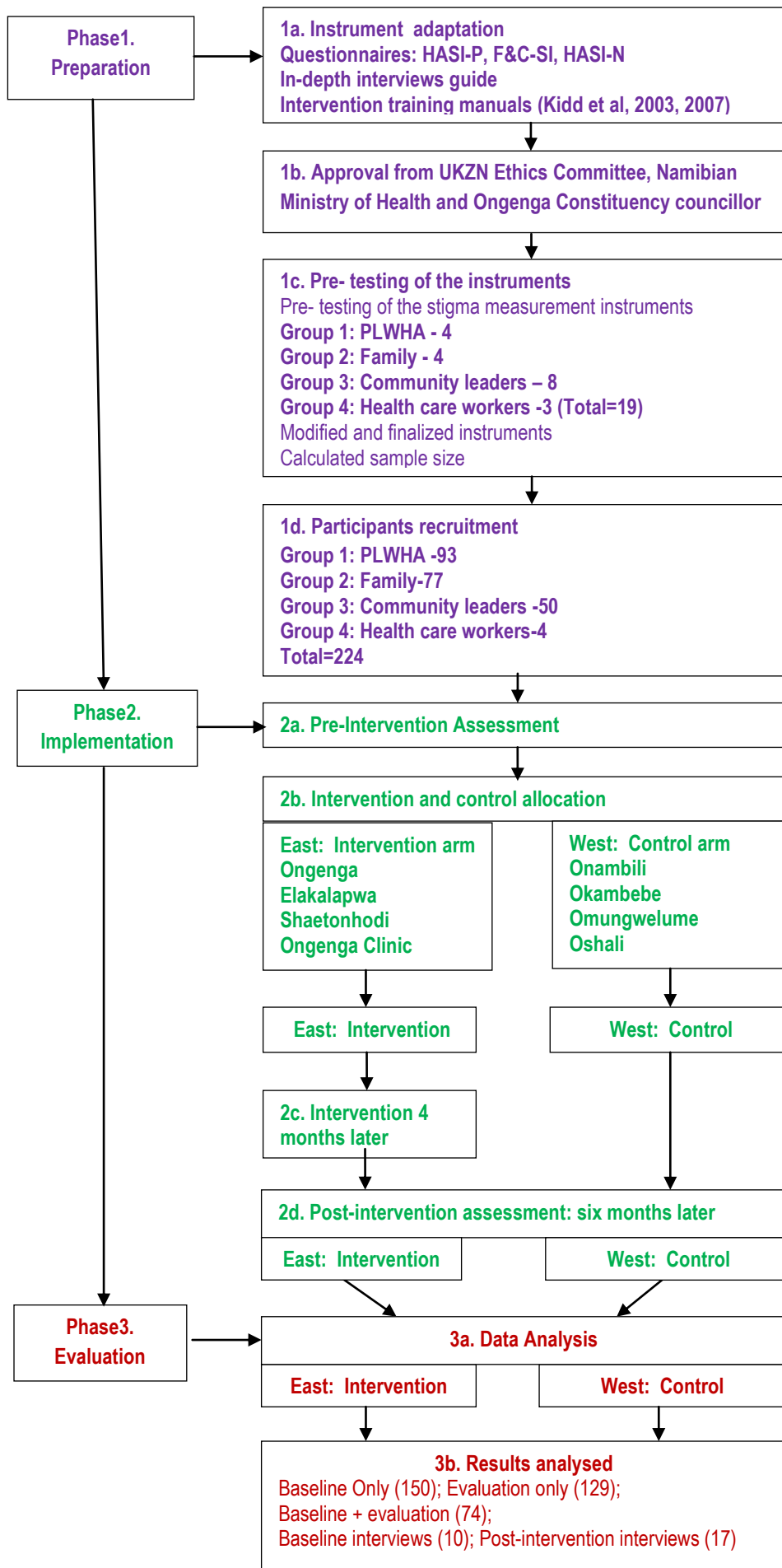


Figure 3.2 Flow diagram: for HIV/AIDS stigma reduction intervention

3.5 PHASE 1: PREPARATION

The preparation phase consisted of a number of activities that were necessary before the study could begin such as development of study instruments, obtaining approval from the relevant authorities, piloting the stigma measurement instruments and meetings with community leaders.

3.5.1 Study instruments

The study consisted of three components: three different survey questionnaires for the four groups in both arms, the same in-depth interviews for groups 1, 3 and 4 (PLWHA, community leaders and health care workers) in both arms, and two training workshop manuals for groups 1 & 3 (PLWHA and community leaders) in the intervention arm. The three questionnaires were administered at baseline and at the end of the study in both arms to allow for a comparison of the data both within and between the groups. The in-depth interviews were conducted at the start of the study in both arms and at the end only in intervention group to evaluate the effectiveness, while the intervention workshops took place after the baseline survey.

All three measurement instruments were translated into Oshiwambo, a local Namibian language that is mostly spoken in Ongenga Constituency, by the researchers. To ensure their correct translation, two language teachers (language specialists) were hired to translate the measurement instruments back to English to ensure their equalization. The measurement instruments and their sources are summarized and presented in Table 3.1 below.

Table 3.1 Study instruments and their sources

Group	Instrument	Source of instrument
Group 1: PLWHA	HASI-P In-depth interview Intervention tool	Holzemer et al. (2007) The researcher Kidd and Clay (2003) and Kidd et al. (2007)
Group 2: Family members	F&C-SI	The researcher
Group3: Community leaders	F&C-SI; In-depth interview Intervention tool	The researcher The researcher Kidd and Clay (2003) and Kidd et al. (2007)
Group 4: Health care workers	HASI-N In-depth interview	Uys et al. (2009) The researcher

3.5.2 Description of instruments

3.5.2.1 HASI-P Questionnaire

A self-report HIV/AIDS stigma measurement instrument that has been used to measure stigma from five African countries was adapted to form instrument for **Group 1** of this study, namely PLWHA, to establish the level of stigma they experienced. This was the *HIV/AIDS Stigma Instrument-People Living With HIV/AIDS (PLWHA) (HASI-P)* developed by Holzemer et al. (2007) which was developed with PLWHA in three phases from 2003-2006.

The HASI-P is a 33-item instrument that measures six factors of HIV related stigma. These include verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion and workplace stigma. According to the authors HASI-P instrument was validated with a sample of 1,477 PLWHA from Lesotho, Malawi, South Africa, Swaziland, and Tanzania. The instrument's scale's alpha reliabilities and the concurrent validity were confirmed by authors through correlating stigma scores with Symptom

frequency, Quality of life, Life satisfaction and Overall Functioning. Its Cronbach alpha is >0.70 which show that it is reliable.

However, the researcher omitted the health care neglect factor and its items intentionally, as this study was conducted in the community rather than in the health setting. Therefore, the modified instrument for this study consisted of 25 items instead of 33 (Appendix 5). The four-level Likert scale was applied as in the original instrument. The adapted factors and items in the modified instrument were as follows:

1. **Fear of Contagion:** this refers to any fear of close or direct contact with PLWHA such as touching, using, or sharing any object with a person who is HIV positive. (E.g. Not wanting to eat together with someone or share utensils because of his/her HIV status). This factor has six items.
2. **Verbal Abuse:** this refers to any verbal behavior that intended to harm the PLWHA (e.g. telling someone that s/he her/his HIV status is a punishment by God, or says: “you have looked for it”). This factor has seven items.
3. **Social Isolation:** this refers to deliberately limiting social contact and/or breaking relationships with PLWHA (e.g. stop being a friend of someone due to his/her HIV status). This factor has five items.
4. **Workplace Stigma:** this refers to any form of discrimination regarding employment/work opportunities based on HIV positive status (e.g. Denied someone promotion or fired from the job as a result of having HIV). This factor has two items.
5. **Negative Self-Perception:** this refers to internalized stigma. Negative evaluation of self based on HIV positive status (e.g. Feeling worthless because of HIV status; feeling guilty for having HIV/AIDS). This factor has five items.

The same questionnaire was completed by PLWHA at baseline and at evaluation assessment to enable a comparison of the responses of both groups. In-depth interviews were conducted with 13 (PLWHA) participants at the end of the study to assess the intervention impact.

3.5.2.2 F&C-SI Questionnaire

The family support members and the community leaders were requested to complete Family and Community Stigma Instrument (F&C-SI) questionnaire. The researcher had extensively modified a measurement instrument from a section of HIV/AIDS-related stigma instrument developed by Johns Hopkins University Centre for Communication Programs in collaboration with University of Namibia (UNAM) in 2002, which was developed for a Namibian survey. The researcher complemented this questionnaire with questions based on AIDS stigma literature. The researcher named the extensively modified measurement instrument: *Family and Community Stigma Instrument (F&C-SI)* (Appendix 5). F&C-SI is a 34-item instrument with three sections. Section 1 was for demographical data, Section 2 has five factors with 24 items and Section 3 has three factors with ten items. The developed factors and their items are as follow:

1. **Community attitude towards PLWHA:** this refers to community members' behavior towards PLWHA in the community (e.g. Treating PLWHA with sympathy or isolating them). This factor has four items.
2. **Family attitude towards PLWHA:** this refers to family members' behavior towards PLWHA in the family (e.g. Treating PLWHA with more sympathy than the other family members who are not PLWHA or mistreating them). This factor has four items.

3. **Personal attitude towards PLWHA:** this refers to the people/community's general understanding regarding an individual HIV status (e.g. a person should disclose her/his HIV status to others or should keep it a secret). This factor has five items.
4. **Household stigma towards PLWHA:** this refers to how households interact and treat PLWHA (e.g. including or excluding PLWHA in family matters discussions). This factor has eight items.
5. **Community opinion on PLWHA:** this refers to how community members interact and treat PLWHA (e.g. disallowing a person from community gathering because of HIV status). This factor has four items.

Section 3 of this instrument has three factors with ten items. They were divided as follows:

1. **Close Relationship with PLWHA:** (e.g. having a friend, relative or family member who is HIV positive). This factor has two items.
2. **Caring for Sick PLWHA:** refers to willingness to care for a sick PLWHA in home setting (e.g. caring for a family member who is HIV positive and has either malaria, TB, diarrhoea or was involved in an accident). This factor has five items.
3. **Fear of Contagion:** (e.g. fear of sharing toilet, shaking hands or eating food prepared by PLWHA). This factor has three items.

F&C-SI used both continuous and categorical scales of Likert scale and has a Cronbach alpha of 0.724. The 24 items in Section 2 were measured with continuous scale (strongly disagree to strongly agree) while Section 3 items were measured with categorical scale (yes or no). This instrument was used to measure community-based HIV/AIDS stigma among the families as well as among the community members and opinion leaders. It was

peer reviewed before pilot testing it with community members from a different constituency that is not part of the main study.

3.5.2.3 HASI-N Questionnaire

The health care workers' questionnaire was the *HIV/AIDS Stigma Instrument-Nurse* (HASI-N) developed by Uys et al. (2009) and used without modification (Appendix 5). HASI-N is a 19-item instrument that comprised of two factors one is for nurses stigmatizing patients and the other for nurses being stigmatized as a result of their professional activities. The questionnaire was designed to explore the experiences of nurses and PLWHA on stigma, and both emic and etic views were captured. A 4 level Likert-scale to measure received (external) and associated stigma was developed (never, once or twice, several times, most of the time), and it has a Cronbach alpha of 0.90. The items on HASI-N were pilot tested during phase two among nurses in Lesotho, Malawi, South Africa, Swaziland, and Tanzania.

The adapted HASI-N has the following factors and items:

1. **Nurses Stigmatizing Patients** (e.g. A nurse kept her/his distance when talking to an HIV/AIDS patient; health worker do not want to touch PLWHA patient). This factor has ten items.
2. **Community Stigmatizing Nurses** (e.g. People said nurses who provide HIV/AIDS care are HIV positive). This factor has nine items.

The HASI-P and HASI-N were tested in health care settings and validated by their developers in five African countries. As they are not copyrighted, they can be used freely.

3.5.2.4 In-depth Interviews guide

The community members and opinion leaders participated in individual in-depth interviews to address specific areas. The interviews were conducted by the researcher, the intention being to obtain information on stigma in the family and community to explore the issue of stigma in detail rather than a questionnaire and to be able to probe for additional information based on what came to the fore during the in-depth interview. The interview consisted of the following four main questions:

1. What are your views and opinions on the HIV/AIDS stigma in your community?
2. What do you regard as your role in reducing HIV/AIDS stigma in your community?
3. In your view what can be done to reduce HIV/AIDS stigma?
4. Is there anything else you want to tell me?

3.5.3 The intervention

3.5.3.1 Stigma Reduction training manuals

The researcher developed two stigma reduction training manuals, one for the PLWHA support group leaders (Group 1) and the other for opinion/community leaders (Group 3). As outlined in Chapter 2, the Diffusion of Innovations theory enables information to be disseminated, and in this study, the intention was to determine whether it is possible to change people's attitudes and behaviours to PLWHA through community intervention efforts. Support group leaders and opinion leaders are regarded as influential people therefore training them would accelerate the diffusion of change from small community to the entire area. The training manuals were therefore developed to instruct people who would then conduct workshops to train others on stigma reduction (Appendix 7).

These training manuals were adapted from “Understanding and Challenging HIV/AIDS Stigma” Toolkit for Action, that was developed by Kidd & Clay (2003) from researches in Ethiopia, Tanzania and Zambia where they were tested and found to be useful in stigma reduction. In addition, the researcher adapted some information from a trainer’s guider developed by Nawa Life Trust Namibia, for stigma reduction. The training manuals provided the information needed to conduct community training and used different teaching methods and a participatory learning approach.

Group 1 (PLWHA): A training manual was developed for the PLWHA support group leaders who ran workshops with their group members, the intention being to determine the levels of stigma and discrimination they experienced and provide them with the skills to train their community members in stigma reduction strategies. It is attributed that PLWHA trainees would influence diffusion through their networking with other support group members, who could adopt change easily due to their individual benefits from stigma reduction. A participatory learning approach was used in group discussions and is detailed further in Chapter 4.

Group 3 (Community leaders): The intention of the manual for community leaders was to provide them with the tools to train and mobilize communities in stigma reduction. The use of opinion leaders is well documented in the literature as the heart of applying diffusion of innovations concepts (Dearing, 2009) and was therefore appropriate to include them in training for stigma reduction. A participatory approach was used with group discussions and covered the following topics:

1. Naming the problem: stigma, causes and effects
2. Our own experiences as stigmatizing others

3. More understanding and less fear
4. Caring for PLWHA in the family
5. Community support for PLWHA
6. PLWHA have rights too
7. Moving to action.

These training manuals were partially tested with participants during the pilot study. However, further editing on the training manuals continued throughout the intervention process and the final versions are provided in Appendix 7.

3.5.4 Validity and reliability of study instruments

Validity refers to whether the instrument measured what it is supposed to measure and contributes to the scientific integrity of a research project; while reliability refers to the capacity of measurement instruments to produce consistently valid measurements (Nicoll and Beyea, 1997). Firstly, to ensure validity and reliability, the researcher used measurement instruments that were developed and tested in five African countries. The newly extensively modified instrument (F&C-SI) was pre-tested for content validity together with the other study tools. The new instrument is reliable as its Cronbach alpha is 0.724 that is considered acceptable, although values above 0.8 are preferable. The translated Oshiwambo version instruments were peer reviewed as well as pilot tested before their use in the main study.

3.5.5 Trustworthiness

Trustworthiness is a method of establishing rigour in a qualitative research without sacrificing relevance (Lincoln and Guba, 1985). This study used mixed methods, therefore I adhered to the principles of trustworthiness throughout the process to maximise the

validity and reliability of the study's qualitative findings. The following principles were applied: credibility, transferability, dependability and confirmability.

Credibility was ensured by different activities such as member checking, prolonged engagement and peer debriefing. Member checking was done by verifying the information, interpretation and conclusion with study participants who were interviewed. Prolonged engagement was ensured as I spent a reasonable time in the study setting and engaged with participants to establish rapport and win their trust. Peer debriefing provided me with an opportunity to eliminate bias that might have clouded good judgement. I consulted with impartial colleagues to critically review the implementation of my research methods and provided feedback accordingly. I had also presented proposal prior to this study to several seminars at the School of Nursing (Howard College) for critically review from academics.

Transferability is the strategy, which is used to ensure applicability. In this study I provided the background information about the participants, the context and the study setting to allow others to assess how transferable the findings could be. That would help the readers to make theoretical conclusions, which could be useful to replicate it in different settings. I provided the study overview and explained the process and this maximises the dependability if other researchers would like to repeat the same study with the same participants.

Confirmability refers to the objectivity of the researcher with respect to the phenomenon under study. This was applied by using tape recorder during the interviews, coding the

data, and categorized data into themes and subthemes. That helped to confirm the general findings and led to study implications.

3.6 PRE-TESTING STUDY

A pre-testing study was conducted to evaluate the suitability of the stigma assessment instruments as well as the training manuals that were to be used at the intervention workshops on a small sample of residents who live outside the study area. It was conducted in the rural community of Engela Constituency of Ohangwena Region in February 2010, the results from which were not included in the main study. The purpose of the pre-testing study was the following:

1. Test the survey instruments
2. Test the intervention training manuals
3. Determine the study sample size

Participants for the pre-testing study were purposively selected with the assistance of support group leader from ARV clinic. They were selected as follows: four PLWHA, four family members, eight community leaders and three health care workers resulting in a total of 19 participants. The pre-testing study overview is presented in Figure 3.3.

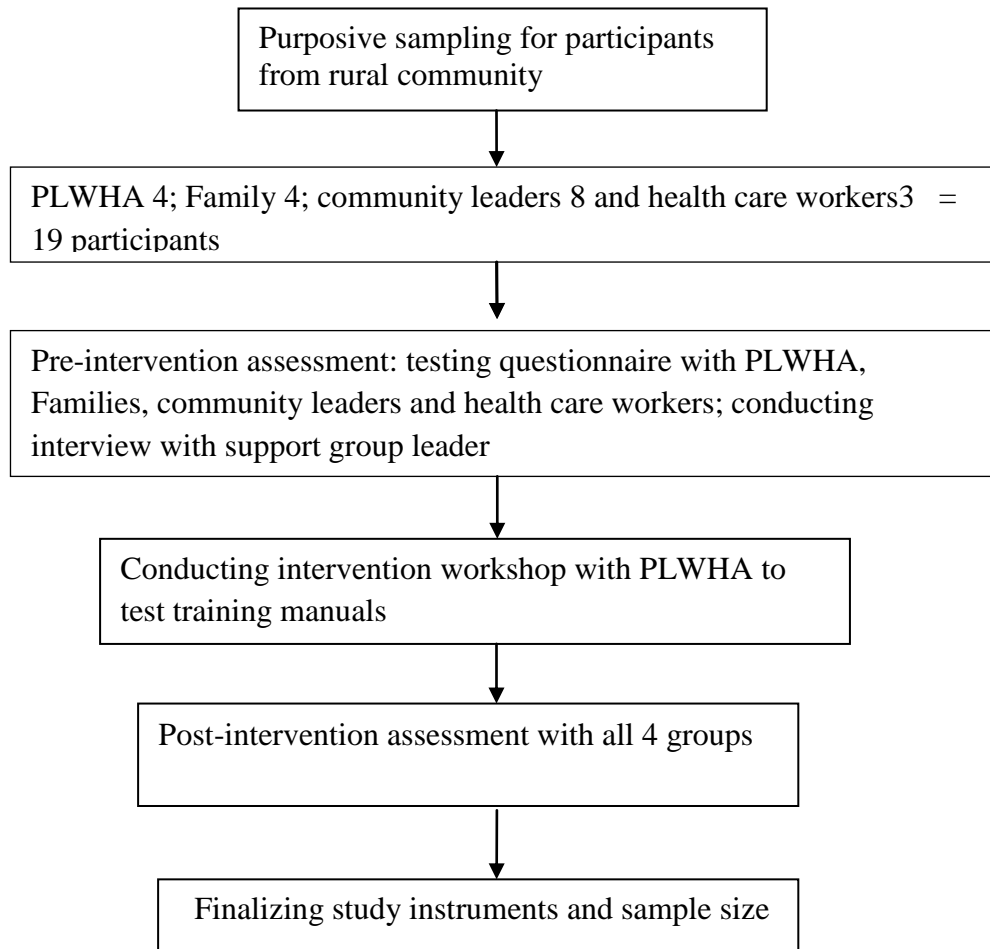


Figure 3.3 Flow diagram: pre-testing study

3.6.1 Survey instruments

The HASI-P and HASI-N instruments were pilot tested with the newly modified F&C-SI to establish their construct and content validity and to improve the questions, format and scales. As Holzemer and Uys had conducted focus groups and individual in-depth interviews when they developed the HASI-P and HASI-N instruments, they were not retested for this study. As a result, in-depth interview was only conducted with one support group leader during pilot testing.

3.6.2 The training manuals

The HIV/AIDS stigma reduction instruments and training manuals were tested for content validity, clarity and understandability with the same participants as those tested the

questionnaires. While five PLWHA participated in an intervention workshop for three days however, one of the participants was not part of those who participated in pre-intervention assessment and her data were not counted in the pilot. Finalizations of study instruments were done accordingly after completion of pilot study.

3.6.3 The sample size

The researcher had several consultations with a statistician during the preparation stage of this research proposal and due to lack of baseline information on measuring level of HIV/AIDS stigma in Namibia it was suggested to determine sample size with pilot study results. A further consultation with a statistician was made to assist with sample size calculations on completion of the pilot study.

The Number Cruncher Statistical System (NCSS) statistical software was used to calculate the sample size using the assumption that the difference in stigma was -0.5282 with a standard deviation (SD) of 0.4382. A sample size of eight (8) PLWHA participants was calculated to achieve 83% power to detect a difference of 0.5 between the null hypothesis mean of 0.0 and the alternative hypothesis mean of -0.5 with an estimated standard deviation of 0.4 and a significance level of 0.05000 using a two-sided one-sample test. However, as this was considered too small to conduct a two-armed intervention study, it was decided to include all Opawa PLWHA support group members. Several community meetings were held before the researcher started with recruitment of study participants.

3.7. COMMUNITY MEETINGS AND RECRUITMENT

After receiving ethical approval from University of KwaZulu-Natal's Humanities & Social Sciences Ethics Committee and from the Namibian Ministry of Health and Social Services, as well as permission from Ongenga Constituency Councilor, participants' recruitment began in February 2010. The researcher met with various community leaders and organizations to inform them of the project and obtain their support in recruiting suitable study participants. It was agreed to use the radio to announce community meetings at which the researcher would introduce the study and its purpose, aims and objectives. Through this medium, the community was informed about the dates, time and venues and who would be eligible to participate.

Although the constituency has 70 villages those which are far from PLWHA support group centres (branches) were excluded, only the ones which are near formed part of community meetings. As it was not possible to hold meetings at each of seven villages where support group centres are located, six meetings took place with events being combined due to their proximity as indicated below.

In an effort to inform the community about the study, the researcher had meetings with a number of organizations and individuals before recruitment started. On arrival in the area, she met with following people and organisations to secure their support and to share information:

1. The Constituency Councillor on the 17th February 2010 to inform him that the study was about to start as per their telephone discussions and agreement.
2. The Opawa PLWHA support group coordinator on the 18th February 2010 who informed their village branch group leaders

3. A local parish congregation on the 21st February 2010 to inform them of the study and to request that they participate if invited.

Following these introductory meetings, a number of community meetings took place, the intention being to inform and recruit participants. These were spread throughout the study area in an effort to ensure that there would be sufficient participants to divide the area into control and intervention arms. Face to face interpersonal communication is recommended in diffusion of innovations as an effective way to convey the message as it gave the researcher a chance to explain the reasons for change. That was why a number of meetings took place within the seven identified villages to target the four groups of study participants. The meetings were arranged by the appropriate persons after they were informed of the purpose of the study in general, and the meetings in particular.

3.7.1 Omungwelume and Okambebe combined meeting: 20 February 2010

A combined meeting of Omungwelume and Okambebe was scheduled to take place on 20 February 2010 to address and recruit study participants into the control and intervention arms. Shortly before the meeting, the researcher visited an income generating project of the PLWHA Support Group for that area to meet their members and introduce them to the research. Thereafter, the researcher and support group coordinator went to the meeting where permission was granted by the headman for the researcher to address the community members about the study. The researcher informed community members about the study and its purpose as well as the reasons for choosing their area for her research project. Eligible community members were selected randomly with help of the village headman and were recruited for the study. Only a few of PLWHA support group

members showed an interest due to their perceived concerns about confidentiality and privacy and they were recruited for the study. As a result of the poor response self-reporting questionnaires were left with the support group coordinator for the PLWHA and their families, which were collected one week later.

Despite local teachers being present at the community meeting it was difficult to recruit them as study participants. For example, three took questionnaires but did not return them. The same applied to two church leaders who declined to participate in this study, despite a thorough explanation of its purpose.

3.7.2 Oshali Village meetings: 23 February 2010

Two meetings were held in this village to inform the community about the study, the first being a community meeting, which was well attended and people asked questions freely. The second was with members of the local PLWHA support group who were seen separately at their coordinator's house. The village support group coordinator facilitated recruitment for five co-members and questionnaires were handed over and collected after three days. Three teachers from this village had agreed to participate and were interviewed as opinion leaders. The inclusion for these teachers would help to influence their learners to become the early majority adopters on stigma reduction.

3.7.3 Shaetonhodi and Elakalapwa Villages meetings: 24 February 2010

Two meetings were held in two villages to inform the community about the study. However, it was mainly attended by PLWHA support group members who were very open and spoke with the researcher about their HIV positive status freely, making it easier to recruit them. As with the other groups, self-report questionnaires were left with two

support group coordinators who facilitated their completion and returned them to the researcher after one week.

3.7.4 Onambili meeting: 25 February 2010

A meeting was organised with the constituency councillor and support group coordinator to recruit PLWHA and address community members about the study but was poorly attended due to rain and only two persons arrived. As a result, the Opawa Support Group coordinator was approached to recruit members from the centre. However, only two persons were recruited from that village.

3.7.5 Ongenga Village meetings: 4 March 2010

The last meetings were held on the 4th of March at the local parish, the local clinic and PLWHA support group centre. The researcher visited Ongenga clinic (provides ARV) and spoke to health care workers and PLWHA support group members. Four health care workers were recruited and given self-report questionnaires, which were collected the next day. The support group members were recruited by their coordinator and their self-report questionnaires were collected after a week.

The visit to that village was extended to local parish, which is nearby to inform church leaders about the research and they were very helpful during the course of this study. Three congregation board members from local parish were recruited and participated in intervention workshop as well as one teacher from a local school. They were among the opinion leaders (early adopters) who played active role to influence and mobilize community members on changing negative attitude towards PLWHA and stop stigmatizing them.

3.8 STUDY POPULATION

This study was conducted in a rural community of mainly subsistence farmers, while some people operate their own businesses. Many Ohangwena Region inhabitants are unemployed (67% women, 78% men), as a result they depend on crop production and livestock for food security. Persons who are 60 years old and above receive a monthly social grant of N\$500 (R500) from the government, on which many households depend for livelihood. The regional office of the Ministry of Regional & Local Government, Housing & Rural Development (MRLGH) occasionally provides food to needy people but it is not enough to feed them for the month as the amount is calculated on the urban mean size (4 persons) instead of the rural mean (4.9 persons) (MOHSS, 2008a). Only a few people in this area have higher schooling, and research shows that there is a link between level of education and understanding of HIV transmission, which has implications for the level of stigma and discrimination (MOHSS, 2008a).

More than 70% of the people in this area have access to radio, which plays an important role in giving information on numerous issues including HIV/AIDS and was therefore used to announce community meetings for this study. Other important information was shared during the community meetings, at any gatherings and at schools where the learners are requested to inform their parents and guardians. Exposure to the print media, which is either in English or Afrikaans and not the local language, is less than 10% in this region (MOHSS, 2008a), and social mobilization was therefore an important strategy to inform people about the study. Community and opinion leaders who are influential people in the community also played active and important role in sharing information, the intention being for as respected members of the community to be able to influence

people's opinions and attitudes to PLWHA. That would help to accelerate diffusion of innovation regarding stigma reduction in the constituency.

The people in this area suffer from illnesses such as seasonal Malaria, TB and HIV/AIDS related diseases. Health services are provided by three clinics in the constituency, all of which are within 10 km from each village and accessible by walking to some inhabitants. Among those three, only one clinic has a community counsellor, offers ARVs services to PLWHA on a monthly basis, as well as voluntary counselling and testing for HIV (VCT) occasionally. The health care workers from this clinic were included in this study due to its HIV services. The few mobile clinics provide family planning and immunizations services as well as treatment for chronic diseases such as hypertension, but not ARVs. Despite the availability of these services, some people prefer to seek treatment from traditional healers, particularly those who believe that they are bewitched, a common assumption in HIV/AIDS related illnesses.

Four specific groups (PLWHA, family members, community leaders and health care workers) had been identified to participate in the study, some of which would participate in an intervention, and the others to establish whether it is possible to effectively disseminate information about reducing stigma through information diffusion. The intention was to equip the intervention arm with new information about why discriminating and stigmatizing people is harmful and inappropriate, to learn how to fairly treat PLWHA, change their perceptions and behaviour, and in turn influence others through a process of information diffusion. It was decided to include the following four groups in the study due to their experience of stigma, or their ability to change it. The study population in each group is detailed below.

a. Group 1: PLWHA. Opawa Support Group members were selected due to their HIV status being known by their coordinators, participation was voluntary. People living with HIV/AIDS were included in this study as diffusion could easily occur due to their individual benefits from stigma reduction intervention. As they are local support group members the researcher believed that they would be able to influence others who are HIV positive on how to protect themselves from stigma and how to cope with it. This group was regarded as change agents who influence communication channels and the innovation through contacts approach.

b. Group 2: PLWHA family members. The families of the support group members, being their caregivers and treatment supporters, who would play an important role in stigma reduction in households with HIV positive persons, participation was voluntary.

c. Group 3: Community leaders. Community members and opinion leaders were included as influential people in the community who can help to influence changes in attitudes and behaviours. They are the early adopters who would influence the early majority to change due to their social pressure. Their opinions and views were needed to contribute to suggesting plans and strategies at constituency level to therefore reduce stigma and discrimination. A simple random sampling approach was used for community members and participation was voluntary.

d. Group 4: Health Care workers. Health care workers from Ongenga clinic where HIV counselling and testing (HCT) and ARVs services are provided are responsible for caring for PLWHA, and may also experience stigma of association as health care

providers. They were regarded as the potential adopters within a client system and were therefore important to include them in this study.

3.8.1 Participants recruitment

Once the four groups had been identified and the necessary permission granted and meetings held, it became necessary to recruit participants into the study. The recruitment details of each group are as follow:

a. Group 1: PLWHA

Group 1 were People living with HIV/AIDS (PLWHA) who are members of Opawa Support Group in Ongenga Constituency the only support group in that community consists of seven centres (branches) and a total of 227 members at the time of this study. The number of members at each centre ranges from 19-49 with a mean membership of 32.4. Some members were orphaned school children younger than 18 years of age, who could not be recruited.

There are seven Opawa centres, one in each village included in the study. Support group members meet at those centres twice a month to share information and give each other moral support. They have income generating projects where they work in order to earn money, but they are at the infant stages. Opawa Support Group leaders/coordinators recruited 93 local support group members who were eligible to participate. The support group coordinators visited PLWHA in their respective homes for recruitment to ensure confidentiality, and some were recruited during their biweekly meetings. The researcher left self-report questionnaires with support group leaders who in turn gave them to recruited PLWHA for completion.

b. Group 2: Family members

PLWHA recruited their family member or friend of their choice to whom they had disclosed their HIV status to be a participant in the study. A total of **77 participants were recruited and** 16 PLWHA did not nominate family members or close relatives (93 PLWHA). It was not possible to identify them as there was no link on the questionnaires to the PLWHA. Random sampling was not done for family members.

c. Group 3: Community leaders

This group consisted of community members and opinion leaders who did not necessarily have PLWHA in their families/households. The reason for their inclusion was to get a broad overview and input from the general community. They were recruited after community meetings with the assistance of their representatives such as village headmen. Those who were willing and eligible were recruited after they were selected through a **simple random sampling process**. Their names were put in a box and half of the names were selected after each meeting. All the interested opinion-leaders such as teachers, church leaders, peer educators and village headmen were included in the study. **Fifty participants** were recruited for this group.

d. Group 4: Health care workers

These are health care workers from a local clinic, where PLWHA receive their ARV on a monthly basis, were recruited as group four participants. There were only **four health care workers** consisting of a registered nurse, enrolled nurse, nursing auxiliary and a community counsellor at the clinic at the time of the study, therefore all of them were recruited and participated in this study. The other two clinics in the constituency do not provide ARV to PLWHA that was why they were excluded from this study.

3.8.2 Inclusion and Exclusion Criteria

The researcher explained to the community representatives who were involved in the selection process the pre-screening purpose and process, which was also explained to people who came forward during the study recruitment. The inclusion and exclusion criteria were explained to the participants to ensure that they did not feel excluded unfairly and understood that this was a research project. The Opawa Support Group leaders were trained on how to screen and select eligible participants to ensure inclusion and exclusion criteria were adhered to during the selection process. The inclusion and exclusion criteria for PLWHA in Table 3.2, for Family members in Table 3.3, for Community leaders in Table 3.4, and Health Care workers in Table 3.5.

Table 3.2 Group 1: PLWHA inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
<ul style="list-style-type: none"> • 18 years old or older 	<ul style="list-style-type: none"> • Younger than 18 years of age
<ul style="list-style-type: none"> • HIV positive; either on ART or member of a support group 	<ul style="list-style-type: none"> • Not prepared to select a family member
<ul style="list-style-type: none"> • Prepared to select 1 family member 	<ul style="list-style-type: none"> • Unwilling to adhere to study schedule
<ul style="list-style-type: none"> • Willing to adhere to study schedule 	<ul style="list-style-type: none"> • Lived outside the study community
<ul style="list-style-type: none"> • Lived in the community where the study is taking place 	<ul style="list-style-type: none"> • Has an obvious psychological/psychiatric disorder that would invalidate informed consent process
<ul style="list-style-type: none"> • Was able to understand and sign the informed consent process 	

Table 3.3 Group 2: Family members' inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • 18 years old or older 	<ul style="list-style-type: none"> • Younger than 18 years old
<ul style="list-style-type: none"> • Selected by PLWHA participant 	<ul style="list-style-type: none"> • Unwilling to adhere to study schedule
<ul style="list-style-type: none"> • Willingness to adhere to study schedule 	<ul style="list-style-type: none"> • Living outside the study community
<ul style="list-style-type: none"> • Living in the study community 	

Table 3.4 Group 3: Community leaders' inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Must be 18 years or older 	<ul style="list-style-type: none"> • Younger than 18 years old
<ul style="list-style-type: none"> • Willing to adhere to study schedule 	<ul style="list-style-type: none"> • Unwilling to adhere to study schedule
<ul style="list-style-type: none"> • Living in the study community 	<ul style="list-style-type: none"> • Living outside study community

Table 3.5 Group 4: Health care workers

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • 18 years or older 	<ul style="list-style-type: none"> • Younger than 18 years old
<ul style="list-style-type: none"> • A staff member of a clinic that provides ARV 	

3.8.3 Allocation to control and intervention arms

The seven villages that were included in the study were selected as a result of Opawa support group centres (branches) being located in each one. They were divided into two geographical areas, west and east, the east to serve as the intervention arm and the west to be the control arm. This separation was done to minimize the likelihood of cross-contamination between the two trial arms, and reduced the threats of internal validity such as information diffusion to the control arm.

Table 3.6 Number of participants recruited at baseline into two arms of the study

Participants	Intervention arm number (east)	Control arm number (west)
Group 1: PLWHA	48	45
Group 2: Family	39	38
Group 3: Community leaders	26	24
Group 4: Health care workers	4	none

East: Intervention Arm

Three of those villages, namely Elakalapwa, Shaetonhodi and Ongenga were in the eastern intervention arm and within walking distance to Ongenga Clinic, where PLWHA collect their medication on monthly basis. Each village has a school but they share one church that is located at Ongenga village. The constituency office is also located at Ongenga, after which it is named.

West: Control Arm

The four villages namely, Omungwelume, Oshali, Okambebe and Onambili are far from each other but they are all situated at the west side of the constituency. Each has a school, Omungwelume and Okambebe have clinics, people from Onambili use the same clinic in Okambebe but those two clinics do not offer ARVs. Although Oshali is in the west, it is close to Ongenga where people go for health and church services.

Community and opinion leaders who were not Opawa Support Group members were assigned according to their community locations, either west or east, which were then randomized to either intervention or control arm. This was done by a draw between two pieces of paper which was written '*intervention arm*' or '*control arm*', and one was drawn. Another two pieces of paper written '*East*' or '*West*' were placed in another box, and one was drawn. An independent person, who was a non-study participant, was requested to make a draw. The two drawn papers were then used to randomise the community to either of the trial arms. The east community was selected randomly as the intervention trial arm while west community served as control trial arm.

3.9 PHASE 2: IMPLEMENTATION

Once the pre-testing study had been completed, the sample size was decided upon and adjustment to the questionnaires and intervention instruments made, participants were selected from the seven identified centres and nearby villages to participate in the study. The first data collection took place from February to March 2010 in both intervention and control arms and was followed by intervention in the Intervention group in July 2010. The second assessment was done six months later from December 2010 to January 2011 in both study arms.

The researcher used two data collection methods, self-administered survey questionnaires (all groups) and in-depth interviews with selected members from groups 1, 3 and 4 (PLWHA, community leaders and health care workers). This provided both quantitative and qualitative approaches data. The sample size consisted of 93 PLWHA (Group 1), 77 Family members (Group 2), 50 community members and opinion leaders (Group 3), and four health care workers (Group 4) made a total of 224 participants. There were 10 interviewees at baseline and 17 at end of this study. The sample size has decreased at the end of the study as a result new participants were recruited to replace the lost ones that led to 129 post-intervention only groups and the number is presented in Table 3.7.

Table 3.7 Groups of participants who participated in the baseline and evaluation Surveys

Participant numbers	Group 1	Group 2	Group 3	Group 4	Total
Baseline survey only	60	55	35	N/A	150
Evaluation survey only	61	61	7	N/A	129
Baseline & evaluation survey	33	33	4	4	74
Total participants	154	149	46	4	353

3.9.1 Baseline survey

The baseline survey was conducted with all study participants jointly before the community was separated into two study arms, intervention and control. In-depth interviews and a pre-intervention assessment (baseline survey) were conducted to measure the level and types of community-based HIV/AIDS stigma and discrimination among PLWHA, their families, community members and opinion leaders as well as from health care workers before community randomization.

Questionnaire survey: The survey enabled the researcher to obtain information about the extent and nature of HIV/AIDS stigma and discrimination. Despite all three instruments being self-administered, the researcher recruited five persons and support group leaders as researcher assistants to assist with completing questionnaires for participants who were either illiterate or who requested assistance. The researcher explained the questionnaires and how they should be completed to support group leaders as researcher assistants. After informed consent was obtained, the data was collected from the following groups.

a. Group 1: PLWHA

Members of the PLWHA support group were asked to complete a questionnaire (HASI-P) to measure community-based HIV/AIDS stigma level. The PLWHA support group leaders gave HASI-P questionnaires to the 93 support group members who consented to participate in the study following a presentation by the researcher. They also collected the completed forms to ensure privacy and confidentiality as some PLWHA did not feel comfortable disclosing their information to the researcher who was regarded as an outsider.

b. Group 2: Family members

Group two participants were recruited to participate in the study by their family members who attend the PLWHA support group meetings, and were only required to complete the questionnaire (F&C-SI). The F&C-SI questionnaires for the family members were given to the PLWHA with an explanation about its contents, the need for signed informed consent, and the value of the study. Support group leaders collected the completed forms from their group members and contacted the researcher who collected them.

c. Group 3: Community leaders

The researcher gave questionnaires (F&C-SI) to eligible community members and opinion leaders who were randomly selected to participate. After giving their consent, a thorough explanation of questionnaires was done before they complete them. The recruited researcher assistants were available to assist community members who had difficulties in completing the questionnaires, which was done to prevent bias from the researcher. Four village headmen and three congregation board members who participated in the intervention workshop were given questionnaires before they started with activities of the intervention workshop. Explanation was made and they were informed that their participation is voluntarily.

d. Group 4: Health care workers

The health care workers were contacted at the clinic where the researcher spoke to the Registered Nurse (R/N) in charge and explained the purpose of the study and the questionnaire. HASI-N questionnaires were given to the R/N who distributed it to her staff members and were collected by the researcher the next day.

3.9.2 In-depth interviews

The researcher used in-depth interviews to cover specific areas, with probing strategies were applied to obtain the maximum amount of data from participants. A voice-recorder was used to ensure data capture and it was transcribed verbatim after the interviews, and field notes were taken. The data from the interview scripts and field notes were compiled together and used as a source for qualitative data analysis. Qualitative data was complemented with information from the two intervention workshops discussions. Individual in-depth interviews were conducted with one PLWHA member, seven community leaders and two health care workers.

a. Group 1: PLWHA

One support group coordinator, who was also HIV positive, was selected for in-depth interview to give a general overview on how they were being treated by their family and community.

b. Group 3 &4: Community leaders and health care workers

In-depth interviews were conducted with nine participants who consisted of a constituency councillor, a pastor, three teachers, a registered nurse, two community counsellors, and a peer educator.

3.9.3 Implementation Workshops

The two intervention workshops for PLWHA and community leaders were planned for May 2010 but due to excessive rain and flooding this could not take place as the researcher was not able to reach the study area. As a result, the program was delayed until

July 2010 when the flood water had subsided. The two workshops are detailed further in Chapter 4.

3.9.4 Community involvement

Inhabitants of Ongenga Constituency were actively involved in this research project as their community representatives were consulted prior to this study. Selected community leaders consisted of village headmen, representatives from local parish and one local teacher participated in the intervention training workshop. The researcher had informal and formal discussions with community members regarding stigma reduction in their constituency. Community leaders who were interviewed gave their opinions and made suggestions, which are included in this study recommendations.

3.9.5 Contacts with infected and affected groups

The researcher visited PLWHA income generating project in the constituency to encourage them that they can still be productive citizens regardless of their HIV status. During the intervention workshops, PLWHA who were not participants were asked to help with food preparation. That was done to demonstrate that there is no risk of getting the virus by eating food prepared by a person who is living with HIV. The researcher visited the ARV clinic and chatted with PLWHA in order to make community members aware that it is not a shame to be seen talking with someone who is HIV positive. That was also done to normalise the situation of interaction with people living with HIV.

3.10 PHASE 3: EVALUATION

The stigma assessment questionnaires were administered twice to both arms during the study, the first being at baseline (February 2010 and March 2010) and the second being six months post-intervention (December 2010 and January 2011). This was done to establish if the intervention had reduced the levels of stigma in the intervention arm, and to determine if there were any resulting noticeable differences in stigma levels between the two arms. The researcher conducted a supportive evaluation with the workshop trainees after three months (November 2010) after the intervention. This provided an opportunity for the researcher to discuss the process with those who attended the intervention workshops.

a. Group 1: PLWHA

The stigma assessment was done in both arms to assess any changes post-intervention using HASI-P questionnaire. Twelve participants from intervention arm, who have participated in the training workshops, were interviewed to evaluate their progress and effectiveness of the intervention. One participant who was not part of the training was also interviewed to assess any change in stigma.

b. Group 2: Family members

Family members of people living with HIV from both arms were given questionnaire (F&C-SI) to evaluate stigma for the second time. No family member was included in post-intervention interviews as they were excluded in the first interviews. Although the researcher acknowledged that it could be useful to get their views about changes brought by the intervention and as they are in close contact with PLWHA they could play an important role to diffuse the new information in family systems.

c. Group 3: Community leaders

This group of community members and opinion leaders was assessed with F&C-SI questionnaire post-intervention that was done with both arms. However the researcher conducted in-depth interviews with four opinion leaders from intervention arm only, the reason being to determine if there were any changes in stigma level in the community that received the intervention.

d. Group: Health care workers

The stigma assessment questionnaire (HASI-N) was administered twice with health care workers from one local clinic, but no interviews were conducted with them post-intervention. This group did not have control arm as it was mentioned already in population section.

3.11 DATA ANALYSIS

The data was analysed separately for each group for the pre- and post-intervention assessment stages and the in-depth interview. Once this had been done, comparisons were made within and between the different arms and groups. Comparisons of results between and within arms and groups were assessed using Independent Samples t-test and Paired Samples t-test. Quantitative data was analyzed using the PASW Statistics 18, which stands for Predictive Analytics Software, the latest version at the time of this study. Data was first entered into Microsoft Excel before transferred to PASW Statistic 18. Data was screened for missing and out of range values and for distributional properties. A statistician was consulted to assist and guide the researcher on data analysis. This was done to ensure credibility and validity of study results. Descriptive Statistics were used to

describe the study sample in relation to both dependent and independent variables. The results of the questionnaires were analysed first, followed by the in-depth interviews.

The qualitative results were analyzed using coding system. Data was categorized into certain themes according to the interview questions as well as in link with the aims and objectives of the study so that they could be evaluated. The researcher opted to do content analysis technique. This started during the data collection process that served as the template to guide the analysis. The keys in data helped the researcher to understand and interpret the raw data. Furthermore, the researcher looked for similarities and differences in the data. Subsequently, data was explored to identify common themes and establish units of meaning. The researcher analyzed qualitative data manually as the participants in interviews were few (only ten at baseline and 17 at evaluation) and it was less complicated than using computer programs. The findings of post-intervention assessment were analyzed and compared with the pre-intervention assessment results. The results of pre and post-assessments as well as the intervention effectiveness and outcomes are presented in Chapter 5.

3.11.1 Questionnaires

The data of three questionnaires: HASI-P, F&C-SI and HASI-N were analysed according to the four study groups and two arms as it was presented in methodology chapter under study overview phase three.

1. Baseline data of both arms jointly
2. Pre- and post-intervention data comparisons
3. Post-intervention data only (separately)

a. Group 1: PLWHA (HASI-P)

Baseline survey data was analysed in both arms jointly to find out the level of external and internal stigma experienced by PLWHA. Thereafter data from people who participated both at pre- and post-intervention assessment was analysed and compared. Data for groups who participated in post-intervention assessment only was analysed separately for the two arms without any comparison.

b. Group 2 : Family members (F&C-SI)

The baseline data was analysed jointly first, followed by comparison between the two arms and lastly separately post-intervention only groups.

c. Group 3: Community leaders (F&C-SI)

The baseline data was analysed jointly first for both arms, followed by pre-and post-intervention comparison between the two arms and lastly analysis for post-intervention groups only, done separately. Due to the decreased number of participants at evaluation survey, pre-and post-intervention assessment of Group 2 and 3 (family and community leaders) were combined to facilitate data analysis smoothly.

d. Group 4: Health care workers (HASI-N)

The baseline and post-intervention data was analysed separately in the intervention arm only and was compared within the group self, no control.

3.11.2 In-depth Interviews

a. Group 1, 3 and 4 (PLWHA, community leaders and health care workers):

Qualitative data from in-depth interviews of all three groups was analysed jointly from

both arms followed by post-intervention results from the intervention arm only. Data from training workshops are analysed and included in Chapter 4, where intervention is described and presented.

3.12 DATA MANAGEMENT

The completed questionnaires were kept by the researcher in a locked cabinet to which only she had access during the study period. A computer with a special password only known by the researcher has been used to house the data once it had been electronically captured. The raw data will be kept with the School of Nursing at Howard College (UKZN) for the next five years, after which it will be discarded as per research and institution policy.

3.13 CONCLUSION

This chapter covers the methodological aspects of the entire study. The research design, which is a quasi-experimental non-equivalent control group pre- and post-test, was explained. The overview of the study was presented in a diagram where the three phases of study are well indicated. The three measurement instruments that were used at baseline and at evaluation survey after six months and the intervention tools that were used for intervention were described. The pilot testing and validity of study instruments were highlighted. The community meetings that were used to introduce this study to community members were discussed, followed by participants' recruitment. The study population, their characteristics such as employment, education and access to media as they can contribute to stigma reduction and sampling approach were explained. The different study

groups of participants were presented followed by data collection techniques, intervention process, data analysis by specific software and data management was explained.

CHAPTER 4

COMMUNITY-BASED HIV/AIDS STIGMA REDUCTION INTERVENTION

4.1 INTRODUCTION

The intention of this study was to measure the level of stigma in a rural community. The second objective was to develop a community-based HIV/AIDS stigma reduction intervention and the third one was to implement it in a rural community, after which the level of stigma and discrimination would again be evaluated to determine the effectiveness of the intervention. This chapter provides a description of how the intervention was developed and implemented using different strategies in the intervention arm for six months. These strategies consisted of contacts with infected and affected people, community involvement and training of two 3 day workshops, the first for Opawa PLWHA support group members (leaders) and the second for community and opinion leaders in the east of Ongenga Constituency. The intention of the workshops was to train members of both groups (PLWHA and community leaders) who would then train others and mobilize the community in stigma reduction. Training of these two groups, as influential people and opinion leaders in the community would help to accelerate change and reduce stigma in the families and community levels through the diffusion of innovation.

The training workshop activities were based on “Toolkit for Action” that was developed by Kid and Clay (2003). However, additional activities, which were regarded as suitable and appropriate for the participants were included and these are discussed in detail in this chapter. The process and outcomes of both workshops are also presented in this chapter.

4.2. WORKSHOP FOR OPAWA PLWHA SUPPORT GROUP MEMBERS

The workshop participants were nominated by the Opawa centres' chairpersons and were selected due to their training abilities or past experiences in giving information to others, as well as their experience in mobilizing the community on HIV/AIDS related issues. The expectation was that their experience would enable them to train others or disseminate information about stigma reduction. Those who were unable to travel to the venue on a daily basis were accommodated at the church facilities, which were near to the workshop venue. The workshop program for support group members is presented in Appendix 8.

The training's aims and objectives were explained, which included providing them with knowledge and skills on stigma reduction strategies which they could apply and train others on in their communities. The specific training objectives were to:

- Explore the causes of stigma and discrimination using participatory dialogue and pictures.
- Explore participants understanding of the meaning and impact of community-based HIV/AIDS stigma through personal experiences, participatory dialogue and debate.
- Discuss the impact of stigma on different groups (PLWHA, family, and community) using participatory discussion, group works and role plays.
- Explore and discuss PLWHA understanding of how they can protect themselves from stigma using participatory discussions, scenarios and role plays.
- Empower PLWHA on positive living strategies for a long and health life.
- Develop an action plan on how to reduce community-based HIV/AIDS stigma in their community.

The training objectives were met by addressing the following eight topics over three days:

Day 1:

- Naming the problem, stigma through pictures, own experiences as stigmatized
- Effects of stigma on different groups: PLWHA, families and community

Day 2:

- Types of stigma in the family
- How to reduce stigma in the family, the neighborhood and community
- How to protect ourselves and others against stigma

Day 3:

- Positive living with HIV/AIDS
- PLWHA can lead long and full lives, and
- Moving to action
- The role of PLWHAs as opinion leaders and change agents
- Diffusion of Innovation strategies for stigma reduction in the community

4.2.1 PLHWA Workshop: Day 1

Day 1: The workshop started at 08h00 in the morning at the Regional office's board room whereby the 18 participants were registered to enable the facilitator to follow them up for technical support purposes. The participants were all Christians and it is a norm in that community to open any gathering with a prayer. After an opening prayer, the facilitator (the researcher) gave a brief introduction and outlined the reasons for researching HIV/AIDS stigma. The participants were divided into pairs as an ice-breaker, after which they indicated that their expectations were to know how to reduce stigma.

The different teaching strategies used during the participatory workshop included group works, role plays, brainstorming, discussions, report back and presentations. Participants were encouraged to ask questions, give their views, opinions and comments, and were asked to respect what had been shared and to keep the information confidential. The following topics were covered on Day 1:

- a. Naming the problem, stigma through pictures, own experiences as stigmatized
- b. Effects of stigma on different groups: PLWHA, families and community

a. Naming the problem, stigma through pictures, own experiences as stigmatized

The concept of stigma was introduced and they were asked how they understand it and to identify a local word/term. The outcome for the discussion was that there is no single word in the local language, Oshiwambo, and that it could only be understood by defining it with a sentence. In spite of the absence of local word for stigma, it was clear that the participants understood what it was from their explanations and examples during the discussion.

Participants were then divided into three groups of six where they chose a chairperson and a presenter. They were given the following three topics to discuss:

1. Main causes of stigma
2. Main forms of stigma (types)
3. Effects of stigma

The discussions were then presented to the full group after which there was general discussion on the topic. Feedback from the group work identified several examples of the causes, forms and effects of stigma which are presented in Table 4.1. The facilitator added on the list what was not mentioned by the groups.

Table 4.1 Feedback on stigma causes, forms and effects

Causes of stigma	Forms of stigma	Effects of stigma
1. Unemployment 2. Poverty 3. Less understanding on how HIV is transmitted 5. Alcohol misuse (abuse) 6. Hunger	1. Mistreated by others 2. Staring at a person who is HIV positive 3. Inhumane treatment 4. Name calling 5. Discriminated by health care workers 6. Employment discrimination	1. Stress 2. Misbehaving 3. Separation and divorce 4. Deteriorating of health 5. Suicide and death

The participants were encouraged to give their views and opinions due to their personal experience of stigma. They initially shared their experience on stigma in pairs and those who felt comfortable to share with the whole group were encouraged to do so. With regard to forms of stigma one participant said: *“When people talking about us they use certain phrases such as ‘those who go to line’, referring to ARV clinic. We feel bad to be called like that.”* The effects of stigma were expressed in these statements: *“Stigma makes some people to misbehave, for example they do not use condoms although they know that they can infect others.”* *“There is a case of someone throws ARVs in the bushes next to the road from the clinic. We observed it but could not locate the person who does that. Maybe that person is afraid to be seen taking medication.”*

b. Effects of stigma on different groups: PLWHA, families and community

The participants were divided into three groups of six and were instructed to choose a chair person and a presenter. Each group was allocated one of the groups to discuss the

effects of stigma, namely PLWHA, families and the community, the results of which are presented in Table 4.2.

Table 4.2 Feedback on effects of stigma on different groups

Effects on PLWHA	Effects on family	Effects on community
1. Deteriorating of health	1. Discrimination by neighbors	1. Social isolation
2. Depression	2. Social isolation	2. Name calling of specific villages
3. Hopelessness	3. Family conflicts	3. Negative labeling
4. Stress	4. Separation and divorce	4. Hate
5. Suicide		

The feedback from group works was further discussed by the whole group and participants gave practical examples as they experienced it. One participant said: *“My neighbour’s children were told not to play with mine because I am HIV positive. That is unfair, my children are not sick and do not have the virus.”* Another one gave example that: *“Some villages are given names reflecting to people who are living with HIV in that specific area.”*

The first day closed with a summary of what had been addressed and an outline of what was to take place the following day.

4.2.2 PLWHA Workshop: Day 2

Day 2 started at 08h00 after all participants were provided with breakfast to enable them to take their antiretroviral medication. The day was started with a prayer after which one participant led a review of the previous day’s activities which helped them to remember what had taken place and enable them to proceed smoothly with the activities of the day.

The topics for day two were:

- a. Stigma in the family
- b. How to reduce stigma in the family, the neighbourhood and community
- c. How to protect ourselves and others against stigma.

a. Stigma in the family

During the discussion of stigma and its effects on the family, participants identified several examples of how they experience it in their households. Based on those examples, a scenario was simulated and four participants were asked to role play it using fictitious names.

The scenario: Haimbodi who is 54 years old and his wife Mukwalu 49 have two daughters Namtenya 26 and Naufiku 22. Namtenya, who is HIV positive, is her father's favourite, and he protects her from his wife's verbal abuse. The mother tries to discredit her simply because she is HIV positive. Naufiku, the youngest daughter is her mother's favourite and she spoils her. In spite of Namtenya being on ARVs, her mother sometimes prevents her from eating in the morning before taking her medication, particularly when her father is not at home. Her mother claims that Namtenya just wants to eat but when it comes to work she does not contribute much. On the other hand, she supports anything done by Naufiku without complaints. She calls Namtenya bad names and tells her that she deserves her HIV because she had looked for it. On several occasions, Haimbodi tried to talk to his wife and tell her not to discriminate against Namtenya and to stop calling her bad names due to her HIV status. As a result, his wife started to accuse him of also being HIV positive, this being the reasons for him protecting Namtenya. This caused a

conflict in Haimbodi's family (household) and led to the separation and divorce of Haimbodi and Mukwalu.

After the role play, the participants were asked about what they observed and how they felt when they watched the role play. They expressed their observations in these statements: *"The role play was funny but that is how we are treated by our own families."* *"If we can use these kind of role plays in the community they will realise that stigma hurts and might stop stigmatizing us."* Those who role played the scenario were also given a chance to say how they felt either by stigmatizing others or being stigmatized. The rest of the group brainstormed stigma and its effects in the family. Some participants came up with more personal experiences on how they experience stigma in their households. Some reported that mothers, who are regarded as the most caring parents, are the main ones stigmatizing the HIV positive family members. That is evident from these statements: *"My mother told children in our house not to accept food from me. She says that I will give them my disease."* The other one said: *"My mother calls me bad names whenever she is under the influence of alcohol."* It was agreed that alcohol abuse plays a role in causing stigma in the families. After a long discussion on stigma in the family and its effects the next session of the day was introduced.

b. How to reduce stigma in the family, neighborhood and community

The participants were divided into three groups of six and given instructions to choose the chair persons and presenters. All three groups discussed how to reduce stigma in different contexts, such as in the family, the neighbourhood and the community. After brainstorming the topics in their groups they identified examples of strategies to reduce it

in different contexts. The feedback from group works and from the facilitator on how to reduce stigma in different contexts is presented in Table 4.3 below.

Table 4.3 Feedback on how to reduce stigma in different contexts

In the family	In the neighbourhood	In the community
<ol style="list-style-type: none"> 1. Praying together 2. Counselling 3. Education on basic information on HIV/AIDS 4. Involvement of spiritual leaders 5. Informing households about the workshop/ giving them feedback about what has been done and said 	<ol style="list-style-type: none"> 1. Involvement of house owners 2. Education on basic information on HIV/AIDS 3. Counselling 4. Good relationships among neighbours 	<ol style="list-style-type: none"> 1. Consultation with Constituency Councillor's office to announce community meetings through the radio, to address and/or inform the community members about stigma and its effects on different players 2. Educate community members on how one can and cannot get HIV 3. Do dramas, songs and poems on HIV/AIDS stigma either in the radio or at any community gathering

The participants indicated that despite identifying strategies, it will not be easy to confront and address their neighbours and community members. As a result, the researcher informed them that another workshop with community opinion leaders and representatives would be held as part of the study. That workshop would inform them about the negative consequences of stigma and discrimination, and how to prevent and overcome them. The next session for the day that was about protection against stigma was introduced.

c. How to protect ourselves and others against stigma

The participants were divided into three groups and were asked to brainstorm the question about “*how to protect themselves and others against stigma*”. Each group identified suggestions that were discussed on feedback and the facilitator added to the list. The suggestions on protecting against stigma were as follows:

- Receiving continuous counseling
- Ignore those who say bad things about oneself
- Forgiveness
- Make peace with others who discriminate/stigmatize you
- Going to church services and praying
- Listening to music
- Self-employment to earn income
- Joining support groups

These were brainstormed by the whole group and relevant as well as practical examples were given to make it more understandable. The participants were given a chance to identify which strategies would be more applicable to their own situations. One participant said: “*When people say bad things about me, I just ignored them, and it helps. If I am at home I listen to music then I feel better.*” Another one said: “*We need to forgive people who infected us, some are no more but we are lucky to be alive and get ARVs.*” They were encouraged to try several strategies to protect themselves from stigma and choose the most suitable ones. One participant suggested that: “*It is better to try to earn income so that households will stop stigmatize us. For example we can make traditional baskets and sell them at the open markets.*” “*We should help with household chores when we are not*

sick.” There were breaks in-between the sessions and participants did icebreakers to prevent boredom. The day sessions ended with songs and a prayer at 16h30.

4.2.3 PLWHA Workshop: Day 3

Day 3 sessions started with a prayer and two participants gave review of the previous day’s activities. They indicated that role plays and dramas are easy to understand as people relate to them easily. Day 3 consisted of the following three sessions:

- a. Positive living with HIV/AIDS
- b. PLWHA can lead long and full lives
- c. Moving to action
- d. The role of PLWHAs as opinion leaders and change agents
- e. Diffusion of Innovation strategies for stigma reduction in the community

a. Positive living with HIV/AIDS

The brainstorming strategy was chosen for this topic and each participant was given a blank piece of paper and a pen to write one or more things on how to live positively with HIV/AIDS. They gave the following examples which are part of living positively with the disease and the facilitator added on the list.

Examples of positive living with HIV/AIDS

- Safe sex and/or abstain from sex
- No alcohol, smoking, substances (drugs)
- Limit stress
- Being spiritual
- Relationship with God
- Prayers/ being spiritual

- Hygiene
- Peace
- Accepting one's HIV status
- Eat healthy food
- Seek medical treatment on time
- Not stressing oneself about the past
- Exercises
- Remember that one is lucky to be alive
- 'Keep HIV for oneself' that is Avoiding infecting others
- Treatment adherence
- Work when one can
- Avoid becoming pregnant or consult health professional before becoming pregnant
- Rest and sleep when tired

After concluded session one, the facilitator introduced the next session.

b. PLWHA can lead long and full lives

The session on leading long and full lives was related to living positively, which was done in the previous session therefore less time was spent on it. However, it was emphasized that it is individuals' responsibility to take care of their health by adhering to living positively. At the same time it was also emphasized that being HIV positive does not make anyone less human, therefore they have the same rights as other people and should be treated as such. That led to the next session of the day.

c. Moving to action

One of the objectives for this intervention workshop was to develop an action plan on how to reduce community-based HIV/AIDS stigma in their constituency. It was therefore appropriate to have this topic of moving to action in the program. During the brainstorming and discussions throughout the workshop, moving to action was the aim and a plan was needed to enable participants to implement it. As a result, they came up with the following examples to reduce stigma in their communities:

- Giving feedback about the workshop to other support group members
- Re-educate families, neighbours and communities on basic facts of HIV/AIDS and stigma
- Information sharing with others on how HIV is transmitted
- Train others on stigma reduction
- Call for community meetings through their community leaders
- Mobilizing community members on stigma reduction by using dramas, songs, and role plays.
- Work in collaboration with existing community committees, which deal with HIV/AIDS matters in their constituency.

They were encouraged to keep in touch with the facilitator in case they needed more information or assistance regarding mobilizing and training others on stigma reduction. They were also told and encouraged to work with the Councillor's office and other community based organizations that deal with HIV/AIDS related activities in their communities. That would help to sustain the stability of the program of stigma reduction in their community. The next session was to motivate them as change agents in this intervention and was delivered in form of a speech.

d. The role of PLWHA as change agents

Research has proven that peer influence has strong effects on intervention delivered by peers (Dearing, 2009). Based on that the researcher attributes that training for PLWHA support group members on stigma reduction would influence the diffusion of information to co-members and non-members who are living with HIV. As a result of diffusion of information on coping skills and how to protect them from stigma, they would become empowered and self stigma would be decreased. That was why this session was included as a motivation for workshop participants to sensitize them that they have an important role as opinion leaders and change agents to make this intervention a success.

It was further explained that they were specifically selected to attend the training workshop as they were regarded as informal opinion leaders and change agents who would influence communication channels on stigma reduction in their respective support groups and communities. As change agents they have advocacy, information and implementation support roles in intervention. The training equipped them with information on stigma reduction in general and coping skills in particular, they were expected to go and train others as well as to mobilize community members to stop stigmatizing people living with HIV/AIDS. They were also made aware of their human rights and were encouraged to advocate for them at all times. Thereafter the next session on strategies to diffuse information on stigma reduction was introduced.

e. Diffusion of Innovation strategies for stigma reduction in the community

In addition to what participants said in moving to action, the facilitator informed them that there are certain strategies, which could help them to convey the message on stigma reduction smoothly and these are:

- **The knowledge of the intervention:** Information on stigma and how it can be reduced should be clearly communicated. They should inform others why is important to stop stigma and how that can be done. For example they can inform others that chatting with them (PLWHA), sharing utensils and eat food prepared by a person who is HIV positive will not transmit the virus. Tell people that by discriminating persons with HIV will prevent them to be open about their status, which can result in new infections and fuel the epidemic.
- **Multi-involvement:** reducing stigma is not the responsibility of individuals or groups alone, it requires different groups such as mass media, community leaders, families, NGOs, community-based organizations and faith-based organization. To make this intervention a success involvement of those groups is essential. Therefore workshop participants were advised to work hand in hand with local community-based organizations and village committees, which deal with HIV/AIDS matters at constituency level. They were told to collaborate with existing groups that deal with community issues in their respective villages. They were informed that they can use radio to do dramas to convey the message to listeners on stigma and how it affects the stigmatized people.
- **Timing:** is a very important component in disseminating information therefore participants were advised to use any opportunity to convey the message on stigma reduction. For example when the larger media is attentive such as during AIDS awareness campaigns they can use that opportunity to conduct them to be given a platform to inform community members about stigma reduction intervention in their constituency. Participants were also informed that when they go to mobilize community members they should choose the right time, for example not in the morning while people are busy working in their fields but rather go in the

afternoon. They can also address people at any community gatherings as long as they follow prescribed rules in their social system such as asking permission from village headmen or from constituency councilor.

The last session of the day was strategies for stigma reduction that influence social change and was given in a lecture form. Before the closing remarks, participants were asked to evaluate the workshop individually. The workshop ended at 14h30 on the 23 July 2010.

4.3 WORKSHOP FOR COMMUNITY LEADERS

The second workshop was held for community and opinion leaders from 27-29 July 2010 at the Ongenga Constituency Regional Office. The invitation was done with assistance from the constituency councilor's office, and letters of invitation were sent to ten village headmen. Invitation was extended to the board members of Ongenga Parish, which nominated three members to attend the workshop. The invitation letters were delivered by hand, and the participants consisted of four village headmen, three congregation board members and one teacher from a local school were able to attend, a total of eight people.

Due to time limits the workshop could not be rescheduled to accommodate those who were unable to attend. As the workshop took place on week days, it was difficult for teachers to attend, as a result only one from a nearby school was able to come. The workshop program for the community leaders is presented in Appendix 8.

Many of the participants for this workshop are older than the first group and the introduction was therefore done differently. Each was asked to introduce themselves and outline their role in the community, and mention their expectations from the workshop.

This helped them to feel comfortable and free to express themselves during the workshop.

The following seven topics were covered during this workshop:

Day 1:

- a. Naming the problem: what is stigma, causes and effects
- b. Our own experiences of stigmatizing others
- c. More understanding and less fear

Day 2:

- a. Caring for PLWHA in the family
- b. Community support for PLWHA

Day 3:

- a. PLWHA have rights too
- b. Moving to action.

4.3.1 Community leaders' workshop: Day 1

Day 1 started with welcoming remarks, an introduction, detailing their expectations, setting ground rules, workshop logistics, and training/workshop objectives. The training activities covered on the first day consisted of the following topics:

- a. Naming the problem: what is stigma, causes and effects
- b. Our own experiences of stigmatizing others
- c. More understanding and less fear

a. Naming the problem: what stigma is, its causes and effects

The meaning of stigma was dealt with and participants could not identify one local word for it and it was therefore explained with a sentence in local language. After much discussion the participants were able to identify and understand what it was. They were

able to identify forms of stigma, causes and effects either at household or at community level and their feedback is presented in Table 4.4.

Table 4.4 Feedback on stigma forms, causes and effects as identified by community leaders

Types/forms of stigma	Causes of stigma	Effects of stigma
<ul style="list-style-type: none"> • Isolation and rejection • Mistreating of PLWHA • Gossiping • Name calling • Hunger (stop giving food to PLWHA) 	<ol style="list-style-type: none"> 1. Lack of information 2. Lack of knowledge 3. Unemployment 4. Poverty 	<ol style="list-style-type: none"> 1. Separation/divorce in the family 2. Deteriorating of one’s health 3. No treatment adherence 4. Alcohol abuse 5. Suicide

Participants expressed types of stigma in these statements: *“Gossiping is very common in the community whenever people suspect that a person is HIV positive.”* *“In some households, people neglecting sick persons who are HIV positive as they stop giving them food.”* One participant indicated that: *“Poverty and unemployment make people to discriminate their relatives who are HIV positive. Sometimes food is not enough but people are scared to go and report at village headmen to be assisted with food from relieve program.”*

b. Our own experiences of stigmatizing others

Participants were asked to share in pairs their experiences of how they had stigmatized others or seen how this had been done. They were asked to reflect on how it feels to stigmatize someone, and those who felt free to share with the whole group were

encouraged to do so. They acknowledged that they were all involved in stigmatizing people who are living with HIV/AIDS in one way or another. In some cases, they are not aware that they stigmatizing PLWHA or/and their families. Due to low numbers of participants, they were divided into two groups of four, and were tasked with discussing stigma in different contexts such as in the family and in the community. Each group was requested to select a chair person and a presenter who would do presentation on behalf of the group. The results of group work activities and additional from the facilitator are presented in Table 4.5 as follow:

Table 4.5 Feedback on stigma towards family and in the community

Stigma towards family with PLWHA	Stigma in community
<ol style="list-style-type: none"> 1. Isolation and rejection of family/household with a person who is HIV positive 2. Neighbors visit to see the condition of the PLWHA (to see how s/he looks like) 3. Not allowing children to play with a neighbor's children who are suspected to have HIV/AIDS 4. Some people stop visiting the family with a person who is HIV positive 5. Gossiping and bad name calling 	<ol style="list-style-type: none"> 1. Gossip about anyone who looks thin/slim 2. Bad name calling 3. Not employing someone who looks "sick" 4. Stop visiting families with PLWHA

During the discussion, people indicated that they stigmatize PLWHA due to a fear of getting infected and a lack of knowledge on how HIV is transmitted. These were expressed in the following statements: *"Sometimes people fear of getting the virus by helping sick person who is HIV positive particularly if they have sores. Many people*

cannot afford to buy hand gloves to protect them when they have to care for sick person at home. They want to help but they have no resources.” The next exercise was to establish the knowledge of participants about HIV transmission as well as about their fear of contracting the virus through non-sexual contact.

c. More understanding and less fear

The facilitator introduced the activity on knowledge assessment and explained that they would get statements with which they should either agree or disagree. Those participants who disagreed with any statement were asked to raise their hands and to motivate their choice. The following statements were used to test the knowledge:

- HIV and AIDS is the same thing.
- You can tell if a person has HIV just by looking at them.
- There are four body fluids that can transmit HIV from one person to another.
- An HIV negative mother will pass the virus to her baby if the father is HIV positive.
- A person can get HIV by hugging an HIV positive person.
- A person can get HIV by infected saliva.
- If one's partner goes for an HIV test and the result is positive, that means you are also infected.
- An HIV positive woman can pass the virus to her baby during delivery.
- If both partners are HIV positive there is no need to use a condom as a result that they have the same virus.
- An HIV positive woman should not get pregnant.

The facilitator explained the statements and gave correct information accordingly. This exercise triggered many questions and answers were provided. For example one participant asked: *“Can a person get HIV from someone who has the virus via a human bite?”* Another one asked: *“What advice can I give to someone who is HIV positive and wants to have a baby without stigmatizing her?”* One participant wanted to find out: *“Is it possible for husband to be HIV positive while his wife is negative?”* Thereafter, fears about contracting HIV through non-sexual contact were assessed.

The participants were divided into pairs and asked to share their fears about HIV and AIDS, after which they were then asked to share them with the whole group. The results of this exercise were:

- Getting infected
- Isolation by others
- Leaving children as orphans
- Shame, people talking about us
- Being rejected by family members
- Becoming a burden to family
- Unable to care for one self
- Helplessness
- Dying slowly and painfully

After the discussion on these fears, day 1 was ended with a prayer due to that all workshop participants were Christians and it was a norm in that community.

4.3.2 Community leaders' workshop: Day 2

Day 2 started with a review of the findings from Day 1 and the topics for the day were outlined. These were:

- a. Caring for PLWHA in the family
- b. Community support for PLWHA

a. Caring for PLWHA in the family

The first activity was done through a brainstorming strategy and each participant was given a piece of paper to write down the challenges of caring for PLWHA. The result of this activity revealed that the two biggest challenges were:

- Lack of knowledge and skills on how they can best look after their family members who are living with HIV/AIDS
- Lack of resources such as money, food and cleaning materials

After brainstorming their concerns on this activity the next one on effects of stigma on family with a person living with HIV/AIDS one was introduced.

This activity was to discuss how HIV affects the family, and participants were divided into pairs to discuss the immediate and the longer term effects of HIV on the family as well as on PLWHA. The results are presented in Table 4.6

After this activity the participants were divided into two groups of four where they were asked to discuss what practical things they can do to support PLWHA family members. Each group selected a chairperson and a presenter. The results of their discussions and additions from the facilitator regarding how to support family were:

- Encourage PLWHA to accept their HIV status
- Ensure that they adhere to treatment (ARVs)
- Encourage them to go to clinic/hospital when they feel sick
- Refer or inform them about where they can get necessary assistance
- Get support from church
- Provide them with food and other basic needs such as money to go to hospital.
- Encourage them to join local support groups for PLWHA
- Arrange for counselling when necessary
- Involve them in family discussions
- Show them love and emotional support

Table 4.6 Feedback on effects of stigma on family and PLWHA

Immediate effects on family	Longer term effects on family	Effects on PLWHA
1. Burden on caring for the PLWHA 2. Fear of infection 3. Fear of what the neighbours will say once they find out 4. Do not know what to do	1. Conflict in the family 2. Loss of income and financial problem particular if the PLWHA was the breadwinner. 3. Children drop out from schools to look after the sick parent/s 4. Children become orphans 5. Loss of property when husband died and wife became a widow	1. Loss of job and income 2. Depression 3. Self blaming 4. Feeling guilty

The participants were asked to explain and elaborate on these points, and provide additional information based on how they can support PLWHA in family such as reducing stigmatizing. For example one participant suggested that: *“Persons who are HIV positive should be involved in family discussions, they have good ideas like any other person. Sometimes they are the ones who have money to solve a family problem if they are excluded they will not be able to help.”* Another participant raised a concern that: *“Sometimes if you tell a family member who is HIV positive not to overwork, they regard it as discrimination.”* The next activity, which was about community support for PLWHA was introduced thereafter.

b. Community support for PLWHA

The facilitator divided participants into pairs and asked them to come up with suggestions for mobilizing community support for PLWHA, particularly in Ongenga Constituency. The participants came up with the following suggestions:

- Projects for income generating (for example gardening, chicken project, making traditional baskets and clay pots). Village headmen who attended the workshop indicated that they are willing to provide a piece of land to PLWHA for gardening.
- Refer PLWHA for necessary assistance such as to food relieve program at constituency level.
- Fundraising to get financial assistance for their support groups.
- Encourage PLWHA to adhere to treatment so that they can live longer and lead productive lives.

- To strengthen the community committees, which deal with HIV/AIDS matters at constituency level.
- Conduct community meetings to educate them about HIV/AIDS stigma reduction.

It was further discussed that there are committees in the community, which deal with HIV/AIDS related issues at the constituency level. These committees need to collaborate with PLWHA support group members to inform the whole community about the stigma intervention reduction efforts that had been developed through this workshop. This would help to “normalize” HIV/AIDS and reduce stigma in the community. Likewise if the PLWHA become productive in their projects, the other community members would accept them and stop stigmatizing them. This was the last session of Day 2 which ended at 16h30.

4.3.3 Community leaders’ workshop: Day 3

Day 3 started with a prayer and addressed the following issues:

- a. PLWHA have rights too
- b. Moving to action.

a. PLWHA have rights too

Participants were divided into pairs, given blank papers and were asked to write down PLWHA rights. They were then asked to discuss those rights under the following headings:

- Which of these rights do families try to remove and why?
- What are the effects on the PLWHA of being denied these rights?

- What can be done to reaffirm and reinstate those rights?

The discussion that followed indicated that families try to remove some of these rights such as not letting them speak for themselves. When there are families discussions, PLWHA are excluded even if they are the centre of discussion. It was indicated that some families deny PLWHA food due to their inability to contribute to household chores, and are treated unfairly either at family or community level. The session concluded that being HIV positive does not make a person less human, it is therefore wrong to remove a person's rights due to their HIV positive status. PLWHA should be educated on their rights so that they can be reaffirmed.

It was also acknowledged that PLWHA have responsibilities, which were identified in the next activity. Participants were divided into pairs and asked to identify and discuss PLWHA responsibilities. They decided that it is their duty as community leaders to make PLWHA aware of their rights and responsibilities, and to ensure that other community members respect those rights. However, PLWHA should also know that they are responsible for taking care of themselves when they can, that they must adhere to treatment, and protect others from infection. The rights and responsibilities are summarised in Table 4.7.

b. Moving to action (Diffusion of Innovations strategies in stigma reduction)

The last session of the workshop was to discuss what action opinion and community leaders could take to reduce stigma in their respective communities. This was done by giving each participant a piece of blank paper to write his/her idea of action, after which the facilitator collected all the papers and facilitated the discussion. The following points were suggested:

- Conduct community meetings to inform community members about the developed stigma reduction intervention in their constituency.
- Collaborate with existing community committees, which deal with HIV/AIDS issues at community and constituency level.
- Educate community members that a person cannot get HIV through casual contact.
- Encourage community members to accept support group members who undergone training on stigma reduction when they visit their homes. (Not to deny them entrance).

Table 4.7 Rights and responsibilities of PLWHA

PLWHA Rights	PLWHA Responsibilities
1. to speak/talk	1. to take care of their families when they can
2. to work/ employment	2. to work and earn income or to do self employment
3. to movement	3. to contribute to household chores when they can
4. to have shelter	4. those who are students or learners to continue with schooling
5. to have food	5. to practice safe sex and protect their partners from infection
6. to have fair treatment	6. to educate others about HIV/AIDS, particularly the younger

The facilitator informed them that they were selected for this workshop due to their respective roles in the community and they were regarded as the right people to convey the message on stigma reduction. The village headmen would hold community meetings and give feedback to their villagers. They were informed that there is a group of trained PLWHA who will mobilize community on stigma reduction, they should grant them

permission and needed assistance when they approach them as village headmen. The congregation board members were informed that they can use the platform at church services and board meetings to give the message and diffuse information on what they have learnt during the workshop. That would help to accelerate the rate of the intervention. The teacher represented their school and therefore would give feedback to teachers about the workshop, and will inform learners at their school about stigma and its negative effect on those who are stigmatized. Learners would help to diffuse information as they will tell their parents and guardians about stigma intervention reduction which to be implemented in their constituency. That was the last activity of the day, after which participants were asked to evaluate the workshop. The facilitator closed it officially and thanked all of them for their active participation.

4.3.4 Community involvement

The inhabitants of Ongenga Constituency were involved in the study and their leaders in the intervention. The researcher conducted in-depth individual interviews with selected opinion leaders who gave their suggestions on how stigma should be reduced in the family and community levels. During the intervention workshops, eight community leaders attended and were trained as ambassadors of stigma reduction in their respective villages. The trained community leaders would help to disseminate information about the intervention and they would also influence change in their social systems. The literature recommends that community involvement with combination of other strategies can reduce stigma in the community (Heijnders and Van der Meij, 2006). Therefore it was used in combination with training and contacts with affected groups as strategies to address and reduce stigma at constituency level.

4.3.5 Contacts with infected and affected groups

According to Dalky (2011) contact based strategies were found significant in reducing stigma for mental illness. In addition, Corrigan et al. (2007) cited in Dalky claimed that personal contact seems to have a broader impact on reducing mental illness stigma than the educational strategy (Corrigan et al., 2007 cited in Dalky, 2011). In this study the researcher used contacts with infected and affected groups to normalize HIV/AIDS and to influence change behaviours and attitude of the community. During the visit at ARV clinic the researcher was chatting with PLWHA who came to collect their medication in order to show the public that there is nothing wrong to be seen talking with a person who is HIV positive. In addition PLWHA who were not part of the training were asked to help with food preparation for workshop attendees. That was done to show people that one cannot get HIV by eating food prepared by PLWHA.

4.3.6 Control arm: Health education

The training sessions for PLWHA participants from control arm were conducted on the 2-4th August 2010. Ten support group members from the control arm were selected by their coordinators to attend the training and were given health education on general topics rather than HIV. They were provided with general health education sessions for three days to be in line with intervention dosage as it was stipulated in the research proposal. The number of activities for the control arm was not equal to those of the intervention but the researcher spent equal time with participants to control dosage effect. Although the ideal in nursing interventions dosage is to apply all the dose components: amount, frequency and duration (Reed et al., 2007), it is not always feasible in community research. The researcher believes that the content plays an important role in intervention effectiveness rather than the amount of activities. This is supported by Conn, Rantz, Wipke-Tevis and

Maas (2001) that the intervention effectiveness can be influenced either by content or mode of delivery (Conn et al., 2001). In this study the mode of delivery was the same, which was face- to -face interaction but the content was different. It was therefore attributed that the outcome from the intervention arm would rather be judged based on the content than on the process. Furthermore, Glasgow, Vogt and Boles (1999) argued that effectiveness of the intervention varies depending on the nature of the target groups, the skill and resources available to the program (Glasgow et al., 1999). The following topics not related to HIV were covered: nutrition, exercises, rest and sleep, alcohol abuse and general hygiene. This group will be provided with stigma reduction training after the completion of this study.

4.4 CONCLUSION

This chapter outlined the two workshops that formed the intervention for study, one for PLWHA and the other for community leaders. The PLWHA outlined the types of discrimination that affected them and identified ways that these could be addressed. The community leaders acknowledged the types of stigma and discrimination that PLWHA experienced and identified ways that they, in their positions of leadership, could assist with preventing and reducing it. Both groups of participants participated actively in the workshops, and provided constructive ways of ‘moving to action’. They were motivated as opinion leaders and change agents who would influence diffusion of information on stigma reduction. The other strategies which are community involvement and contacts with infected and affected groups were discussed briefly. The control arm was given general health education not related to HIV and was explained in this chapter.

CHAPTER 5

STUDY RESULTS AND DATA ANALYSIS

5.1 INTRODUCTION

The aim as well as the third and fourth objective for this study sought to establish the following:

- To measure the level of HIV/AIDS stigma (external, internal and associated) in a rural community in Namibia.
- To evaluate the effectiveness of the interventions to reduce stigma in people living with HIV/AIDS (PLWHA), their families and the community as well as to compare the outcome of the evaluation with a group that did not receive the intervention.

This chapter describes the three main components, which form the study results and findings. Those three main components that are described in this chapter are:

- 1) The baseline survey results of community-based HIV/AIDS stigma measurement both quantitative and qualitative
- 2) The post-intervention results from all groups of participants
- 3) The evaluation of the effectiveness and impact of interventions by presenting and comparing the study arms post-intervention.

This study used four groups of participants, multi-measurement instruments and multi-levels data presentations, therefore, the results are presented according to groups and their instruments at different levels. Different statistical tests included descriptive and analytic

statistics; independent samples t-test and paired samples t-test were used to analyze data.

The following instruments were used on the four groups that participated in the study:

a. Questionnaire:

Group 1: HASI-P for PLWHA

Group 2: F&C-SI for family

Group 3: F&C-SI for community leaders

Group 4: HASI-N for health care workers

b. In-depth interview

Group 1: PLWHA

Group 3: Community leaders

Group 4: Health care workers

The results will be presented in this order: the demographic data are presented first, followed by quantitative baseline data of both arms combined, then pre-and post-intervention groups of both arms will be presented and compared. The results of post-intervention data from groups who only participated at evaluation survey, both from intervention and control will be analysed separately. The qualitative results consisted of baseline interviews, which will be analysed jointly from both arms as they were collected before the community was separated geographically into two sites. The post-intervention interviews results were analysed separately for intervention arm only, due to control exclusion as a result of the interview questions, which focused on changes after the intervention. The results are presented in the following order of events as they occurred in the study.

1. Baseline data included all four groups (PLWHA, family members, community leaders and health care workers) from both arms (n=224),

2. Results and comparisons of both intervention and control arms (n=74) who participated before and after the intervention.
3. Post-intervention group: for those who were not part of baseline assessment (n=129),
4. Qualitative data from ten participants (community leaders, health care workers and one person living with HIV) before intervention, notes from training workshops participants (18 support group members and eight community leaders) and feedback results from selected persons (n=17) (PLWHA and community leaders) as part of evaluation survey are presented.

5.2 DEMOGRAPHIC RESULTS OF STUDY PARTICIPANTS

At baseline survey 224 participants took part in this study of whom, 93 are PLWHA, 77 family members, 50 community members and opinion leaders and four health care workers. The majority of them were women who made up 67%, their age ranges between 18-81 and most are Christians who belong to Lutheran, Roman Catholic and Anglican churches, less than 5% are from other religion denominations. At the post-intervention phase the number of participants has decreased from 224 to 203 due to loss of participants who were replaced with new people. Out of the returned number 129 (61 PLWHA +68 family and community leaders) were new people who did not take part at the baseline assessment. Therefore, at the end all people who participated were 353 (224 +129). However, that was a limitation and this loss could be as a result of the following:

1. Lack of understanding the importance and seriousness of research
2. Lack of incentives to individual participants
3. Loss of interest to participate

4. Personal reasons such as illness or death

5.2.1 Group 1: PLWHA

Ninety three PLWHA, who are support group members and/or on ARVs participated and their gender, age, and religious denominations are presented in charts and tables. Most PLWHA participants are women and the age group, which is mostly represented is 36-45 and that formed 40% (n=37). The majority of participants (70%, n=65) are from the Lutheran denomination, 15% (n= 14) are Roman Catholics and 10% (n=9) are Anglicans that all fall under Christianity and only 5% (n=5) belong to other religions.

The results on gender revealed that the majority (84%, n=78) of PLWHA participants are women, while men made 16% (n=15) only. This confirmed that most of support group members are women. This can be either linked to that many people who are infected are women or they are the ones who are involved in HIV/AIDS related response. The age were presented in five groups as shown in Figure 5.1 and they show that most age groups participants were between the ages of 36-45 (40%, n=37), while the smallest age group was 56-66 (4%,n=4).

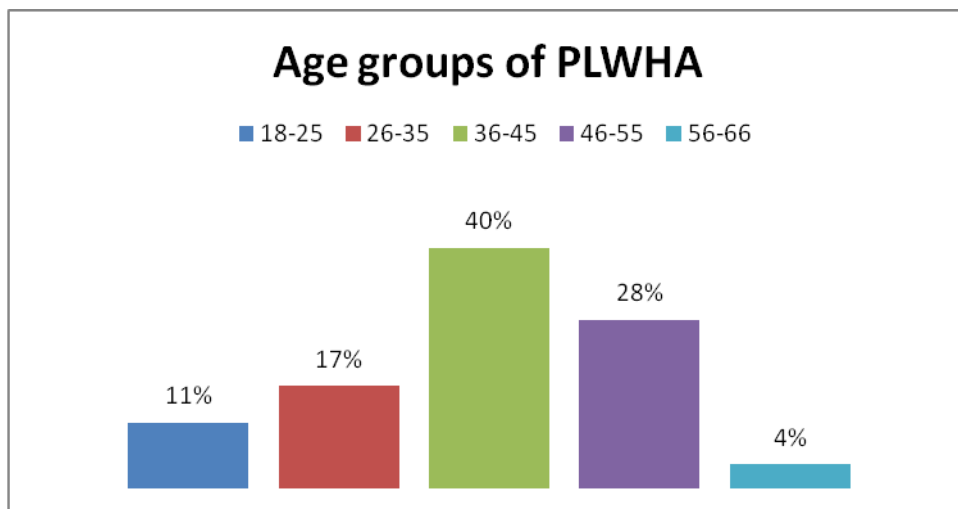


Figure 5.1 Description of PLWHA according to age groups

With regard to religion, the majority (69%, n=64) of participants are Lutherans, followed by 15% (n=14) of Roman Catholics and 10% (n=9) of Anglicans. Only 5% (n= 5) belong to other religions and one participant did not indicate religious denomination.

Table 5.1 Description of PLWHA according to their religious denominations

Religion	Number	Percentage
Lutherans	64	69%
Roman Catholics	14	15%
Anglicans	9	10%
Others	5	5%
Missing	1	1%
Total	93	100%

5.2.2 Group 2: Family members

Seventy seven family members participated in this study, although the requirement was for each PLWHA participant to nominate one family member, 16 did not nominate supporters. That was not possible to identify who had nominated and who did not as there was no information link between PLWHA and family participants. As a result the number of family participants was less than PLWHA group.

The demographic data of family members, which included their gender, age, religion and education levels are presented in charts and tables. Like in the other groups, women were the majority in this category as they made 65% (n=50). This could be due to that many caregivers and treatment supporters of PLWHA are women, therefore they were nominated as family members to participate in this study. The age group of 31-40 had represented 30% (n=23) of participants in this category, followed by 18-30 and 41-50 groups who made 24% (n=18) each. The majority of participants (69%, n=53) are

Lutherans as indicated in Table 5.2. At least 58% (n=45) of participants from family group completed their secondary education with 11% (n=8) who completed tertiary education. The age of family members was grouped into five categories ranged from 18-30 to 61 and above. The results in Figure 5.2 indicate that the most age group of family members was between 31-40 years (30%, n=23), followed by 18-30 (24%, n=18) and 41-50 (24%, n=18) groups. The age groups from 51-60 and 61- above were less represented at 12%(n=9) and 10% (n=8) respectively and one was missing.

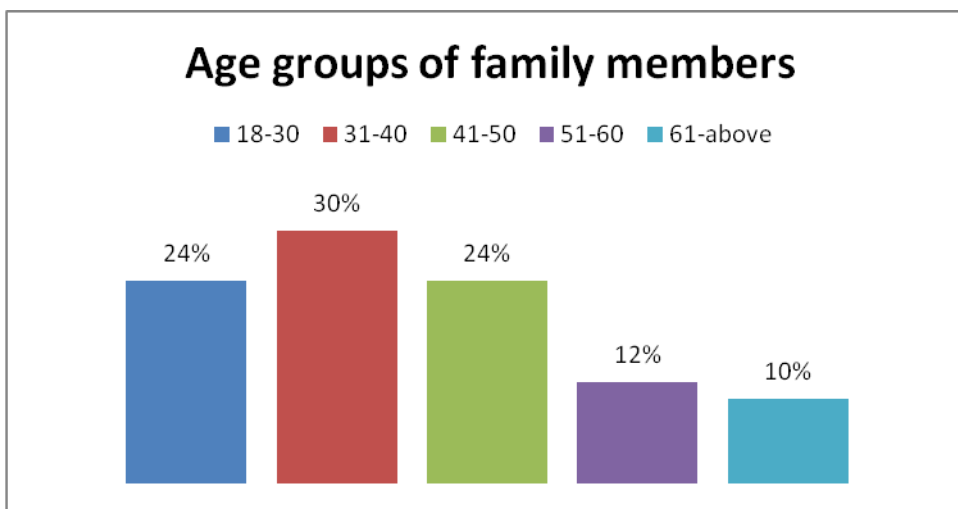


Figure 5.2 Description of family members according to age

The majority of family members (69%, n=53), (19%, n=15) and (9%, n=7) are Christians and 3% (n=2) belong to other religions.

Table 5.2 Description of family members' religion

Religion	Number	Percentage
Lutherans	53	69%
Roman Catholics	15	19%
Anglicans	7	9%
Others	2	3%
Total	77	100%

Thirty percent of family participants had only primary education, more than half (58%, n=44) had secondary and 11% (n=8) of them had completed tertiary level.

Table 5.3 Description of the education of family members

Education level	Frequency	Percentage
Primary	23	30%
Secondary	44	58%
Tertiary	8	11%
Missing	1	1%
Total	77	100%

5.2.3 Group 3: Community leaders

Fifty community members and opinion leaders participated in this study and their demographic data include gender, age groups, religious denomination and education level. The majority of this group were women 68% (n=34) and the age group of 18-30 was the highest (44%, n=22). The majority (76%, n=38) are Lutherans and 52% (n=26) completed secondary education and their demographic data distributions are presented in charts and tables.

Like in the other groups, women are the majority as the result show that 68% (n=34) participants from the community members are women, while 32% are men. The results in Figure 5.3 show that the age group between 18-30 has the majority, which makes 44% (n=22), followed by age group of 61-above that is 20% (n=10). The least age groups are 31-40 and 51- 60 which made up 10% (n=5) each.

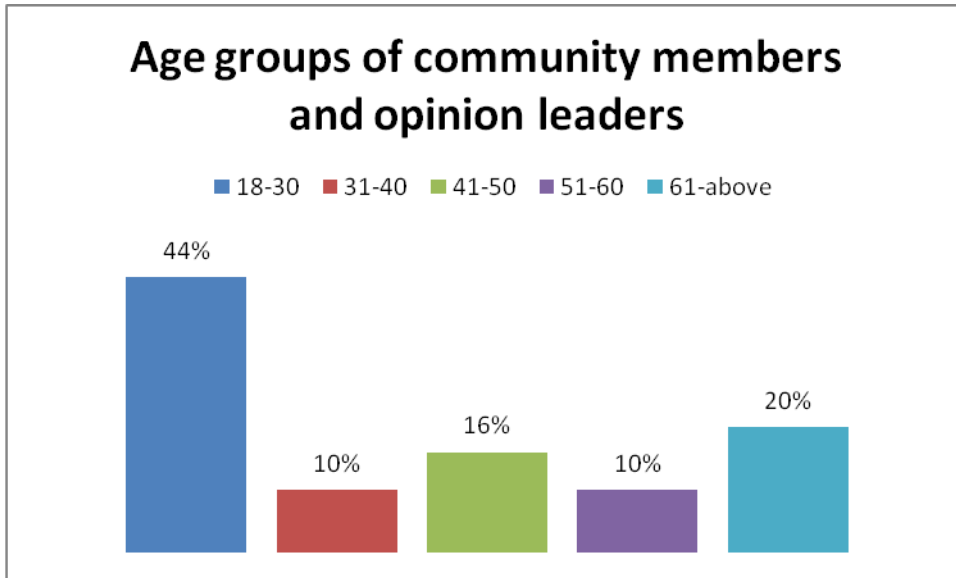


Figure 5.3 Description of community leaders by age groups

The majority (76%, n=38) are Lutherans, followed by Roman Catholics (18%, n=9), while Anglican made 6% (n=3).

Table 5.4 Description of community leaders according to their religion

Religion	Frequency	Percentage
Lutherans	38	76%
Roman Catholics	9	18%
Anglicans	3	6%
Others	0	0%
Total	50	100%

The education level of community members and opinion leaders as it was revealed by these results in Table 5.5 show that 28% (n=14) have only primary, with 52% (n=26) completed secondary and only 20% (n=10) of them had completed tertiary education.

Table 5.5 Description of education level of community leaders

Education level	Frequency	Percentage
Primary	14	28%
Secondary	26	52%
Tertiary	10	20%
Total	50	100%

5.2.4 Group 4: Health care workers

Four health care workers from the only clinic that provides ARV in the constituency participated in this study and their demographic data are presented in the charts and tables below. Their gender is equally distributed as two of them are men and two are women. Three of them are in the age group of 46-55, while one is 29 years old. All four health care workers are Christians as three are Lutherans and one Roman Catholics. Furthermore, there is rank equal distribution whereby each rank is represented by one health care worker.

The results on gender show that there is equal distribution of health care workers who participated in this study due to that two are women and another two are men. Three of the health care workers are in the age group of 46-55 (75%, n=3) and only one was in the age group of 29-35 (25%, n=1) and none was between 36-45 years old. All of health care workers are Christians who belong to Lutheran and Roman Catholic denominations respectively.

The results of rank distribution show that each category of health care workers who participated in this study is represented by one person (Registered nurse, Enrolled Nurse, Nursing assistant and other).

5.3 QUANTITATIVE BASELINE RESULTS

The baseline results are presented jointly from both arms and separately according to the four groups of participants under these headings below.

- a. Group 1: PLWHA
 - i. External stigma
 - ii. Internal stigma
- b. Group 2: Family members
 - i. External stigma
- c. Group3: Community leaders
 - i. External stigma
- d. Group 4: Health care workers
 - i. External stigma
 - ii. Stigma of association

a. Group 1: PLWHA

Ninety three PLWHA, who are support group members participated in this study before the community was separated geographically into two study arms, intervention and control. They have used HASI- P questionnaire, which consisted of five factors with 25-items to measure level of stigma. Both external and internal stigma was measured and the

results were analysed with PASW Statistics 18 program. The descriptive statistics, which provided means with their standard deviations, are presented in tables below. The keys of presentation in tables are as follow: No.= number of participants per item, never=0, once or twice=1, several times=2 and most of the time=3. The mean scores of the factors were calculated by summing up the items under each factor which range from 0 to 3 and they should be interpreted that *the closer to 0 the lower the stigma and the closer to 3 the higher the stigma*. To minimise the number of columns in the tables, the results of *several times* and *most of the time* have been summed up to make one score. Although 93 PLWHA participated in baseline survey, there were some missing data that led to number of participants in some items to be less than 93, and these were indicated in the tables accordingly.

1. External stigma

The main factors that were used to measure **external stigma** as experienced by PLWHA included the following:

- Fear of contagion through casual contacts such as sharing eating utensils,
- Verbal abuse such as name calling, blaming, judging and scolding,
- 3. Social isolation such as avoiding, ending friendships with them, and cutting visits,
- 4. Work place stigma such as denying a person work benefits due to being HIV positive

2. Internal Stigma

The main factor that was used to measure **internal stigma** as experienced by PLWHA is negative self perception, which can be feeling worthless or guilty by having the disease. Among these factors verbal abuse and social isolation were experienced most as they have

the mean scores of 1.1942 and Standard Deviation (Std Deviation) of 1.0213 as well as mean score of 1.0220 and Std Deviation of 0.9637 respectively. Workplace stigma and negative self perception were also experienced minimally. The least experienced was stigma due to fear of contagion. The mean scores of stigma factors as experienced by PLWHA are presented in Table 5.6

Table 5.6 Mean scores of stigma experienced by PLWHA at baseline

Factors	No.	Mean	Std Deviation
Fear of contagion	93	0.4362	0.6860
Verbal abuse	92	1.1942	1.0213
Social isolation	93	1.0220	0.9637
Workplace stigma	86	0.5058	0.9471
Negative self perception	91	0.6868	0.9033

i. External stigma

The four factors that were used to measure external stigma as experienced by PLWHA include fear of contagion, verbal abuse, social isolation and workplace stigma.

Fear of contagion: At baseline survey stigma due to fear of contracting HIV through non-sexual contacts was least experienced as the majority of PLWHA participants (71%, n=65 to 85%, n=78) reported never experienced it in the last three months at the time of this study. On the statement of being asked to leave due to coughing 11% (n=10) of them experienced it once or twice and 17% (n=16) experienced it more than twice. On the statement of being told not to touch someone’s child, 24% (n=22) (17%, n=16 and 7%, n=6) participants have experienced it, out of this percentage (24%) there were 17% who experienced it several times or most of the time and 7% once or twice. Approximately

19% (n=17) (5%, n= 4: once or twice and 14%, n=13: several times and most of the time) reported made to drink last from the cup.

Table 5.7 **Frequencies of experienced stigma due to fear of contagion**

Items	No.	Never	Once or twice	Several times & most of the time
I was told to use my own eating utensils	92	85%	1%	13%
I was told not to touch someone's child	92	75%	7%	17%
I was made to drink last from the cup	89	76%	5%	14%
I stopped eating with other people	89	82%	4%	10%
I was made to eat alone	90	83%	1%	13%
I was asked to leave because I was coughing	92	71%	11%	17%

Verbal abuse: At base line survey more than half (55%, n=50) of PLWHA reported being called names several times and most of the time due their HIV positive status. A third of them reported verbal abuse in the form of blaming, judging, insulting and offensive songs as revealed by results in Table 5.8.

Social isolation: With regard to social isolation, although the results in Table 5.9 show that more than half of participants never experienced stigma in the form of social isolation, one third of them experienced it several times and most of the time. There are 36% (n=33) and 37% (n=34) of participants who indicated that people ended their relationships and friendship as well as cut their visits. Furthermore, one third (34%, n=30) indicated that people avoided them when they learnt that they are HIV positive.

Table 5.8 **Frequencies of verbal abuse experienced by PLWHA**

Items	No.	Never	Once or twice	Several times & most of the time
I was called bad names.	91	38%	5%	55%
People sang offensive songs when I passed by.	91	56%	1%	41%
I was told that I have no future.	89	57%	4%	40%
Someone scolded me.	89	42%	11%	43%
I was told that God is punishing me.	90	63%	2%	31%
Someone insulted me.	89	52%	11%	33%
I was blamed for my HIV status.	91	54%	4%	40%

Table 5.9 **Frequencies of experienced stigma in the form of social isolation**

Items	No.	Never	Once or twice	Several times and most of the time
Someone stopped being my friend.	92	58%	5%	36%
A friend would not chat with me.	84	58%	2%	30%
People avoided me.	89	53%	9%	34%
People cut down visiting me.	89	58%	1%	37%
People ended their relationship with me.	91	57%	5%	36%

Workplace stigma: With regard to workplace stigma the results in Table 5.10 revealed that it is less experienced as only 15%(n=13) and 17% (n=15) of participants experienced it several times and most of the time.

Table 5.10 Frequencies of experienced workplace stigma

Items	No.	Never	Once or twice	Several times and most of the time
Someone tried to get me fired from my job.	86	72%	3%	17%
My employer denied me opportunities.	85	73%	3%	15%

ii. Internal stigma

There is only one factor that was used to measure internal stigma in PLWHA, which is negative self perception.

Negative self perception: At the base line survey, most PLWHA (56%, n=51 to 77%, n=70) reported that they never experienced feelings of negative perception due to their HIV status in the last three months at the time of this study. However, a third of participants (33%, n=30) confirmed feeling brought trouble to their families and more than 20% (n=18) reported felt ashamed, worthless and no longer persons as well as that they do not deserve to live.

Table 5.11 Frequencies of negative self perception among PLWHA

Items	No.	Never	Once or twice	Several times and most of the time
I felt that I did not deserve to live.	91	77%	1%	19 %
I felt ashamed of having this disease.	89	71%	4%	21%
I felt completely worthless.	91	70%	3%	25%
I felt that I brought a lot trouble to my family.	90	56%	8%	33%
I felt that I am no longer a person.	90	75%	1%	21%

Results of PLWHA

The baseline results showed that people living with HIV/AIDS experience stigma in different ways. Verbal abuse was reported by more than half of participants, social isolation by one third, negative self perception was experienced particularly feeling guilty for bringing trouble to their families. Workplace stigma and fear of contagion were minimal.

b. Group 2: Family members

The family members used the F&C-SI questionnaire, which had eight factors with 34-items. These items consisted of both negative and positive statements to prevent response bias, therefore the ones, which were positive-worded, have been reversed with SPSS program before the total scores have been calculated. The particular items, which have been reversed from positive to negative are indicated with a star (*) on the results tables. They were interpreted as ‘the higher the score, the higher the stigma’ and are presented according to eight factors which were used to measure stigma in the family and community.

Seventy seven family members participated but there are some missing data and they are indicated accordingly. The mean scores were calculated by summing up the items under each factor and range from 1 to 5 (strongly disagree to strongly agree) that should be interpreted as *the closer to 0 the lower the stigma and the closer to 5 the higher the stigma*. The findings revealed that community attitude towards PLWHA has the highest mean score of 2.5465 and Std Deviation of 0.9419, followed by family attitude with a mean of 2.4134 and Std Deviation of 0.8774. The household stigma mean score is 2.0993

with Std Deviation of 0.9714. The fear of contagion scored the least with a mean of 1.0132 and Std Deviation of 0.0653. The scores are presented in Table 5.12 below.

Table 5.12 Mean scores of family members' results

Factors	No.	Mean	Standard Deviation
Community attitude	77	2.5465	0.94198
Family attitude	76	2.4134	0.87744
Personal attitude	75	1.8733	1.01373
Households stigma	77	2.0993	0.97144
Community opinion	77	1.7911	0.89504
Close Relationship with PLWHA	77	1.2208	0.53492
Caring for sick PLWHA	77	1.0364	0.07764
Fear of contagion	76	1.0132	0.06534

i. External stigma

This type of stigma was measured with eight factors including community attitude, family attitude and personal attitude towards PLWHA, household stigma, community opinions on PLWHA, close relationship with PLWHA, caring for sick, PLWHA and fear of contagion through non-sexual contacts. The percentage of strongly disagree and disagree are added together as total percentage but indicated in the brackets, the same applies to agree and strongly agree frequencies.

Community attitude towards PLWHA: The findings revealed 73%, n=56 (31%: agree and 42%: strongly agree) of participants who agreed that PLWHA are treated like everybody else in the community, but 36%, n=26 (15% and 21%) agreed that they are mistreated. Furthermore, results in Table 5.13 revealed 35% (n=25) who disagreed that

persons who are HIV positive are treated with sympathy. There are 21%, n=15 (11% and 10%) who reported that they are social isolated from or by other community members.

Table 5.13 Different views of participants with regard to community attitude towards PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
They are just treated like everybody else *	77	16%	6%	5%	31%	42%
They are treated with more sympathy than everybody else *	74	35%	9%	4%	26%	26%
They are isolated from other members of the community	72	49%	15%	15%	11%	10%
They are mistreated by other members of the community	71	41%	14%	8%	15%	21%

Family attitude towards PLWHA: The results in Table 5.14 show 19% (n=14), (4%, n=3: strongly disagree and 15%, n=11: disagree) of participants who disagreed with item that PLWHA in the family are treated like any other households and 32% (n=24) (16%, n=12: agree and 16%, n=12: strongly agree) confirmed that they are mistreated. More than half of participants (51%, n= 38: strongly disagree + 19%, n= 14: disagree) disagreed that PLWHA are social isolated from or by other family members but 44%, n=33 (11%, n=8 and 33%, n=24) disagreed that they are treated with more sympathy.

Personal attitude towards PLWHA: The majority of participants 82%, n=62 (41%: agree and 41% strongly agree) agreed that PLWHA should be offered more sympathy. There are 69% (n= 52) who were in disagreement with the statement that PLWHA should be separated from the community. More than half of participants 68% (n= 51) (35% agree

and 33% strongly agree) agreed that HIV positive status should be disclosed but one third agreed that it should be kept private.

Table 5.14 Different views regarding family attitude to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
She or he is just treated like any other family member*	75	15%	4%	5%	29%	47%
She or he is treated with more sympathy *	75	33%	11%	7%	29%	20%
She or he is isolated from family members and friends	74	51%	19%	8%	9%	12%
She or he is mistreated by family and friends	74	46%	16%	5%	16%	16%

Table 5.15 Different views with regard to personal attitude to PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
People who have HIV or AIDS should be offered more sympathy and moral support*	75	15%	3%	0%	41%	41%
People who have HIV or AIDS should be separated from other members of the community	75	69%	12%	5%	9%	4%
If a person knows that she or he is HIV positive she or he should keep it private	74	32%	20%	8%	22%	18%
A person who has HIV or AIDS should tell others	75	17%	11%	4%	35%	33%

Household stigma: With regard to household stigma such as not sharing blankets with PLWHA, be left out of family discussions, be kept away from visitors, not cook for family, not play with children, results in Table 5.16 revealed that majority of participants between 52% (n=40) and 87%(n=67) of participants disagreed with those statements. There are at least 10%, n=7 (5% and 5%) whom agreed that PLWHA should stay away from visitors, 26%, n= 19 (8% and 18%) are in favour of excluding them out of family

discussion and 42%, n=32 (17% and 25%) indicated that they cannot cook for household members.

Community opinions on PLWHA: Results in Table 5.17 revealed that 85%, n=65 (25% and 60%) of participants agreed that teachers who have HIV or AIDS can be allowed to teach at schools. The majority of participants (59%, n=45 to 73%, n=56) disagreed with statements such as learners who are living with HIV should not attend schools, PLWHA should not be allowed at community gatherings as well as dismissal from work upon disclosing their status.

Table 5.16 Different views of participants on household stigma

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
A person who has HIV or AIDS can share blankets with other households*	77	12%	5%	1%	34%	48%
A person who has HIV or AIDS should use separate blankets	74	61%	18%	3%	14%	5%
A family member who has HIV or AIDS should be left out of family discussions and decision making	74	55%	15%	4%	8%	18%
A family member who has HIV or AIDS should be included in family discussions and decision making*	75	12%	5%	4%	27%	52%
A family member who has HIV or AIDS should stay away from visitors	75	68%	19%	3%	5%	5%
A family member who has HIV or AIDS cannot cook for the family	75	36%	16%	5%	17%	25%
A family member who has HIV or AIDS should share meals with other households*	74	14%	9%	3%	27%	47%
A family member who has HIV or AIDS should not play with children	74	51%	12%	3%	12%	19%

Table 5.17 Community opinions on PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
Teachers who have HIV or AIDS can be allowed to teach at schools*	75	8%	4%	3%	25%	60%
Students or learners who have HIV or AIDS should not be allowed to attend school	77	61%	14%	1%	6%	16%
A person who has HIV or AIDS should not attend community gatherings such as weddings	76	59%	11%	3%	7%	20%
A person who has HIV or AIDS should be dismissed from his or her work upon disclosing his or her HIV status	77	73%	21%	3%	1%	1%

Close relationship with PLWHA: Regarding the number of participants who have a relative or friend with HIV/AIDS, 84% (n=64) of participants confirmed that they have PLWHA either living in their houses or somewhere else, 13% (n=10) said no, and 3% (n=2) did not indicate.

Caring for sick PLWHA: The results on caring for sick PLWHA confirmed that majority of participants (99%, n=76) are willing to take care of relatives if they are ill, either suffered from an accident, have Malaria, TB or Diarrhoea. There are 16% (n=12) who indicated that most families in their community would not be willing to take care of a relative who is ill with HIV or AIDS.

Fear of contagion: The results from the items which measured stigma due to fear of contagion in the family indicated that majority of participants (96% to 100%, n=77) confirmed that they would eat food prepared by someone who has HIV or AIDS, would shake hands as well as share a toilet. There are at least 4% (n=3) who indicated their unwillingness to shake hands with someone who has HIV or AIDS.

Family members' baseline results

Majority of family members disagreed that PLWHA are mistreated or socially isolated either in the family or in the community. Household stigma is reported particular from the items: 'not to cook for the family' 44%, (n=33) (17% +25%) and 'not play with children' 31%, (n=24) (12%+19%). Family members are willing to care for their sick relatives, although there was one (1%) who was unwilling to care for someone after an accident.

c. Group 3: Community leaders

Fifty participants consisted of community members and opinion leaders have completed F&C-SI questionnaire and their results are presented according to the factors that were used to measure stigma. The findings indicate that community attitude factor scored the most with mean of 2.3967 and Std Deviation of 0.8138 followed by family attitude factor with a mean of 2.3567 and Std Deviation of 0.9785. The household stigma has a mean of 1.9037 and Std Deviation of 0.8894. The fear of contagion factor scored the least with mean 1.0204 and Std Deviation of 0.1055. The mean scores are presented in Table 5.18 below.

Table 5.18 Mean scores of community leaders' results

Factors	No.	Mean	Std Deviation
Community attitude	50	2.3967	0.8138
Family attitude	50	2.3567	0.9785
Personal attitude	50	1.6900	0.8915
Households stigma	50	1.9037	0.8894
Community opinion	50	1.6650	0.8625
Close Relationship with PLWHA	50	1.5300	0.3558
Caring for sick PLWHA	50	1.0720	0.1125
Fear of contagion	49	1.0204	0.1055

i. External stigma

External stigma against PLWHA in community and opinion leaders was measured with eight factors including community attitude, family attitude, personal attitude towards PLWHA, household stigma, community opinions to PLWHA, close relationship with PLWHA, caring for sick, PLWHA and fear of contagion through non-sexual contacts.

Community attitude towards PLWHA: Majority of group three participants who are 76% (n=38) (34% agree and 42 % strongly agree) agreed that PLWHA are treated the same like everybody else, but 37% (n=18) (24% agree and 13% strongly agree) agreed that they are mistreated and not treated with sympathy. There are 28% (n=14) (13% agree and 15% strongly agree) who confirmed that they are social isolated. The majority (77%, n= 35) (62%+11%) of participants have disagreed with this item: “they are isolated from other members” and “they are mistreated by community.”

Table 5.19 Different views with regard to community attitude towards PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
They are just treated like everybody else *	50	14%	8%	2%	34%	42%
They are treated with more sympathy than everybody else *	46	24%	13%	9%	22%	33%
They are isolated from other members of the community	45	62%	7%	2%	13%	15%
They are mistreated by other members of the community	45	42%	11%	9%	24%	13%

Family attitude towards PLWHA: On different views regarding stigma in the family, 76% (n=38) (34% and 42%) of participants agreed that PLWHA were treated like any

other household member. With regard to mistreating 34% (n=17) (20% and 14%) confirmed that they are mistreated. Although the majority 74% (n=37) (66% and 8%) disagreed on the statement of isolation from and/or by the family there were 20% (n=10) (12% and 8%) agreed that they are being isolated.

Table 5.20 Different views of participants with regard to family attitude to PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
She or he is just treated like any other family member*	50	20%	2%	2%	34%	42%
She or he is treated with more sympathy *	48	33%	4%	8%	29%	25%
She or he is isolated from family members and friends	48	66%	8%	4%	12%	8%
She or he is mistreated by family and friends	49	51%	4%	10%	20%	14%

Personal attitude towards PLWHA: Majority of participants 84% (n=42) (40% and 44%) agreed that people who are HIV positive should be offered more sympathy and moral support, 89% (n=44) (80% and 6%) disagreed that they should not be isolated from or by the other community members. The findings in Table 5.21 show 70% (n=34) (37% and 33%) who confirmed that a person who is HIV positive should tell others, but there is 22% (n=11) who agreed and 22% (n=11) strongly agreed that it should be kept private.

Table 5.21 Different views of participants with regard to personal attitude to PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
People who have HIV or AIDS should be offered more sympathy and moral support*	50	8%	8%	0%	40%	44%
People who have HIV or AIDS should be separated from other members of the community	49	83%	6%	2%	0%	8%
If a person knows that she or he is HIV positive she or he should keep it private	49	35%	12%	8%	22%	22%
A person who has HIV or AIDS should tell others	49	24%	6%	0%	37%	33%

Household stigma: The majority of this group mostly agreed with the positive statements and disagreed with the negative ones. There are 84% (n=42) (40% and 44%) who agreed that people living with HIV can share blankets with household members and only 16% (n=8) who disagreed with that statement. The majority 87% (n=43) (25% and 62%) confirmed that PLWHA should be included in family discussions and decision making. There are 30% (n=15) (16% agree and 14% strongly agree) participants who confirmed that they cannot cook for the family and 25% (n=12) (8% agree and 17% strongly agree) indicated that they should not play with children.

Table 5. 22 Different views of participants with regard to household stigma

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
A person who has HIV or AIDS can share blankets with other households*	50	10%	6%	0%	40%	44%
A person who has HIV or AIDS should use separate blankets	48	64%	10%	2%	8%	14%
A family member who has HIV or AIDS should be left out of family discussions and decision making	46	61%	17%	2%	6%	13%
A family member who has HIV or AIDS should be included in family discussions and decision making*	48	12%	0%	0%	25%	62%
A family member who has HIV or AIDS should stay away from visitors	49	77%	8%	0%	4%	10%
A family member who has HIV or AIDS cannot cook for the family	49	55%	14%	0%	16%	14%
A family member who has HIV or AIDS should share meals with other households*	49	10%	4%	0%	35%	51%
A family member who has HIV or AIDS should not play with children	47	59%	15%	0%	8%	17%

Community opinion on PLWHA: Results in Table5.23 show that there are 83% (n=41) (26% and 57%) who agreed that teachers who have HIV or AIDS can be allowed to teach at schools. More than 80% (n=40) (77% + 6%; 75% +8% and 79%+ 14%) are in disagreement with these items of excluding PLWHA from schools and community gatherings as well as dismissing them from work after disclosing their HIV status.

Table 5.23 Different views with regard to community opinions on PLWHA

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
Teachers who have HIV or AIDS can be allowed to teach at schools *	49	16%	0%	0%	26%	57%
Students or learners who have HIV or AIDS should not be allowed to attend school	48	77%	6%	0%	4%	12%
A person who has HIV or AIDS should not attend community gatherings such as weddings	49	75%	8%	0%	4%	12%
A person who has HIV or AIDS should be dismissed from his or her work upon disclosing his or her HIV status	48	79%	14%	0%	2%	4%

Close relationship with PLWHA: Regarding the number of community members and opinion leaders who have PLWHA, 64% (n=32) indicated that they have and 36% (n=18) that they do not have.

Caring for sick PLWHA: The majority of community members and opinion leaders participants are willing to take care of sick relative, but 10% (n=5) of them reported that they would not care for someone who had an accident and 2% (n=1) would not take care for a relative who has TB. On the question of most families and their willingness to care for PLWHA, 24% (n=12) indicated that people in their community will not be willing to look after their sick relatives who are either have HIV or AIDS.

Fear of contagion: The findings revealed that 96% (n=48) of participants have no fear of getting HIV through non-sexual contacts but 4% (n=2) indicated not willing to eat food prepared by someone who has HIV or AIDS and 2% (n=1) would not shake their hands. None of community members reported had a problem sharing a toilet with PLWHA.

Community leaders' results

The results from community members and opinion leaders revealed that although stigma exists it is low in the community as majority disagreed with isolating and excluding them from public gatherings. Majority of them indicated their willingness to care for sick relatives who are HIV positive or have AIDS. However, there are few who would not be willing to eat food prepared by PLWHA, or shake hands with them.

d. Group 4: Health care workers

Four health care workers consisted of one nursing assistant, one enrolled nurse, one registered nurse and one community counsellor participated in this study. Their questionnaire measured two variables, which were nurse stigmatising patients and nurses being stigmatised by other people. At baseline survey all four health care workers reported that they never experienced patients being stigmatised due to their HIV status in the last three months at the time of the study. The mean scores is the sum of items under each factor and range from 0 to 3, *they should be interpreted as the closer to 0 the lower the stigma, the closer to 3 the higher the stigma*. There was at least stigma of association experienced by health care workers but minimal with a mean of 0.1389 and Std Deviation of 0.1666. The mean scores of the two factors testing stigma by health care workers and stigma of association towards caregivers are presented in Table 5.24 below.

Table 5.24 Mean scores of stigma reported by health care workers pre-intervention

Variable factors	No.	Mean	Standard deviation
Nurse stigmatising patient	4	0.000	0.000
Community stigmatizing nurses	4	0.1389	0.1666

i. External stigma

Nurse stigmatising patient factor was used to measure external stigma from health care workers against PLWHA from.

Nurse stigmatising patients: The results revealed that no stigma towards patients by health care workers was observed at baseline survey.

ii. Stigma of association

Stigma of association towards health care workers was measured with one factor that is nurse being stigmatised by community members.

Community stigmatizing nurses: Two health care workers (50%, n=2) reported that spouses of nurses fear that they bring virus to their families and another two (50%, n=2) reported that people say that they get the virus by taking care of patients who are HIV positive or have AIDS.

5.4 COMPARISONS OF PRE- AND POST- INTERVENTION RESULTS

The comparison of results was done only with groups, which participated at both pre- and post-intervention to see if there were any significant differences. The other reason for comparison was to check the effectiveness of the intervention package that was developed and implemented in the intervention community. The results of comparisons between the arms and within the groups are presented in this order:

- a. Group 1: PLWHA (HASI-P) (n=33)
 - i. Pre-intervention: comparison between intervention and control arm
 - ii. Post-intervention: comparison between intervention and control arm
 - iii. Intervention arm: comparison between pre and post-intervention

- iv. Control arm: comparison between pre and post-intervention
- b. Group 2 & 3: Family members and community leaders (combined) (F&C-SI)(n=37)
 - i. Pre-intervention: comparison between intervention and control arm
 - ii. Post-intervention: comparison between intervention and control arm
 - iii. Intervention arm: comparison between pre and post-intervention
 - iv. Control arm: comparison between pre and post-intervention
- c. Group 4: Health care workers (HASI-N) (n=4)
 - i. Intervention arm: comparison between pre and post-intervention

a. Group 1: PLWHA (HASI-P)

The intervention and control group were not divided equally from the beginning as a result of study design which is quasi-experimental. At post-intervention the number of PLWHA who participated at baseline had decreased from 93 to 33 only. Eighteen out of 33 were from the intervention and 15 were from the control group. There are 121 participants who had only participated once either at baseline or at the evaluation phase (60 pre-intervention only and 61 post-intervention only) as a result they were excluded from the group comparisons. Therefore, only the results for those who participated at pre- and post-intervention were compared. The number of PLWHA participants at different times is shown in Table5.25.

Table 5.25 Number of PLWHA participants at different times

Groups	Pre-intervention	Post-intervention	Pre-intervention only	Post-intervention only	Pre-and post-intervention
Intervention arm	48	51	30	34	18
Control arm	45	43	30	27	15
Total	93	94	60	61	33

The factors mean scores, which were reported high at baseline survey such as verbal abuse, social isolation and workplace stigma have slightly decreased but fear of contagion had increased from mean 0.1574 to 0.3148 in the intervention arm. Likewise, negative self perception had increased from mean score of 0.0889 with Std Deviation of 0.2928 to mean 0.2667 with Std Deviation of 0.4899. However, in the control arm all mean scores had increased at post-intervention assessment. The data comparisons from both arms pre and post-intervention are presented in tables, intervention arm mean scores are in Table 5.26 and from control arm are in Table 5.27 below.

Table 5.26 Comparison of mean scores from intervention arm pre and post-intervention

Intervention arm scores (n=18)				
Pre-intervention			Post-intervention	
Factors	Mean	Std Deviation	Mean	Std Deviation
Fear of contagion	0.1574	0.3404	0.3148	0.7645
Verbal abuse	1.2183	1.0156	0.6429	0.9654
Social isolation	0.8667	0.8401	0.3083	0.6975
Workplace stigma	0.5000	1.1504	0.1111	0.4714
Negative self perception	0.0889	0.2928	0.2667	0.4899

Table 5.27 Comparison of mean scores from control arm pre and post-intervention

Control arm scores (n=15)				
Pre-intervention			Post-intervention	
Factors	Mean	Std Deviation	Mean	Std Deviation
Fear of contagion	0.4056	0.5535	0.9556	1.1674
Verbal abuse	1.1878	1.0539	1.3524	1.2239
Social isolation	1.2000	1.3374	1.2456	1.2505
Workplace stigma	1.0600	1.1274	1.5000	1.3964
Negative self perception	1.0000	1.1927	1.4267	1.3770

The results from the two arms were compared by using two t-tests, which are **Independent Sample t-test and Paired Samples t-test**. The Independent-Samples t-test was used to test for a difference in the scores between intervention and control arms at baseline survey (pre-intervention) and post-intervention. A Paired Samples t-test was used to evaluate for changes in the scores by comparing the results within groups at pre and post-intervention. The scores of the following: 1) fear of contagion, 2) verbal abuse, 3) social isolation, 4) workplace stigma as well as 5) negative self perception were computed and tested for differences, their results are presented below:

i. Pre-intervention: comparison between intervention and control arms (Independent Samples t-test)

The Independent Samples t-test was used to test for a difference and/or similarities in factors stigma scores experienced by people living with HIV between intervention and control arms.

Fear of contagion: The t-test for a difference between intervention and control arms showed no statistical significant difference at baseline ($p=.12$). The mean score in fear of contagion from intervention arm was 0.1574 with a Std Deviation of 0.3404 and from control was 0.4056 with a Std Deviation of 0.5535.

External stigma

Verbal abuse: When the same test was conducted for verbal abuse score there was no statistical significant difference between intervention and control arm at baseline ($p=0.574$). The mean score of intervention arm was 1.2183 with a Std Deviation of 1.01563 and for the control the mean score was 1.1878, with Std Deviation of 1.0539.

Social isolation: A comparison was made between intervention and control arms in the social isolation score and there was no statistical significant difference between the two arms at baseline survey ($p=0.31$). The mean score from intervention arm was 0.8667 with a Std Deviation of 0.8401 and from control it was 1.2000 with Std Deviation of 1.3374.

Workplace stigma: A comparison of the workplace stigma score between intervention and control groups show no statistical significant difference ($p=0.28$). The mean score from intervention group was 0.5000 with Std Deviation of 1.1504 and from control it was 1.0600 with Std Deviation of 1.1274.

Internal stigma

Negative self perception: The only score that show significant difference between intervention and control arm at baseline was the negative self perception ($p=0.00^*$) that was higher in control. Particularly the mean score from intervention arm was 0.0889 with a Std Deviation of 0.2928 and from control the mean was 1.000 with Std Deviation of 1.1927.

ii. Post-intervention: comparison between intervention and control arm (Independent Samples t-test)

The same factors that were tested for differences at baseline were compared again post-intervention to evaluate the effectiveness of the intervention package and the Independent Samples t-test was used.

External stigma

Fear of contagion: There was no significant difference in fear of contagion score post-intervention ($p=0.068$). The mean score from intervention arm was 0.3148 with Std

Deviation of 0.7645 and mean score from control was 0.9556 with Std Deviation of 1.1674.

Verbal abuse: When the score of verbal abuse was compared between intervention and control arm after intervention the results show no significant difference ($p=0.072$). The mean score from intervention arm was 0.6429 with a Std Deviation of 0.9654 and from control the mean was 1.3524 with Std Deviation of 1.2239.

Social isolation: The results on comparison in social isolation score show that there is statistically significant difference between the two arms after intervention ($p= 0.017^*$). The mean score from intervention arm was 0.3083 with Std Deviation of 0.6975 and from control mean was 1.2456 with Std Deviation of 1.2505.

Workplace stigma: The workplace stigma has decreased in intervention arm as there was a statistical significant difference in score between those who received the intervention and those who did not ($p=0.008^*$). The mean score in work place stigma from intervention arm was 0.1111 with Std Deviation of 0.4714 and mean 1.5000 with Std Deviation of 1.3964 from control.

Internal stigma

Negative self perception: There was a statistical significant difference in negative self perception score between the group who received intervention and those who did not ($p=0.006^*$). The mean score from intervention group was 0.2667 with Std Deviation of 0.4899 and from control the mean was 1.4267 with Std Deviation of 1.3770.

iii. Intervention arm: comparison between pre and post-intervention (Paired Samples t-test)

The Paired Samples t-test was used to test for any change in fear of contagion, verbal abuse, social isolation, workplace stigma and negative self perception scores before and after in the arm that received intervention.

External stigma

Fear of contagion: There was no significant change in fear of contagion score before and after within the arm that received intervention ($p=0.223$). The mean score of fear of contagion before intervention was 0.1574 with Std Deviation of 0.3355 and after intervention it was 0.3148 with Std Deviation of 0.7535.

Verbal abuse: The test for difference in verbal abuse score before and after intervention show a statistical significant difference ($p=0.013^*$). Specifically the mean score before intervention was 1.2183 with Std Deviation of 1.001 and after intervention the mean was 0.6429 with a Std Deviation of 0.9516.

Social isolation: The social isolation score has decreased and shows a statistical significant difference before and after intervention ($p=0.004^*$). The social isolation mean score before intervention was 0.8667 with a Std Deviation of 0.82808 and after the mean was 0.3083 with Std Deviation of 0.6874.

Workplace stigma: The workplace stigma scores show a decrease after intervention, which means that there is a statistical significant difference ($p=0.021^*$). The mean score before intervention was 0.5000 with Std Deviation of 1.13389 and after the mean was 0.1111 with Std Deviation of 0.4646.

Internal stigma

Negative self-perception: The negative self perception score before and after intervention show no statistical significant difference ($p=0.086$). Particularly the mean score before intervention was 0.0889 with Std Deviation of 0.28862 and after the score was 0.2667 with a Std Deviation of 0.4828.

iv. Control arm: comparison between pre and post-intervention (Paired Samples t-test)

The Paired Samples t-test was conducted within the control group to test for a difference in fear of contagion, verbal abuse, social isolation, workplace stigma and negative self perception scores before and after intervention.

External stigma

Fear of contagion: The fear of contagion score has increased after intervention and shows a statistical significant difference in the arm that did not receive intervention on stigma reduction ($p<0.001^*$). The mean score in fear of contagion before intervention was 0.4056 with Std Deviation of 0.5439 and after intervention it was 0.9556 with Std Deviation of 1.1471.

Verbal abuse: There is no significant change in verbal abuse score before and after intervention, the results show no statistical significant difference ($p=0.079$) in the control arm. Specifically the mean score before intervention was 1.000 with Std Deviation of 1.1720 and after the mean was 1.3524 with a Std Deviation of 1.2027.

Social isolation: The social isolation score shows no statistical significant difference before and after intervention in the control arm ($p=0.797$). The social isolation mean score

before intervention was 1.1878 with a Std Deviation of 1.0356 and after the mean was 1.2456 with Std Deviation of 1.2288.

Workplace stigma: There is no significant change in workplace stigma scores before and after intervention in the control arm ($p=0.44$). The mean score before intervention was 1.5000 with Std Deviation of 1.4411 and after the mean was 1.7857 with Std Deviation of 1.3546.

Internal stigma

Negative self-perception: The negative self perception score before and after intervention show no statistical significant difference in the control group ($p=0.107$). Particularly the mean score before intervention was 1.0600 with Std Deviation of 1.1078 and after the score was 1.4267 with a Std Deviation of 1.3531.

PLWHA pre- and post-intervention results

The results of PLWHA revealed significant difference on negative self perception scores between the two arms at baseline, as it scored higher in the control than in the intervention. After intervention verbal abuse, social isolation, work place stigma have decreased in the arm that received intervention but there were no significant changes in fear of contagion and negative self perception. In the control arm fear of contagion has increased but there were no significant changes in verbal abuse, social isolation, workplace stigma and negative self perception scores.

b. Group 2 & 3: Family members and community leaders (combined) (F&C-SI)

The number of family and community members who participated has decreased from 127 to 105 at evaluation phase of the study. Out of 105 participants only 37 have participated

before and after, 20 are from intervention group while 17 are from control their results are compared and presented below. As the number of community leaders has decreased to four their results are combined together with group two (families) to enable the researcher to do data analysis and comparisons (they used the same measurement instrument).

The mean scores of family members and community leaders from intervention and control groups before and after intervention are presented in Table 5.28 and Table 5.29 respectively. The results show that most scores were higher in the control than in the intervention arm at baseline except for 'caring' which has a mean of 1.0471 and Std Deviation of 0.0874 in the control but in the intervention mean was 1.0842 with Std Deviation of 0.1675. Overall the results show slightly changes and differences from both groups after intervention, few scores decreased while some increased. For example fear of contagion mean score remained the same in intervention group 1.000 with Std Deviation of 0.000 but it has increased in the control from mean 1.0196 with Std Deviation of 0.0808 to mean 1.0784 with Std Deviation of 0.2214 after intervention.

Independent Samples t-test and Paired-Samples t-test were conducted to evaluate the significant difference between the two arms and within the groups before and after intervention. The scores of these factors: 1) community attitude, 2) family attitude, 3) personal attitude, 4) households stigma, 5) community opinions, 6) close relationship, 7) caring and 8) fear of contagion were tested and compared.

Table 5.28 Mean scores from intervention arm of family and community leaders pre and post-intervention

Intervention group scores (n=20)				
Factors	Pre-intervention		Post-intervention	
	Mean	Std Deviation	Mean	Std Deviation
Community attitude	2.2750	0.6829	2.5625	0.9796
Family attitude	2.0875	0.7480	2.6875	1.0602
Personal attitude	2.2875	0.6751	2.3750	0.5987
Household stigma	1.6563	0.7925	1.7991	0.7061
Community opinion	1.3250	0.4299	1.7875	0.9186
Close relationship	1.2000	0.2991	1.1250	0.2221
Caring	1.0842	0.1675	1.0600	0.1142
Fear of contagion	1.0000	0.000	1.000	0.000

**i. Pre-intervention: comparison between intervention and control arm
(Independent Samples t-test)**

The Independent Samples t-test was used to test for a difference in stigma scores between intervention and control arms.

External stigma

Community attitude towards PLWHA: the independent t-test for difference in community attitudes scores from family members and community leaders was conducted to compare results from intervention and control arms at baseline. There was no statistical significant difference between the arms ($p=0.206$). Particularly the mean score of intervention arm was 2.2750 with a Std Deviation of 0.6829 and for the control arm the mean score was 2.6471, with Std Deviation of 1.0041.

Family attitude towards PLWHA: There is no significant difference between the two arms in family attitude towards PLWHA at baseline ($p=0.324$). The family attitude mean score from intervention arm was 2.0875 with a Std Deviation of 0.7480 and from control mean was 1.1217 with Std Deviation of 2.5735.

Personal attitude towards PLWHA: When the two arms were compared there was no statistical significant difference in personal attitude towards PLWHA score between those received intervention and those who did not ($p=0.911$). The mean from intervention arm was 2.2875 with a Std Deviation of 0.6751 and from control the mean was 2.3088 with Std Deviation of 0.4195.

Household stigma: There was no significant difference in household stigma score between the two arms at baseline ($p=0.495$). The mean score from intervention arm was 1.6563 with a Std Deviation of 0.7925 and from control mean was 1.8183 with Std Deviation of 0.6029.

Community opinions regarding PLWHA: The results of comparisons show that there was no significant difference in community opinions score between the two arms at baseline survey ($p=0.092$). The mean from intervention arm was 1.3250 with Std Deviation of 0.4299 and from control the mean was 1.6765 with Std Deviation of 0.7794.

Close relationship with PLWHA: The results of those who were asked if they have a close relative or friend who is living with HIV/AIDS did not show significant difference between the two arms ($p=0.354$). The mean from intervention group was 1.2000 with a Std Deviation of 0.2991 and from control mean was 1.2941 with Std Deviation of 0.3091.

Caring for sick relative: There was no significant difference in willingness to care for sick PLWHA relative or friend score between intervention and control arm ($p=0.418$). The mean from intervention arm was 1.0842 with a Std Deviation of 0.1675 and from control the mean was 1.0474 with Std Deviation of 0.0874.

Fear of contagion: The results from comparison test show that there is no significant difference between the two arms with regard to fear of HIV infection through non-sexual casual contacts (p=0.332). The mean from intervention arm was 1.000 with Std Deviation of 0.000 and from control mean was 1.0196 with Std Deviation of 0.0808.

Table 5.29 Mean scores from control arm of family and community leaders pre and post-intervention

	Control group scores (n=17)			
	Pre-intervention		Post-intervention	
Factors	Mean	Std Deviation	Mean	Std Deviation
Community attitude	2.6471	1.0041	2.3971	0.8362
Family attitude	2.3971	1.1217	2.5735	0.9951
Personal attitude	2.3088	0.4195	2.3824	0.5528
Household stigma	1.8183	0.6029	2.4149	0.8305
Community opinion	1.6765	0.7794	1.9412	0.7832
Close relationship	1.2941	0.3091	1.1176	0.2811
Caring	1.0471	0.0874	1.1529	0.2960
Fear of contagion	1.0196	0.0808	1.0784	0.2214

**ii. Post-intervention: comparison between intervention and control arm
(Independent Samples t-test)**

Independent samples t-test was conducted to test for a difference in scores between the two arms after intervention.

External stigma

Community attitude towards PLWHA: There was no statistical significant difference in community attitude towards PLWHA between the two arms after intervention ($p=0.413$). The mean score from intervention arm was 2.5625 with a Std Deviation of 0.9796 and mean from control was 2.3971 with Std Deviation of 0.8362.

Family attitude towards PLWHA: There was no significant difference in family attitude towards PLWHA score between intervention and control arm at the final assessment ($p=0.584$). The mean from intervention arm was 2.6875 with Std Deviation of 1.0602 and mean from control was 2.5735 with Std Deviation of 0.9951.

Personal attitude towards PLWHA: When the test was conducted for difference in personal attitude towards PLWHA score between the two arms after intervention it showed no significant difference ($p=0.857$). The mean from intervention arm was 2.3750 with a Std Deviation of 0.5987 and mean from control was 2.3824 with a Std Deviation of 0.5528.

Household stigma: After intervention there was a statistical significant difference between the two arms in household stigma score ($p=0.017^*$). Particularly the mean from intervention arm was 1.7991 with Std Deviation of 0.7061 and mean from control was 2.4149 with Std Deviation of 0.8305.

Community opinions: There was no significant difference in community opinions regarding PLLWHA score between the two arms after intervention ($P=0.385$). The mean from intervention arm was 1.7875 with Std Deviation of 0.91865 and mean from control was 1.9412 with Std Deviation of 0.7832.

Close relationship with PLWHA: There was no significant difference with regard to those who have a close relative or friend who is living with HIV or AIDS between those from intervention and control arms ($p=0.809$). The mean from intervention arm was

1.1250 with a Std Deviation of 0.2221 and mean from control was 1.1176 with Std Deviation of 0.2811.

Caring for sick relative PLWHA: The results were compared for caring score and there was no significant difference between the two arms ($p=0.261$). The mean from intervention arm was 1.0660 with Std Deviation of 0.1142 and mean from control was 1.1529 with Std Deviation of 0.2960.

Fear of contagion: There was no significant difference between the two arms after intervention in fear of contagion score ($p=0.163$). The mean from intervention group was 1.000 with Std Deviation of 0.000 and mean from control was 1.0784 with Std Deviation of 0.2214.

iii. Intervention arm: comparison between pre and post-intervention (Paired Samples t-test)

A Paired Samples t-test was conducted to evaluate the effectiveness of the intervention on family and community members from the intervention arm.

External stigma

Community attitude towards PLWHA: The results show that there was no statistical significant difference in community attitude scores before and after intervention among those who received the intervention ($p=0.097$). The mean before intervention was 2.2750 with Std Deviation of 0.67416 and the mean after intervention was 2.5625 with Std Deviation of 0.96700.

Family attitude towards PLWHA: There is statistical significant difference in family attitude towards PLWHA scores between before and after intervention ($p=0.002^*$). The mean score before intervention was 2.0875 with a Std Deviation of 0.7383 and mean after intervention was 2.6875 with Std Deviation of 1.0465.

Personal attitude towards PLWHA: There was no statistical significant difference in personal attitude towards PLWHA before and after intervention ($p=0.556$). The mean at baseline was 2.2875 with a Std Deviation of 0.6663 and mean after intervention was 2.3750 with Std Deviation of 0.5910.

Household stigma: There was no statistical significant difference in the household stigma score before and after intervention ($p=0.364$). The mean before intervention was 1.6563 with Std Deviation of 0.7822 and mean after intervention it was 1.799 with Std Deviation of 0.6970.

Community opinion on PLWHA: There was a statistical significant difference in community opinion score before and after intervention ($p=0.004^*$). At baseline mean was 1.3250 with Std Deviation of 0.4244 and after intervention mean has increased to 1.7875 with Std Deviation of 0.9067.

Close relationship with PLWHA: The scores on participants who have close relative with HIV/AIDS the results show no statistical significant difference between the two times ($p=0.205$). At baseline mean was 1.2000 with Std Deviation of 0.2952 and mean after intervention was 1.1250 with Std Deviation of 0.2192 after intervention.

Caring for sick relative PLWHA: The willingness to care for sick PLWHA relatives did not show statistical significant difference before and after intervention ($p=0.324$). At baseline the mean score was 1.0842 with Std Deviation of 0.1652 and after intervention the mean was 1.0632 with Std Deviation of 0.1148. There was no difference before and after intervention as the fear of contagion score remained the same and could not be computed.

iv. Control arm: comparison between pre and post-intervention (Paired Samples t-test)

A Paired Samples t-test was conducted to test for a difference in stigma scores before and after intervention in the control arm.

External stigma

Community attitude towards PLWHA: There is a statistical significant increase in community attitude scores from baseline ($p < 0.000^*$). At baseline the mean score was 2.6471 with Std Deviation of 0.9888 and at the end line the mean was 3.7353 with Std Deviation of 0.5982.

Family attitude towards PLWHA: The family attitude score show a statistical significant difference before and after intervention in the control arm ($p < 0.00^*$). Particularly the mean score at baseline was 2.3971 with Std Deviation of 1.1046 and at post-intervention assessment the mean was 3.4265 with Std Deviation of 0.6322.

Personal attitude towards PLWHA: The test for a difference in personal attitude score show a statistical significant increase from baseline to post-intervention assessment ($p < 0.00^*$). The mean score at baseline was 2.3088 with Std Deviation of 0.4131 and at end line it has increased to mean 3.6765 with Std Deviation of 0.4905.

Household stigma: The test for a difference in household stigma score show a statistical significant increase in the control arm post-intervention ($p < 0.00^*$). Particularly the mean score at baseline was 1.8183 with Std Deviation of 0.59376 and post-intervention the mean score was 4.0116 with Std Deviation of 0.4410.

Community opinion on PLWHA: The test for a difference in community opinions towards PLWHA score show a statistical significant increase as it increased at post-intervention ($p = 0.012^*$). The mean score at baseline was 1.6765 with Std Deviation of 0.7675 and at evaluation survey the mean score was 2.1373 with Std Deviation of 0.6590.

Close relationship with PLWHA: The test for a difference in family and community members who have close relatives with HIV/AIDS score did not show a statistical significant difference before and after intervention ($p=0.103$). The mean score was 1.2941 with Std Deviation of 0.3044 before and has decreased to mean of 1.1765 with Std Deviation of 0.2985 after intervention.

Caring for sick PLWHA: The test for a difference in caring score at baseline and end line show no statistical significant difference ($p=0.171$). Particularly the mean score at baseline was 1.0471 with Std Deviation of 0.0861 and at post-intervention the mean score was 1.1029 with Std Deviation of 0.2470.

Fear of contagion: The test for a difference in fear of contagion scores at baseline and end line show a statistical increase ($p=0.005^*$). The mean score at baseline was 1.0196 with Std Deviation of 0.0796 and at evaluation survey the mean score was 1.1373 with Std Deviation of 0.2029.

Family and community leaders' results

There was no statistical significant difference in the stigma scores between the two arms at baseline survey. At post-intervention the only significant difference was in household stigma score that was decreased in the intervention arm. The results from the Paired-Samples test from intervention arm show a significant difference in family attitude towards PLWHA as well as in community opinion after intervention. From the control arm most of the mean scores show significant increase at post-intervention assessment except for close relationship and caring for sick PLWHA relatives.

c. Group 4: Health care workers (HASI-N)

Four health care workers consisted of one nursing assistant, one enrolled nurse, one Registered nurse and one community counsellor participated in this study. Their questionnaire measured two variables, which were nurse stigmatising patients and nurses being stigmatised by other people. Health care workers had no control group due to absence of ARV clinic in the west community side. The baseline and evaluation surveys were conducted with one group of health care workers from that same clinic. Therefore, only Paired-Samples t-test was conducted to evaluate any change in the stigma scores within the group before and after intervention.

With regard to healthcare workers stigmatising patients, the results in Table 5.30 revealed presence of stigma after intervention, although it was not reported at baseline survey. Two participants reported experienced a nurse scolded a patient and another one who made patient to wait for care on the basis of HIV status. There is also slightly increase on stigma of association towards health care workers post-intervention as three of them reported the fear of spouses and people say that nurses get HIV by taking care of PLWHA. For example one participant reported that people say that nurses who provide HIV care are positive too.

Table 5.30 Mean scores of health care workers stigma

Factors	Pre-intervention (n=4)		Post-intervention (n=4)	
	Mean	Standard deviation	Mean	Standard deviation
Nurse stigmatising patient	0.000	0.000	0.075	0.0886
Community stigmatizing nurses	0.1389	0.1543	0.2778	0.1969

i. Intervention arm: comparison between pre and post-intervention

A Paired-samples t-test was conducted to test for a difference in nurse stigmatising patient score before and after intervention.

External stigma

Nurse stigmatising patient: The results show that there is a statistical significant difference before and after intervention in nurse stigmatising patient score ($p=0.048^*$).

The mean score before intervention was 0.00 with a Std Deviation of 0.00 and after intervention it was 0.0750 with Std Deviation of 0.0886.

Stigma of association

Community stigmatizing nurses: There is a statistical significant difference in nurse being stigmatized score before and after intervention ($p=0.005^*$). The mean score before intervention was 0.1389 with Std Deviation of 0.1543 and after intervention the mean score was 0.2778 with Std Deviation of 0.1969.

Health care workers results

The results from health care workers revealed a statistical significant increase in both ‘nurses stigmatising patients’ and ‘community stigmatizing nurses’ scores at evaluation phase. They show that health care workers experienced stigma of association as a result of misconception in the community as well as fear from spouses that nurses who care for PLWHA patients can be infected during the course of their work and bring the virus to their families.

5.5 RESULTS OF POST-INTERVENTION GROUPS ONLY

Six months after intervention, an assessment was done to evaluate if there was any change in the level of HIV/AIDS stigma in rural community as well as to determine the impact of intervention. It was mentioned in the introduction of this chapter that 129 participants have only participated after intervention therefore their results are presented separately as post-intervention groups only without any comparison. Sixty one of that group were PLWHA, 34 are from intervention site and 27 are from control. There are 68 family and community leaders consist of 34 from intervention (East site) and another 34 from control (West site). The number of community leaders was less, therefore their results are combined with family members and presented jointly, and they have used the same instrument (F&C-SI). As a result of too many tables in this chapter some findings are presented only in summaries and they are in this order:

- a. Group 1: PLWHA intervention arm (n=34)
- b. Group 1: PLWHA control arm (n=27)
- c. Group 2 &3: Family members and community leaders intervention arm (n=34)
- d. Group 2&3: Family members and community leaders control arm (n=34)

a. Group 1: PLWHA Intervention arm

Thirty four PLWHA from east site had only participated after the intervention, majority of this group were women (65%), their age ranges between 19-49 with a mean of 36.4706 and a standard deviation of 9.6804 and they are all Christians. The descriptive results in Table5.31 revealed that verbal abuse was most experienced by this group followed by social isolation and fear of contagion through casual contacts. Negative self perception was less experienced with a mean of 0.1647 and standard deviation of 0.2890. The least experienced stigma was at the workplace.

Table5.31 Mean scores of stigma experienced by PLWHA (intervention arm)

Factors	No.	Mean	Std Deviation
Fear of contagion	34	0.2402	0.4753
Verbal abuse	34	0.5840	0.8752
Social isolation	34	0.3912	0.6947
Workplace stigma	34	0.1061	0.3481
Negative self perception	34	0.1647	0.2890

External stigma

Four factors were used to measure external stigma experienced by PLWHA from **intervention arm** include fear of contagion, verbal abuse, social isolation and work place stigma.

Fear of contagion: With regard to fear of getting HIV through non-sexual contact, the item of ‘was asked to leave due to coughing’ scored the highest with 27% (12% and 15%). Twelve percent reported being made to eat alone or drink last from the cup. Majority of participants (73% to 94%) reported that never experienced it.

Table 5.32 Frequencies of experienced stigma due to fear of contagion

Items	No.	Never	Once or twice	Several times and most of the time
I was told to use my own eating utensils	34	91%	3%	6%
I was told not to touch someone's child	34	94%	0%	6%
I was made to drink last from the cup	34	88%	6%	6%
I stopped eating with other people	34	94%	0%	6%
I was made to eat alone	34	88%	0%	12%
I was asked to leave because I was coughing	34	73%	12%	15%

Verbal abuse: The findings show 20% (n=7) to 24% (n=8) of participants who reported experienced verbal abuse in the form of name calling, sing offensive songs, judgment and blaming either several times or most of the time.

Table 5.33 Frequencies of verbal abuse as experienced by PLWHA

Items	No.	Never	Once or twice	Several times and most of the time
I was called bad names.	34	65%	15%	20%
People sang offensive songs when I passed by.	34	73%	3%	24%
I was told that I have no future.	34	76%	18%	6%
Someone scolded me.	34	65%	15%	20%
I was told that God is punishing me.	34	73%	6%	21%
Someone insulted me.	34	71%	12%	17%
I was blamed for my HIV status.	34	79%	0%	21%

Social isolation: Stigma in the form of social isolation was experienced by 21% (6% and 15%) of participants who reported that they were avoided by others and another 21% (3% and 18%) indicated that people did not want to chat with them. There are 15% who confirmed that people end their relationships, friendships as well as cut visits.

Table 5.34 Frequencies of experienced stigma in the form of social isolation

Factor items	No.	Never	Once or twice	Several times and most of the time
Someone stopped being my friend.	34	85%	6%	9%
A friend would not chat with me.	32	73%	3%	18%
People avoided me.	33	76%	6%	15%
People cut down visiting me.	34	85%	0%	15%
People ended their relationship with me.	34	85%	0%	15%

Workplace stigma: With regard to stigma at workplace only 9% (n=3) of participants reported that someone tried to fire them from their job. The majority of participants reported that they were never denied opportunities and none tried to fire them as a result of their HIV status.

Internal stigma

The self stigma experienced by PLWHA from **intervention arm** was measured with one factor which is negative self perception.

Negative self perception (intervention arm): Regarding self stigma 9% (n=3) of participants reported that they felt not deserve to live, 12% (n=4) (3% and 9%) ashamed of being HIV positive, while 15% (n=5) (3% and 12%) revealed that they felt brought trouble to their families. None participants have reported being felt worthless due to being HIV positive.

Table 5. 35 Frequencies of negative self perception among PLWHA

Factor items	No.	Never	Once or twice	Several times and most of the time
I felt that I did not deserve to live.	34	91%	0%	9%
I felt ashamed of having this disease.	34	88%	3%	9%
I felt completely worthless.	34	100%	0%	0%
I felt that I brought a lot trouble to my family.	34	85%	3%	12%
I felt that I am no longer a person.	34	100%	0%	0%

b. Group1: PLWHA Control arm

Twenty seven PLWHA from control arm only participated after the intervention. The majority of this group were women (63%, n=17), their age ranges between 27-52 with a mean of 38.5556 and a standard deviation of 8.1492 and they are all Christians. The descriptive results in Table5.36 revealed that verbal abuse was most experienced by this group followed by social isolation and negative self perception. Workplace stigma was less experienced with a mean of 0.8043 and standard deviation of 1.18455. The least experienced stigma was fear of contagion with mean of 0.6796 and standard deviation of 0.9403.

Table5.36 Mean scores of stigma experienced by PLWHA from control arm

Factors	No.	Mean	Std Deviation
Fear of contagion	27	0.6796	0.9403
Verbal abuse	27	1.4832	1.1235
Social isolation	27	1.2130	1.0627
Workplace stigma	23	0.8043	1.1845
Negative self perception	27	1.2056	1.2594

External

The four main factors which are fear of contagion, verbal abuse, social isolation and work place stigma were used to measure stigma experienced by PLWHA who participated at post-intervention only from the **control arm**.

Fear of contagion: The results in Table5.37 revealed that PLWHA experienced stigma due to fear of getting the virus through non-sexual casual contacts such as using same utensils, it is reported by 34% (n=9) (4% and 30%) another 33% (n=8) (7% and 26%) who indicated that they were asked to drink last from the cup. There are 37% (n=10)(19% and 18%) who confirmed that they were asked to leave as a result of coughing.

Table 5.37 Frequencies of experienced stigma due to fear of contagion

Items	No.	Never	Once or twice	Several times and most of the time
I was told to use my own eating utensils	27	66%	4%	30%
I was told not to touch someone's child	26	74%	4%	19%
I was made to drink last from the cup	26	63%	7%	26%
I stopped eating with other people	26	67%	7%	22%
I was made to eat alone	26	67%	11%	19%
I was asked to leave because I was coughing	27	63%	19%	18%

Verbal abuse: Stigma in the form of verbal abuse was reported high as more than half of participants experienced it in different ways either once/twice, several times or most of time. The item of being called names scored the highest as there are 70% (n=19) (4% and 66%) of participants who indicated it.

Table 5.38 Frequencies of verbal abuse as experienced by PLWHA

Items	No.	Never	Once or twice	Several times and most of the time
I was called bad names.	27	30%	4%	66%
People sang offensive songs when I passed by.	27	37%	4%	59%
I was told that I have no future.	26	30%	11%	55%
Someone scolded me.	27	37%	22%	41%
I was told that God is punishing me.	27	44%	4%	52%
Someone insulted me.	27	41%	4%	55%
I was blamed for my HIV status.	27	48%	0%	52%

Social isolation: With regard to social isolation 63% (n=17) (4% and 59%) of participants reported that people avoided them, more than 40% (n=11) reported that friends stopped their friendship as well as ended relationships. The results in Table 5.39 revealed that people do not want to chat with those who have HIV or AIDS as it was indicated by 45% (n=12) (4% and 41%) of participants.

Table 5.39 Frequencies of experienced stigma in the form of social isolation

Items	No.	Never	Once or twice	Several times and most of the time
Someone stopped being my friend.	27	48%	15%	37%
A friend would not chat with me.	27	48%	4%	41%
People avoided me.	27	37%	4%	59%
People cut down visiting me.	26	55%	4%	37%
People ended their relationship with me.	27	48%	11%	41%

Workplace stigma: Work place stigma was less experienced, however 22% (n=6) of participants reported that someone tried to fire them and 26% (n=7) indicated that they were denied opportunities by their employers.

Internal stigma

Internal stigma experienced by PLWHA post-intervention group only from **control arm** was measured using negative self perception factor.

Negative self perception: The majority 59% (n=16) (55% and 4%) of participants reported that they felt that they brought trouble to their families, 45% (n=12) (41% and 4%) confirmed feeling that they do not deserve to live and 48% (n=13) (41% and 7%) felt worthless.

Table 5.40 Frequencies of negative self perception among PLWHA

Factor items	No.	Never	Once or twice	Several times and most of the time
I felt that I did not deserve to live.	27	55%	4%	41%
I felt ashamed of having this disease.	27	59%	19%	22%
I felt completely worthless.	27	52%	7%	41%
I felt that I brought a lot trouble to my family.	27	41%	4%	55%
I felt that I am no longer a person.	26	59%	0%	37%

c. Group 2 & 3: Family members and community leaders Intervention arm

The group of post-intervention only consisted of 30 family members and four community leaders who did not participate at baseline survey and majority of them (71%, n=24) are women, their age range from 25-77 years with a mean of 46.6471 and a standard deviation of 14.0537 and all are Christians. Sixty one percent (n=21) had primary education and only 8% (n=3) had completed tertiary level.

The results in Table 5.41 revealed that attitude scores are high than the other scores. For example the community attitude score has mean of 2.7955 with Std Deviation of 1.0959 and family attitude score has mean of 2.6515 with Std Deviation of 1.0566. Personal attitude mean score was 2.4394 with standard deviation of 0.5797. However, household stigma is low with mean of 1.7370 and standard deviation of 0.7351. Most participants are willing to care for sick PLWHA relatives and fear of getting HIV through non-sexual contacts is low among family members from the intervention site.

Table 5.41 Mean scores of stigma as reported by families and community leaders

Factors	N	Mean	Std Deviation
Community attitude	33	2.7955	1.0959
Family attitude	33	2.6515	1.0566
Personal attitude	33	2.4394	0.5797
Household stigma	34	1.7370	0.7351
Community opinion	32	1.5313	0.8000
Close relative PLWHA	32	1.0313	0.1229
Caring for sick PLWHA	34	1.0309	0.0904
Fear of contagion	33	1.000	0.000

External stigma

External stigma against PLWHA reported by family members and community leaders from **intervention arm** (post-intervention only) was measured with eight factors including community attitude, family attitude and personal attitude towards PLWHA, household stigma, community opinions to PLWHA, close relationship with PLWHA, caring for sick, PLWHA and fear of contagion through non-sexual contacts.

Community attitude towards PLWHA: With regard to community attitude towards persons who are HIV positive, 77% (n=26) (38% agree and 39% strongly agree) of participants agreed that PLWHA are treated the same like everybody else, 53% (n=18) (41% agree and 12% strongly agree) confirmed that they are treated with more sympathy. On the item of isolation from or by other members, 44% (n=12) (35% strongly disagree and 9% disagree) disagreed, while 15% (n=4) were unsure but 21% (n=6) (15% agree and 6% strongly agree) confirmed that they are being isolated.

Table 5.42 Different views regarding to community attitude

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
They are just treated like everybody else *	33	32%	6%	3%	38%	39%
They are treated with more sympathy than everybody else *	32	26%	9%	6%	41%	12%
They are isolated from other members of the community	27	35%	9%	15%	15%	6%
They are mistreated by other members of the community	28	26%	15%	12%	26%	3%

Family attitude towards PLWHA: The results revealed that 76% (n=25) (47% agree and 29% strongly agree) of family members and community leaders confirmed that a person who is HIV positive or has AIDS is treated the same like everybody else in the household. There are 38% (n=11) (29% strongly disagree and 9% disagree) who disagreed that they are not treated with more sympathy. Twenty four percent (n=8) (18% agree and 6% strongly agree; 12% disagree and 12% strongly disagree) confirmed that PLWHA are isolated by others and they are mistreated by families and friends.

Table 5.43 Different views of participants with regard to family attitude to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
She or he is just treated like any other family member*	33	21%	0%	0%	47%	29%
She or he is treated with more sympathy *	31	29%	9%	15%	21%	18%
She or he is isolated from family members and friends	32	41%	12%	18%	18%	6%
She or he is mistreated by family and friends	32	41%	6%	23%	12%	12%

Personal attitude towards PLWHA: The findings indicate 61% (38% agree and 23% strongly agree) who are in agreement that PLWHA should be offered more sympathy and moral support. Majority of participants 79% (n=24) (73% strongly disagree and 6% disagree) indicated their disagreement on PLWHA isolation from other or by community members. There are different opinions with regard to HIV disclosing as 44% (n=14) (35% agree and 9% strongly agree) of participants agreed that it should be kept private, while 41% (n=13) (38% strongly disagree and 3% disagree) confirmed that it is not necessary to tell others.

Household stigma: The findings on household stigma indicate that majority of participants between 67% and 97% are in disagreement with negative statement such as PLWHA should not share blankets, be kept away from visitors, not cook for the family and not play with the children. There are 21% and 24% (18% and 6%) of participants who did not agree with inclusion of PLWHA in family decision making, sharing meals and blankets with other households.

Table 5.44 Different views with regard to personal attitude to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
People who have HIV or AIDS should be offered more sympathy and moral support*	32	23%	6%	3%	38%	23%
People who have HIV or AIDS should be separated from other members of the community	31	73%	6%	6%	6%	0%
If a person knows that she or he is HIV positive she or he should keep it private	32	32%	9%	9%	35%	9%
A person who has HIV or AIDS should tell others	32	38%	3%	6%	26%	21%

Table 5.45 Different views of participants with regard to household stigma

Frequencies in %						
Items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
A person who has HIV or AIDS can share blankets with other households*	34	21%	0%	0%	50%	29%
A person who has HIV or AIDS should use separate blankets	34	79%	18%	0%	3%	0%
A family member who has HIV or AIDS should be left out of family discussions and decision making	34	82%	3%	6%	9%	0%
A family member who has HIV or AIDS should be included in family discussions and decision making*	33	18%	6%	0%	26%	47%
A family member who has HIV or AIDS should stay away from visitors	32	79%	9%	0%	6%	0%
A family member who has HIV or AIDS cannot cook for the family	32	62%	12%	6%	12%	3%
A family member who has HIV or AIDS should share meals with other households*	31	21%	0%	3%	38%	29%
A family member who has HIV or AIDS should not play with children	32	76%	12%	3%	3%	0%

Community opinions on PLWHA: The results in Table 5.46 show that majority of participants between 77% and 85% confirmed that teachers and learners who are HIV positive can be allowed to attend school and PLWHA can attend community gatherings like any other person as well as should not be dismissed from work upon disclosing their status.

Table 5.46 Different views with regard to community opinions to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
Teachers who have HIV or AIDS can be allowed to teach at schools*	31	15%	0%	0%	15%	62%
Students or learners who have HIV or AIDS should not be allowed to attend school	32	76%	9%	0%	3%	6%
A person who has HIV or AIDS should not attend community gatherings such as weddings	32	79%	0%	3%	6%	6%
A person who has HIV or AIDS should be dismissed from his or her work upon disclosing his or her HIV status	32	79%	6%	0%	3%	6%

Close relationship with PLWHA: The findings indicate that all participants (94%) who responded on the question about close relationship with PLWHA indicated that they have a relative or friend who is HIV positive or has AIDS. Two participants did not respond to this question.

Caring for sick PLWHA: The majority (91% to 97%) of family members and community leaders participants indicated that they would be willing to take care of a HIV positive person family member or relative who is sick with malaria, TB, diarrhoea and/or was involved in accident but 3% revealed that they would not take care of a person who has TB or diarrhoea. There are 9% who reported that most families in their community would not be willing to care for PLWHA. Two to three participants (6%-8%) opted not to complete some of the questions.

Fear of contagion: The results revealed that there is no fear of contagion through day-to-day casual contacts reported by family members who participated after intervention from the intervention site, although two participants opted not to answer.

d.Group2: Family members and community leaders post-intervention only Control arm

There are 34 participants consisted of 32 family members and two community leaders from control site who participated only after intervention but did not take part at baseline survey. Out of this number 71% of them are women, their age range between 23-79 with a mean of 44.79 and Std Deviation of 13.8734 and they are all Christians.

The factor of community attitude towards PLWHA scored the highest with a mean of 2.7353 and Std Deviation of .98076, followed by family with a mean of 2.4265 with a Std Deviation of 0.80606. The household stigma has a mean of 2.1056 with Std Deviation of 0.54924 and fear of contagion is the least with a mean of 1.1176 with Std Deviation of 0.25797.

External stigma

External stigma against PLWHA reported by family members and community leaders from **control arm** (post-intervention only) was measured with eight factors including community attitude, family attitude and personal attitude towards PLWHA, household stigma, community opinions to PLWHA, close relationship with PLWHA, caring for sick, PLWHA and fear of contagion through non-sexual contacts.

Community attitude towards PLWHA: With regard to community attitude, 38% (29% and 9%) of participants revealed that PLWHA are not treated the same in the community,

another 62% (6% and 56%) reported that they are not treated with more sympathy. There are 67% (64% and 3%) and 59% (50% and 9%) who reported that PLWHA are neither isolated nor mistreated by other members of the community.

Table 5.47 Mean scores of stigma by families and community leaders from control arm

Factors	No.	Mean	Std Deviation
Community attitude towards PLWHA	34	2.7353	0.98076
Family attitude towards PLWHA	34	2.4265	0.80606
Personal attitude towards PLWHA	34	2.2377	0.48075
Households stigma	34	2.1056	0.54924
Community opinion	33	1.8712	0.64384
Close relationship with PLWHA	34	1.1471	0.23125
Caring for sick PLWHA	34	1.1588	0.22978
Fear of contagion	34	1.1176	0.25797

Table 5.48 Different views of participants regarding to community attitude

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
They are just treated like everybody else *	34	29%	9%	0	15%	47%
They are treated with more sympathy than everybody else *	32	56%	6%	6%	20%	12%
They are isolated from other members of the community	34	64%	3%	9%	6%	12%
They are mistreated by other members of the community	34	50%	9%	3%	14%	17%

Family attitude towards PLWHA: With regard to family attitude 76% (53% and 23%) agreed that PLWHA are treated the same in their families, while 53% reported that they

are treated with more sympathy. There are 71% (59% and 12% as well as 65% and 6%) of participants who indicated that PLWHA are neither isolated nor mistreated by family members.

Table 5.49 Different views with regard to family attitude to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
She or he is just treated like any other family member*	34	18%	3%	3%	23%	53%
She or he is treated with more sympathy *	34	17%	23%	6%	0	53%
She or he is isolated from family members and friends	34	59%	12%	6%	9%	14%
She or he is mistreated by family and friends	34	65%	6%	3%	12%	14%

Personal attitude towards PLWHA: The findings in Table 5.50 show that majority of participants (91%=82% + 9%) are against the separation of PLWHA from other members of the community. With regard to disclosing of HIV status, 55% (41% and 15%) agreed that it should be kept private, while 35% (23% and 12%) indicated that they should tell other people.

Table 5.50 Different views with regard to personal attitude to PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
People who have HIV or AIDS should be offered more sympathy and moral support*	34	18%	3%	0	44%	35%
People who have HIV or AIDS should be separated from other members of the community	33	82%	9%	3%	0	3%
If a person knows that she or he is HIV positive she or he should keep it private	34	23%	15%	6%	41%	15%
A person who has HIV or AIDS should tell others	34	53%	9%	3%	23%	12%

Household stigma: With regard to household stigma, results in Table 5.51 show that majority of participants disagree with negative statements such as use of separate blankets, left out of family discussions and kept away from visitors. There are 41% who agreed that PLWHA cannot cook for the family and another 47% who agreed that they should not play with children.

Table 5.51 Different views of participants with regard to household stigma

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
A person who has HIV or AIDS can share blankets with other households*	34	12%	12%	6%	41%	29%
A person who has HIV or AIDS should use separate blankets	33	76%	6%	3%	9%	3%
A family member who has HIV or AIDS should be left out of family discussions and decision making	34	41%	17%	0%	35%	6%
A family member who has HIV or AIDS should be included in family discussions and decision making*	34	12%	0%	9%	9%	71%
A family member who has HIV or AIDS should stay away from visitors	34	85%	6%	0%	3%	6%
A family member who has HIV or AIDS cannot cook for the family	33	32%	9%	15%	32%	9%
A family member who has HIV or AIDS should share meals with other households*	34	12%	0%	3%	18%	67%
A family member who has HIV or AIDS should not play with children	32	29%	9%	9%	32%	15%

Community opinion regarding PLWHA: The results revealed that majority of participants 74%, n=25 (9% agree and 65% strongly agree) agreed with the statement that teachers who are HIV positive should be allowed at schools. There are between 56%

(n=18) and 82% (n=27) who disagreed with statements, which say that learners who are HIV positive should not go to school, PLWHA not attend community gatherings, should be dismissed from work once disclosing their status. However, there are 32% (n=11) of participants who strongly agree that learners should not allowed to go to school if they are HIV positive or has AIDS.

Table 5.52 Different views with regard to community opinions on PLWHA

Frequencies in %						
Factor items	No.	Strongly disagree	Disagree	Unsure	Agree	Strongly agree
Teachers who have HIV or AIDS can be allowed to teach at schools*	34	12%	0%	12%	9%	65%
Students or learners who have HIV or AIDS should not be allowed to attend school	33	50%	6%	9%	0%	32%
A person who has HIV or AIDS should not attend community gatherings such as weddings	33	79%	3%	3%	3%	9%
A person who has HIV or AIDS should be dismissed from his or her work upon disclosing his or her HIV status	33	79%	3%	3%	3%	9%

Close relationship with PLWHA: There were 97% (n=33) of participants who indicated that they have close relatives who were either HIV positive or have AIDS, and 73% (n=25) live in the same house with PLWHA.

Caring for sick PLHWA: The majority (82%, n=28) of family members and community leaders indicated that they would be willing to take care of a HIV positive person family member or relative who is sick with malaria, TB, diarrhoea and/or was involved in accident, but 18%(n=6) revealed that they will not. Ninety seven percent indicated that they will take care of a relative/ family member who is sick with Malaria, 94% (n=32) will take care for someone who has TB while 76% (n=26) are willing to care for a person who

has diarrhoea. There are 24% (n= 8) who reported that they will not take care of someone who has diarrhoea.

Fear of contagion: The findings show less fear of getting HIV through day-to-day casual contacts as 79% (n=27) are willing to share toilet, 94% (n=32) will eat food prepared by PLWHA and 91% (n=31) are willing to shake hands with them. There are at least 6% (n=2), 9% (n=3) and 21% (n=7) who responded negatively on those questions.

5.6 QUALITATIVE DATA PRESENTATION (BASELINE)

Qualitative approach was used in a concurrent embedded strategy to complement the quantitative data. The aim of the qualitative data is not to generalize the findings across the population but rather to get insight and understanding on the respondents' perspective and meaning of the phenomenon under study.

In-depth individual interviews were conducted with ten community opinion leaders consisting of the constituency councilor, a local pastor, three teachers from local different schools, a registered nurse from the local clinic, which offers ARV in the constituency, a support group coordinator (represents PLWHA), a peer educator from a local Police Station, and two community counselors. Out of these ten interviewees, six were men while four were women and their age ranged from 25 to 55 years. These interviewees were sampled purposively due to their positions and influential roles in the community. They were also regarded as the most suitable respondents to answer the interview questions. A coding system was used on the interviews' scripts, instead of identification numbers. The researcher used coding system whereby cut and paste function in a word processor was

applied to move bits of text around. Data from the interviews' scripts are presented according to interview guide questions and categories, which emerged from them and they are presented in this order:

Question 1: What are your views and opinions on the community-based HIV/AIDS stigma in your community?

- a. Themes and categories
 - i. External stigma:
 - Stigma in community
 - Stigma in family
 - Stigma at schools
 - Stigma at health facilities
 - ii. Internal stigma
 - Negative self perception
 - iii. Stigma of association
 - Families with PLWHA
 - Health care workers

Question2: What do you regard as your role in reducing HIV/AIDS stigma in your community?

- a. Themes
 - i. Education and information sharing
 - Educating on HIV/AIDS facts
 - Education on acceptance

- Education on change behavior
- ii. Counseling and referring to other services
 - Counseling and referring roles
- iii. Family involvement
- iv. Individual help

Question3: In your view what can be done to reduce community-based HIV/AIDS stigma?

a. Themes

- i. Reducing stigma at community level
 - Community meetings;
 - Education and training of influential people
 - HIV/AIDS Stigma awareness campaigns
 - Involvement of other stakeholders
- ii. Reducing stigma at family level
 - Discourage isolation
 - Acceptance of others and oneself
 - Continuous counseling
- iii. Reducing stigma at individual level (PLWHA)
 - Reducing self stigma
 - Support for PLWHA

Question4: Do you have anything else that you want to tell me?

a. Themes

i. Additional information

5.6.1 Question 1: What are your views and opinions on the community based HIV/AIDS stigma in your community?

The participants who were interviewed gave different answers on this question. They came up with positive as well as negative answers. Some indicated that stigma is still high in some contexts while some felt that it has decreased. From the answers of participants the three types of stigma namely external, internal and stigma of association were experienced and they are discussed in the different contexts where it happens. They were categorized as follows: external stigma in community; in family; at schools; and at health facilities; internal stigma which leads to negative self perception among PLWHA and the last one is stigma of association towards caregivers as well as to families of infected persons. These types of stigma, which are emerged from data, are presented with evident quotes or statements from the interviews scripts and notes from stigma reduction training workshops.

a. **Group 1, 3 and 4 (PLWHA, community leaders and health care workers)**

The results from all groups 1, 3 and 4 from both intervention and control arms are presented jointly under the three types of stigma: external, internal and stigma of association.

i. External stigma:

People living with HIV/AIDS experience stigma and discrimination at different levels in the community, family, at schools and health facilities and are presented below.

Stigma in the community: With regard to stigma in the community participants gave positive as well as negative responses. Some participants indicated that stigma in the community has decreased as a result of more understanding regarding HIV transmission. They further pointed out that community members do not fear contracting the virus through casual contacts anymore as it was the case in the previous years. Some participants indicated that cases of stigma among community members are very rare. Some felt that due to the ARVs people who are living with HIV and/or AIDS do not look sick any more, as one participant said: *“Stigma has decreased, I think is because of ARVs because people do not look sick anymore.”*

However, there were different responses from some participants who indicated that stigma is still present in the community. One participant indicated that the type of stigma, which is more common in the community, is staring too much at PLWHA. Verbal abuse is also observed among community members particularly when they quarrel with PLWHA, it was reported. One participant indicated that people fear to eat food prepared by PLWHA. The other one indicated that gossiping about PLWHA is high among community members as it was expressed through the following statements:

“Gossiping about people who are HIV positive is very high in our community.

People are afraid to disclose their HIV status because of stigma.”

“There is stigma in the community, for example some people are afraid to buy food prepared by people who are HIV positive. People fear of getting the disease. Even me, I am uncomfortable buying food from people who are HIV positive.”

At the intervention workshop one participant indicated that they do not have intimate friends anymore as people are afraid of them and it was expressed in this statement:

“Men do not ask us out anymore. They are afraid that we are going to infect them although we know about safer sex.”

Participants expressed stigma in these terms: *“Some PLWHA abuse alcohol because they do not want others to know that they are HIV positive. Yes stigma does exist.”*

“Some people are afraid to be seen taking medication (ARVs). Some are stressed that is why they abuse alcohol to forget their problems.”

Stigma in the family: The findings from the interviews revealed that stigma is experienced in families as some participants reported that PLWHA are being mistreated by their families and relatives. One participant indicated that children particularly orphans are suffering the most from stigma in the family and they are verbally abused by their relatives, it was pointed out. They are called names and relatives use bad languages towards them such as *“we are not the ones who caused your mother’s death”* (*‘hafye twa lya nyoko’* in local language). It was reported that PLWHA, particularly those on ARVs are the targets/victims of stigma by their families and relatives. Some participants reported that stigma towards people who are on ARVs might be as a result of poverty, low income and shortage of food in some households. Participants indicated that PLWHA who are on ARVs have to eat before taking their medication, although, food is a problem

in some households that is why families feel that they finish food. This is evident from this incident:

“There was a case of someone who was cooking so that s/he can take ARVs, and his/her mother just came and put water on the fire to stop him/her from cooking.”

Another participant said:

“Some families complain that PLWHA finish food, but they do not contribute to household chores.”

It was further reported that some PLWHA are verbally abused by their families and relatives. They use bad phrases and word such as: *“you have looked for it.”*

Another form of stigma that was reported in the family is fear of sharing bed or blankets with someone who is HIV positive. It was revealed that some relatives do not want to care of their sick PLWHA or take them to health facilities when they need medical services. Sometimes the problem is money for transport, as it was indicated. The participants who participated in the training workshop also indicated that PLWHA are mistreated and abused verbally by their own mothers. In many cases it happens when they are under the influence of alcohol, as it was indicated by participants. It is therefore assumed that poverty and alcohol abuse contribute to stigma in the families however, it is not clear what its level in the family is, as it was indicated by one participant.

Stigma at schools: Participants gave different views on stigma at schools. The teachers who were interviewed are not from the same schools, it is therefore understandable for them to have different views and opinions on level of stigma. Two participants indicated that they have counselling services at their schools while some do not have. It might be the contributing factor to their different responses. Above all, there are positive and

negative responses on stigma at school level. One participant indicated that at his/her school there is no stigma observed at all either among the learners or among the staff members. The same participant reported that there is counselling service at their school. However, two participants indicated that stigma is experienced among learners at some schools. There is peer discrimination amongst learners as it is reported by two participants. Examples of forms of stigma at schools are expressed in the following statements:

“Some learners do not want to play with infected learners or to share books with them.”

“They do not want to be in same group work with those learners.”

“Learners at our school do not want to associate with those learners who are believed to be HIV positive. I think the reason for this is fear of contagious.”

It was pointed out by some participants that learners who are HIV positive are being verbally abused, insulted by others and gossiping as form of stigma is high among learners. It was further reported that there were cases of learners disclosed other learners' HIV status at school. That is evident from this incident:

“You know how children are. They like gossiping. There are those who go to ARV clinics to collect their medication and when they see others there, they go and tell the other children whom they saw at the clinic. When they come to school they will tell their friends and classmates.”

Despite stigma being high among learners in some schools, some participants reported that staff members at some schools are empathetic to HIV positive learners. They do not stigmatize or discriminate others on the basis of their HIV status as one participant said:

“Teachers are more empathetic to learners who are HIV positive. They try not to disclose the learners’ status to other learners, although they are not formally informed by parents about learners’ status. Parents are not opening up to teachers. I think they are afraid that their children will be stigmatized and discriminated against, once their HIV status became known at school level.”

Although there are those staff members who are empathetic and do not discriminate against others, some participants reported that at their schools some stigmatized their colleagues who are HIV positive and do not want to talk to them. It was further pointed out that they are discriminated regarding work benefits such as attending workshops and distribution of educational materials. Furthermore, stigma is also experienced at some schools during parents’ meetings. Presence of stigma among staff members at schools is expressed in these statements:

“Teachers who are seen as HIV positive are not nominated to attend workshops.”

“When there is a need to transfer one teacher to another school, the others prefer the one who is HIV positive to be the one who should be transferred.”

“During parents’ meeting both parents and teachers do not want to listen at the views and opinions of those who are suspected to be HIV positive.”

“Those who were my friends before I disclosed my status they do not want to talk to me anymore. My stuff including a box with my ARVs was thrown out of the office at school.”

“When I go to HIV/AIDS related workshops I am forced to fill in unpaid leave but sports teachers are not requested to fill in unpaid leave when they go for sports workshops. Why me? I feel that this is also discrimination.”

The schools, which reported stigma, are the ones without counselling services. It is therefore, assumed that counselling services at schools can reduce stigma at school level.

Stigma at health facilities: Stigma at health facilities can be either towards the health care providers being stigmatised by the community or towards patients by the staff members. To get a clear understanding on stigma in health facilities, both health care providers as well as the health service consumers (patients) were interviewed. The participants who are health care providers reported that there is no stigma in health facilities due to that many people understand that they cannot get HIV by non-sexual casual contact. One participant indicated that she is not sure about stigma in the in-patients as she does not work with them. The absence of stigma at health facilities is expressed in this statement:

“Hospital is fine, there is no stigma. For example old nurses draw blood without wearing gloves. They do not want patients to feel discriminated.”

Despite the reports about absence of stigma at health facilities, one participant reported that it still exists at some. The same participant revealed that some health care workers particularly the doctors do not want to touch PLWHA patients. They only want to prescribe ARVs but not other medication such as vitamins. Verbal abuse as a form of stigma is also reported at health facilities. According to one participant verbal abuse by health care workers is expressed in these terms: *“What is the use to take vitamins?”*

“You are finishing medications.”

“Do you know that you are waiting for AIDS?”

One participant confirmed that: *“Stigma is alive at health facilities.”*

ii. Internal stigma

Negative self perception: According to Greeff et al. (2008b) internal stigma (self stigma) refers to thoughts and behaviours stemming from the person's own negative perception about him-/herself based on his/her HIV status. One participant reported that PLWHA do stigmatizing them as they isolate themselves and regard themselves as sick people. Self stigma was reported as well as confirmed by one participant and was expressed in the following statement:

“I feel that they feel discriminated even though it is not like that. Sometimes they do not want to do anything because they believe that they are sick. They do not want to accept that HIV is just a lifelong disease like any other disease such as high blood pressure or diabetic.”

Self stigma was also confirmed by one participant who educates others not to feel guilty due to having the disease as it was expressed in this statement:

“I educate PLWHAs not to feel guilty of being HIV positive or having AIDS. People need more understanding that will help them to reduce stigma.”

iii. Stigma of association

Stigma to families with PLWHA: Although the results from individual interviews did not reveal any form of stigma due to association either in the families or amongst the caregivers, the participants who participated at intervention workshops indicated that in some communities, households with PLWHA are being labelled and discriminated against by their neighbours and as a result children are discouraged to play with those from houses suspected to have HIV positive person/s.

Stigma to health care workers: The health care workers who completed HASI-N questionnaire also indicated that nurses who care for HIV positive patients experienced stigma of association as people say that they are HIV positive too. Some participants indicated that spouses of nurses who care for HIV positive patients were afraid that their wives/husbands will bring them the virus. However, from the interviews none mentioned about it.

5.6.2 QUESTION 2: What do you regard as your role in reducing HIV/AIDS stigma in your community?

The participants were selected on the basis of their respective roles and responsibilities in the community. It was, therefore, appropriate to ask them what they regard as their roles on reducing community-based HIV/AIDS stigma in their respective contexts and work environments. Different categories with regard to roles and responsibilities had emerged from their responses and among them are the following: educating; informing; counselling; referring to other services; involving family members as well as preaching the commandment of “Love your neighbour” and treat others as you want to be treated. These categories and subcategories are described below.

i. Education and information sharing

Participants gave a range of their responsibilities and roles in reducing community-based HIV/AIDS stigma. Most of them indicated that they have responsibilities of educating and informing others, including learners and staff at schools, community members, family members of PLWHA, care takers for children, who are on ARVs, patients who come to health facilities as well as the general public. Education and information is subdivided in

sub-categories of education on HIV/AIDS facts, education on accepting others and education on change behaviour.

Education on HIV/AIDS facts: Education should concentrate on giving people correct information about HIV/AIDS facts, correct misconceptions and myths surround the disease. At schools teachers give information in relevant subjects such as Life Skills, as some participants said:

“I teach learners about facts of HIV/AIDS for example tell them that HIV is not death sentence.” “I give learners information on how one can be infected and how HIV cannot be spread.” “I make them understand that HIV cannot be transmitted by casual contacts with people who are living with HIV“

Education on acceptance: Some participants reported that they educate and inform community members about human rights to see PLWHA as others and not to discriminate them, for example as one participant said: *“People should see PLWHA as normal as others.”*

Moreover some participants indicated that people should start regarding HIV as any other manageable chronic disease such as Hypertension, Diabetes and Cancer. That would help people to treat PLWHA as anyone with a chronic disease. The role of educating others to accept PLWHA is expressed in these terms:

“I have responsibility to educate people that if we stop stigmatize and discriminate people who are HIV positive that will help them to prolong their lives.”

“I also educate people to accept that HIV is just like any other disease.”

Participants indicated that community members are also being informed and educated that stigma and discrimination cause stress among PLWHA. It was further reported that some of the roles and responsibilities are to educate people to accept PLWHA in their community and families. This is evident from these statements:

“I have to educate community members not to stigmatize because stigma can cause stress.” “Giving information to community members and educating family members to accept relatives who are HIV positive. That will help to reduce stress and suicide.”

“I educate them to accept their relatives who are infected to reduce stress.”

“We tell people to accept others who are living with HIV and put themselves in their shoes.”

Furthermore, some participants indicated that they have roles to educate PLWHA not to feel guilty of having HIV, but rather accepting it as other chronic diseases. Some have responsibilities to educate PLWHA to live positively with the disease such as refrain from alcohol abuse. As one participant confirmed that:

“My role is to educate and inform PLWHA on negative side of using alcohol while on ARVs. I educate them not to feel guilty of being HIV positive or having AIDS.”

Education on change behaviour: The education and information on changing behaviour is meant for both community and family members as well as for PLWHA. The participants indicated that people need to change their behaviour in order to reduce community-based HIV/AIDS stigma and help to improve the lives of those infected and

affected. The community need to stop discriminate others on the basis of their HIV status. On the other hand PLWHA also need to stop discriminating and isolating themselves from the others. One participant suggested that as influential people in their community they should act as role models to influence others to change their behaviour towards PLWHA. The need for changing behaviour is emphasized with these statements:

“If we stop stigmatize and discriminate people who are HIV positive that will help to prolong their lives.”

“I should be a role model not to discriminate or stigmatize others because they are different from the rest of the group. That helps to normalize the situation.”

“At many times when you mention that stigmatizing PLWHA can cause them to commit suicide, it softens the family members and start accepting and treating them well.”

ii. Counselling and referring to other services

Counselling and referring roles: Some participants indicated that they have counselling roles whereby they also address stigma and encourage PLWHA to refrain from practices that put their lives at risk such as abusing alcohol, although they feel stressed. One participant pointed out that s/he tells them not to feel guilty for being HIV positive. Counselling roles were expressed in these statements:

“I encourage individuals to accept their HIV status, not to feel bad every time people talk bad about them.”

“They should not be stressed all time, not to isolate themselves. This will help them to keep their CD4 counts at normal level.”

“They should work when they are not sick so that family members will stop discriminating them.”

“I tell PLWHA not to regard their disease as more serious than the others. They should understand that there are ARVs, which prolongs their lives even though it is a lifelong treatment.”

One participant pointed out that during counselling s/he encourages PLWHA to disclose their HIV status to other community members to get emotional support. Those participants who do not have counselling skills reported that they refer either PLWHA or their families for counselling services when there is a need. Some participants indicated that they refer them to other services such as to Regional Office for feeding programs when they identify food shortage problems. This was expressed in these statements:

“I do conduct face-to-face meetings with relatives and families of PLWHA. I do refer family members for counselling services.”

“I do follow-up in the villages to see if there any change after referral services.”

“I do also check the households’ income and refer them to regional office for feeding program.”

iii. Family involvement

Family involvement in any program that aims to improve the lives of PLWHA is essential and that was supported by some participants who indicated that education and information on how stigma affects them should be given from house to house as it was expressed in these statements:

“Education and information should be given from house to house to make people understand what stigma does to PLWHA.”

“Groups, which do counselling in the villages, should be increased.”

Another one pointed out that the caretakers of children need to be educated on ARVs so that they can stop mistreating them. Furthermore, one participant reported that families and partners are being involved in PMTCT and feeding counselling. The same participant indicated that this involvement will reduce stigma towards the HIV positive mothers or mothers to be as family members would understand why they made certain choices regarding baby feeding and will give them necessary support. That is evident from one participant who said:

“I do involve family members and partners when I do PMTCT and feedings counselling. That helps to reduce stigma.”

iv. Individual help

Although giving individual help cannot be regarded as a direct role to reduce stigma, it was judged appropriate to include it in this report as an indication that despite stigma being experienced in different contexts, there are some individuals who treat PLWHA with empathy. This study found that some people walked the extra mile to offer financial help (using their own money) to the needy PLWHA either to learners at school or to individuals who ask assistance for transport money to go to health facilities, when it is necessary. Giving individual help is evident from these statements:

“Sometimes I give them support such as financial or food from feeding program.”

“I do offer financial help giving money to individuals, for example giving money for transport to go to health facilities or even give food.”

Some participants regarded it as their role to make the environment friendly towards PLWHA. This is confirmed by one participant who said:

“Our school environment is not that friendly as we have some classrooms which are built with zinc and sometimes it becomes too hot. When it is too hot I excuse those learners if necessary. They are also being excused when they go and take their medication.”

The ten participants who were interviewed revealed that they have different roles to play to reduce community-based HIV/AIDS stigma in their respective areas. They have responsibilities towards other community members due to their influential roles in their respective communities.

5.6.3 QUESTION 3: In your view, what can be done to reduce community-based HIV/AIDS stigma?

One of this study’s objectives was to develop a community-based HIV/AIDS stigma reduction intervention, the researcher wanted to find out from these influential people what their suggestions were, therefore, this question addressed that aim. Those who were interviewed came up with many ideas and several suggestions. Some categories and sub-categories that emerged from the interviews included community meetings; education as well as training of influential people; HIV/AIDS stigma awareness; discourage isolation;

acceptance (others and oneself); continuous counselling; support for PLWHA, involvement of other stakeholders namely media, NGOs, church, as well as males.

i. Reducing stigma at community level

Community meetings: With regard to community meetings, some participants pointed out that it would be the appropriate step to reduce community-based HIV/AIDS stigma in their constituency. The meetings should be held for both HIV positive as well as HIV negative community members. The community members who attend these meetings will influence their households on stigma reduction strategies. One participant indicated that it would be necessary to give community leaders active roles and more involvement in educating community members during those meetings. Community meetings as a suggested strategy to reduce stigma was expressed in these suggestions:

“Community meetings with both people who are HIV positive and those who are negative. Include all community members in those meetings regardless of their HIV status.”

“Community meetings as well as regional council meetings should also address stigma.”

“Involvement of headmen of the villages and constituency councillor to invite influential people to talk on HIV/AIDS with community members”

“The leaders should give relevant and practical examples of stigma that are experienced by communities.”

Research has found that conducting community meetings when dealing with community problems and developments may be a success if it is done by influential people. Therefore

the community meetings suggested by participants to reduce community-based HIV/AIDS stigma in a rural community could be regarded as being useful.

Education and training of influential people: Some participants suggested that education and training on stigma reduction should start with the community and opinion leaders so that they can influence others. It is believed that they have more opportunities where they can influence others on stigma reduction. One participant suggested that education about HIV/AIDS facts including stigma reduction should be done by community leaders. They should give relevant and practical examples of it as they are experienced and observed by the community itself. Some participants suggested that education should target and address verbal abuse as it is the most form of stigma in families and community. It was further suggested that Constituency Councillor can educate people during community meetings; school principals can do it at schools' parents' meetings; and pastors can talk about it during church services. These influential people in the community can educate their members not to discriminate others as HIV/AIDS affects all. The suggestions of educating influential people on stigma reduction are expressed in these statements:

“The community leaders can educate their members not to discriminate others because everyone is affected.”

“The headmen of the villages should take the lead.”

“The schools parents meetings should discuss the issue of stigma against learners who are on ARVs.”

HIV/AIDS stigma awareness campaign: Some participants suggested that there is a need to make community members aware of HIV/AIDS stigma and that can be done through awareness campaign. It should target verbal abuse and social isolation as they were reported the most common forms of stigma either in the community or in the families. The need for stigma awareness campaign was expressed in these statements:

“We need community mobilisation to tackle stigma.”

“Education should target and address verbal abuse because it is the most common type of stigma in families.”

“Education and information should be given from house-to-house to make people understand what stigma does to PLWHA.”

“We can also use media, especially the radio.”

Involvement of other stakeholders: Participants indicated the need to involve other stakeholders such as the media, NGOs, church, schools and particular men in stigma reduction activities. Two male participants revealed that other men are not involved in HIV/AIDS response, although they are regarded as the heads of their households. They indicated that there is a need to encourage their involvement so that they can influence others. The need for their involvement was expressed by two participants who said:

“Males do not want to take part in HIV/AIDS issues, they regard it as women’s things, but if they do participate they will be able to influence others as they are regarded as the heads and leaders in the community. “

“Men should be involved because they regard HIV as women disease. Men should be educated to educate and inform other men on HIV/AIDS issues if we want to reduce stigma.”

Another participant suggested involvement of school principals and boards to deal with HIV positive learners particularly the ones on ARVs, as it was expressed in this statement:

“The schools parents meetings should discuss the issue of stigma against learners who are on ARVs. I feel that parents should at least inform the school principals on learners who are on ARVs for support and adherence purposes.”

“The offices of the school inspectors should be involved as part of community activities” “The school boards should also be involved in reducing stigma.”

Participants reported that radio is very effective in giving information as many community members listen at it. That is evident from these statements:

“We can also use media, particularly the radio.”

“Radio is very effective and we can use it to reduce HIV/AIDS stigma in our community.”

Despite of many participants’ preferences for the radios being the most useful channel of communication in the community, one participant indicated that people do not pay attention to media anymore, it depends on what is the topic, who is talking and where is this person comes from. That was expressed in this statement:

“People are become too used to media as such that they do not pay attention anymore. In my view media is not real effective anymore because it depending on whom, what or where it is being done.”

With regard to involvement of others one participant indicated that the church can play an important role in reducing stigma as it has other programmes, which deal with social

issues in the community. There are also some organisations, which could contribute to stigma reduction such as Namibian Red Cross Society (NRCS) and Take Control of the Epidemic (TCE) as it was suggested by one participant. It was also indicated that VCT mobiles need to be increased in the villages that would help people to go for testing, know their status and reduce stigma. These were expressed by these statements:

“We have to re-educate community using different sources and channels. For example we can use the church, NGOs such as Red Cross, TCE and so forth.”

“We need VCT mobile to reach people in the villages particularly males. We need community mobilisation to tackle stigma.”

The same participant further suggested that there is a need for PLWHA projects, which will help them to generate some income and improve their livelihood.

“The Ministry of Gender Equality and Child Welfare can introduce projects that will help PLWHA to earn income. The ministry can also motivate for budget allocation from the government“

On the problem of stigma amongst learners at schools, the following suggestions were made:

“Parents should at least inform the school principals on learners who are on ARVs for support and adherence purposes. The offices of the school inspectors should be involved as part of community activities. The school boards should also be involved in reducing stigma. If all stakeholders in the community development take part in stigma reduction, we will succeed.”

ii. Reducing stigma at family level

Discourage isolation: Social isolation was indicated as one of the most experienced stigma by PLWHA for example it was reported that people avoid them, cut their visits, ended their friendships as well as stop their relationships. It was therefore appropriate to elaborate on this form of stigma to discourage it as it could be resulted from either PLWHA themselves or from others. The participants gave suggestions on how to discourage or stop it either the internal or external one.

With regard to discouraging self isolation, participants suggested that PLWHA should start socializing with other people who are not HIV positive. For example they can join social groups such as choirs, youth and sports clubs that will help to reduce stigma and isolation among people who are living with HIV/AIDS as it was indicated by participants. This was expressed in the following statements:

“Support group members need to encourage others (PLWHA) not to isolate themselves but to socialize with other people as well as to participate in community activities such as sports, choir groups, and so forth.”

“Encouragement for example to pray not to isolate themselves”

“People who are living with HIV/AIDS should be encouraged not to look for sympathy but just to be “normal”

Furthermore, people should be educated not to isolate or avoid those who are living with HIV or have AIDS but rather accept and help them as one participant said:

“I think that we need a strategy to identify needy people who are HIV positive so that they can be assisted and reached out. “

Acceptance (others and oneself): All ten participants who were interviewed felt that it is important to educate community members as well as families to accept people living with HIV or AIDS. Likewise, it is also important for PLWHA to accept their HIV positive status and themselves. That would help them to live positively with the diseases. One participant suggested that: *“Households need to forgive one another to reduce stress and stigma.”*

The importance of acceptance in relation to stigma reduction was expressed in these statements:

“To reduce stigma, people should accept HIV/AIDS as any other disease. Once stigma is reduced, HIV will be reduced and then maybe one day we will have a cure.”

“Counselling at health facilities should emphasise on accepting PLWHAs in the families and community.”

“The community members should know how to help those who are infected to accept their condition.”

Continuous counselling: Participants indicated that counselling play an important part in stigma reduction, therefore, PLWHA, their families and relatives need to be counselled continuously. It could help people to accept their beloved ones who are infected and as a result would reduce stigma. At the same time it would help PLWHA to cope with different problems related to their condition. There is also a need to educate caregivers at family and in the community on effects of stigma on ARVs adherence and it was suggested that:

“Care takers of children who are on ARVs need to be educated to treatment adherence as well as not to abuse children verbally because that is stigma”

On the issue of orphans who are being mistreated by their relatives, one participant suggested that:

“The Ministry of Gender and Child Welfare need to involve communities particularly on the issue of orphans who are on ARVs because they are also being discriminated by families/ relatives. The women and child protection unit can fight against children stigma.”

One participant revealed that there is a need to increase counselling services in the community as it was expressed in this statement:

“Groups which do counselling in the villages should be increased.”

It was further reported that counselling improves self-confidence among PLWHA as it was stated by one participant who said:

“Self-confidence among people who are HIV positive will help to reduce stigma.”

The need of ongoing counselling was expressed in this statement:

“Counselling services should be done continuously.”

One participant suggested spiritual counselling and said that:

“PLWHA need to be counselled spiritually to find inner peace with God. PLWHA need to be counselled not to fear death, educate them spiritually not to regard themselves as dying, but to know that everyone has to die whether HIV positive or not. That will help to decrease self stigma among PLWHA. “

iii. Reducing stigma at individual level

Reducing self stigma: Some participants revealed that PLWHA stigmatising themselves by either isolating from others or by feeling guilty of having the disease, therefore they need to be counselled continuously and educated on self stigma that would help them to accept their condition. One participant said this:

“PLWHA need to be counselled spiritually to find inner peace with God. They need to be counselled not to fear death, educate them spiritual not to regard themselves as dying, but to know that everyone has to die whether HIV positive or not. That will help to decrease self stigma among PLWHA.”

Support for PLWHA: People living with HIV could be supported in different ways either socially, emotionally or financially, that will help to reduce stress and stigma. That is evident from one participant who revealed that there is a need to assist PLWHA particularly those who are in need of basic things such as food, and suggested the following:

“I think that we need a strategy to identify needy people who are HIV positive so that they can be assisted and reached out.”

“Encourage self-confidence among people who are HIV positive will help to reduce stigma.”

Those who discriminate and stigmatise others need to be educated on the effects of stigma on PLWHA and their associates. One participant suggested that preaching the Great Commandment of Love would contribute to stigma reduction as it was expressed in these statements:

“I do educate or tell people to love their neighbours as The Great Commandment of Love according to the Bible. ‘Love God, love your neighbours as you love yourself.’”

“Christian education is important. This helps them to exercise The Great Commandment of love.”

5.6.4 Question 4: Do you have anything else that you want to tell me?

i. Additional information

In addition to the above suggestions made by participants, the emphasis is on education, information, voluntary counselling and testing, use of media particular the radio and involve men in all programmes that deal with HIV/AIDS responses as well as with stigma reduction.

5.7 POST-INTERVENTION QUALITATIVE RESULTS

An evaluation on the impact of intervention was conducted in August 2011 with selected 17 people consisting of 12 PLWHA who participated in the training workshop, one support group member who was not part of training, the constituency councillor, his personal assistant and two community leaders. Out of this number four of them were men and their ages ranged from 31 to 60 years old. The number of interviewees was stopped when data was saturated. The aim of this evaluation was to find out if there were any changes regarding stigma either in the families or in the community after implementation of intervention. In-depth individual interviews were conducted with semi-structured questions. The main questions were about what trainees have done after the training and

any observed change in stigma after intervention activities in the community that received intervention.

The quantitative data instruments focused on measuring factors such as fear of contagion, verbal abuse, social isolation, workplace stigma, negative self perception, attitudes towards PLWHA, household stigma and caring for sick relatives. It was therefore appropriate to base the qualitative evaluation post-intervention on the same factors to evaluate change in the community that received the intervention.

a. Group 1 &3 (PLWHA and community leaders)

Among those whom were interviewed at least two participants indicated that there is no change in stigma but majority (15) reported positive changes either in the families or in the community. The qualitative findings are presented according to the measured factors under different types of stigma as follow:

i. External stigma

Fear of contagion: Many participants who were interviewed post-intervention indicated that fear of contagion has decreased. People have more understanding on how HIV is transmitted as a result there is less fear and they are more willing to share meals with PLWHA as well as eat food prepared by them. That is evident from these statements:

“People do understand now, they do not fear to get HIV through casual contacts such as sharing meals with PLWHA as it was in the past before our training “

“There is less fear and more understanding on how HIV is transmitted.”

“It seems that people understand that they cannot get the virus just by using the same plate or cup with infected person.”

Verbal abuse: With regard to verbal abuse participants indicated that it has decreased after intervention and is evident from these statements:

“Verbal abuse has decreased after intervention people do not call us names anymore. People are more accepting than before”

“Verbal abuse has decreased after our training we are not called bad names anymore. Gossiping is not higher anymore like in the past.”

“There is change for example calling us names has decreased and people do not sing offensive songs anymore like they used before. “

“We are no more called bad names and remarks such as “you have looked for it” have decreased.”

“There were people who used to gossip and made bad remarks about those who are living with HIV, but now they stopped. Some of them are also tested HIV positive and started treatment like us. So they cannot gossip anymore”

“They accepted their relatives who are HIV positive and treat them well, no more blaming and judging them for having the virus.”

However there is one participant who reported that she still experience verbal abuse from her mother and is evident from this:

“My mother gave me a particular name that reflects on my HIV status. Whenever she talks with children about me she uses that name. I do not know what to do to stop that habit, I only ignore her.”

Social isolation: The people who were interviewed after intervention have reported that social isolation has also decreased in the families as well as in the community. PLWHA said that:

“People do not avoid us anymore like in the past. May be they realised that they cannot contract HIV just by being with us.”

“Some people have changed they do not discriminate us anymore but there are still those who are avoiding us.”

Workplace stigma: Stigma at workplace was not reported by many as a result of low employment therefore there were no reports of it after intervention.

Attitudes towards PLWHA: Negative attitudes towards PLWHA in the families have decreased after intervention as it was revealed by participants. It was reported that families and relatives are more helpful than before and community members are more willing to attend meetings which are related to HIV/AIDS. This was expressed in these statements:

“People who used to discriminate PLWHA regarding food, have changed. PLWHA are not neglected or discriminated anymore. Family members are more helpful than before and accepted their PLWHA relatives”

“Many people accepted PLWHA and do not discriminate them anymore.”

“Yes, there is change for example community members are more willing to attend meetings that address HIV/AIDS issues. The HIV/AIDS meetings are well attended after your intervention.”

“I think the questions which they completed before have also made them to realise that some behaviours and acts are discrimination towards people who are living with HIV/AIDS as a result it contributes to stigma reduction.”

Household stigma: The results on household stigma revealed that there is change as it was expressed in the following statements:

“We did not receive reports on stories of abuse in households like in the past. It seems that families have accepted their relatives who are living with HIV/AIDS.”

“People are willing to share meals and use same utensils with those who are living with HIV/AIDS.”

“Stigma has decreased we are not mistreated anymore like in the past.”

“Orphans are not mistreated anymore.”

“The discrimination on using separate utensils has also decreased”

“In households people are more helpful than before.”

Caring for sick relative PLWHA: Fifteen out of 17 persons who were interviewed, reported that families of people living with HIV are more helpful than before. Two of participants have indicated that there are no reports of negligence of PLWHA in families, which brought to their office like in the past when there were cases of mistreatment.

ii. Internal stigma

Negative self perception: There are reports of PLWHA who are stigmatising themselves as it was revealed by participants who were interviewed. This was expressed in these statements:

“Sometimes PLWHA feel that they are discriminated but in reality they are stigmatising themselves. There is a need for counselling.”

“Self stigma is still a problem because some people are abusing alcohol to reduce their stress.”

“Some people who are living with HIV/AIDS still do not want to join support groups and adherence to treatment is still not good.”

Although there are still PLWHA who are stigmatising themselves, there are those who accepted their condition and have no more negative self perception as it was indicated by these participants who said:

“There are also more PLWHA who go for ARVs as they are not shy anymore. PLWHA look healthy as they accept their illness.”

“Many people who are HIV positive have joined support group and I think it is because of our training on stigma reduction.”

“People are more open than before and do not feel guilty of having the virus.”

“For example those who used to throw ARVs away had stopped and there are more people (PLWHA) who started treatment after we informed them about protecting ourselves from stigma”

iii. Stigma of association

There were no reports on stigma of association at post-intervention evaluation either from health care workers or from families with people living with HIV/AIDS.

5.8 CONCLUSION

This chapter presented the quantitative and qualitative data and the findings revealed a range of different outcomes regarding level of HIV/AIDS stigma in a Namibian rural community. Majority of participants were women and their age ranges between 18 and 81. The Lutheran denomination was most represented followed by Roman Catholic and Anglican. Only few participants belong to other religions, which were not listed on the scale. The most frequently represented PLWHA was the 36-45 age group, while in

families the majority were between 31 and 40 years of age. Many participants had at least primary education and they can read and write but only few have completed tertiary level.

At baseline assessment with regard to PLWHA stigma scores, fear of contagion was the least while verbal abuse and social isolation scored the most. Workplace stigma was low although there are cases of PLWHA who indicated that they are discriminated by their colleagues and were denied opportunities. Low stigma was also reported in health care facility (ARV clinic), but associated one was experienced by health care providers. The results from in-depth interviews revealed stigma from health care providers in some health facilities.

The results further revealed that there are negative attitudes towards PLWHA from family and community members. PLWHA on ARVs were reported as the most stigmatised in families by their relatives. Although household stigma scored high, many participants (family and community) indicated their willingness to care for sick relatives as they responded positive from 'caring' items. Negative self perception was reported by one third of PLWHA at baseline and few interviewees reported that they observed it. When the results were compared between intervention and control groups it was found that there was no statistical significant difference in PLWHA stigma scores at baseline survey except for negative self perception, which was higher in the control arm. After intervention the results showed statistical significant difference in scores of social isolation, workplace stigma and negative self perception in intervention arm. Verbal abuse score has slightly declined in intervention and increased in control arm but there was no statistical significant difference.

Results from interviews indicated that social isolation and verbal abuse have declined after intervention. Attitudes of families and community have also changed after intervention as there were no cases of mistreated PLWHA reported at the regional office like it was before. PLWHA also reported that families and relatives are more friendly and helpful than before. Negative perception and self stigma still exist as it was reported by PLWHA through interviews after intervention.

With regard to comparisons between intervention and control groups of family and community members only household stigma score showed a statistical significant difference at evaluation phase as it declined in the intervention arm. In the control group six scores showed a significant increase at the end assessment. After intervention all the scores in nurse stigmatising patient and nurse being stigmatised have increased. The results from the post-intervention groups only showed higher stigma from the control arm than the intervention.

CHAPTER 6

DISCUSSION, RECOMMENDATIONS AND CONCLUSION

6.1 INTRODUCTION

This study aimed to measure the level of stigma as well as to develop, implement and evaluate a community-based HIV/AIDS stigma reduction intervention in a rural Namibian community, therefore the findings have been organized according to the objectives and research questions outline in Chapter 3. According to Holzemer et al. (2007) external stigma refers to all discriminatory behaviors and acts towards a person who is HIV positive or has AIDS, and it includes fearing contagion, negating, abusing, rejecting, avoiding, blaming and gossiping. The levels of stigma were determined in four community groups, PLWHA, their families, community leaders and health care workers, in both an intervention and control arm. The study consisted of questionnaires, in-depth interviews and a stigma reduction intervention. The discussion associated with the results from each group, as well as the differences between them, is presented in this chapter. The study limitations are presented and a number of recommendations made about the usefulness of the intervention strategy. The implications for the appropriateness of the theoretical models underpinning this research are also discussed and conclusions drawn about the appropriateness of implementing similar interventions in other parts of the country.

To meet the study objectives, the following activities took place, the results for which were reported in Chapter 5:

1. The level of HIV/AIDS stigma (external, internal and associated) in Ongenga Constituency was measured.

2. A community-based HIV/AIDS stigma reduction intervention in a rural community was developed.
3. A community-based HIV/AIDS stigma reduction intervention was implemented in Ongenga Constituency.
4. An evaluation was conducted to determine the effectiveness of the intervention and to compare the results between intervention and control arms.

6.2 MAJOR CONCLUSIONS OF THE STUDY AND DISCUSSION OF FINDINGS

Five objectives were identified to determine the levels of stigma in the rural Ongenga Constituency, and the discussion is presented for each participating group as it relates to each objective.

6.2.1 Objective 1: To measure the level and extent of HIV/AIDS stigma in the constituency

Although there are a few studies which explored and assessed HIV/AIDS stigma in Namibia, its level and extent were not measured quantitatively before. It was therefore essential to address this objective before proceeding with developing an intervention to reduce stigma. Measuring the levels and extent of stigma was done using the F&C-SI questionnaire developed and HASI-P by Holzemer et al. (2007) as well as HASI-N by Uys et al. (2009) adapted by the researcher. These research instruments classified the three different types of stigma as external, internal and associated, these being supported by findings from previous researches elsewhere in Africa (Holzemer et al., 2007a). The discussion will be presented for each of the four groups followed by a comparison of the control and intervention arms.

a. Group 1: PLWHA

People living with HIV/AIDS are the primary recipients of stigma and discrimination, and in this study, were members of the Opawa Support Group. The results are a combination of the answers to the questionnaire and the outcome of the discussions that took place during the intervention workshops. The three different types of stigma detailed below are external, internal and associated.

i. External stigma

At baseline assessment, statistical analysis has shown that external stigma was high and included the following four factors: fear of becoming infected through casual contacts, verbal abuse, social isolation of persons who are HIV positive and discrimination at workplace based on their status all of which detailed below. These findings are consistent with results from previous studies elsewhere in Africa (Nattabi et al., 2011, Nghifikwa, 2011).

Fear of contagion: According to Nattabi et al. (2011) in their Ugandan study stigma due to fear of contagion was higher ($p=0.004$) as experienced by older respondents who are on ARVs. However this study findings on stigma score due to fear of becoming infected through non-sexual casual contacts is low as majority of PLWHA (66 to 79) reported that they never experienced it in the last three months at the time of assessment. Likewise family and community participants (96% to 100%; $n=127$) confirmed that they do not have problem with day-to-day contacts with people who are living with HIV for example they would eat food prepared and share toilets with persons who are HIV positive or have AIDS. They have also indicated that they are willing to care for sick relatives who are HIV positive. Following the results one can possibly attribute that there is more understanding

on HIV transmission and less fear that people cannot get infected by caring and interacting with PLWHA.

In this study participants were given a series of statements to indicate how often they experienced stigma as a result of fear of contagion and it was found that only 17% (n=16) of PLWHA reported that they were asked to leave due to coughing but this could be linked to TB rather than to HIV. People are aware that coughing is one of the signs of TB and this could be the reason for asking PLWHA to leave when they started to cough and does not necessary mean that they discriminate them due to fear of getting HIV. There are few participants (family and community members) who indicated their unwillingness to care for sick relatives with HIV/AIDS, and some did not feel comfortable to eat food prepared by an infected person. Similar findings have been reported by Greeff et al. (2008b) from the five African countries study where respondents revealed that people were afraid to shake their hands and opted to greet verbally. Some reported that people avoided to come into contact with plates used by PLWHA (Greeff et al., 2008b). Avoidance by family and community due to being HIV positive was also reported by Nghifikwa (2011). This could be interpreted as a lack of knowledge on the basic facts of how HIV is transmitted that could be corrected by education and more information.

Although PLWHA in this study reported cases of being stigmatized due to fear of contagion, it did not occur frequently. It can therefore be argued that there is less fear of becoming infected through non-sexual casual contacts and more understanding on how HIV is transmitted. Interventions in knowledge on basic facts of HIV transmission needs to be strengthened in order to reduce stigma among families and community members.

Apinundecha et al. (2007: 1162) reported that “an intervention that increases HIV/AIDS knowledge might reduce community stigma towards PLWHA.”

Verbal abuse: Verbal abuse has manifested in different ways as this study found that PLWHA experienced being called names, being blamed for immoral behaviors such as promiscuous, judged as well as insulted either by family or by community members. These findings are similar to what has been reported from a current study in Namibia (Nghifikwa, 2011). The study findings revealed that verbal abuse was high with a mean score of 1.1942 at baseline survey and many PLWHA (n=37) reported that they were blamed for having the virus, insulted by others for being HIV positive and were told that they have no future. This information confirms what has been reported by Greeff et al. (2008b) as respondents in their study reported that they were called prostitutes and people sing funeral songs when they talk about them.

According to the results of this study there are people who still believe that HIV is a punishment from God and this could be linked to the belief that those who have the virus are promiscuous and have immoral behaviors. Similarly the Siyam’kela project in South Africa (Dlamini et al., 2007) reported that PLWHA were called ‘Satan’s people’ by church members. This belief could be the cause of verbal abuse and it could prevent people to go for HIV testing as they are afraid to be judged and labeled as promiscuous once they tested positive. Literature confirmed that stigma delays voluntary HIV testing and interferes with access and treatment that helps to prolong lives of PLWHA (Holzemer and Uys, 2004, Health and Development Networks, 2006). Nevertheless literature indicated that the church and faith based organizations play an important role in de-stigmatizing HIV/AIDS as well as caring for PLWHA (Uys et al., 2005).

Verbal abuse was also reported in the health facilities where care providers are expected to sympathize with PLWHA. According to Greeff et al. (2008b) respondents in their study revealed that they were denied spiritual care when admitted in hospitals as they were regarded as sinners. Similar findings from this study revealed that health care providers directed bad phrases and words to persons who are HIV positive or have AIDS such as that ‘they are finishing medications’ as well as denying them essential services. These findings are supported by researches in five African countries who reported that health care providers mistreat and deny PLWHA needed services such as oxygen and blood transfusion. Some reported that they were told that they are AIDS patients and going to die (Kohi et al., 2006, Dlamini et al., 2007, Greeff et al., 2008b) .

Verbal abuse was not only directed to adults who are living with HIV, but was also experienced by children who are orphans due to HIV/AIDS as it was reported by interviews and from workshop participants. Participants reported that orphans who are HIV positive and are on ARV experienced verbal abuse from their guardians and relatives. In some cases they are insulted with words and phrases such as: “we are not the cause of your mother’s death” (“hafye twa lya nyoko”). Few studies have published stigma on children but the report from literature review conducted by Deacon and Stephney (2007) revealed that orphans suffer from direct stigma and discrimination as well as from courtesy. Orphans who are HIV positive suffer from direct stigma and discrimination while those who are negative are subjected to courtesy stigma (Deacon and Stephney, 2007). These reports are supported by findings from this study. Although stigma on children was not the focus of this study it is equally important to explore more on how they experience it, particular those who are orphans or having HIV positive caregivers.

That will help to plan and develop stigma reduction interventions which are appropriate and relevant to their needs.

According to the Health and Development Networks report from Toronto conference HIV-related stigma is influenced by many factors including food security (Health and Development Networks, 2006). This is supported by the findings from this study as it was revealed that there were incidents of PLWHA who are blamed by family members and relatives of “just eating and doing nothing”. Participants reported that verbal abuse is triggered by food shortage in some households and is more experienced by PLWHA who are on ARV as they need to eat before taking their medications. During the training workshop discussions participants reported that they experienced stigma in their own families where they are blamed and judged for being HIV positive and are discriminated with regard to food preferences. “Research and experience have confirmed that HIV/AIDS and food insecurity are increasingly entwined in a vicious cycle” (Health and Development Networks, 2006).

Reports from HIV/AIDS stigma conference in Toronto (2006) suggested that it is important to establish food security as there is a link between verbal abuse and food preferences, which is a vital tool in stigma reduction before starting with ARV. These reports confirmed the findings of this study that there is a link between stigma, poverty and lack of basic commodities, which could be alleviated with either income generating projects or social grants to unemployed PLWHA who are on lifelong treatment (Health and Development Networks, 2006).

Although some studies have shown that women are the source of support in dealing with family members who are living with HIV (Lekganyane and du Plessis, 2011), this study show different results as women were reported as the perpetrators in verbal abuse who used bad phrases and words towards relatives who are HIV positive particular when they are under the influence of alcohol. That is strange and disturbing as women are regarded as caring and caregivers for sick family members and relatives. The study results revealed that alcohol contributes to verbal abuse towards PLWHA in the families as some participants reported that this form of stigma is worse when persons are under the influence of alcohol. However, verbal abuse by women could be linked to frustration as they care for their sick relatives with limited help and resources. It is, therefore, reflecting an urgent need to train more women on stigma, effects on PLWHA and how it can be reduced. At the same time males should be encouraged to be involved in stigma reduction as it was suggested by several men participants in this study.

Verbal abuse findings from this study are similar with results from researches elsewhere, where it was reported in the form of words, offensive songs and phrases directed to PLWHA either by relatives, health care providers or community members (Dlamini et al., 2007, Rutledge et al., 2008).

Social isolation: According to Greeff et al. (2008b) social isolation can be as a result of either people who avoid persons who are HIV positive or from PLWHA who withdraw themselves from their family and community due to fear of rejection (Greeff et al., 2008b). This was confirmed by PLWHA support group members who participated in the training workshops who reported stigma in different ways such as isolation and rejection of families and households, which have persons who are HIV positive. According to this

study's findings sometimes neighbours visit to see the condition of the sick person so that they can go and gossip, after which they stop visiting. Some people stop visiting the family, start gossiping and calling them names, which is common in the rural areas. There are reports of children not allowed to play with a neighbour's children who is suspected having HIV/AIDS. Similarly Greeff et al. (2008b) reported the same stigma where children were told not to go to the homestead of a person who is HIV positive.

Social isolation by families was reported by Greeff et al. (2008b) in five African countries study where respondents confirmed that PLWHA were chased away by family members once they tested HIV positive. Evidently this study found that PLWHA are being isolated socially by family, friends and community members, the mean score of social isolation at baseline was 0.96371. PLWHA participants (36%, n=33) reported that some people who were their friends stopped their friendships after they learnt about their HIV positive status. It was found that people do not want to chat with PLWHA (30%, n=28) and do not visit them (37%, n=34) anymore as they used before knowing their status. This reflects either on fear of being associated with someone who is HIV positive or it could be linked to shame related to the most common mode of its transmission. There are reports of persons being isolated socially by colleagues at workplace due to their positive status. This form of stigma can cause stress and depression in PLWHA, therefore people need to be educated and informed on stigma reduction strategies. It is high time for HIV/AIDS to be seen and regarded as any other chronic disease so that infected and affected people can enjoy equal rights in a culture of acceptance, openness as well as compassion.

Reports from Asia Pacific Regional Analysis 2011 report on PLWHA stigma index reported that many people who are HIV positive choose not to have sexual relationship,

despite sex being a normal part of human life (UNAIDS, 2011). That is different from this study's findings where some female participants reported that they have been isolated sexually and do not have boyfriends anymore as men are afraid to approach them. This could be linked to fear of infection although there are wide-scale evidence that healthy consensual sexual practice facilitates sense of well-being and safe sexual practice precluding HIV transmission risk (UNAIDS, 2011). This type of isolation can hinder HIV prevention as people will not disclose their status if they know that they will be rejected. There is a need to re-educate people that PLWHA can have normal intimate relationships as long as they practice safer sex.

This study found out that some PLWHA isolated and regarded themselves as sick people and they withdrew from society. They isolate themselves to avoid rejection or disclosing their HIV status. In some cases they do it to protect their beloved ones from stigma of association as social isolation may correspond to low level of disclosure to family and friends. Similar reports from the Asia Pacific Regional Analysis (UNAIDS, 2011) indicated that many people withdraw from work, education and training opportunities as well as decided not to apply for promotion as a result of their HIV status. Research has confirmed that social isolation and withdrawal are barriers to HIV response as they prevent PLWHA to seek for health care, despite needing access to medical services. PLWHA and their caregivers should be educated on the disadvantages of self isolation, social withdrawal and its effects on their well-being. Counselling services need to be tailored to reach them, their families as well as community at large.

Workplace stigma: The questions about stigma at work place were not answered by many participants and this could be due to their unemployment status. The study findings

revealed that only few (15% to 17%) participants experienced stigma at workplace. There are few cases for discriminatory acts against PLWHA at workplace such as not willing to chat with a colleague who is HIV positive or not nominated to attend educational workshops. The low level of stigma at work place could be as a result of policies and more understanding on HIV/AIDS facts. According to Mahendra (2007) low stigma reflects on growing knowledge and how it contributes to less stigma (Mahendra et al., 2007). This could also be linked to Namibian policy that stipulates that both employers and employees have a mutual responsibility to prevent discrimination on the basis of HIV status in the workplace (AIDS Law Unit of the Legal Assistance Centre, 2000).

ii. Internal stigma

Internal, felt, imagined or self stigma is the shame and fear associated with HIV/AIDS as a result it impacts on people's daily life, it affects the way in which they cope with their HIV positive status and how they behave (Brouard and Wills, 2006).

Negative self-perception: Results of this study revealed that internal stigma is experienced by people who are HIV positive. Out of 93 PLWHA participants 19% they felt that they did not deserve to live, 21% were ashamed of having the disease, 25% felt worthless, 21% said they no longer felt like persons. These kinds of feelings could result in negative actions such as stress, depression and decision to commit suicide. The study further revealed that 33% felt that they brought trouble to family. The feeling of bringing trouble to the family can be associated with blame and judgment from families and relatives. In some instances PLWHA feel guilty when there are not enough resources in the household and the less that is there is spent on them. Feeling guilty and a burden to their loved ones do not necessary mean families have the same feelings against them.

Although it is less than half of participants who reported self stigma, it is still a concern as it is the chief obstacle in HIV response in Namibia.

Studies have shown that self stigma blocks HIV response, for example in India an HIV positive mother was afraid to stop breastfeeding her baby due to fear of her family to suspect her HIV status. A man in Botswana decided not to take ARV as he associated HIV with death. A sex worker in Cambodia does not visit clinic regularly for STI treatment due to fear of blame and judgment from health care workers (Brouard and Wills, 2006).

According to Banda an HIV activist from Zambia in her presentation at XVI International AIDS Conference in Toronto, the worst type of stigma is self-stigma that is mostly experienced by PLWHA who did not fully accept their seropositive status. That makes people to be inactive and less productive as such they will develop low self esteem, self-imposed challenges, stagnancy and self pity (Banda cited in Health and Development Networks, 2006). Similarly this study found that PLWHA experienced self-stigma for example it was pointed out that they regard themselves as “sick” although they are well. As a result they do not participate in household chores and that makes them more vulnerable to external stigma.

Participants in this study suggested that continuous counselling is needed for PLWHA as they are stressed and sometimes for no reason. Self stigma was also reported in a Ugandan study (2011) where it remains powerful as participants describing themselves as “useless” and “same as dead” (Nattabi et al., 2011). The authors for Ugandan study suggested that future interventions should be aimed at empowering PLWHA that will help to improve their quality of life. Equally, this study supports these suggestions.

b. Group 2 & 3: Family members and community leaders

Families of PLWHA, community members and opinion leaders were part of study participants who reported stigma as they observe and how they view it that will be presented under external.

i. External stigma

The study findings on external stigma from the above mentioned groups include community, family and personal attitudes towards people who are HIV positive that are combined and will be discussed together. The other factors which were measured are household stigma, community opinions, having close relationship with PLWHA, caring for sick relatives and fear of contagion.

Attitudes towards PLWHA: People's attitudes towards PLWHA vary from person to person, there are those who have negative while others have positive. This study found that PLWHA are somehow mistreated and/or treated differently in some families and in communities, although the majority answered positively. Negative attitude towards family members who are HIV positive was reported by Rao et al. (2007) in Chicago study where respondents confirmed being mistreated by their mothers (Rao et al., 2007).

Household stigma: Few family and community participants confirmed that PLWHA should be excluded in family decision making although in some cases they are the key topics in those discussion. Their rights of freedom of expression are being violated in this regard. Families of people living with HIV need to understand that they have rights just like any other member and that should be respected.

Community opinions regarding PLWHA: Although many participants reported that they do not have a problem with HIV positive teachers to continue teaching at schools, there are reports of those who are discriminated by their colleagues due to their status. This study further found that at parents-teachers meetings, PLWHA were discriminated as they are not listened to when they talk or air their opinions. The same goes for the HIV positive learners as other children do not want to be in the same group work in their respective classes. This could be linked to fear of getting infection, which needs to be corrected by teachers at school level. However if the teachers themselves are not well informed on basic facts of HIV/AIDS it will be difficult for them to guide learners accordingly. The programs such as '*My future is my choice*', which deals with HIV/AIDS related matters at school level should be strengthened in the constituency. This program can influence change on stigma reduction at schools that could be diffused to the whole community.

There are schools which have counselling services and they reported low stigma, it therefore, assumed that there is a link between the two: the more accessible counselling services, the lower the stigma at schools. The relevant authorities need to look into this matter of recruiting counsellors at public schools that would help to address and reduce stigma among learners and teachers. Nonetheless, further studies are needed to explore more on this assumption and targeted interventions aimed at decreasing stigma at schools might be necessary.

Caring for sick relative PLWHA: This study's findings have shown that many people are willing to care for their sick relatives who have HIV or AIDS, although there are less than 10% who revealed their unwillingness. There are few who

indicated that they will not care for someone who had an accident and this reflects the fear of getting HIV via the possibility of coming into contact with infected blood. It is difficult to know if these findings reflect the reality or participants just decided to give the most social acceptable answers. However, few participants opted not to answer these questions and it can be attributed to either unwillingness or feeling guilty to admit it.

This study findings show low stigma from health care workers regarding caring and treating HIV positive patients although two participants complained of unfair treatment or discrimination at health facilities. They indicated that physicians do not want to touch them and some medical doctors refused to prescribe vitamins. These findings of unfair treatment are however rejected by reports from previous researchers in Namibia such as Nghifikwa (2011), who reported that her study respondents indicated that health care workers treat PLWHA with sympathy and as a result they have positive experiences in health facilities. More studies are needed to explore stigma in health facilities in Namibian context before a final conclusions should be made on the level of stigma in those settings.

ii. Stigma of association

Families with PLWHA experience stigma of association as sometimes they are held responsible for the behaviour and lifestyles of their family members which led to HIV infections (Li et al., 2008). Health care workers also experience stigma of association as the care providers to persons who are HIV positive or have AIDS. These two recipients of associated stigma are discussed below.

Associated stigma to families: Families and relatives of people living with HIV/AIDS often experience stigma and discrimination due to their association with infected family member. According to studies on impacts of HIV/AIDS stigma on family, in Nigeria when one family member becomes infected the whole family is called an *AIDS family* by other villagers, in Indonesia the entire family would experience rejection by the local communities and in Thailand the whole family faces discrimination as a result of a member who is HIV positive (Li et al., 2008). Although participants of this study reported that neighbours stigmatize families with HIV positive individuals, stigma of association was not experienced frequently. One can possibly attribute this to the fact that many people in Ongenga Constituency accepted that HIV can affect any family.

Associated stigma to health care workers: According to Holzemer and Uys (2004) health care workers are the recipients of stigma as they provide care to PLWHA and they are also regarded as the source of stigma by persons who are HIV positive (Holzemer and Uys, 2004). This study found that health care workers were associated with HIV/AIDS as people in the community believe that persons who care for PLWHA patients have the virus as well. Participants in this study reported that spouses of nurses fear that they will bring them HIV. This study did not explore stigma of association against caregivers with other participants rather than the four health care workers from the ARV clinic. It was one of this study's limitations however future researchers can take this further.

The research question one on the level of stigma in the constituency was answered and addressed in these study findings. The research question two of this study asked

if there are different types of stigma and how do they change after intervention. The first part of the question on different types of stigma was answered through findings and discussion, while how do they change after intervention will be addressed under objective 4.

6.2.2 Objective 2: To develop a community-based HIV/AIDS stigma reduction intervention

A community-based HIV/AIDS stigma reduction intervention was developed in a rural community after the researcher obtained ethical clearance from UKZN, Namibian Ministry of Health and Social Services and permission from constituency councillor. The starting points were community meetings to sensitize people about the research in their area, followed by baseline assessment. After baseline survey and separation of community geographically, the intervention process started with selection of trainees. The support group members for training were selected by Opawa Support Group leadership and community leaders were nominated in consultation with constituency office and Ongenga Congregation Board. Apart from training workshops, the researcher implemented contacts with infected and affected groups and community involvement as intervention strategies to reduce stigma in the constituency.

The aim of this intervention was to reduce stigma and the objectives were to train people living with HIV who are members of the support group and community leaders of Ongenga Constituency on HIV/AIDS stigma reduction strategies as well as to mobilize the community to stop stigmatizing PLWHA. These trainees trained other support group members and mobilized community at the intervention villages to reduce stigma in their constituency. After completion of the study trainees would be expected to continue with

training and mobilization for the entire constituency. Based on the Diffusion of Innovations theory, it is attributed that these trainees would influence the community members in the intervention arm to reduce stigma and later the entire constituency would be informed and adapt change.

Community leaders were included as they are influential people to help the diffusion of information from small group to the entire community. The literature found that opinion leaders could be the reason for a diffusion to be effective as long as their attitude is favourable to the new ideas or practice. They are among the early adopters and as such they could influence the early majority through their social influence (Dearing, 2009). The community leaders from this study who were trained in stigma reduction reported that they held community meetings with their villagers and informed them about stigma and why the change is needed. It is attributed that their influence has contributed to stigma reduction in the intervention community. Research has shown that involving PLWHA in prevention education is as an important tool to break the deep-rooted stigma associated with the disease. It was therefore appropriate to train them to become ambassadors of stigma reduction in their own community. The purpose of developing an intervention was to have a sustainable program that will deal with stigma reduction on constituency level and to enable it to function after the researcher completed her study and left.

Training workshops: As a result 18 PLWHA who are Opawa Support Group members and eight community leaders were trained in stigma reduction at two workshops for three days each (the detailed report on workshops is discussed in Chapter Four). After their training these trainees went back to their respective villages where they mobilized community members irrespective of their HIV status on stigma reduction. Trained

PLWHA reported that they trained others who are support group members and together they continue to mobilize their community on understanding stigma, its negative impacts and how it should be reduced. The trained community leaders who consisted of four village headmen and three Ongenga Congregation board members and one teacher reported that they gave feedback and conducted meetings where they informed others about stigma reduction strategies. The trainers reported that they were met with challenges and difficulties when they visited some villages therefore they need support in different ways such as back up by local community-based organisation and financial resources.

Contacts with infected and affected groups: Having contacts with affected and infected groups is also recommended by studies on stigma reduction as that would help to improve community attitudes towards them, and that leads to change behaviour. According to Heijnders and Van der Meij (2006) having contacts with affected and infected groups as an intervention strategy aims to increase knowledge regarding specific health condition (in this case HIV/AIDS stigma) within a particular community. It also aims to develop community skills in dealing with stigma (Heijnders and Van der Meij, 2006).

Community involvement: Literature documented that community involvement in any health promotion program or research is essential as it promotes their quality of life, improves their health and empowers them. In this study community members were represented by constituency councillor as well as by community leaders. These representatives were involved from the preparation stage of this study and during the community meetings where they were informed about the research in their constituency and its purpose. Their views, ideas and suggestions regarding stigma reduction in their constituency were considered and respected by the researcher.

The training workshop for stigma reduction had also included community leaders who represented their people and they have contributed to discussions and suggested plans for action in the constituency. Community mobilization is continuing in the same constituency to educate people on stigma reduction strategies in the family as well as in the community. Further interventions using community involvement approach when targeting stigma reduction, are needed.

6.2.3 Objective 3: To implement a community-based HIV/AIDS stigma reduction intervention in a rural community.

Intervention has been implemented as two workshops were conducted with different groups. The first one was for the support group members and the second one was for community leaders. Both workshops aimed to train participants on stigma reduction. Study and workshop participants identified several issues that causes stigma, forms and its effects on different groups and suggested what should be done to address it. They explained and suggested the plan of action at individual, family and community level. Their input is included in the final versions of the two training manuals (see Appendix). The content for these manuals are not necessarily the same although both are on stigma reduction. The reason for having two groups is due to their different needs and experiences related to stigma. The support group members are the stigmatized while the community leaders represent the people who stigmatizing PLWHA but both are based on the Toolkit For Action “Understanding and challenging HIV Stigma” developed by Kidd and Clay (Kidd and Clay, 2003).

a. Group 1: PLWHA training manual

The training manual for PLWHA was finalized after the intervention workshops and it would be made available to community based organizations that deal with HIV/AIDS related matters in the communities as well as to support group members whenever there is a need to train other people who are living with HIV at community level. The findings from the study revealed that there is a need to include counselling as well as coping skills in stigma reduction intervention. There are reports from participants that PLWHA have stress problems and they need continuous counselling that will help them to cope and reduce self negative perception.

Following these findings it was established that more intervention training is needed by both community members as well as by people who are living with HIV. The researcher will hire someone to translate both training manuals in local language (Oshiwambo), which can be used by community leaders and PLWHA support group members to educate others. The other plan is to extend training to the youth in the constituency to become peer educators for stigma reduction but that will depend on resources availability. Workshop participants suggested that future intervention trainings need to be longer than three days and they indicated that it was useful and promise to apply what they learnt.

b. Group 3: Community leaders training manual

The training manual for community leaders was also finalised after the training workshops and new information was added in. The content for this manual is meant for people who stigmatise PLWHA. Therefore it can be used by community leaders and other people who have interest in HIV/AIDS stigma reduction but it is not for people who are living with HIV.

6.2.3.1 Recommended Strategies on how to use these training manuals

Based on the Toolkit for Action on stigma reduction by Kidd and Clay (2003) and Kidd et al (2007), several teaching and learning strategies with participatory approaches can be used (Kidd and Clay, 2003, Kidd et al., 2007). The study found that participatory learning strategies are useful in stigma reduction training. The PLWHA workshop participants in this study recommended the use of role plays, dramas and songs as the most suitable ways to convey the messages in the community.

Group works were useful to get ideas, views and opinions from participants as they created a platform for all to contribute to discussions. People who are not comfortable to talk in a big group, can open up when they are in small group works, therefore this strategy is also recommended for future stigma reduction trainings. The participants found it refreshing to have icebreakers and energizers in between the sessions. Quizzers were useful in knowledge assessment exercises and are recommended particularly with the community members training.

Audience of the manuals: These manuals are meant for anyone who will be able to train other people in HIV/AIDS stigma reduction being a person who is living with HIV, a family member, community member, peer educator or anyone who is interested in stigma reduction training. They are not copy righted and can be used freely as long as it is in the interest of improving the quality of life for PLWHA and their beloved ones.

6.2.4 Objective 4: To evaluate the effectiveness of intervention

Findings from the evaluation have shown that there are changes in some PLWHA stigma scores such as verbal abuse, social isolation, negative self perception and work place

discrimination based on HIV status, after implementation of intervention. It shows that intervention was partly effective although it did not succeed to reduce all the stigma scores.

When control and intervention groups were compared it was found that stigma was higher in control arm than in intervention at baseline. After intervention it increased in control while decreased in the community that received intervention. The decrease in the intervention arm could be attributed to effectiveness of the intervention program and the increase in the control groups could be as a result of awareness triggered by research in the area. During post intervention interviews participants indicated that many activities related to HIV in the constituency are done at the Regional office, which is located in Ongenga village (intervention site), that could be the reason for having lower stigma there than in the control area before intervention. One participant pointed out that at intervention site they involve community members in their support group meetings that could explain the low stigma in that site.

During post-intervention interviews participants reported that there are changes in stigma in their community as well as in their families. For example they indicated that family members are helpful and treat them well after they were informed about stigma and its impacts. According to the findings PLWHA who were not support group members before intervention they joined. There are increases in people attending ARV clinic those who were afraid of being seen taking medication are now free and open about their status. It was further revealed that more people do attend community meetings addressing HIV/AIDS matters, which was not the case before intervention. These findings confirm what the other studies reported after intervention on stigma reduction in the community

(Heijnders and Van der Meij, 2006, Apinundecha et al., 2007). According to this study there are reports that men are more involved as they go for VCT to know their HIV status and talk about AIDS openly.

Although majority of participants (15 out of 17) who were interviewed after intervention reported positive changes there are two who revealed that they still experience the same stigma such as verbal abuse in their families. Future interventions need to target family education on stigma reduction in the households. The research question on how do types of stigma change after intervention has been addressed in the discussions above and was found that external and associated stigma were changed, but the intervention did not change internal stigma significantly.

6.2.5 Objective 5: To compare the results between intervention and control groups

The comparison of study results between intervention and control groups are presented according to participant groups but Group 2&3 (family members and community leaders) are combined as they used the same measurement instruments (F&C-SI).

a. Group 1: PLWHA results comparisons

The comparison analysis between the two arms (intervention and control) reached a conclusion that there was no statistical significant difference in four stigma scores (fear of contagion, verbal abuse, social isolation and work place stigma) experienced by PLWHA in both intervention and control group at baseline. The only statistical significant difference observed was in negative self perception score ($p < 0.00^*$), which was higher in the control (mean= 1.000; standard deviation=1.1927) than in intervention group (mean=0.0889; standard deviation=0.2928). As the developers of HASI-P instrument

(Holzemer et al., 2007b) did not conduct interventions, there was no studies found either to support or reject these findings.

The independent t-test was conducted to compare findings from control and intervention groups at evaluation phase. The findings have shown statistical significant differences in the following stigma scores: social isolation ($p=0.017^*$), workplace stigma ($p=0.008^*$), negative self perception ($p=0.006^*$) but there were no significant changes in fear of contagion and verbal abuse scores. Fear of contagion is not much a concern as it was low in both arms although increases in control at evaluation survey. According to these results verbal abuse remains a problem in Namibian society therefore, targeted interventions should aim at different strategies rather than the one was used in this study to decrease that form of stigma.

When a paired samples t-test was conducted within the control group it was found that fear of contagion score has increased at evaluation survey ($p=0.001^*$). It can be argued that awareness from the previous questionnaire at baseline influenced the results post-intervention. Participants became aware that certain behaviour towards them by others is stigma, but they did not know that at baseline assessment. The other scores (verbal abuse, social isolation, workplace stigma and negative self perception) did not show significant changes at evaluation phase, although they have increased slightly.

The paired t-test from intervention group indicated statistical significant decrease in three stigma scores: verbal abuse ($p= 0.013^*$), social isolation ($p=0.004^*$) and workplace stigma ($p=0.021^*$). The fear of contagion ($p=0.223$) and negative self-perception ($p=0.086$) scores did not show significant changes during evaluation phase in the group

that received intervention. These findings are supported by Ugandan study where negative self perception was found higher in patients who were on highly active antiretroviral therapy (Nattabi et al., 2011). That indicates the need for targeted intervention to empower PLWHA.

b. Group 2& 3: Family and community leaders results comparison

According to independent t-test results there was no statistical significant difference in the stigma scores, community attitude ($p=0.206$), family attitude ($p=0.324$), personal attitude ($p=0.911$), household stigma ($p=0.495$) and community opinions ($p=0.092$) between the intervention and control groups at baseline survey. In reference to questions of having a close relative or friend with HIV, willingness to care for sick PLWHA and fear of contagion scores there was no statistical difference between intervention and control group at baseline.

When the two arms/groups were compared after intervention the only significant difference was in household stigma score ($p=0.017^*$). Although the other stigma scores did not show statistical significant changes they had slightly decreased in the intervention group and increased in the control. The researcher attributed that decrease in the intervention group is a result of the intervention which they received, and therefore concluded that it worked, although it did not make statistical significant differences.

The results from the paired-samples t-test from intervention group show a significant difference in family attitude score ($p=0.002^*$) towards PLWHA as well as in community opinion ($p=0.004^*$) at evaluation phase. From the control group most of the stigma scores such as community attitude ($p<0.00^*$), family attitude ($p<0.00^*$), personal attitude

($p < 0.00^*$), household stigma ($p < 0.00^*$), community opinions ($p = 0.012^*$) and fear of contagion ($p = 0.005^*$) show significant increase at evaluation survey except for close relationship and caring for sick PLWHA relatives. The results of stigma scores from control group have increased at evaluation phase and this could be linked to awareness influenced by seeing the same questionnaire at baseline. In the intervention group one can conclude that the community mobilisation as part of interventions had influenced changes in the attitudes of participants towards PLWHA.

A general conclusion is that stigma has decreased in the group that received intervention and increased in the control community, although not all the scores have shown statistical significant differences. These findings support the hypothesis that people living with HIV who live in the intervention area will report low stigma in comparison with those from the control group. It further supports the literature (Apinundecha et al., 2007) that involving the affected and infected groups in stigma reduction is important and it works. It can be argued that if this intervention should be expanded to the whole constituency, stigma will be reduced significantly.

c. Group 4: Comparison of health care workers' results

This study could not establish stigma with health care workers from the control group due to the absence of ARVs services in that area. As a result the comparison of findings was only done using a paired samples t-test and they show that there is a statistical significant difference before and after intervention in the two stigma scores: nurse stigmatizing patient score ($p = 0.048^*$) and nurse being stigmatized ($p = 0.005^*$). The assumption was for the stigma scores to decrease after intervention, however the opposite happened. The

increase could be interpreted as a result of stigma awareness in the area, which has been absent at baseline. No studies were located which support or reject these findings.

Although many studies have been conducted globally, further researches with intervention designs are needed to reduce stigma in health care settings in the Namibian context. The third research question was asking how effective the chosen intervention to reduce stigma in the community was. Based on the findings on comparisons of results from the two study arms, it could be concluded that the intervention was effective although for future studies additional strategies would be recommended.

6.3 GUIDELINES FOR COMMUNITY HIV/AIDS STIGMA REDUCTION INTERVENTION IN A RURAL COMMUNITY

These guidelines are based on the lessons learnt and the experience from this study on assessment of HIV/AIDS stigma and development of intervention in a rural community. Randomised control trials (RCT) are considered as the “gold standard” of evidence to support the effectiveness of interventions, but when they are not feasible other designs such as quasi-experimental can provide evidence-based to inform practice. These guidelines therefore are based on evidence from a quasi-experimental non-equivalent control group before and after intervention design. The evidence from the study is complemented with information from literature on HIV/AIDS stigma reduction interventions (Apinundecha et al., 2007) and findings from in-depth interviews, which were conducted with community and opinion leaders and PLWHA support group members from the community.

6.3.1 Purpose and scope of guidelines

- These guidelines aim to help health service providers and facilitators to plan for stigma reduction interventions in the community based on evidence-based interventions.
- These guidelines' focus is on PLWHA who are the recipients of stigma, their families and health care providers as they experience stigma of association.
- When education approach is chosen, the developed training manuals should be used to guide training on stigma reduction (Appendix 7).

These guidelines are developed for rural communities to address the three types of stigma: External, internal and associated stigma, which has been reported by literature and emerged from the assessments. It is important to be aware of and understand these three types of stigma before planning to intervene.

i. External stigma

External stigma refers to received and enacted stigma, which includes any experience behaviours, attitude or discrimination acts towards PLWHA. The following factors can be used to assess external stigma.

- *Fear of contagion* through non-sexual casual contacts for example not willing to share utensils, not touching, let person eat alone, let person drink last from the cup, ask person to leave due to coughing, not want to share toilet, shake hands and eat food prepared by a person who is HIV positive.
- *Verbal abuse* such as name calling, singing of offensive songs, blaming, moral judgment, scolding and insulting people who are HIV positive on the basis of their status.

- *Social isolation* for example ending friendship and relationship, avoidance, rejection and stop visiting a person who is HIV positive.
- *Workplace stigma* for example fired from work, denied opportunities due to being HIV positive.
- *Attitudes*, for example treat PLWHA differently, disclosing their HIV status without permission, and gossiping about them.
- *Household stigma* such as making PLWHA to use separate blankets, left out of family discussions and decisions, stay away from visitors, not allowed to cook for family, not allowed to play with children.
- *Community opinion* for example to say that teachers who are HIV positive should not be allowed to teach at schools, HIV positive learners should not go to school, PLWHA should not attend community gatherings, and they should be dismissed from work upon disclosing.

ii. Internal stigma:

This refers to self -stigma, as a result of HIV positive status and includes these examples:

- *Negative self perception*: fear of judgment and self blaming, person feels not deserve to live, ashamed for having the disease, feeling worthless, feeling guilty by bringing trouble to family, feeling no longer a person.

iii. Stigma of association:

Stigma of association refers to stigma either to families/associates or to health care providers of PLWHA.

- *Stigma to families of PLWHA:* for example called names or gossiping about the family.
- *Stigma to health care providers:* by saying that health care workers who work with HIV positive patients are also positive or they will bring virus to their spouses.

6.3.2 Strategies to consider for HIV/AIDS stigma reduction

Research encourages evidence-based guidelines for practice therefore the researcher developed guidelines for stigma reduction in community, based on this study findings. These strategies, which are education, community involvement and contacts with infected and affected groups, were implemented during the intervention of this study as recommended by literature (Heijnders and Van der Meij, 2006, Apinundecha et al., 2007). The intervention that has been carried out showed significant differences between the two study arms and it is therefore recommended for future use. Research has shown that combination of strategies is more effective than using a single approach. Another strategy that was absent in this study but is recommended for future stigma reduction is *counseling approach*. This approach is recommended as it will help to address internal stigma, PLWHA will be taught coping skills and those who need counseling services should be assisted accordingly. The guidelines recommend these combined approaches: **E**ducation, **C**ommunity involvement, **C**ontacts with affected and infected groups and **C**ontinuous counselling, that will be named **ECCC approach** and is presented Figure 6.1.

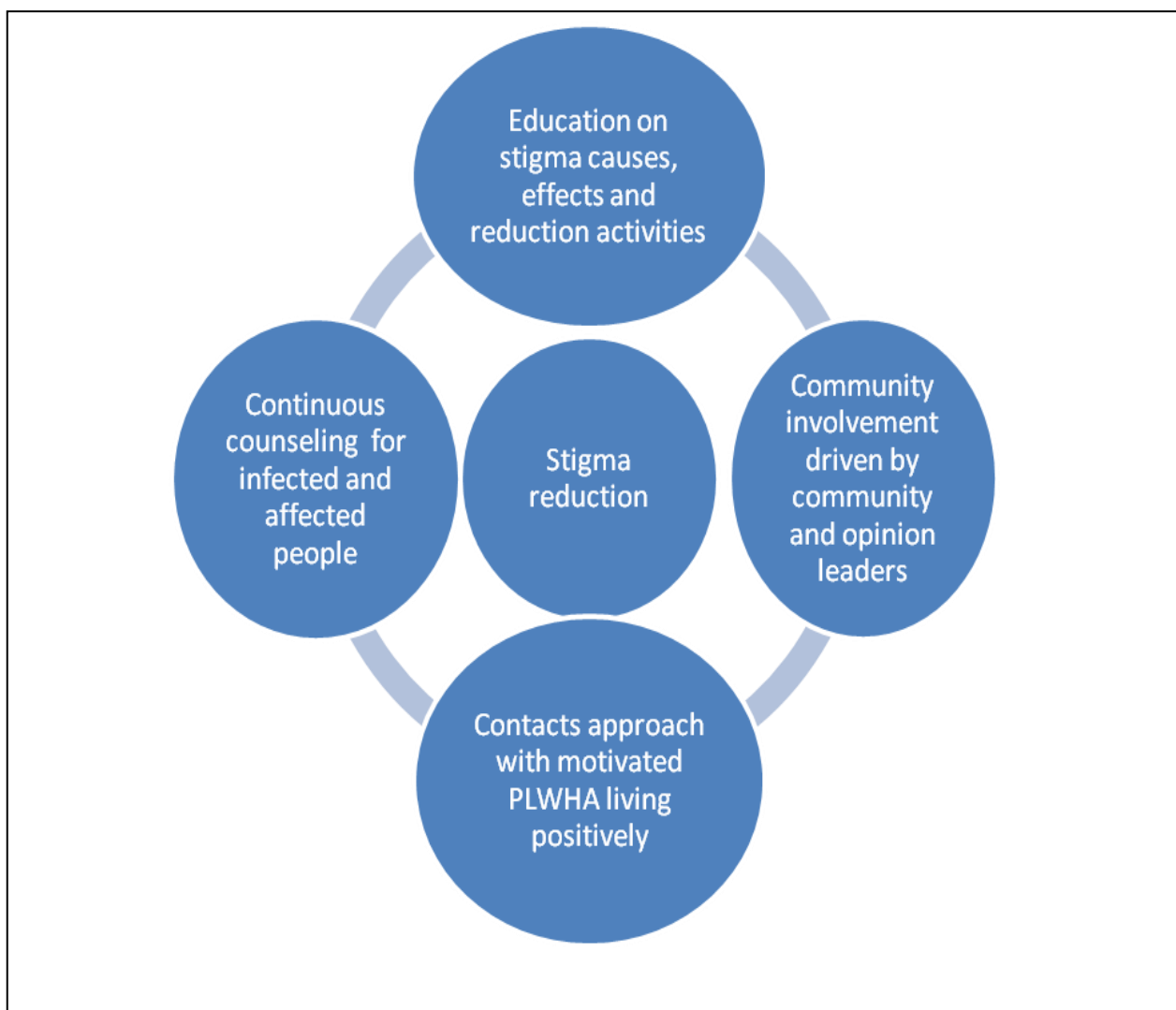


Figure 6.1 Strategies of the ECCC Approach

Concepts in the combined ECCC approach

The four strategies in are all linked to stigma reduction and should be implemented as a combination in order to obtain significant changes.

a. Education approach

Education strategy should be implemented through training workshops and awareness campaign. Two training manuals (Appendix 7) have been developed and should be used

for training on stigma reduction. One manual should be used to train people living with HIV on stigma reduction the other one should be used to train community leaders, although it can also be used to train other groups such as community peer educators, youth, faith-based organization and community-based organization staff. The content of these two manuals can be used to train health professionals on stigma reduction as well. Some units' content can be used in schools to sensitize learners on stigma and its effects either on the infected or affected groups.

Education approach in stigma reduction will address the following:

- HIV/AIDS in general for example how HIV is transmitted and how is not, to reduce fear of getting it through non-sexual casual contact.
- Educate people about stigma, its causes, and effects on the stigmatized people and teach them reduction activities.
- Education should address the most identified forms of stigma such as verbal abuse, social isolation and negative self perception.
- Implications of reducing stigma and community benefits

The education approach can be implemented in the following ways:

- Training workshops for identified and eligible trainees/participants on HIV/AIDS stigma reduction (preferable community and opinion leaders and PLWHA support group members).
- Training of the youth to become ambassadors of change and peers educators in their respective communities to influence people behavior and attitudes towards PLWHA.
- At schools teachers of Life skills subjects should teach learners about stigma, the ways of HIV transmission to increase their knowledge that will result in less fear and less stigma towards other learners who are HIV positive.

- Create a platform for students and learners to have essays competitions on HIV/AIDS stigma reduction and publish the winning essays in local newspapers.
- Use media particularly the radio to inform and educate community about HIV/AIDS stigma, causes and effects on the stigmatized as well as on the general public.
- Create a platform in the local radio stations for questions and answers on HIV/AIDS in general and on stigma in particular.

b. Community involvement: driven by community and opinion leaders

Community involvement in any program that thrives to improve people's health or that of their beloved ones is essential. Interpersonal communications between experts (on stigma reduction) and the general public, opinion leaders, health care workers and among families of people living with HIV/AIDS and friends, are equally important as using mass media to convey the message. All available platforms such as after church services, at schools, community gatherings, sports clubs meetings and youth forums should be used to inform the people about stigma, its effects on persons who are being stigmatized and what should be done to stop or reduce it. The following ways should be considered to implement this strategy:

- Use community meetings to sensitize the people about HIV/AIDS stigma and how it fuels the new infections, prevents ARV adherence, prevents HIV status disclosure and affects the stigmatized groups.
- Use relevant and practical examples of stigma as it is experienced by people who are HIV positive.
- Address verbal abuse and social isolation as they are the most identified forms of external stigma in the families and community.

- Use mass media to create awareness campaign on stigma reduction particularly the radio, which is listened by majority of the rural communities who do not have access to televisions and newspapers.
- Media should address the misconceptions and myths on HIV transmission, thereby increasing the knowledge and decreasing fear of contagion from non-sexual casual contacts.
- Media should stop showing and advertising negative messages on HIV/AIDS such as “AIDS kills”. Replace those negative advertisements with new positive messages that encourage people to stop stigmatizing others.
- Use internet services such as Face book and Twitter as well as cell phone texting to mobilize and sensitize community members on HIV/AIDS stigma and how it can be addressed.
- If it is possible let HIV/AIDS stigma also be discussed in the Parliament to get support from the government level.
- Community members should be made aware about PLWHA’s rights and at the same time people who are living with HIV need to be informed about their rights and responsibilities.
- Men should take the lead in stigma reduction as they have done in the independence struggle of the country.
- Schools parents meetings should discuss the issue of stigma against learners who are on ARV so that they can be given necessary support while at schools without violating their confidentiality rights. That will also improve treatment adherence.

c. Contact approach: Motivated PLWHA living positively

Contact with infected and affected groups can occur at different levels such as physical for example being in the same room with people who are HIV positive, eating together or just being seen chatting with them without any fear of associated stigma. Verbal contact can be implemented by asking motivated PLWHA who are well counselled and living positively to give testimonials on stigma that will help people to realise the seriousness and its effects and how it blocks the HIV prevention as well as adherence to treatment. PLWHA should be trained in stigma reduction to be the ambassadors of change. People will be likely to listen and change their attitudes and behaviours if they hear stories of stigma from those who have first hand information, persons who experienced it personally. The following should be considered when implementing contacts approach:

- HIV/AIDS should become an openly spoken disease and not a whispered condition. That should be the starting point for stigma reduction which can contribute to more HIV status disclosures, but it does not mean confidentiality will be removed.
- Use audio-visual such as films e.g. “Remember Eliphaz” (local Namibian film) from Ministry of Defense to show the people how community hurts the stigmatized groups. Other relevant films or pictures can be shown to sensitize the community about stigma.
- Invite well prepared, motivated and counseled PLWHA living positively to give testimonials to community members. Let them tell their stories how they experienced stigma.
- Families of people who are living with HIV should be actively involved in stigma reduction interventions.

d. Continuous Counseling: for People living with HIV/AIDS and their families

Counselling is defined as a process that enables a person to sort out issues and make informed decision affecting their lives. It involves talking to a person in a way that helps to solve a problem or create a condition that makes a person to understand or improve behaviour, values or life circumstances. Research showed that HIV/AIDS is associated with emotional stresses (Rao et al., 2007) and therefore needs counselling as an appropriate means to help and support people who experience emotional problems (Kaleeba et al., 1997). Self stigma and emotional stresses can be addressed by:

- Providing counseling services at schools to address stigma towards teachers and learners who are HIV positive.
- Establishing more counseling services which are needed in the community to help PLWHA to overcome self stigma and to deal with emotional problems.
- PLWHA need to be trained in coping skills with HIV/AIDS in general and with stigma in particular.
- Families of people who are HIV positive should be provided with counseling when there is a need.

6.3.3 Enabling HIV/AIDS stigma reduction through Diffusion of Innovation

A HIV/AIDS stigma reduction intervention should be implemented through the influence of innovators who can be the campaigners for the innovation (e.g. health care providers, community-based organization staff, PLWHA support group members and community leaders). These innovators will use the combination of stigma reduction strategies that include education, community involvement, contacts approach and counseling to reduce stigma (Figure 6.1). Through these strategies the innovators/adopters at different stages of Diffusion Theory (Early adopters, Majority Early Adopters, Late Adopters, and Laggards)

will adopt a change in their attitudes and behavior towards the PLWHA. This change in attitude of the innovators/adopters will influence the PLWHA negative self -perception.

Influential people such as community and opinion leaders will play an important role to influence other community members to change their attitude and behaviors towards PLWHA. The community leaders and PLWHA who will be trained in stigma reduction will become the early adopters. These early adopters will mobilize the community on stigma, its causes and effects on the stigmatized and how it fuels the epidemic. If these early adopters are provided with enough support they will be able to influence the majority who will follow their example and change their attitude towards PLWHA. When the early majority adopts change, stigma will be reduced, that results in less self stigma among those infected and affected by HIV/AIDs. The motivated PLWHA will influence others to realize that stigma is harmful, creates social inequalities in society and will be in the position to promote the importance of HIV prevention. PLWHA will use contacts approach to mobilize the community to facilitate their support.

The guidelines for HIV/AIDS stigma reduction in Nambia will direct campaigners and those who will be in decision making positions to plan and implement stigma reduction interventions. In the absence of health care facilities the guidelines can be implemented in community settings and can be modified to meet the needs of health care facilities. The implementation of these guidelines will reduce internal, external and associated HIV/AIDS stigma.

A flow diagram 'Enabling HIV/AIDS Stigma Reduction through Diffusion and Innovation Theory' is illustrated in Figure 6.2.

6.3.4 Expected outcomes

It is expected that if the four combined strategies, which are education, community involvement, contacts approach and counseling are successfully implemented in the community people will become aware of HIV/AIDS stigma and how it fuels the epidemic that will result in these changes:

- Stigma will decrease in small groups first and through peer influence it will be diffused to the bigger groups, then the whole community will stop or reduce stigmatizing PLWHA and their families.
- PLWHA will report low stigma in their families and in community and will start living positively with the disease.
- If stigma decreases, more people will be willing to go for HIV testing as they will no more afraid to know their status and possible rejection due to stigma.
- If stigma decreases, people who are on ARVs will adhere to treatment and their health will improve.
- If stigma decreases, PLWHA will feel free and disclose their HIV status to their beloved ones without fear of rejection.
- The decrease of stigma will result in decreased HIV infections as people will be open about their status and start practice safer sex.
- Reduction in stigma will encourage men to accompany their partners to ANC clinics for PMTCT programs.
- As a long term goal with stigma decrease, hospitalization due to HIV related conditions will decrease as PLWHA will seek medical services on time.
- The decrease in stigma will result in reduction in the number of orphans due to HIV/AIDS as HIV positive parents will live longer and lead productive lives.
- Stigma reduction will result in a generally low mortality rate related to HIV/AIDS.

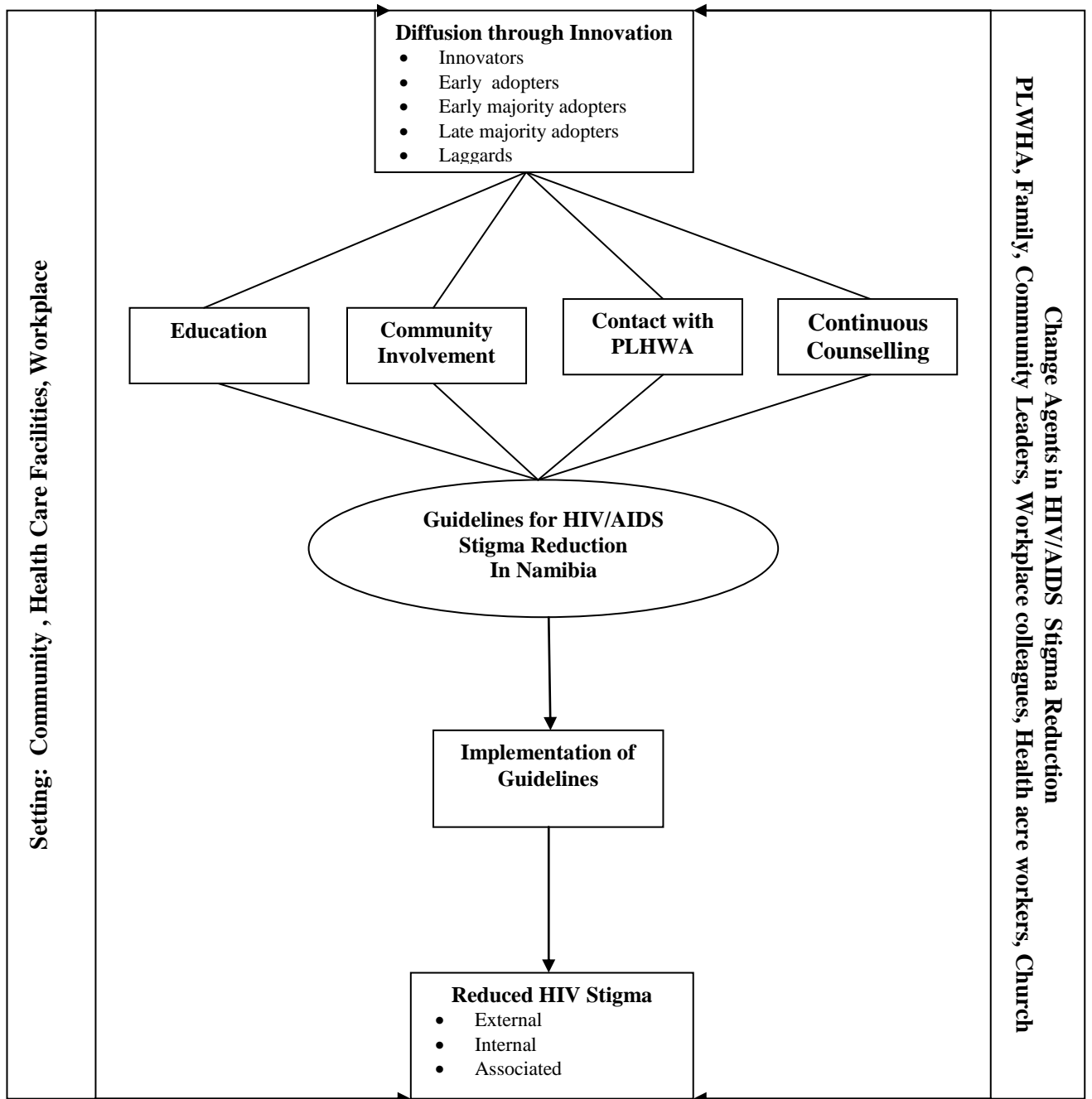


Figure 6.2. Flow diagram: Enabling HIV/AIDS Stigma Reduction through Diffusion and Innovations Theory.

6.3.5 Instructions for HIV/AIDS stigma reduction

The four combined approaches should be used to reduce stigma in the community and that can be done by applying the following instructions that are detailed below.

a. Education approach: training (manuals)

- Identify communication channels that can be used to convey the message effectively: Ministry of Health, Academic Health institutions, Faith-based organizations, Ministry of Education and Mass media.
- For an example in Namibia the following organizations may benefit from using these guidelines: such as the School of Nursing and Public Health (at University of Namibia), Faith-based organization e.g. Catholic AIDS Action (CAA) and PLWHA support groups.
- Collaborate with other stakeholders to identify eligible people to be enrolled for training on stigma reduction
- Budget for training materials, sessions and for human resources

b. Community involvement

- Identify the key person/s who will be the gatekeeper and inform community members about the innovation (stigma reduction)
- Collaborate with community representatives or key persons to obtain community entry
- Use mass media and internet services to obtain views and opinions from the public
- Mobilize resources needed for the intervention purposes

c. Contact approach

- Identify motivated PLWHA living positively who can give testimonials on stigma experiences
- Search and identify films/ audio visual materials, which can be shown to community with a message on experiences of stigma
- Collaborate and work closely with local PLWHA support groups and community-based organizations
- If possible approach motivated public figures or celebrities who disclosed their HIV status to address the community to help normalize the situation.

d. Continuous Counselling: PLWHA and their families

- Identify lay counselors in the community who can provide continuous counseling to PLWHA and their families.
- Identify persons who are willing and eligible for training to become counselors in their respective communities.
- Collaborate with stakeholders and training institutions to arrange for training in HIV/AIDS counseling skills.
- Budget for the training of counselors

6.3.6 The intended users

These guidelines should be used by people who wish to embark on HIV/AIDS stigma reduction using community and opinion leaders and PLWHA support group members in the community. They can be used by health professionals, community peer educators, faith-based organization and community-based organization staff when they plan stigma reduction interventions. In Namibia the following will be provided with copies of these

guidelines: Ministry of Health and Social Services (MOHSS), Training institutions such as University of Namibia (UNAM) and National Health Training Center (NHTC), Faith-based organization such as Catholic AIDS Action (CAA), PLWHA support groups such as Tonata and Opawa.

Target population: These guidelines target PLWHA, families and health care providers and general public who stigmatize others.

6.3.7 Settings in which the guidelines will be implemented

HIV/AIDS is one of the biggest challenges for Namibian Health System with stigma attached to it its impact will continue to be felt on the health service for longer unless something is done earlier than later. One of the principles of Primary Health Care (PHC) is community participation, developing these guidelines for rural community is in line with that principle. These guidelines are designed for the Community Health System to contribute to the response of HIV/AIDS challenges in general and to address stigma in particular. They are designed particularly for rural communities the reason being community and opinion leaders are more influential in rural areas than in urban. The interpersonal relationships in rural communities are more open and people have close links unlike in the urban areas where everybody minds his/her own business. It will be therefore more feasible to disseminate information on stigma reduction and implementing other strategies to influence people in the rural communities to change their attitudes towards people who are HIV positive (using interactions among communities). Although these guidelines were developed based on the Namibian rural situation they can be used anywhere if they are regarded suitable for that context.

6.3.8 Change agents of these guidelines:

- a. PLWHA:** they should be motivated to be trained as change agents who influence other people's attitudes and behaviors towards them. They should be motivated to be able to give testimonials that will convince community members to reduce or stop stigma.

- b. Families:** families of PLWHA should be supported and given enough information on caring for their sick relatives who are HIV positive, how to reduce stigma in households and to support them psychologically. They should be counseled when the need arises so that they can cope and accept their family members who are HIV positive. If the family members are supported and motivated on stigma reduction they could influence change among relatives, in their neighborhood and later on in the community.

- c. Community Leaders:** They should be motivated so that they can play an important role to influence their subordinates on stigma reduction. The eligible community and opinion leaders should be trained in stigma reduction to mobilize the community at large.

- d. Health Care Workers:** they have an important role to play in stigma reduction as the service providers such as provision of counseling, care and treatment to PLWHA and their families. Health care workers should be given necessary support in the form of training, skills building and resources to enable them to carry their duties successful.

6.3.9 Essentials for the guidelines

The success of these guidelines will depend on the following:

- Willingness and preparedness of the community members to participate in the interventions activities.
- Availability of necessary resources to conduct trainings and run the awareness campaigns on HIV/AIDS stigma
- Collaboration between all the stakeholders
- Well motivated community leaders to take the lead in stigma reduction
- Sufficient support to PLWHA who will act as change agents
- Sufficient support to facilitators of the interventions
- The correct timing of the intervention related activities

6.3.10. How these guidelines will be rolled out in Namibia

The researcher will arrange a meeting with stakeholders such as representatives from Ministry of Health and Social Services (Namibia), School of Nursing and Public Health (from University of Namibia), Faith-based organization namely Catholic AIDS Action (CAA) and Ministry of Regional & Local Government, Housing & Rural Development (MRLGH) to inform them about the guidelines. These will be the people who will disseminate information to their staff who will implement them. They will be provided with copies of the training manuals that should be used for training workshops.

6.3.11 Conclusion

The purpose of these guidelines is to assist, guide and direct service providers on what they can do to reduce stigma in the rural communities. If they are implemented appropriately there is a greater chance that stigma will be reduced significantly. That will

lead to more positive living with the disease, low HIV infections, improvement on ARV adherence, efficacy of PMTCT, low mortality rates related to HIV/AIDS, low costs on hospitalization and a productive and healthy community.

6.4 LIMITATIONS OF THE STUDY

HIV/AIDS is a sensitive topic, with researchers (Akintola, 2004) documenting that to undertake research into HIV/AIDS can be a long and difficult process, particularly if it includes people who are living with the disease. The researcher experienced challenges and difficulties in conducting this study (Akintola, 2004).

The first challenge was a low turnout for the scheduled meeting with support group members, despite of the meeting being announced by their support group coordinator in the radio beforehand. Although some community meetings were well attended there was one that was poorly attended due to rain. Some local church leaders and teachers were reluctant to participate in this study, although they took questionnaires they never returned them. The other limitation was lack of sufficient resources due to unavailability of research funds. That made it impossible for the researcher to give incentives to study participants (PLWHA) as a norm.

As the pre-intervention assessment was conducted between February and March (2010), which are the rain months in Namibia, it was not easy for the researcher to access some areas due to flooding which made the roads impassable. This led to the researcher to end her first visit prematurely, as a result follow up, was impossible, at the areas which were

poorly attended. The researcher had planned to conduct intervention workshops in May 2010, but she was only able to go back in July 2010 once the water has subsided.

Support group coordinators who assisted in recruiting co-members and their families did not adhere to the inclusion criteria, and as a result it was observed during data analysis that more than half of participants were lost at the evaluation phase and were replaced with new ones without consulting the researcher first. This resulted in the researcher analysing these data separately and independent of each other as it could not be linked. That was a challenge as well as limitation to data analysis. It is therefore recommended that future researchers should rather use other sampling frames of participants, which is more reliable and not biased that will ensure credibility for study results.

The researcher acknowledges that the modified F&C-SI has some limitations. The F&C-SI consisted of both negatively and positively worded items, but during analysis it was found that this complicated the survey and they were revised to be negatively worded. It is therefore recommended that for future use, this instrument be revised to make all the items negatively worded and avoiding same questions in opposite ways. As this study was conducted in a rural community, its findings could not be generalised for urban communities that is its limitation.

6.5. RECOMMENDATIONS

During the intervention training workshops and through individual interviews participants made suggestions and gave their opinions to the researcher. They are, therefore, considered and formed part of these recommendations.

6.5.1. Recommendations for further research

Future intervention research should target: the affect of stigma on children, stigma in health facilities, food insecurity and its links to stigma, a comparison between the levels and types of stigma in rural and urban areas.

6.5.2. Recommendations for stigma reduction

The following are recommended to reduce HIV/AIDS stigma in rural communities in the four groups used in the study.

a. PLWHA

- More counseling services are needed in the community to help PLWHA to overcome self stigma
- PLWHA need to be trained in coping skills with HIV/AIDS in general and with stigma in particular
- Income generating project should be strengthened and supported to enable unemployed persons to earn income

b. Family members

- Families and caregivers of PLWHA need counseling and psychological support that would empower them and contribute to stigma reduction in family.
- Males should be involved in caring for sick PLWHA in their households or should provide resources to alleviate burden from women, so that they will stop verbal abuse that might be caused by frustration.

c. Community and opinion leaders

- Re-education and strengthening on basic facts of HIV transmission in order to reduce fear of contagion and increase more understanding. Use radio as a medium of communication, as well as community leaders to convey the message.
- Community meetings were identified as effective strategy to give information to community members, it is therefore recommended and it needs to be applied in stigma reduction. Local community-based, faith-based organizations and other related groups in the constituency need to collaborate in stigma reduction activities.
- Food insecurity needs to be addressed among the people who are living with HIV by increase and support income generating projects at constituency level. A needs assessment can be conducted by the constituency office to identify and register needy people who are HIV positive (if they disclosed their status) for food relieve program.
- Community members should be made aware about PLWHA's rights and at the same time people who are living with HIV need to be informed about their rights and responsibilities.
- HIV/AIDS stigma component needs to be incorporated into school curriculum to enable teachers to address it and transform the knowledge to their learners. It is believed that if the learners understand stigma and its negative effects on others that can influence their behaviors and reduce stigma.
- The topic of stigma should be included in school curriculum and should be spoken about during parents-teachers meetings. There should be an open door policy between parents of learners who are on ARVs and school principals that will help to increase support for children when they are at school environment.

- “*My future is my choice*” program need to be strengthened and implemented at all schools in the constituency.

d. Health workers

- More counseling trainings/courses for eligible and interested people are needed to enable the Ministry of Health and Social Services to provide ARVs services and other HIV related services to rural areas health facilities.
- More counselors are needed to be allocated at all clinics in the constituency that will help to decrease the number of patients at Ongenga Clinic, which is currently the only one provides ARVs in that community. More counselors will be able to do continuous counseling for PLWHA and their families to reduce stress and self stigma. They will also contribute to VCT services in the constituency.

6.6. CONCLUSION

This study assessed the level and extent of HIV/AIDS stigma in a rural Namibian community and concluded that it manifests in different ways. Verbal abuse, social isolation and negative self perception were the most forms of stigma experienced by people living with HIV either in their families or in the community. An intervention to reduce stigma was developed, implemented and evaluated in a rural community and was a success although it did not succeed to reduce all the stigma scores significantly. There are significant decreases in household and workplace stigma, social isolation, as well as in the family attitudes and community opinions towards people who are HIV positive. In the control group six scores in family and community stigma have increased significantly after the intervention, which can be linked to awareness. Although one can claim that the intervention was effective, it was unable to reduce verbal abuse and negative self perception scores significantly in the group that received intervention.

Finally the study concluded that using multi-strategies intervention in stigma reduction is effective and developed evidence-based guidelines that suggested that future intervention can follow the same approaches and add counselling strategy to address stigma in the community and made recommendations for improvement. The guidelines are based on the Diffusion of Innovations and its enabling HIV/AIDS stigma reduction in community. Finally the researcher advises future researchers to give more attention on their sampling approaches to avoid the same problems of losing a number of participants at the evaluation as it was experienced in this study.

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APPENDIX 1: APPROVAL LETTER FROM UKZN ETHICS COMMITTEE



12 December 2009

Mrs P Angula
P O Box 20216
Windhoek
9000
NAMIBIA

Dear Mrs Angula

PROTOCOL: Developing and evaluating a community-based HIV/AIDS stigma reduction intervention in Ongenga Constituency of Ohangwena Region, Namibia
ETHICAL APPROVAL NUMBER: HSS/0962/2009: Faculty of Health Sciences

In response to your application dated 20 November 2009, Student Number: **209506891** the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given **FULL APPROVAL**.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Professor Steve Collings (Chair)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

SC/sn

cc: Dr B P Ncama
cc: Dr J Frohlich
cc: Mr S Reddy

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

APPENDIX 2: APPROVAL LETTER FROM THE NATIONAL ETHICS COMMITTEE, MOHSS, NAMIBIA

9 - 0/0001



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: (061) 2032562
Fax: (061) 272286

E-mail: hilmanangombe@yahoo.com

Enquiries: Ms. H. Nangombe Ref.: 17/3/3/AP

Date: 26 January 2010

OFFICE OF THE PERMANENT SECRETARY

Mrs. Penehafo Angula
P. O. Box 20216
Windhoek
Namibia

Dear Mrs. Angula,

RE: Developing and evaluating a community based HIV/AIDS stigma reduction intervention in Ongenga constituency of Ohangwena region, Namibia.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. Kindly be informed that approval has been granted under the following conditions:
 - 3.1 The data collected is only to be used for academic purpose;
 - 3.2 A quarterly progress report is to be submitted to the Ministry's Research Unit;
 - 3.3 Preliminary findings are to be submitted to the Ministry before the final report;
 - 3.4 Final report to be submitted upon completion of the study;
 - 3.5 Separate permission to be sought from the Ministry for the publication of the findings.

Yours sincerely,


MR. K. KAHURE
PERMANENT SECRETARY



"Health for All"

**APPENDIX 3: PERMISSION LETTER FROM ONGENGA CONSTITUENCY TO
CONDUCT WORKSHOP ACTIVITIES**



OHANGWENA REGIONAL COUNCIL

ONGENGA CONSTITUENCY

TEL. 065 268380
FAX: 065 268301

P. O. Box 793
OHANGWENA

Our Ref.:.....

Your Ref.:.....

Enquiries: *R. N. Hangula*

20 July 2010

Mrs. Penehafo Angula
P. O. Box 20216
Windhoek

Dear Mrs. Angula

**VENUE FOR COMMUNITY WORKSHOP AT ONGENGA
CONSTITUENCY**

Your letter on the above subject refers.

It is with pleasure to inform you that our office has approved your request and permits you to make use of our Boardroom to conduct an HIV/AIDS stigma reduction workshop to the community members.

We hope the workshop will also benefit the proposed participants.

We wish you the best of luck with your studies.

Sincerely Yours

Shimutwikeni
L. Shimutwikeni

REGIONAL COUNCILLOR



All official correspondence must be addressed to the Regional Councillor

APPENDIX 4: INDIVIDUAL PARTICIPANT CONSENT FORM

Dear participant,

I am Penehafo Angula, a PhD student from University of Kwazulu-Natal, South Africa. I am going to ask you questions for my research that I hope will benefit your community and possibly other communities in future.

As a student it is expected for me to conduct this research as part of fulfilment of my degree. I am conducting this research regarding community-based HIV/AIDS stigma. I am interested in finding out more about how is stigma experienced in your community. The purpose of this study is to measure the level of community based HIV/AIDS stigma, to develop and implement community-based HIV/AIDS stigma reduction intervention and evaluate the outcomes of the intervention. The results of this study will be released in a thesis. Your personal details will not be released only averaged information.

I have chosen your community as I never came across any HIV/AIDS stigma research that was ever conducted in this constituency. I have observed that this community is just affected by HIV/AIDS like any other in your region. I will ask questions to a number of people in your community. You will be given a self-report questionnaire to complete. This will be done two times at different months. After combining your answers I hope to learn more about HIV/AIDS stigma in your community and will make plans on how to reduce it.

Please understand that your participation is voluntary and you are not being forced to take part in this study. The choice of whether to participate or not is yours alone. However, I would really appreciate it if you share your thoughts with me. If you choose not to take part in answering these questions, you will not be affected in any way whatsoever. If you agree to participate, you may stop at any time and discontinue your participation. If you refuse to participate or withdraw at any stage, there will be no penalties and you will not be prejudiced in any way.

I will not be recording your name anywhere on the questionnaire, and no one will be able to link you to the answers you give. Only the researcher and her supervisors will have access to the unlinked information. All individual information will remain confidential.

The questionnaire will take more or less 30 minutes to complete. I will give you a questionnaire that you have to complete. Please be open and honest as possible when answering these questions. Some questions may be of a personal and/ or sensitive nature. You may choose not to answer these questions. I will also be asking some questions that you may not have thought about before and which involve thinking about the past or the future. I know that you cannot be absolutely certain about the answers to these questions, but I am asking you to think about them. When it comes to

answering these questions there is no right or wrong answers. If you feel that you need to talk to me after I left you can contact me on this number **0812489408** (Namibian cell phone number). After completion of this study I would like to come back and give you feedback about my study results and future actions.

If you have any complaint regarding any aspect of this study you can contact the office of Ongenga Constituency councilor at these telephone numbers: **065-268380 or 065-268301.**

.....

CONSENT

I hereby agree to participate in research regarding community-based HIV/AIDS stigma reduction intervention. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop my participation at any point should I not want to continue and that this decision will not in any way affect me negatively.

The purpose of the study has been explained to me, and I understand what is expected of my participation. I understand that this is a research project whose purpose is not necessarily to benefit me personally but will benefit our community. I have received a telephone number of a person to contact should I need to speak about my issues that may arise in completing this questionnaire. I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

I understand that, if at all possible, feedback will be given to my community on the results of the completed research.

.....

.....

Signature of Participant

Date

INDIVIDUAL PARTICIPANT CONSENT FORM (Oshiwambo version)

Ombapila yepitikilo lokukufa ombinga

Omukufimbinga omufimanekwa,

Edina lange aame Penehafo Angula, omulihongi koUniversity yaKwazulu-Natal, koSouth Africa. Ohandi ningi omapekaapeko moshikandjohoololo sheni shaNgenga nelalakano oku kwafela oku shunifa okatongotongo oko haka ningilwa ovanhu ovo tava lumbu nombuto yoHIV noAIDS pedu.

Eshi oshili oshitopolwa shelihongo lange longhatu youndokotolapangi. Onda hala nee okutala kutya okatongotongo oko taka ningilwa ovanhu ava tava lumbu nombuto yoAIDS okeli ngahelipi moshitopolwahoololo sheni. Elalakano lomapekaapeko aa okutala kutya ovanhu ava tava lumbu nombuto oveli we navo ngahelipi omu moshitopolwahoololo sheni, nongeenge ohava taliwa ko tuu ngaashi ovanhu aveshe ile opena okatongo. Nokonima nee shima nda mono ouyelele ou ohandi ka tala kutya opamukalo ulipi hatu dulu okushunifa okatongotongo aka pedu. Ohandi ka tala yoo kutya okatongotongo okashuna pedu shifike peni konima yeenghendambala odo handi ka ninga. Ohandi ke mu shiivifila oshidjemo shomapekaapeko ange konima ngee nda mane.

Onda hoolola oshitopolwahoololo sheni (shaNgenga) opo ndi ninge mo omapekaapeko shaashi fiyo opapa inandi shakeneka natango sha pamishangwa tashi holola omapekapeko ena sha nomukifi woHIV noAIDS a ningwa moshikandjohoololo sheni shaNgenga. Nonande pakutala kwange oshitopolwa eshi nasho osha dengwa kombuto yoAIDS ngaashi ngoo oitopolwa ikwawo. Ohandi ka yandja eembapila domapulapulo kovanhu vomoshitopolwahoololo sheni. Onda hala nee mu nyamukule omapulo aa eli meembapila edi handi ke mu pa. Eshi ohandi ke shi ninga nee oikando itatu meemwedi nhatu da yooloka. Nokonima ohandi ka kala ndina ouyelele shina sha nokatongotongo oko taka ningilwa ovo tava lumbu nombuto yoAIDS. Nohatu ka tala nee kutya opamukalo ulipipo hatu lwifa okatongotongo oko.

Ekufombinga loye momapekapeko aa otali di kwoove mwene, ndele hakefininiko. Oove mwene to tokola kutya oto kufa ombinga ile ahowe. Ashike ehala lange oleli kutya ngeenge otashi dulika u kufe ombinga opo ndi ude omadilaadilo oye shinasha nokatongotongo oko taka ningilwa ovo tava lumbu nombuto yoAIDS. Ashike ngeenge ino hala okukufa ombinga momapekapeko aa, kapena oshilanduli shasha. Nongeenge wa tokola okukufa ombinga ndee to ninguluka ondjilakati, etokolo loye mwene na oto dulu okushi ninga pehena oshilanduli. Edina loye itali shangwa mo mombapila oyo to nyamukula. Hano kapena ou taka shiiva kutya olyelye anyamukula ombapila oyo. Aame ashike pamwe nomuhongi wange handi kakala ndina oufemba wokumona kutya ombapila eyi oya dja koshitopolwa shilipi.

Otashi ku pula ngaho ominute milongo nhatu (30) lwaapo opo u yadeke ombapila yomapulapulo. Ohandi ke kupa nee ombapila yomapulo oyo to ke i yadeka ove mwene. Moku i nyamukula kwafe nge nee u kale wa manguluka ove u lombwele nge oshili. Nongeenge nee ope na omapulo amwe afa opaumwene u wete kutya ito dulu oku anyamukula, oto dulu oku a fiyapo. Omapulo amwe otashi dulika ito dimbulukwa naana nawa, ashike owa pumbwa okudiladila nawa opo u dimbulukwe. Kape na enyamukulo la puka onghene keshe osho to ka nyamukula ohandi shi tambulako. Ngeenge owa pumbwa okupopya naame konima ngee nda shuna oto dulu oku dengela nge kongodi yange ei: **0812489408**. Ngeenge nda mane omapekapeko aa ohandi ka aluka ndi uye ndi mu lombwele oidjemo yao. Fye hatu ka tokoleni nee kutya oshike shina okuningwapo. Nongeenge nee opena sha inoshi panda shina sha nomapekapeko aa oto dulu okudengela tate kanshela kombelewa yaye kongodi ei tai landula apa: **065-268380 ile 268301**.

.....

EPITIKILO

Onda itavela okukufa ombinga momapekapeko aa enasha nokatongotongo oko taka ningilwa ovo tava lumbu nombuto yoHIV noAIDS. Ondi udite ko kutya ekufombinga eli kalili pafininiko. Ondi udite ko yo kutya ohandi dulu okuli kufa mo efimbo keshe ngeenge inandi hala vali okuya komesho nekufombinga momapekapeko aa nopehena

oshilanduliko. Onda lombwelwa nawa elalakano lomapekapeko aa naasho nda teeleva ndi ninge. Ondi shishi yo kutya elalakano lomapekapeko aa kali na ouwa wopaumwene ashike otali kwafele ovakalimo vomoshitoplwahoololo shetu. Onda pewa ongodi oko handi dulu okudengela ngeenge opena sha ndili omhinge nasho. Onda shilipalekwa yo kutya ouyelele ou handi yandye otau ka kala oshiholekwa shaashi edina lange itali holoka mo mombapila oyo nda nyamukula. Onda lombwela yo kutya otashi dulika ndika pewe oidjemo yomapekapeko aa.

.....

Eshaino lomukufimbinga

Efiku

APPENDIX 5: STUDY QUESTIONNAIRES

1. HASI- P Questionnaire for People living with HIV/AIDS (English version)

Demographic data:

Gender: 1.Male:

2.Female:

Age:

Religion:

Name of support group centre:

The following questions are related to received/external HIV/AIDS stigma and discrimination. Here is the list of events that may have happened to you during the past 3 months. Please indicate how often these events happened to you because of your HIV status.

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

14. Someone insulted me.				
15. People avoided me.				
16. People cut down visiting me.				
17. People ended their relationship with me.				
18. I was blamed for my HIV status.				
19. Someone tried to get me fired from my job.				
20. My employer denied me opportunities.				

The following questions are related to internalized stigma. These questions are asking about your thoughts and feelings because of your HIV status.

How often have you thought or felt this way during the past 3 months because of your HIV status	Never	Once or twice	Several times	Most of the time
21. I felt that I did not deserve to live.				
22. I felt ashamed of having this disease.				
23. I felt completely worthless.				
24. I felt that I brought a lot trouble to my family.				
25. I felt that I am no longer a person.				

HASI-P Questionnaire (Oshiwambo version)

Omapulapulo kovanhu ovo tava lumbu nombuto yoHIV noAIDS

Oukwatya woye

Oukashike kookanhu: 1. Omulumenhu

2. Omukainhu

Ouna eedula ngapi?.....

Oho yi kongeleka ilipi?.....

Edina longudu (Support Group center) apa hamu ongala oshike?
.....

Omapulo taa landula oku na sha nokatongotongo oko haka ningilwa ovanhu ovo tava lumbu nombuto yoHIV noAIDS. Apa ota pa landula omusholondodo woiningwanima oyo ta peya we i ningilwa molwaashi u na ombuto yoHIVnoAIDS moule weehani nhatu da pita. Didilika enyamukulo loye pukamwe komoukololo ava: nande-nande; lumwe ile luvali; omalupita; oikando ihapu.

Meehani nhatu da pita olungapi wa ningilwa eshi tashi landula molwaashi una ombuto yoHIV ?	Nande-nande	Lumwe ile luvali	Omalupita	Oikando ihapu
1. Onda lombwelwa kutya nandi lile moililomwa yange aame andike.				
2. Okwa tiwa inandi kwata/ inandi kuma okaana kovanhu.				
3. Onda pewa ndi nwe hauxuninwa mokakopi .				
4. Onda xulifa po okulila pamwe novanhu				
5. Ohandi lilile aame andike.				
6. Okwa tiwa nandi djepo povanhu shaashi ohandi kolola				
7. Ngadi okwa xulifa po oukaume/oukahewa wetu naye.				
8. Kaume/kahewa kange wonhumba ina hala vali okupopya naame.				

9. Onda ulwa omadina mayi.				
10. Ovanhu ohava imbi omaimbilo omishe ngeenge handi ende po puvo.				
11. Onda ulwa kutya vati nghina onakwiiwa.				
12. Onda hanyaukilwa komunhu wonhumba.				
13. Onda ulwa kutya vati Kalunga okwa pa nge ehandukilo.				
14. Omunhu umwe okwa fifa nge ohoni (ile okwa lengaifa nge).				
15. Ovanhu ova angala nge.				
16. Ovanhu ihava talele nge po vali.				
17. Ovanhu ova xulifa po omakwatafano pokati ketu navo.				
18. Ohandi velwa eembedi molwaashi ndi na ombuto yoHIV.				
19. Ngadi okwali a hala okukufa nge moilonga yange.				
20. Omuhona wange okwa anyena nge eemhito domauwa omoilonga.				

Omapulo taa landula/shikula okuna sha nomaliudo oye mwene molwaashi u na ombuto yoHIV.

Omadilaadilo aa okwe ku hanga lungapi moule weehani nhatu da pita?	Nande-nande	Lumwe ile luvali	omalupita	Oikando ihapu
21. Ondi udite inandi wana vali okukala nomwenyo.				
22. Ondi udite ohoni molwaashi ndi na omukifi ou.				
23. Ondi udite nda kanifa ongushu younhu.				
24. Ondi udite nda etela ovakwanedimo lange omukundu.				
25. Ondi udite ndihe fi vali ndimunhu.				

2. F&C-SI QUESTIONNAIRE for families and community leaders (English version)

SECTION ONE: Demographic Data

Gender: 1.Male:

2. Female:

Age:.....

Religion:.....

Highest level of school:

1.Primary.....

2.Secondary:.....

3.Tertiary:.....

Indicate your position in this study by putting a cross next to appropriate position.

1. Family member	
2. Community member	
3. Opinion leader	
4. Community leader	

SECTION TWO:The following questions are asking your personal views and opinions.

If you had to describe the way people with HIV or AIDS are treated in your community would you say:	Strongly disagree (SD)	Disagree (D)	Unsure (U)	Agree (A)	Strongly agree (SA)
1. They are just treated like everybody else					
2. They are treated with more sympathy than everybody else					
3. They are isolated from other members of the community					
4. They are mistreated by other members of the community					
If you had a family member who has HIV or AIDS would you say that:	SD	D	U	A	SA

5.She or he is just treated like any other family member					
6. She or he is treated with more sympathy					
7.She or he is isolated from family members and friends					
8. She or he is mistreated by family and friends					
The following questions are asking your personal opinion regarding people living with HIV/AIDS in general	SD	D	U	A	SA
9. People who have HIV or AIDS should be offered more sympathy and moral support					
10.People who have HIV or AIDS should be separated from other members of the community					
11.If a person knows that she or he is HIV positive she or he should keep it private					
12. A person who has HIV or AIDS should tell others					
13. A person who has HIV or AIDS should tell close family members or friends					
The following statements are about family/ households stigma.	SD	D	U	A	SA
14.A person who has HIV or AIDS can share blankets with other households					
15.A person who has HIV or AIDS should use separate blankets					
16. A family member who has HIV or AIDS should be left out of family					

discussions and decision making					
17.A family member who has HIV or AIDS should be included in family discussions and decision making					
18. A family member who has HIV or AIDS should stay away from visitors					
19. A family member who has HIV or AIDS cannot cook for the family					
20.A family member who has HIV or AIDS should share meals with other households					
21.A family member who has HIV or AIDS should not play with children					
The following statement are about community opinions to PLWHA	SD	D	U	A	SA
22.Teachers who have HIV or AIDS can be allowed to teach at schools					
23. Students or learners who have HIV or AIDS should not be allowed to attend school					
24. A person who has HIV or AIDS should not attend community gatherings such as weddings or community meetings					
25. A person who has HIV or AIDS should be dismissed from his or her work upon disclosing his or her HIV status					

SECTION THREE

Answer the following questions by putting a cross in the provided column next to either YES or NO. You should only choose one option.

1. Do you have a close relative or close friend who has HIV or AIDS?

YES	
NO	

2. Do you have a family member in your house who has HIV or AIDS?

YES	
NO	

3. Would you be willing to take care of a family member if she or he had suffered an accident?

YES	
NO	

4. Would you take care of a family member if she or he were sick with Malaria?

YES	
NO	

5. Would you take care of a family member who is sick with Tuberculosis (TB)?

YES	
NO	

6. Would you take care of a family member who is sick with running stomach (Diarrhea)

YES	
NO	

7. Would you be willing to share a toilet with someone who has HIV or AIDS?

YES	
NO	

8. Would you eat food prepared by someone who has HIV or AIDS?

YES	
NO	

9. Would you shake hands with someone who has HIV or AIDS?

YES	
NO	

10. Do you think that most families in your community will be willing to take care of a relative who is ill with HIV or AIDS?

YES	
NO	

Thank you for your time.

F&C-SI QUESTIONNAIRE (Oshiwambo version)

OSHIKOPOLWA SHOTETE: Oukwatya woye

Oukashike kokanhu 1. Omulumenhu

2. Omukainhu

Ouna eedula ngapi?

Owongeleka ilipipo?.....

Owa xulila pondodo ilipi mehongo?.....

Ofikola yopedu:

Ofikola yopombada:

Onghatu yopombada:

Hoolola po shimwe shomwaayi tai landula/shikula apa.

1.Ondili omupambeke wanakulumba nombuto yoHIV noAIDS	
2.Ondi li omukufimbinga omukwashiwana	
3.Ondi li omukufimbinga omuwiliki (omuhongifikola,omufita,omuwilikingudu)	
4.Ondi li omuleli wopashiwana	

OSHIKOPOLWA OSHITIVALI

Omapulo taa shikula apa otaa pula eshiivo loye eshi homono nghee ovanhu ava tava lumbu nombuto hava kaliwa navo momudingonoko ile momukunda weni.

Didilika mokakololo kamwe kaava nghee ovanhu ava tava lumbu nombuto hava kaliwa navo momudingonoko ile momukunda weni	Itandi tu kumwe nasho nande-nande	Ondi li omhinge nasho	Kandi shishi	Ohandi tu kumwe nasho	Ohandi tu kumwe nasho lela-lela
1. Ohava talika ko ashike ngaashi ovanhu aveshe.					
2. Ohava talika ko nonghenda shi dulife povanhu vakwawo					
3. Ove li kalekelwa /ohava ningilwa ondjoolola ile okayova					
4. Ohava ningwa nayi kovakwashiwana vakwawo					

Ngeenge ouna omukwanedimo loye e na ombuto ototi ngahelipi kwaashi:	Itandi tu kumwe nasho nandende	Ondili omhinge nasho	Kandi shishi	Ohandi tu kumwe nasho	Ohandi tu kumwe nasho lelelela
5. Oha talika ko ashike ngaashi ovakwanedimo / ovaneumbo vakwawo					
6. Oha etelwa onghenda shi dulife povakwanedimo vakwawo					
7.Oha ningilwa ondjoolola ile okayova kovakwanedimo vakwawo					
8. Ohava ningwa nayi kovakwanedimo nokookaume ile kookahewa kavo					
Omadiladilo oye okuli ngahelipi shina sha novanhu ava tava lumbu nombuto yoHIV noAIDS					
9. Ovanhu ava tava lumbu nombuto nava etelwe onghenda vo nava yambididwe panghalafano					
10.Ovanhu ava tava lumbu nombuto yoHIV ile oAIDS nave likalekelwe kokule novakwashiwana vakwawo					
11.Omunhu ngeenge okuna ombuto yoHIV ile oAIDS nashi kale oshinima shaye shopaumwene					
12. Omunhu ngeenge okuna ombuto yoHIV ile oAIDS na lombwele ovanhu vakwawo					
Omapulo taa landula/shikula otaa pula shina sha nonghalo yomomaumbo.	Itandi tu kumwe nasho nandende	Ondi li omhinge nasho	Kandi shi shi	Ohandi tu kumwe nasho	Ohandi tu kumwe nasho lelelela
13.Omunhu e na ombuto yoHIV ile oAIDS ota dulu okulongifa omakumbafa oo taa longifwa kovaneumbo lavo					
14 .Omunhu e na ombuto yoHIV ile oAIDS na longife omakumbafa aye oye aeke.					

15. Omunhu e na ombuto yoHIV ile oAIDS ina kwatelwa meenghundafana dovakwanedimo laye					
16. Omunhu e na ombuto naye nakwatelwe mo meenghundafana dovakwanedimo laye					
17. Omunhu e na ombuto yoHIV ile oAIDS na kalekwe kokule novaenda					
18. Omunhu e na ombuto itashi dulika a telekele ovaneumbo lavo					
19. Omunhu e na ombuto yoHIV ile oAIDS ota dulu okulya pamwe novaneumbo lavo					
20. Omunhu e na ombuto i na danauka nounona vambulavo					
Omapulo taa landula otaa pula shinasha nonghalo pokati kovanhu ava tava lumbu nombuto novakwashiwana vakwawo	Itandi tu kumwe nasho nandende	Ondili omhinge nasho	Kandi shishi	Ohandi tu kumwe nasho	Ohandi tu kumwe nasho lelela
21. Ovahongifikola ovo vena ombuto yoHIV ile oAIDS otava dulu okuhonga ofikola					
22. Ovahongwa ovo vena ombuto yoHIV ile oAIDS inava pitikilwa okuya kofikola					
23. Omunhu e na ombuto yoHIV ile oAIDS ina ya peenbingo dovanhu vahapu ngaashi pomafundula ile poyoongalele yonhumba					
24. Omunhu e na ombuto yoHIV ile oAIDS na tewe mo moilonga shima a holola kutya okuna ombuto yoHIV					

OSHI TOPOLWA OSHITITATU

Tula enyamukulo loye mukamwe komoukololo ava tava shikula apa. Nyamukula heeno ile ahowe.

1. Ou na omukwanedimo /omupambe ile kaume/kahewa koye e na ombuto yoHIV ile oAIDS?

HEENO	
AHOWE	

2. Meumbo leni omuna omunhu e na ombuto yoHIV ile oAIDS?

HEENO	
AHOWE	

3. Ngeenge omukwanedimo loye e na ombuto yoHIV ile oAIDS okwa li moshiponga shohauto oto kala wa hala oku mu yakula noku mu kwafela?

HEENO	
AHOWE	

4. Ngeenge omukwanedimo loye otavele omalaria(olwiidi) oto mu file ngaho oshisho noku mu yambidida?

HEENO	
AHOWE	

5. Ngeenge omukwanedimo loye ota vele oTB (otiibi) oto mu file oshisho noku mu yakula meumbo?

HEENO	
AHOWE	

6. Ngenge omukwanedimo loye okuna oshimela oto mu file ngaho oshisho noku mu kwafela?

HEENO	
AHOWE	

7. Oto hale ngaho okulongifa okandjuwo haka longifwa komunhu ta lumbu nombuto yo HIV ile e na oAIDS?

HEENO	
AHOWE	

8. Oto li oikulya ya telekwa komunhu e na ombuto yo HIV ile ena oAIDS?

HEENO	
AHOWE	

9. Oto minike nomunhu e na ombuto yoHIV ile e na oAIDS?

HEENO	
AHOWE	

10. Eshi to diladila ovakwashiwana vahapu vomumundionoko ile vomomukunda weni otava hale okufila oshisho ovakwanedimo lavo ovo tava vele ve na ombuto yoHIV ile oAIDS?

HEENO	
AHOWE	

3. HASI-N QUESTIONNAIRE for Health care workers (English version)

Demographic Data

Gender: 1.Male:

2. Female:

Age:.....

Religion:.....

Qualification (rank):.....

Please mark how often you observed the event during the past three months	Never	Once or twice	Several times	Most of the time
1. A nurse provided poorer quality care to an HIV/AIDS patient than to other patients				
2. A nurse shouted at or scolded an HIV/AIDS patient				
3. A nurse kept her distance when talking to an HIV/AIDS patient				
4. A nurse ignored the physical pain of an HIV/AIDS patient				
5. A nurse refused to feed an HIV/AIDS patient				
6. A nurse did not check the condition of her HIV/AIDS patient in the unit/ward				
7. A nurse made an HIV/AIDS patient wait until last for care				
8. A nurse made an HIV/AIDS patient do things for himself/herself to avoid touching him/her				
9. A nurse left an HIV/AIDS patient for a long time in a soiled bed				
10. Nurses made HIV/AIDS patients wait for care				
11. People said nurses who provide HIV/AIDS care are HIV-positive				
12. People said nurses would only work with HIV/AIDS patients if they had AIDS themselves				
13. Someone said that nurses who care for HIV/AIDS patients spread the disease				
14. People said nurses who work in homecare are HIV-positive				
15. Someone called a nurse names because she takes care of HIV/AIDS patients				
16. A nurse was stigmatized because of the HIV/AIDS services she provides				

17. The spouse of a nurse who cares for HIV/AIDS patients feared that the nurse would bring the virus from work and give it to him/her				
18. People said that nurses get infected by taking care of people with HIV/ AIDS				
19. People made negative remarks about nurses involved with HIV/AIDS care				

HASI-N QUESTIONNAIRE (OSHIWAMBO VERSION)

Oukwatya woye

Oukashike kokanhu: 1. Omulumenhu

2. Omukainhu

Ouna eedula ngapi?

Owongeleka ilipi?

Ombadi yoye yopauhakuli oilipipo?

Didilika moukololo ava eshi wa uda ile wa mona tashi ningwa moule meemwedi/ weehani nhatu da pita.	Nande - nande	Lumwe ile luvali	omalupita	Oikando ihapu
1. Omuhakuli ta yandje epango langhudipala komunaudu wo HIV noAIDS shi dulife kovanaudu vakwao				
2. Omuhakuli ta hanyaukile omunaudu wo HIV noAIDS				
3. Omuhakuli ta popi e li kokule nomunaudu woHIV noAIDS afa emu nyanyala				
4. Omuhakuli te li dimbike ouwehame wopalutu womunaudu woHIV noAIDS				
5.Omuhakuli ina hala okupa omunaudu woHIV noAIDS okulya				
6.Omuhakuli i ta yakula nawa onghalo yomunaudu woHIV noAIDS oo eli meembete				
7.Omuhakuli a teeelifa omunaudu woHIV noAIDS a hakulwe xuuninwa				
8. Omuhakuli ta longifa omunaudu woHIV noAIDS oilonga yopauhakuli shaashi ina hala oku mu kuma				
9. Omuhakuli a kalifa omunaudu woHIV noAIDS momakumbafa a tuta efimbo lile				
10.Omuhakuli a teeelifa olule omunaudu woHIV noAIDS epango				

11. Ovanhu otava ti ovahakuli ava hava hakula ovanaudu voHIV noAIDS navo ovena ombuto yoHIV				
12. Ovanhu otava ti ovanaudu voHIV noAIDS nava hakulwe ashike kovahakuli ovo vena ombuto yoHIV				
13. Ngadi ota ti ovahakuli ava hava longo novanaudu voHIV noAIDS ovo tava tandavelifa ombuto				
14. Ovanhu otava ti ovahakuli ava hava longo momatalelepo ovanaudu momaumbo ovovo vena ombuto yoHIV				
15. Ngadi okwa ifana omuhakuli edina lomusheko shaashi ha pange ovanaudu voHIV noAIDS				
16. Omuhakuli okwa ningilwa okatongotongo shaashi ha hakula ovanhu ava tava lumbu nombuto yoHIV noAIDS				
17. Omukulukadi ile omushamane womuhakuli okuna oumbada kutya omushamane ile omukulukadi waye otemu pe ombuto yoHIV tadi nayo koilonga				
18. Ovanhu otavati ovahakuli ohava kwatwa kombuto yoHIV noAIDS shaashi hava hakula ovo vena ombuto yoHIV				
19. Ovanhu ohava popi nomusheko ngenge tava popi ovahakuli ovo hava ungaunga noHIV noAIDS				

APPENDIX 6: INTERVIEW GUIDE FOR INDIVIDUAL INTERVIEWS

1. What are your views and opinions on the HIV/AIDS stigma in your community?
2. What do you regard as your role in reducing HIV/AIDS stigma in your community?
3. In your view what can be done to reduce HIV/AIDS stigma?
4. Is there any additional information you want to tell me?

A SAMPLE OF INDIVIDUAL INTERVIEW

The interview was conducted as part of baseline survey with a 25 year old male participant and the duration was 45 minutes. The researcher explained the purpose of the research and interview to the interviewee. After the researcher obtained oral consent from the interviewee, the interview started. The original interview was done in Oshiwambo (local language) and was translated in English thereafter. Their dialogue was as follows:

Researcher: First of all I would like to thank you for agreeing to participate in this research. I have three main questions, which I would like to ask. However, there will be more questions in between depending on the answers and information that you will give me. Our interview will take +-30-45 minutes. All information will be kept confidential. Your name will not be linked to any information that I will report in my thesis. My first question to you will be: What are your views and opinions on the HIV/AIDS stigma in your community?

Interviewee: It seems that adults understand and support people who are living with HIV/AIDS, but somehow they do also practise minimal stigma. They do not always practise what they say. On school level some staff members do stigmatise especially if they are aware of someone's HIV status.

Researcher: How do staff members stigmatise others?

Interviewee: Staff members who are HIV positive are being discriminated regarding work benefits such as attending workshops and distribution of materials. Teachers who are seen or suspected to be HIV positive are not nominated to attend workshops. When there is a need to transfer one teacher to another school, the others prefer the one who is HIV positive to be the one who should be transferred. During parents meeting both parents and teachers do discriminate against those who are suspected to be HIV positive either teachers or parents. For example they do not listen at their views and opinions.

Researcher: So parents do also discriminate the people who are living with HIV/AIDS?

Interviewee: Yes and as a result parents of infected children are afraid to come to school when they are called to come and discuss support for learners who are HIV positive. They are afraid to be associated with HIV/AIDS.

Researcher: We talked about stigma among staff members. How is stigma among the learners at your school?

Interviewee: Stigma is high among the learners at our school. There is a case of a staff member who disclosed a learner's status accidentally. There was an incident of a human bite. One of the learners who were involved in this incident is HIV positive, so the teacher told the other learner to go to hospital urgently as the other one has HIV. So can HIV really be transferred in this way?

Researcher: I think we need to talk about that incident after the interview because there are some misconceptions about how HIV is transmitted. You mentioned that stigma is high among learners. Can you please tell me more about that?

Interviewee: There is peer discrimination at our school. Some learners do not want to play with the infected learners. They do not want to share books as we do not have enough books for each and every learner. They also do not want to be in the same group work with those children who are HIV positive and they do not borrow their items to learners who are on treatment. These poor learners are also being abused verbally and they are being insulted. There is no confidentiality as some learners disclose others' HIV status.

Researcher: How do learners know who HIV positive is?

Interviewee: You know how children are. They like gossiping. There are those who go to ARV clinics to collect their medication and when they see others there, they go and tell

their siblings or relatives (other children/teens at their homes) whom they saw at the clinic. When they come to school they will tell their friends and classmates and so it goes.

Researcher: So, that is how their HIV status has been disclosed. My next question is: What do you regard as your role in reducing HIV/AIDS stigma in your community particularly at your school?

Interviewee: I try to identify the causes of stigma and address them accordingly.

Researcher: Can you please elaborate on that?

Interviewee: For example I teach learners about HIV facts by giving them correct information on how one can be infected and how HIV cannot be transmitted. The learners who are infected, I address them individually according to their problems. When there is a learner who is absent from school to go for follow up at hospital, I help them with subjects, which they experience problems so that they can be on par with their classmates, especially on Maths which is my subject. Although I am not a trained counsellor I talk to them to accept their situations. Sometimes I give them support such as financial or food from the school feeding program. When I distribute resources in the class I ensure that they get books as they are being discriminated against by other learners. Our school environment is not that friendly as we have some classrooms, which are built with zinc and sometimes it becomes too hot. When it is too hot I excuse those learners if necessary. They are also being excused when they go and take their medication during school hours.

Researcher: By excusing them, do not you think that it is disclosing their HIV status indirectly?

Interviewee: No, because I do it diplomatically. For example I know that there are learners who take medication at a specific time, I do tell all learners to go for a five minute break.

Researcher: In your view what can be done to reduce community-based HIV/AIDS stigma?

Interviewee: We have to start with community and opinion leaders so that they can influence others to give information and educating other community members. Opinion leaders need training about stigma reduction as they have more opportunities of influencing others. We need to support people who are living with HIV/AIDS in our communities. People who are living with HIV/AIDS should be encouraged not to look for

sympathy but just to be “normal”. Community leaders should be educated about stigma reduction strategies. For example pastors can talk about stigma reduction at church during or after services. They can educate their church members not to discriminate others because everyone is affected by HIV/AIDS. The support group members need to encourage others (PLWHA) not to isolate themselves but to socialize with other people as well as to participate in community activities such as sports, choir groups, and so forth. Encourage self-confidence among people who are HIV positive will help to reduce stigma. Households need to forgive one another to reduce stress and stigma. Distribution of resources should be done in a way that do not discriminate people who are HIV positive. I think that we need a strategy to identify needy people who are HIV positive in our communities so that they can be assisted and reached out.

Researcher: Is there anything else do you want to add on?

Interviewee: Not now. If I remember something important, can I contact you?

Researcher: Yes, I will appreciate it here is my contact number.xxxxxx.... We come to the end of our interview. If you do not mind we can discuss the human bite incident now. (Correct information on how HIV can be transmitted was given to correct the misconceptions). Thank you for your time.

APPENDIX 7: TRAINING MANUALS

1. TRAINING MANUAL FOR PLWHA

INTRODUCTION

This manual is to be used as a workbook for facilitators to train people living with HIV in stigma reduction strategies. The original Toolkit for Action by Kidd and Clay (2003) has been developed for community members as trainees. It is developed in a way that it is suitable for outdoor settings. This training manual will also adopt the same design and approach. However, it can also be used indoors, depending on where the training takes place.

The original toolkit is designed to build awareness about and action against stigma-so help participants move to action. Participants should be encouraged to put their new learning into action, to start challenging stigma in their own lives. The toolkit is designed for collective learning and action. The aim is to get people to meet with their peers, discuss stigma issues and work together to bring about change. Working with others makes it possible for people to learn together about stigma, develop common ideas about what needs to be done, set group or community norms for new attitudes and behaviour, and support each other in working for change. This is the same aim for this training manual to help participants to move from awareness only, but to take action against stigma in order to bring change.

This training manual consists of seven units which are adapted from the original toolkit for action by Kidd and Clay (2003) and second edition by Kidd, Clay and Chiya (2007). Different activities are given to be used in this manual. Nevertheless facilitators are free to come up with additional activities if necessary. Some scenarios used in this manual are taken from Module of Family support (HIV/AIDS Diploma course at UNAM) developed by the author of this manual and some are adapted from the intervention training workshop conducted by the same person (author). These scenarios are based on true stories either in Namibia or elsewhere in the world.

The audience for this manual will be people who are living with HIV/AIDS whether they are support group members or not as long as they disclosed their status and feel free to attend the training. These will be people who will implement strategies from this manual in their respective communities. They are expected to take what they learn from this

manual into action to reduce stigma in their communities. They are expected to share their learning experiences with their families, relatives, neighbours, friends and community at large. They will also obtain some stigma coping skills information from this manual.

This manual will be used as a guide for facilitator/trainer during the training sessions. It has versions for facilitator with some explanation and definitions from textbooks about stigma. Feedback hints for group work are provided for facilitator. However, it does not limit facilitator to give her/his own relevant input. There will be activities which will be done as part of training.

Some literature refers to both stigma and discrimination in their writings. However, in this manual emphasize is more on stigma, because discrimination is regarded as enacted stigma.

Note to facilitators:

HIV/AIDS is mainly transmitted through sexual contact as a result some people feel uncomfortable to talk about it. Talking about sexual issues is regarded as taboo in our communities. It is, therefore, very important to bear these in mind when conducting training in HIV/AIDS related stigma reduction.

As facilitator it is your responsibilities to create a safe, non-threatening environment where feelings, fears and taboos can be discussed and explored openly. The following tips may be helpful:

- Setting clear ground rules and expectations around confidentiality, listening and support is essential.
- Awareness of your own feelings and fears about the topics you are going to cover will also help you to feel more confident during the exercise.
- Participants are more likely to trust you if you can share your feelings openly and by doing this, you lead by example.
- Remember to always leave enough time for participants to share their feelings and help the group to create an atmosphere where participants know they will be listened to.

- Remember that no feeling is wrong but some participants may find it difficult to accept certain feelings.
- Offer participants “time-out” if they need to take a break.
- Feelings are a powerful tools use them with the group to develop drama and role-plays, to build on stories, and as examples for the future.
- If there are any exercises you do not feel comfortable leading, find a co-trainer who can help out. If you have counseling skills, you are more likely to be confident in working with feelings.

It is very important and helpful to start with yourself

You should first use the training manual for yourself to reflect on your own attitudes, values, language and behaviour towards PLWHA—before you try to educate others.

(Adapted from the Toolkit for Action “Understanding and challenging HIV Stigma” developed by Kidd and Clay, 2003).

Instructions to facilitator: Setting the tone for the workshop/training:

Thank participants for making an effort to attend this training and create conducive environment for them to learn. Use participant-centred approach by making participants feel that their concerns and needs are being addressed in this training. When preparing the sessions use practical examples from participants. When closing the sessions, add the provided examples in the manual if they are not mentioned by participants already.

Start each day with something fun that reviews what happened the previous day. Encourage everyone to be creative. You can encourage participants to sing, especially songs related to HIV/AIDS (there are special nice songs for support group members). Let all participants feel comfortable and free to contribute, regardless of their different social status.

TRAINING PARTICIPANTS INTRODUCTION

Instructions to facilitator: Start the first day on a positive note to ensure that participants feel comfortable and get to know each other. There are different ways you can use for participant introductions such as participants interviews, name-tags and find the missing part.

- **Participants interviewing each other:** divide participants into pairs of two. Give them few minutes to interview each other. Thereafter each participant will introduce their partners by name and at least two unique characteristics about themselves for example what they like, dislike and expectations from the training.
- **Name-tags:** the facilitator prepares a name-tag for each participant. Then placing them in a box. Each participant will take a name-tag and locate the person whose name-tag they drew and introduce themselves. (This method is only applicable if the facilitator knows or has a list of participants' names beforehand.)
- **Find the missing piece:** the facilitator writes split words on piece of papers for all group members to get one part of a word. For example these words can be used:

AFTER	NOON;	SWEET	HEART
MILE	STONE;	ICE	CREAM

Each person picks up a piece of paper and looks for the person who has the matching part of his/her word. Once the person found the participant with the matching part of the word they will introduce each other. Each participant will then introduce his/her partner to the rest of the group. Opposite words can also be used for this method of introduction. Words such as:

BLACK	WHITE;	LEFT	RIGHT
EAST	WEST;	BOY	GIRL

These are just some of the methods of introduction. However, facilitators are free to use any other method as long as it is comfortable for participants. If you do training in other language rather than English you can use relevant words in the language you use.

TRAINING OBJECTIVES

The facilitator should explain the training objectives to the participants.

Instructions to facilitator: Tell them that training will be participatory and everyone is going to play the role of both a learner and a facilitator. Encourage participants to feel free to ask if they have any questions during the training. Tell them that there is no “stupid question” and there is no wrong or right answer, whatever they will say, it counts.

Explain to participants that the objectives of this training are to:

- Help participants to understand the meaning and impact of HIV/AIDS stigma through personal experiences, participatory dialogue and debate
- Explore the causes of stigma and discrimination using participatory dialogue and role plays.
- Explore the impacts of stigma on different players (PLWHA, family, and community) using participatory discussion and group works.
- Help them to understand that they can protect themselves from stigma using participatory discussions, scenarios and role plays.
- Help them to understand and recognize that they can lead long and positive lives.
- Come up with an action plan on how to reduce community-based HIV/AIDS stigma in their respective communities and beyond.

EXPECTATIONS AND GROUND RULES FOR THE TRAINING/WORKSHOP

Instructions to facilitator: Ask participants to share with the group what are their expectations from this training. Ask one of participants to write them down on flipchart or on folio paper (or on blackboard). Let participants come up with ground rules which will guide them throughout the training. Explain those rules and add if necessary. Put the rules somewhere where they can be visible at all times during the training. End this activity by asking participant if they have any question, any comment or anything extra to add.

UNIT 1: NAMING THE PROBLEM

Objectives: After completing this unit participants will be able to:

- Understand and identify stigma through pictures and practical examples
- Connect to the issue of stigma on personal and emotional level rather than a theoretical level
- Identify different forms of stigma in different contexts
- Identify the root causes of stigma in different contexts

Introduction

This unit helps participants to understand what is stigma by reflecting on their own experiences as being stigmatised. The aim is to get people to connect to the issue on a personal, emotional level, rather than a theoretical level (through a definition). People can see how stigma affects people through their own experiences of being isolated or excluded and how it hurts. They will be able to recognise the possible root causes of stigma and it is only when we know that, will be able to treat the problem.

ACTIVITY 1

Instructions to Facilitator: Start the activity by doing the following:

- Hand out blank papers to participants.
- Ask participants to write down what they think “stigma” is.
- Let them give practical examples of stigma either experienced or observed.
- To make it easier for participants, they can also write it on their own language.
- What are the local phrases used to refer to people living with HIV
- Let them give examples of words used to differentiate them from the rest of the community.

Note to facilitator: After doing this activity it will be clear that many people do stigmatize in one way or another. How do people stigmatize?

They do it either by saying or by doing.

- They stigmatize when they say things like: “she was promiscuous” or “he deserves it”, “She was looking for it”.
- They do stigmatize when they do things to PLWHA such as isolating, avoiding, excluding them from decision making, gossiping, blaming, abandoning, do not want to be seen with them, staring them in a funny way.

In some cases they are not even aware that they are stigmatizing others.

Instructions to facilitator:

Ask participants to give more examples on how people stigmatize them.

Below are some of examples you can add if they were not mentioned already:

- Minimizing contact with people living with HIV, e.g., forced to sleep in corridor, or in a separate room. Forced to wash at river. Forced to use separate utensils,
- Forced to move out of the family house and move to a new area.
- Gossiping and insults about people living with HIV behind their backs
- Neighbours refusing to lend things to the family with a person living with HIV
- Person living with HIV fired once it was discovered she/he had HIV
- Blaming the woman, e.g., saying she had acquired HIV as a sex worker
- Refusing to admit the child of the person living with HIV into the nursery school
- Keeping the patient waiting a long time
- Breaking confidentiality, e.g., letting other staff and patients know the patient’s Status.
- Physical and social isolation from family, friends and community.
- Loss of rights and decision making power.

ACTIVITY 2

Instructions to facilitator:

- Divide participants into three manageable groups (depending on how big is the whole group).
- Tell them to choose a reporter/presenter from their group

- Give/ hand them flip chart to make notes for their presentation/report back.
 - Let each group discuss one question from these questions in their respective groups:
2. What are the main causes of stigma? (**Why** people stigmatize?)
 3. What are the forms/types of stigma do they come across? (**How** do people stigmatize?)
 4. What are the effects of stigma? (What are the **results** of stigma?)

After brainstorming these questions, let each group report back to the main group.

Instructions to facilitator: You can add on the report back of participants if they did not mention these already.

Examples of causes of stigma may include:

- Insufficient knowledge, Misconceptions, myths, Less understanding of HIV/AIDS
- Fear to get HIV, Fears about death and disease, Lack of recognition of stigma, Moral judgments,
- Poverty , Unemployment, Alcohol misuse (abuse), Hunger / lack of food

Note to facilitator: Below are examples of forms for stigma you can add if participants did not mention them already

Other forms of stigma are: self stigma (stigmatizing oneself by avoiding going to health facility for medical help), stigma by association (because a person is a volunteer she is labelled as HIV positive or she will be called names), stigma by looks/ appearance (because someone is thin people start labelling him/her as HIV positive), type of work (people who are working in organizations/ institutions which are related to HIV/AIDS are mostly stigmatized).

Note to facilitator: Here are some examples of effects/results of stigma from which you can add if they were not mentioned already by participants.

Effects/Results of stigma include:

- Kicked out of family, house, work, rented accommodation, organization, denied opportunities such as promotion or getting scholarship, or rejected for job etc.
- Dropout from school (resulting from peer pressure-insults)
- Stress, Depression, suicide, alcoholism and, even more HIV infections because people will not disclose to their partners and will continue to practice unsafe sex. Misbehaving, Deteriorating of health, death
- Separation and divorce

Instructions to facilitator: Close the session by telling participants that:

Stigma can be defined as when a person is being discredited because s/he is different from the rest of the group. In simple words stigma is when people hold negative thoughts or feelings against other people simply because they are regarded as “different”. It is a process where we (society) create a “spoiled identity” for an individual or a group of individuals. We identify a difference in a person or group, such as a physical difference (e.g., albino), or a behavioural difference (e.g., people having multi sexual affairs) and then mark that difference as a sign of disgrace. This allows us to stigmatize the person or group. Stigmatized people lose status because of these assigned signs of shame that other people consider indications or evidence of sinful or immoral behaviour.

To stigmatize is to label someone, to see them as inferior because of an attribute they have. To stigmatize is to believe that people are different from us in a negative way, to assume that they have done something bad or wrong. When we stigmatize, we judge people, saying they have broken social norms and should be shamed or condemned; or we isolate people, saying they are dangerous or a threat to us. Stigmatizing beliefs lead to discrimination and unfair treatment.

UNIT 2: EFFECTS OF STIGMA ON DIFFERENT GROUPS

Objectives: After completion of this unit participants will be able to:

- Identify the effects of HIV stigma on different players and the epidemic itself

Introduction

This unit's purpose is focusing on effects of stigma and it aims to help people see the importance of stopping it. People will understand that in the long run stigma not only affects PLWHA but families and communities will also be affected therefore it should be stopped if we want to stop the HIV epidemic.

ACTIVITY 3

Instructions to facilitator:

- Divide participants into groups
- Let them choose a presenter who will give feedback on behalf of the group
- Let them discuss the effects of stigma on different groups below:
 1. PLWHA
 2. Family
 3. Community

Note to facilitator: Your participants can come up with different examples depending on what they experienced and observed. Below are the examples effects of stigma on which you can add if they were not mentioned already.

Effects on PLWHA

- Deteriorating of health, Depression, Hopelessness, Stress, Suicide.
- Non adherence to treatment

Effects on family

- Discrimination by neighbours, Social isolation, Family conflicts, Separation and divorce

Effects on community

- Social isolation, Name calling of specific villages, Negative labelling, Hatred

Instructions to facilitator: Close the session by summarising that: Stigma has a range of different effects on different groups of people: people living with HIV, their families, communities, and health institutions. Stigma creates conflict and breakdown in communication. Stigma results in economic losses and it makes families poorer. The shame of stigma affects everyone: people living with HIV, their families, the community, and even health workers who care for them. Stigma results in denial; people will refuse to admit that there is any problem.

UNIT 3: STIGMA IN THE FAMILY

Objectives: After completion of this unit participants will be able to:

- Identify various forms of stigma in the family

Introduction

Families are very important source of emotional support to their members when they have problems. It is, therefore, essential to identify forms of stigma that can be in the households or in family so that they can be addressed. In many cases people are not aware that what they do is stigmatising the person who is living with HIV. Sometimes they think that they are protecting him/her. In some cases they are doing it due to lack of resources and unaware that it hurts the person who is being stigmatised. Families stigmatise by saying bad things or using bad remarks to family member who is HIV positive and that can cause family conflicts.

ACTIVITY 4

Instructions to facilitator: Choose four participants or ask four volunteers and give them instructions to do a role play. You can make/simulate up your own scenario according to examples from your participants

Or you can use this scenario:

The scenario: Haimbodi who is 54 years old and his wife Mukwalu 49 have two daughters Namtenya 26 and Naufiku 22. Namtenya, who is HIV positive, is her father's favourite, and he protects her from his wife's verbal abuse. The mother tries to discredit her simply because she is HIV positive. Naufiku, the youngest daughter is her mother's favourite and she spoils her. In spite of Namtenya being on ARV, her mother sometimes prevents her from eating in the morning before taking her medication, particularly when her father is not at home. Her mother claims that Namtenya just wants to eat but when it comes to work she does not contribute much. On the other hand, she supports anything done by Naufiku without complaints. She calls Namtenya bad names and tells her that she deserves her HIV because she had looked for it. On several occasions, Haimbodi tried to talk to his wife and tell her not to discriminate against Namtenya and to stop calling her bad names due to her HIV status. As a result, his wife started to accuse him of also being

HIV positive, this being the reasons for him protecting Namtenya. This caused a conflict in Haimbodi's family (household) and led to the separation and divorce of Haimbodi and Mukwalu.

Note to facilitator: These names are fictitious simulated by the author of this manual. If you cannot pronounce them due to language differences you are free to change them. The scenario is based on true examples as given by PLWHA participants who have participated in a training workshop with the author of this manual.

Instructions to facilitator: After the role play ask participants to comment on what they saw and observed. Ask those who did the role play how they felt. The participants can come up with more personal experience if they feel free to do so. However that is not compulsory, only those who feel comfortable to tell their experiences can do so.

ACTIVITY 5

Instructions to Facilitator: Reducing stigma in different contexts

- Divide participants into three groups
- Instruct each group to choose a chairperson and a presenter of group feedback
- Give each group a topic to discuss how to reduce stigma in specific contexts, namely in the family, in the neighbourhood and in the community.
- Let each group give feedback after brainstorming the questions.

Note to facilitator: Here are examples but you can add if they were not mentioned already by your participants

Examples of reducing stigma in the family:

- Praying together, Counselling, Involvement of spiritual leaders
- Education on basic information on HIV/AIDS
- Informing households about the workshop/ giving them feedback about what has been done and said about stigma reduction.

Examples of reducing stigma in the neighbourhood:

- Involvement of house owners, Counselling
- Education on basic information on HIV/AIDS
- Good relationships among neighbours

Examples of reducing stigma in the community:

- Consultation with Constituency Councillor's office to announce community meetings through the radio, to address and/or inform the community members about stigma and its effects on different players
- Educate community members on how one can and cannot get HIV
- Do dramas, songs and poems on HIV/AIDS stigma either in the radio or at any community gathering

Instructions to facilitator: Close the session by summarising the main points that were discussed. Explain how stigma blocks both prevention and treatment of HIV and AIDS.

Tell them that fear of stigma:

- Keeps people from learning their HIV status through testing and discourages them from telling their partners, and as a result the partners may contract HIV.
- Keeps people who suspect they are positive from accessing treatment and counselling services.
- Keeps HIV and AIDS underground.
- People are forced to trade off their own lives in order to remain invisible and not be stigmatized.

If, on the other hand, people living with HIV are treated with kindness, support, and care, they will be more likely to:

- Go for testing,
- Disclose to their families, and
- Take safety precautions in their sexual relationships

UNIT 4: COPING WITH HIV STIGMA

Objectives: After completion of this unit participants will be able to:

- Cope with stigma and develop leadership abilities to help and support others
- Develop strategies for confronting stigma and discrimination

Introduction

In any community initiative that aims to combat stigma, it is important to include strategies for supporting people living with HIV to cope with the effects of stigma. People living with HIV can play a crucial role in identifying the many different types of stigma and raising community awareness about the damage and pain brought on by stigma and discrimination.

This unit is designed for use in HIV-positive support groups or training courses. The aim is to strengthen people living with HIV as individuals so that they can cope with stigma and develop leadership abilities to help and support others. The activities allow people living with HIV to share experiences and strategies, develop communication and assertiveness skills, and build self-esteem.

ACTIVITY 6

Instructions to facilitator: this activity is on stigma stories whereby participants expected to do *individual reflection*.

- Ask participants to sit on their own and think about “an occasion when they were treated badly by other people because you have HIV.”
- Allow five minutes of quiet, individual reflection.
- Divide participants into pairs. Ask pairs to share their experiences of being stigmatized.
- Bring the whole group back together and invite people to share their stories. It is not compulsory, only those who feel free to share can do it.

ACTIVITY 7

Instructions to facilitator:

This activity is about *coping strategies*.

- Divide participants into pairs and
- Ask, “What are the personal strategies we use to cope with stigma and discrimination?”
- Write one strategy per card and tape on the wall.
- Eliminate duplication
- Cluster cards into common categories.
- Form small groups and ask groups to select three strategies they think work best and explain why.
- Ask: “What are some of the ways that we cope with stigma with the help of others? How do we support each other as people living with HIV?”
- Record points on flipchart.

Note to facilitator: Below are examples you can add if they are not mentioned already by your participants

- Receiving counselling, Accept our own situation. Be quite
- Ignore those who say bad things about us and do not let it affect us, Forgiveness
- Make peace with others who discriminate/stigmatise us, Avoid situations of stigma
- Going to church services and praying, Disclose our status to friends and family so they can be supportive.
- Listening to music, Talk to friends about experiences of being stigmatized
- Self-employment to earn income, live positively and do useful work.
- Joining HIV positive support groups,

Instructions to facilitator: Closing the session by summarising the main points which were discussed during activities and tell participants to identify which strategies would be more applicable to their own situations. Encourage them to try several strategies to protect themselves from stigma and choose the most suitable ones.

UNIT 5: LIVING POSITIVELY WITH HIV/AIDS

Objectives: After completion of this unit participants will be able to:

- Identify the main features of living positively with HIV [treatment, emotional health, successful disclosure, food & nutrition, and safe sex]

Introduction

Living positively with HIV includes many features such as adherence to treatment, accepting your status and to be emotional healthy. It involves disclosing to family so that they can give help and support to the person who is living with HIV. It involves being responsible for example to go to hospital/clinic when you are sick, and to practice safer sex to protect your partner/s.

ACTIVITY 7

Instructions to facilitator

- Hand blank papers/cards to participants
- Ask them to write down two or more things what they should do to live positively with HIV/AIDS.
- Collect all the papers and cluster them together
- Discuss the written points
- Add what is left out
- Explain what is not clear
- Give participants chance to ask questions

Note: Below are examples on how to live positively with the disease. You can add if they were not mentioned already

Examples of positive living with HIV/AIDS

- Safe sex and/or abstain from sex
- No alcohol, smoking, substances (drugs)
- Limit stress, Not stressing oneself about the past

- Being spiritual, Relationship with God, Prayers
- Hygiene, Eat healthy food
- Seek medical treatment on time, Treatment adherence
- Work when one can, Exercises, Rest and sleep when tired
- Remember that one is lucky to be alive
- Accepting one's HIV status, Keep HIV for oneself
- Avoid becoming pregnant or consult health professional before becoming pregnant

Instructions to facilitator: Bring the session to close by mention the main points that were discussed during the activities. Encourage participants to live positively so that they can lead long and full lives.

UNIT 6: PLWHA CAN LEAD LONG AND FULL LIVES

Objectives: After completion of this unit participants will be able to:

- Recognize that people living with HIV can lead long and productive lives

Introduction

Seeing that this session is more related to living positive, less time could be spent on it. However, it should be emphasised that it is individuals' responsibility to take care of their health by adhering to living positively. At the same time it should also be emphasised that being HIV positive does not make anyone less human. Therefore PLWHA have rights too like any other person and should be treated as such.

ACTIVITY 8

Instructions to facilitator:

- Ask participants: What can people living with HIV do to lead long and productive lives?
- Add these examples if they were not mentioned by your participants

These are some of examples of what PLWHA can do to lead long and productive lives:

- Accept their status and accept themselves as they are
- Tell other family members and close friends, and ask for their support
- Maintain close, supportive, loving relationships
- Find out about getting ARVs
- Get treatment for opportunistic infections
- Avoid re-infection and other STIs
- Practice safe sex
- Get good food and nutrition
- Lead an active, healthy, social life
- Avoid depression and maintain a positive, cheerful attitude

ACTIVITY 9

Instructions to facilitator: You can introduce this activity by saying: In some cases people living with HIV are denied chances to contribute either to household chores or at work. This is also stigma and it makes them to feel belittled or useless.

- Divide participants into four groups
- Give each group a story to read
- Ask them to answer questions at the end

Story 1: Maria has been staying at her sister's house since she got sick. For the last couple of weeks, she has been feeling better and decides to surprise her sister by cooking a special supper. When her sister returns from work, she is shocked to see Maria cooking. Her sister tells Maria that she is too sick to be in the kitchen. Her sister says she would prefer to make her own meals.

Story 2: Nangolo loves football and plays for his local team every week. Recently, he has been sick, but since starting ARV treatment he is beginning to feel better. He turns up for football training one evening, and the coach tells him that he thinks it is better that he does not play since he has been so sick. His place on the team has been given to a younger man.

Story 3: Muharukua teaches mathematics in grade six at a local primary school. For the last few months he has had time off work for sickness. When he returns, the principal tells him that he has been moved to teach non-promotional subject in grade two where the work will be less challenging physically and mentally. Ben feels belittled.

Story 4: Frank is a person living with HIV. He wants to build a house for his family and goes to a credit agency to get a loan. When the credit agency suspects he is HIV-positive, his application is turned down.

- Ask participants to discuss these questions
 1. What happened in each of the stories?
 2. Why it happened?
 3. What does this say about an HIV-positive person's capacity to contribute?

Note to facilitator: After participants gave their report back on the above questions continue to the next activity.

ACTIVITY 10

Instructions to facilitator: Ask participants to read the story below.

Story: A truck driver got sick in 2000 and died in early 2002. When he first became sick, there was lots of gossip by neighbours. People said he acquired HIV on the road. They visited him when he first got sick and then the visiting stopped. The driver's wife, who worked as a tailor in a factory, cared for her husband. She often arrived late at work because of the heavy burden of care giving, and was subsequently fired. After leaving her job, she set up her own small tailoring business in her house. She loved tailoring and many women came to her for dresses. She then discovered she was HIV-positive. She accepted her situation and did all she could to stay healthy, including ARVs. Although her husband died, her own health improved and she became stronger. She is alive today.

- Discuss:
 1. What happened to the husband and the wife?
 2. Why did the wife live a long life?

Instructions to facilitator: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- People living with HIV can live long and productive lives if they are given a chance.
- People living with HIV have many skills and can make a big contribution to their families, jobs, and communities.

UNIT 7: MOVING TO ACTION

Objectives: After completion of this unit participants will be able to:

- Identify realistic, practical and achievable plans to stop and reduce stigma in their families, communities as well as to stop self stigma.

Introduction

One of the objectives for this training is to come up with an action plan on how to reduce community-based HIV/AIDS stigma in community. It is therefore appropriate to have this topic of moving to action in the program. During the brainstorming and discussions throughout the workshop moving to action should be the aim. However, a plan on paper is needed to enable participants to implement it. The participants can come up with different examples as their plan of action. It is however the responsibility of the facilitator to see to that those examples are practical feasible and possible.

ACTIVITY 11

Instructions to facilitator

- Hand cards to participants
- Ask them to write two to three points on this question:
“What will you do after the training to reduce or stop stigma?”
- Cluster the cards together
- Brainstorm and discuss their answers with the group

Note: Below are examples of plan of action to reduce stigma in the community

- Giving feedback about the workshop to other support group members
- Re-educate their families, neighbours and communities on basic facts of HIV/AIDS and stigma
- Information sharing with others on how HIV is not transmitted
- Re-arrange themselves and train others on stigma reduction
- Call for community meetings through their community leaders

- Mobilising community members on stigma reduction by using dramas, songs, and role plays.
- Work in collaboration with existing community committees which deal with HIV/AIDS matters in their constituency.

Note to facilitator: Bring the session to a close by summarising main points that were mentioned during the activities. Encourage participants to work hand in hand with the community representatives, faith based organizations and community based organisations that deal with HIV/AIDS related activities in their respective communities. That would help to sustain the stability of the program of stigma reduction in their communities.

WORKSHOP EVALUATION

Instructions to facilitator:

Before the closing remarks ask participants to evaluate the workshop individually. Thank them for their participation and encourage them to be in touch with relevant stakeholders regarding stigma reduction. End the workshop at the scheduled time.

LIST OF REFERENCES

Angula, P. (2008). *Family Health Support Module for distance education* Windhoek: UNAM

Kidd, R., & Clay, S. (2003). *Trainers' Guide: Understanding and Challenging HIV/AIDS. A Toolkit for Action*. Washington DC: International Center for Research on Women.

Kidd, R., Clay, S. & Chiya, C. (2007). *Understanding and Challenging HIV Stigma: Toolkit for Action* Brighthon.

2. TRAINING MANUAL FOR COMMUNITY LEADERS

INTRODUCTION

The original Toolkit for Action by Kidd and Clay (2003) has been developed for community members as trainees. It is developed in a way that it is suitable for outdoor settings. This training manual will also adopt the same design and approach. However, it can also be used indoors, depending on where the training takes place.

The original toolkit is designed to build awareness about and action against stigma to help participants move to action. Participants should be encouraged to put their new learning into action, to start challenging stigma in their own lives. The toolkit is designed for collective learning and action. The aim is to get people to meet with their peers, discuss stigma issues and work together to bring about change. Working with others makes it possible for people to learn together about stigma, develop common ideas about what needs to be done, set group or community norms for new attitudes and behaviour, and support each other in working for change. This is the same aim for this training manual. To helping participants to move from awareness only, but to take action against stigma in order to bring change in attitudes and behaviours towards people living with HIV/AIDS (PLWHA).

This training manual consists of eight units which are adapted from the original toolkit for action by Kidd and Clay (2003) and second edition for Cambodia training by Kidd, Clay and Chiya (2007). Different activities are given to be used in this manual. Nevertheless facilitators are free to come up with additional activities if necessary.

The audience for this manual will be opinion/community leaders and community members, staff of community based organizations and individuals who want to become peer educators on stigma reduction in their respective communities. They will be the implementers of stigma reduction strategies in the community. They are expected to take what they learn from this manual into action to reduce stigma and to share their learning experiences with their families, relatives, neighbours, friends, colleagues and community at large.

The manual will be used as a guide for facilitator/trainer during the training sessions. Some explanation and definitions from textbooks are given. Feedback hints for group

work are also provided for facilitator. However, it does not limit facilitator to give her/his own relevant input. There are exercises/activities which will be done as part of training and different teaching and participatory methods will be used.

Training manual methods and materials

This training manual uses the following participatory training methods and materials:

Discussions are used as the main component in this manual. Participants will actively participate in the discussion around the subject matter, stigma. Participants will be given activities to reflect and personalize experiences on stigma, either being a victim or a perpetrator.

Case scenarios document realistic situations based on fictional characters are used. This will help people to reflect and analyze situations from the perspective of being a perpetrator and object of stigma. Through scenarios participants are also encouraged to discuss own experience as well as to give their views and feelings on the situations.

Quizzes are used to test participants' level of knowledge on stigma and HIV/AIDS transmission. These participatory activities help participants to get clear answers on issues related to fear of contracting HIV through non-sexual contacts. This will help to increase the knowledge and understanding of HIV/AIDS issues that can result in stigma reduction in the long run.

Report backs are used to bring ideas together after small or buzz groups. Often “round robin” reporting will be used—one new point from each group going round the circle. This ensures that all groups get a chance to contribute equally.

Card storming is a quick way of getting out ideas and getting everyone involved. Participants, working individually or in pairs, write single points on cards and tape them on the wall, creating a quick brainstorm of ideas. Once everyone is finished, the cards are organized into categories and discussed.

Energizers, facilitator can come up with different energizers for participants in between to prevent boredom and keep participants active.

Note to facilitator:

HIV/AIDS is mainly transmitted through sexual contact as a result some people feel uncomfortable to talk about it. Talking about sexual issues is regarded as taboo in our communities. It is, therefore, very important to bear these in mind when conducting training in HIV/AIDS related stigma reduction.

As facilitators it is your responsibilities to create a safe, non-threatening environment where feelings, fears and taboos can be discussed and explored openly. The following tips may be helpful:

- Setting clear ground rules and expectations around confidentiality, listening and support is essential.
- Awareness of your own feelings and fears about the topics you are going to cover will also help you to feel more confident during the exercise.
- Participants are more likely to trust you if you can share your feelings openly and by doing this, you lead by example.
- Remember to always leave enough time for participants to share their feelings and help the group to create an atmosphere where participants know they will be listened to.
- Remember that no feeling is wrong but some participants may find it difficult to accept certain feelings.
- Offer participants “time-out” if they need to take a break.
- Feelings are a powerful tools use them with the group to develop drama and role-plays, to build on stories, and as examples for the future.
- If there are any exercises you do not feel comfortable leading, find a co-trainer who can help out. If you have counselling skills, you are more likely to be confident in working with feelings.

It is very important and helpful to start with yourself

You should first use the training manual for yourself to reflect on your own attitudes, values, language and behaviour towards PLWHAs before you try to educate others.

(Adapted from the Toolkit For Action “Understanding and challenging HIV Stigma” developed by Kidd and Clay, 2003).

Note to facilitator: Create conducive environment for participants to learn. Use participant-centred approach by making participants feel that their concerns and needs are being addressed in this training. When preparing the sessions use practical examples from participants.

Start each day with something fun that reviews what happened the previous day. Encourage everyone to be creative. You can encourage participants to sing, if there are songs which are known by most of participants. Let all participants feel comfortable and free to contribute, regardless of their different social status.

INTRODUCTION OF PARTICIPANTS

Start the first day on a positive note to ensure that participants feel comfortable and get to know each other. There are different ways you can use for participant introductions such as participants interviews, name-tags and find the missing part.

- **Participants interviewing each other:** divide participants into pairs of two. Give them few minutes to interview each other. Thereafter each participant will introduce their partners by name and at least two unique characteristics about themselves for example what they like, dislike and expectations from the training.
- **Name-tags:** the facilitator prepares a name-tag for each participant. Then placing them in a box. Each participant will take a name-tag and locate the person whose name-tag they drew and introduce themselves. (This method is only applicable if the facilitator knows or has a list of participants' names beforehand.)
- **Find the missing piece:** the facilitator writes split words on piece of papers for all group members to get one part of a word. For example these words can be used:

AFTER	NOON; ICE	CREAM
SWEET	HEART; MILE	STONE

Each person picks up a piece of paper and looks for the person who has the matching part of his/her word. Once the person found the participant with the matching part of the word they will introduce each other. Each participant will then introduce his/her partner to the rest of the group.

Opposite words can also be used for this method of introduction. Words such as:

BLACK	WHITE;	LEFT	RIGHT
EAST	WEST;	BOY	GIRL

These are just some of the methods of introduction. However, facilitators are free to use any other method as long as it is comfortable for participants. If you do training in other language rather than English you can use relevant words in the language you use.

Training objectives

Tell participants that training will be participatory and everyone is going to play the role of both a learner and a facilitator. Encourage participants to feel free to ask if they have any questions during the training. Tell them that there is no “stupid question”.

Explain to participants that the training objectives are:

1. To get people to connect to the issue of HIV/AIDS stigma on a personal and emotional level, rather than a theoretical level
2. To get participants to *own the problem* so that they can recognise that we are all involved in stigmatising people living with HIV and AIDS
3. To identify and address some of the feelings involved in stigmatizing others
4. To identify different forms of stigma in different contexts as well as the root causes of stigma
5. To create a conducive environment/opportunities for participants to raise all their fears, concerns and questions they have about HIV/AIDS
6. To address and correct misconceptions and fears about how HIV is transmitted through non-sexual contacts
7. To come up with practical suggestions on how to reduce stigma in their respective areas

Expectations and ground rules of the training /workshop

Ask participants to share with the group what are their expectations from this training. Ask one of participants to write them down on flipchart or on folio paper (or on blackboard). Let participants come up with ground rules, which will guide them throughout the training. Facilitator should explain them and can add if necessary. Put the rules somewhere where they can be visible at all times during the training. End this activity by asking participant if they have any question, any comment or anything extra to add. Thank them for making time to come and attend this training.

UNIT 1: NAMING THE PROBLEM: STIGMA, CAUSES AND EFFECTS

Objectives: After completion this unit participants will be able to:

- Own the problem and recognize that we are all involved in stigmatizing people who are living with HIV.
- Connect to the issue on a personal and emotional level, rather than a theoretical level

Introduction

This unit introduces stigma through a number of optional exercises that bring out what stigma means and how it feels, using pictures, testimonies, stories, and drama. The definition comes later in the unit, after participants have already developed an experience-based understanding of stigma. If you have access to video you can show stigma related movies for example “Remember Eliphaz” part two (a Namibian movie on stigma in the community).

This unit gets participants to name the problem, in order to see that:

- Stigma exists and takes many forms - rejecting, isolating, blaming, and shaming.
- We are all involved in stigmatizing, even if we do not realize it.
- Stigma hurts people living with HIV and those suspected of having HIV.
- Stigma is harmful to us, our families, and our communities.
- We can make a difference by changing our own thinking and actions.

ACTIVITY 1

Instructions to facilitator: Start with first activity by:

- Hand out pieces of paper to participants.
- Ask them to write down what they think “stigma” is.
- Let them give practical examples of stigma either experienced or observed.
- To make it easier for participants, they can also write it on their own language.

- Ask them what are the local phrases used to refer to People living with HIV/ AIDS

Instructions to facilitator: Conclude this activity by summarising the main points, which participants have made during the exercise and add that after doing this activity it is clear that we all do stigmatize in one way or another. We are all guilty of stigmatizing then proceed to the next activity.

ACTIVITY 2

Instructions to Facilitator:

- Divide participants into groups of four to five (depends on the size of the group)
- Ask them to select a chairperson and someone to write down their points
- Ask them to give examples of how do people stigmatize
- Let one person give feedback from each group

Note to facilitator: after participants gave their answers you can add the following if they did not mention them. We do stigmatize either by saying or by doing.

- We stigmatize when we say things like: “she was promiscuous” or “he deserves it”, “She was looking for it”.
- We do stigmatize when we do things such as isolating PLWHAs, excluding them from decision making, gossiping about them, abandoning them, do not want to be seen with them.

Instructions to facilitator: Close the session by saying this: In some cases we are not even aware that we are stigmatizing others. It is very important to find out the reasons why people stigmatize. When we know the reasons and causes, then we will be able to find the solutions and deal with the problem. Literature shows that sometimes people do stigmatize but they are not aware that they are stigmatizing others. Some people do it due to fear of contracting HIV. Some do not want to be associated with HIV as a result they distance themselves from people who have HIV or AIDS.

ACTIVITY 3

Instructions to Facilitator:

- Divide participants into groups
- Let each group choose a presenter
- Ask them to discuss these questions:
 4. Why do people stigmatize? (Causes)
 5. How do people stigmatize? (Forms)
 6. What are the effects of stigma on those who are stigmatized? (results)
- Let each group report back

After each group's presentation facilitator can lead the discussion and add these examples if they were not mentioned already.

Why do people stigmatize? That can be as a result of the following:

- Insufficient knowledge, Misconceptions, myths
- Fear to get HIV, Fears about death and disease,
- Moral judgments,
- Lack of recognition of stigma.
- Lack of information
- Unemployment
- Poverty

Forms of stigma include the following:

- Isolation and rejection from family, friends and community.
- Mistreating of PLWHA
- Gossiping, name calling and condemnation
- Hunger (stop giving food to PLWHA)
- Loss of rights and decision making power.

Other forms of stigma include:

- Self stigma (stigmatizing oneself by avoiding going to health facility for medical help),
- Stigma by association (because a person is a volunteer she is labelled as HIV positive or she will be called names),
- Stigma by looks/ appearance (because someone is thin people start labelling him/her as HIV positive),
- Type of work (people who are working in organizations/ institutions which are related to HIV/AIDS are mostly stigmatized).

Effects of stigma include the following:

- Kicked out of family, house, work, rented accommodation, organization, denied opportunities such as promotion or getting scholarship, or rejected for job etc
- Dropout from school (resulting from peer pressure and insults)
- Depression, suicide, alcoholism and, even more HIV infections because people will not disclose to their partners and will continue to practice unsafe sex.
- Separation/divorce in the family
- Deteriorating of one's health
- Non- adherence to treatment

Facilitators' notes: Definitions of stigma

Stigma can be defined as when a person is being discredited because s/he is different from the rest of the group. In simple words stigma is when people hold negative thoughts or feelings against other people simply because they are regarded as “different”. It is a process where we (society) create a “spoiled identity” for an individual or a group of individuals. We identify a difference in a person or group, such as a physical difference (e.g., physical disfiguration), or a behavioural difference (e.g., people having lots of sex) and then mark that difference as a sign of disgrace. This allows us to stigmatize the person or group. Stigmatized people lose status because of these assigned signs of shame that other people consider indications or evidence of sinful or immoral behaviour.

To stigmatize is to label someone, to see them as inferior because of an attribute they have. Furthermore to stigmatize is to believe that people are different from us in a negative way, to assume that they have done something bad or wrong. When we stigmatize, we judge people, saying they have broken social norms and should be shamed or condemned; or we isolate people, saying they are dangerous or a threat to us. Stigmatizing beliefs lead to discrimination and unfair treatment (Cambodian Version: Toolkit for Action).

Close the session by summarising the main points of the discussion on how stigma can hurt and causes other problems such as depression and prevents people to disclose their status to their beloved ones. As a result it blocks HIV prevention and fuels the epidemic.

ACTIVITY 4

Instructions to facilitator:

- Divide participants into pairs
- Give each participant a blank piece of paper/card
- Ask them to write down one point on form of stigma and its cause.
- Let each pair reads what is on their card
- Identify what forms are mentioned by the majority and select critical ones for discussion
- Tell the group to analyze the following questions:
 1. How will we address those causes?
 2. What are the possible solutions to reduce or stop it?

Instructions to facilitator: Close the session by summarising the main points and emphasise that it is our responsibility to stop stigma by starting with ourselves, in our families and communities. Let us live by example and be role models for stigma reduction. Although we are not infected we are all affected.

UNIT 2: OUR OWN EXPERIENCES AS STIGMATISING OTHERS

Objectives: After completion of this unit participants will be able to:

- Understand how it feels to be stigmatized and will start empathizing with people living with HIV

Introduction

This unit helps the participants to understand how it feels to be stigmatised and making them to empathize with people living with HIV. The exercise for using own experiences requires a lot of trust and openness within the group, so it should not be used as the first exercise. It works better if it is used after 2-3 exercises. By this point, participants are beginning to open up with each other and are now ready to share some of their own experiences.

ACTIVITY 5

Instructions to facilitator: Tell participants:

- Think of a time in your life when you felt isolated or rejected for being seen as different from other people (for example made fun of because you are from a poor family, poor at football, smaller than the others).
- This is a voluntarily exercise is not compulsory but if you feel free you can share with someone whom you feel comfortable.
- Think about these questions:
 1. What happened?
 1. How did it feel?
 2. What impact did it have on you?
- You have few minutes to share your stories with each other
- Remember that what we share here should remain here, it is confidential.

Instructions to Facilitator: Summarising this activity by saying:

This exercise helps us to think and reflect on our own experiences of stigma. It hurts to be stigmatised. After this exercise you realise that we are all involved in stigma in one way or another. When we stigmatize people who are living with HIV, they will feel lonely, ashamed, they feel sad, rejected, unwanted, and lose self confidence. These feelings can lead people not to take care of their health for example by stopping using condoms, not adhere to treatment and refuse to go to health facilities when they are sick. This can fuel the HIV epidemic as people will be afraid to disclose their HIV status and continue to infect others.

UNIT 3: STIGMA IN DIFFERENT CONTEXTS

Objectives: After completion of this unit participants will be able to

- Identify stigma in different contexts and how it affects people living with HIV
- Identify practical things we can do to support people who are living with HIV

Introduction

Stigma in different contexts can be identified by using different exercises depending on what the facilitator choose. Select the method that suits your group.

ACTIVITY 6

Instructions to facilitator:

- Divide participants into three groups (depends on the size of the group)
- Ask them to choose a presenter to report back
- Each group will discuss one of the following topics by giving examples
 1. Stigma in the family
 2. Neighbors stigmatizing neighbors
 3. Stigma in the community
- Report back to the whole group

Note to facilitator: After the report back from groups, you can add the following examples if they were not mentioned by the groups.

Stigma in the family comes in these forms:

- Hiding an HIV patient in the house due to fear of stigma by association by the neighbors/community
- Kicking someone out of the house because of HIV positive status
- Gossiping about a family member who has HIV or AIDS
- Calling people who are living with HIV bad names

- Let them eat alone
- Let them use separate utensils
- Exclude them out of family discussions and decision making

Instruction to facilitator: Ask all groups to discuss this question: What practical things can we do as families to support HIV positive family members?

Note to facilitator: These are some of the examples of what we can do to support HIV positive family members, but remember that participants can come up with their own ideas. There is no right or wrong answer.

- Chat and spend time with them. Make them feel wanted.
- Encourage them to talk openly about their feelings and listen to them.
- Encourage them to disclose their status when the time is right.
- Encourage friends to visit and help them get to know other people living with HIV.
- Help obtain treatment for opportunistic infections and find out about ARVs.
- Provide good food and nutrition.
- Organize the sharing of “caring work” among all family members

Families with people who are living with HIV are also being stigmatised either by neighbours or by other community members.

Stigma by neighbours and in the community comes in these forms:

- Isolation and rejection of the person who has HIV or AIDS
- Let a person to live alone
- Shamed for “bad behaviour”
- Stop visiting someone who has HIV or AIDS
- Gossiping about the family with a person living with HIV
- Stop children to play with a neighbor’s children due to a family member who has HIV or AIDS
- Not to buy food from someone who is HIV positive
- People keep their distance from the person who has HIV or AIDS

ACTIVITY 7

Instructions to facilitator:

- Divide participants into two groups of equal sizes –
- Group A is the family of a person living with HIV;
- Group B is the neighbours.
- Organize two short role-plays: showing the two groups talking separately.
- Family – What are you afraid that the neighbours will say about you?
- Neighbours – What are your fears about the family? Why?

These are the possible fears from the family of a person living with HIV

- Fear of losing regular contact with their neighbours; fear they are judging them behind their backs.
- Fear of losing honour.
- If they ask about him they say he is fine to stop neighbours from judging them.
- They discourage people from visiting.
- If they visit, we keep him in the back room, or we tell them he is sleeping.

The fears of the neighbours

- Fear that their children will get infected so they have stopped them from playing with those from a family with a person living with HIV.
- Family brings shame to the community.
- Judging – he was doing bad things with his IDU friends. He deserves it.
- They visit for a while, then at intervals, and finally they stop.

Note to facilitator:

Let the whole group discuss and brain storm these two questions

- What kind of stigma is going on here?
- What can we do to change things?

Instruction to facilitator: Summarising this session by saying:

Stigma is everywhere, in the homes, neighbourhood, schools and workplace, in the community as well as in health facilities (hospitals and clinics). If we want to stop stigma we have to start with ourselves. Our starting point should be to change the way we think, talk, and act towards people living with HIV/AIDS. We have to change our attitudes and the way we feel about them. Once we change ourselves and our attitudes then we can start to educate and challenge others to stop stigmatizing people who are HIV positive or Have AIDS.

Let us start talking about HIV openly. HIV and AIDS should become a spoken disease and not a whispered condition. It is only by doing that we will stop stigma towards people living with HIV. Start with your family, friends, colleagues, neighbours and get community leaders to speak out against stigma. Reach out to people living with HIV and support them so that they will feel accepted and stop self stigma by looking for necessary services. **Let us work together as a team to stop stigma and make our society a better place for everyone regardless of his/her HIV status.**

UNIT 4: MORE UNDERSTANDING AND LESS FEAR

Objectives: After completion of this unit participants will be able to

- Understand how HIV is transmitted and not transmitted
- Differentiate between myths and facts about HIV and AIDS

Introduction

This unit will re-educate people on the basics on HIV transmission so that people have the right information and full understanding needed to overcome fears and mistaken beliefs about getting HIV through casual contact. At the same time, it will help them see that keeping people living with HIV at a distance and restricting social contact with them is not only unnecessary but also stigmatizing. This unit will also address the myth that an HIV-positive test result means immediate death. When people living with HIV are told this, they are quickly demoralized and give up on themselves.

ACTIVITY 8

Instructions to facilitator:

- Divide participants into three groups
- Give them this case study (see below) after reading it they should answer the questions

***Scenario:** Lea is a single mother of 6 children. She is 23yrs old and is HIV positive. For the last six months she was staying with her older sister, who is married in Windhoek. Lea gave birth two months ago. Her brother-in-law (her sister's husband) has just learned that Lea is HIV positive after she gave birth 2 months ago. He decided to throw/kick her out of his house when he found out about her status. Lea is unemployed and has no income. She has no other relatives in Windhoek. Sometimes she thinks of committing suicide just to end all these problems. (Based on a true story from research results in Namibia [Angula, 2008], but name has been changed)*

- To save time let each group deal with one question
- Ask participants to discuss these questions based on the scenario:
 1. What do you think is the problem in this case study?
 2. Why did Lea's brother-in-law act the way he did?

3. What can be done to stop these types of attitudes and behaviours in the families and community?
 - Let each group report back

Note to facilitator: after participants gave feedback it is your responsibility to explain and give or add to their answers.

Facilitator: give feedback on this activity if participants have not mentioned that already:

The problem in this scenario is **stigma in a family due to fear of getting HIV through non-sexual casual contacts**. This is a clear indication that some people lack knowledge and understanding on how HIV is transmitted. In this scenario the brother-in-law might be afraid of contracting HIV by staying together with a person who is HIV positive or he does not want to be associated with someone who has HIV. He might be fear of **stigma by association**. We will not have a clear answer about why he did that but there is a possibility that **lack of knowledge and understanding, misconception, fear of contagion as well as fear of stigma by association, are the major causes** in this case.

This form of stigma can be corrected by providing people with clear information on how HIV is transmitted. There is a need to tell people that HIV does not spread through non-sexual casual contacts such as staying in the same house, using the same utensils, sharing a toilet or eat food prepared by someone who is HIV positive. These misconceptions that HIV is spread through the air or by mosquito bites need to be corrected so that people will stop stigma due to fear of getting infection on non sexual casual contacts.

ACTIVITY 9

Instructions to facilitator:

- Prepare two cards before hand and write them with capital letters on one card: **AGREE** and another one: **DISAGREE**
- Put each card on opposite sides of the room (eg. one at the back and one in front/ or one left and at the right)
- Ask participants to come to the centre of the room

- Tell them that you are going to read statements and they have to choose either to agree or disagree with the statement
- Those agree with the statement will move to the side where **AGREE** paper is
- Those who disagree with the statement will move to the side where **DISAGREE** paper is.
- Participants are free to move in between after each statement is read
- Let them explain why they agree or disagree with the statement
- Use the following statements to test their knowledge:
 - HIV and AIDS is the same thing.
 - You can tell if a person has HIV just by looking at them.
 - There are four body fluids that can transmit HIV from one person to another.
 - An HIV negative mother will pass the virus to her baby if the father is HIV positive.
 - A person can get HIV by eating food prepared by an HIV positive person.
 - A person can get HIV by mosquito bite.
 - If your partner goes for an HIV test and the result is positive, that means you are also infected.
 - An HIV positive woman can pass the virus to her baby during delivery.
 - If both partners are HIV positive there is no need to use a condom as a result that they have the same virus.
 - An HIV positive woman should not get pregnant.

Note to facilitator: Discuss the questions where most participants are confused about the responses and give them the correct information.

ACTIVITY 10

Instructions to facilitator:

- Hand out cards to participants
- Ask each person to write down his or her three greatest fears about HIV and AIDS,
- Let them write one fear per card.
- Tape the cards on the wall,
- Eliminate repetition,
- Cluster common points.
- After the participants identified their fears divide them into pairs and let them discuss the following question:
How do fears affect our behaviours towards people living with HIV?
- Report back

Instructions to facilitator: Summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants. It is natural to fear HIV and AIDS because there is no cure. This is a human reaction to a disease that can lead to people dying. Now that ARVs are available, however, HIV and AIDS should be treated as a manageable disease, like cancer or diabetes. These fears are often promoted by the media and information, education and communication campaigns as a form of prevention. Instead of scaring people about AIDS, we should empower them to see that they are in control, and that they can do things to avoid HIV.

Tell participants that for HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present, and there must be a route of transmission into the bloodstream. All of these things must be present for someone to get infected with HIV. This is called QQR (Quality, Quantity and Route of transmission).

UNIT 5 CARING FOR PLWHA IN THE FAMILY

Objectives: After completion of this unit participants will be able to:

- Provide care and emotional support to family members who are living with HIV

Introduction

Stigma and caring in the family are closely linked – some forms of stigma are triggered by family members not knowing what to do or how to care for someone who is sick with AIDS. This, coupled with poverty and economic stress, creates frustrations and feelings of being overwhelmed by the duty of care and support. Many family members have little idea how they can best look after family members living with HIV when they get sick. This is an important area of practical knowledge that people need to learn. Many family members have the basic equipment – the love for their close relatives – but they need other knowledge and skills, e.g., how to provide emotional support effectively, respond to health crises, and share the burden of care. To manage HIV better in the household, people need skills, understanding, compassion, and external support, such as access to free treatment. In this unit, participants can explore the challenges of caring for family members living with HIV. With their increased knowledge and sharing, stigma will be reduced.

ACTIVITY 11

Instructions to Facilitator:

- Divide participants into groups
- Give them different scenarios for families with HIV positive family members
- Ask them to brain storm this question: What strategies can families use to cope for caring their loved ones with HIV?
- Let them report back

Instructions to facilitator: After their feedback you can add these if they were not mentioned already.

Strategies for caring and coping with HIV within the family

- Help family members deal with the anger and stigma towards drug use or sex work.
- Do not give up on the person living with HIV. An HIV-positive test result is not a death sentence.
- Help him/her live a longer, healthy life (including use of ARVs).
- Make him/her feel loved, wanted and welcome in the family. Spend time with him/her.
- Educate family members on HIV – help them see there is no reason to fear contact.
- Find out more about ARVs – where to get them, food requirements, etc
- Encourage the person living with HIV to get opportunistic infections treated quickly.
- Provide good food and nutrition.
- Organize the sharing of “caring work” among all family members.

Instructions to Facilitator: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

Families should not give up on their children, even if they are angry with them. Blood is blood, and we need to focus on providing support for family members who are sick. An HIV-positive test result is not a death sentence. If a person living with HIV lives with a positive attitude (including using ARVs) he/she can live a long time. HIV is a condition that can be managed. It is important to learn caring and coping strategies. Families should focus on providing support. All people living with HIV need support from the family.

UNIT 6: COMMUNITY SUPPORT FOR PEOPLE LIVING WITH HIV

Objectives: After completion of this unit participants will be able to:

- Support people who are living with HIV and their families
- Understand that they do not have rights to know other people's HIV status

Introduction

The aims of exercise in this unit are designed to get people talking about how the community can support families living with HIV, without creating more stigmas and why communities do not have a right to know the status of community members.

ACTIVITY 12

Instructions to facilitator: Organise a role play with two scenes

Scene 1:

There is a family sitting alone. Suddenly, they are visited by a large group from a women's organization that express their concern and give them lots of things.

Scene 2:

Members of the women's organization leave. Neighbours, who have just discovered that the family has a person living with HIV, begin to gossip about the family.

Ask participants to discuss these two questions:

1. What happened?
2. How did this visit make the family feel?

Note to facilitator: These are examples but not required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- The women’s organization came with good intentions, but the visit resulted in stigma.
- The family felt invaded – they did not ask for support or help.
- The family felt they were being treated as poor people, as objects of charity.
- They felt ashamed to be seen as unable to stand on their own feet.
- The family had no say in what was provided.
- They felt angry that the women’s organization had shamed them in front of neighbours.

Instructions to facilitator: Organize a report back. Discuss “How could the women’s organization help without exposing the family to more stigma?”

Note to facilitator: Below are examples adopted from Toolkit for Cambodia version what you can use as a guide but let participants come up with their own answers, then add if they did not mention them already.

Examples of how community support can be done without exposing family to stigma

- Meet with the family beforehand, in another place, to find out how to help them.
- Work with and through a local organization of people living with HIV in arranging the meeting.
- Send two or three people to meet with the family. Do not send a big delegation.
- Ask the family to determine areas where they need help, rather than imposing things.
- Advise the family on how they can get support from others.
- Treat them in the way you treat other families. Do not give special treatment.
- Help the family deal with their shame and fear. Promote a positive, non stigmatizing attitude, as in: “It’s not how he got it, but what we can do now.”
- Be reassuring; say: “Don’t worry – we can do something. People may tell you that your life is over, but ARVs and positive living can help you live a long life.”

Instructions to facilitator: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

Community organizations often want to be told who in the community has HIV. They feel they need this information to be able to “support the family and protect the community.” However, information about the results of an HIV test should only be given to the individual, his/her spouse, and the doctor and nurse who are treating the patient. No one else should be given this information. Only the person living with HIV can decide who else should be given this information and that should be respected.

If information on the HIV status of all community members were given to community organizations, this would be a denial of people’s human rights. It would make them a target for stigma.

UNIT 7 PLWHA HAVE RIGHTS TOO!

Objectives: After completion of this unit participants will be able to:

- Recognize the rights of people living with HIV and stop violating them

Introduction

This unit raises the issue of a person living with HIV being denied their rights as a form of stigma

ACTIVITY 13

Instructions to facilitator:

- Divide into pairs and hand out blank cards.
- Ask pairs to brainstorm a list of rights and responsibilities of people living with HIV,
- Writing one point per card and sticking the cards on the wall under the two categories.

Discuss these questions:

1. Which of these rights do families try to remove? Why?
2. What are the effects on the person living with HIV if these rights are denied?
3. What can be done to reaffirm and reinstate those rights?
4. What are some of the responsibilities that go with these rights?

ACTIVITY 14

Role play:

- Divide into small groups.
- Ask each group to select one of the rights and perform a short role-play to demonstrate how this right might be broken.
- Discuss: How can we as families ensure these rights are met?

Rights

- To be respected. To have physical contact. To contribute to family decisions.
- To have friends. To have food. To have sex. To get pregnant. To have a child.
- To have medical care. To have clothing. To have shelter. To be clean.
- To participate in community events.

Responsibilities

Be open to advice. Help out in the house with family chores when you can. Listen to others. Help with earning income when you are well. Practice safe sex.

Rights being violated

People living with HIV expect family members to continue to love them, but out of fear, some families stop all physical contact and stay at a distance. This destroys an HIV-positive person's will to live.

Instructions to facilitator: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

We need to ensure that people living with HIV are involved in making decisions about their lives, even when they get sick. People living with HIV need to understand the stresses on a family, which might mean that all their needs cannot be met. As communities, we can look for ways to support families, which will enable rights and responsibilities to be respected.

UNIT 8 MOVING TO ACTION

Objectives: After completion of this unit participants will be able to:

- Develop a specific plan of action for challenging stigma in their community, and
- Make a public commitment to work individually and collectively to identify, understand, and challenge stigma.
- Work out how to stop stigma and promote care and support for people living with HIV

Introduction

The aim of this unit is to make participants plan what will be their action to stop or reduce stigma after this training. The changes can be done on individuals, groups and at community level. The key message is that we all have responsibility to stop stigma by changing our behaviour and attitudes to people living with HIV as well as to educate others to do the same.

ACTIVITY 15

Instructions to facilitator:

- Hand over blank cards to each participant
- Tell them to write down what their plans are to reduce stigma
- Cluster cards together
- Brainstorm and discuss as a group

Note to facilitator: participants should come up with realistic and practical examples of what they will do to stop stigma in their respective communities, households, work place and so on. Below are examples of what can be done individually and collectively to stop stigma, you can add if they were not mentioned already.

Examples of moving to action to stop stigma:

- Be a role model. Apply what you have learned in your own lives. Think about the words you use to talk about people living with HIV and try to change how you think and act.

- Encourage community leaders to speak out about HIV and AIDS and condemn stigma.
- Encourage people living with HIV to speak out to help people understand how it feels to be the object of stigma.
- Share what you have learned. After the training, tell others what you have learned and get others talking about how to reduce stigma.
- Talk openly about HIV and AIDS. This will help people see that the topic is not shameful or taboo. Talking openly about HIV will also empower people living with HIV and help relieve some of their self-stigma.
- Facilitate discussion with family, friends, and neighbors on stigma.
- What are the most common forms of stigma in your community?
- What perpetuates these abuses? What can be done to change things?
- Avoid using stigmatizing words. Instead of saying “victims,” use positive terms such as “people living with HIV,” and use “us,” not “them.”
- Challenge stigma when you see it in your home, workplace, and community.
- Speak out, name the problem, and let people know that stigma hurts.
- Act against stigma as a community. Each community can look at stigma in their own context and agree on one or two practical things they can do to bring about change.
- Saying “stigma is wrong” is not enough. Help people move to action – agree on what needs to be done, develop a plan, and do it.
- Think big! Start small! Act now! Have a big vision but start with something small.
- And do not wait – act now!

Things you can do as individuals

- Watch your own language and avoid stigmatizing words.
- Support family members who are living with HIV.
- Visit and support people living with HIV and their families in your neighborhood.
- Encourage people living with HIV to use the available services, e.g., counseling, testing, medical care, and antiretroviral drugs (ARVs), and refer them to others who can help, e.g., counsellors.

Things you can do to involve others

- Use informal conversations as opportunities to talk about stigma.
- Use the stigma pictures to get people talking about stigma.
- Use real stories that put stigma into a practical context, e.g., stories of bad treatment
of people living with HIV; stories of good treatment
- Challenge stigmatizing words when you hear them, but do it in a way that does not offend people.
- Get people to think about how their words can hurt.
- Help normalize HIV and AIDS. People living with HIV should be seen as people with
an illness, and not people with bad behaviour.
- Encourage people to talk openly about their fears and concerns about HIV and AIDS.
- Correct myths and misperceptions about HIV and HIV-positive people.
- Promote the idea of a friendly ear and support to HIV-positive people and their families

Things to do to get the Community Acting against Stigma

1. Examples of activities that get people to identify and analyze stigma in community:

- Testimonies by people living with HIV or their families about their experiences of living with HIV
- Language watch: school children or youth groups can make a “listening survey” to identify stigmatizing words used in the community, media, or popular songs
- Community mapping of stigma: get the community to make a map of places where stigma
occurs and display it at a community meetings.
- Community walk to identify points of stigma in community
- Drama by a youth group based on real examples, which can be the trigger for discussion
- Pictures drawn by youth or school children: focus or starting point for discussion
- Community meetings to discuss what has been learned from the above methods and

make decisions about what they want to do, e.g., agreeing on a code of conduct and specific support to families living with HIV and/or orphans.

- Training workshops on stigma for community and peer group leaders

Commitments

- Make sure that people who want to make a difference are given an opportunity to state their commitment to challenge stigma publicly.
- Action starts with commitment, and powerful commitment ensures that obstacles are challenged and overcome.
- The commitment of leaders serves as a role model and encouragement for others.
- Whenever possible, find examples of how one person's commitment led to action that made a difference in his or her community.

Instructions to facilitator: Conclude the session by summarising the main points of discussion and thank participants for their input and suggestions. Tell them to act now and not wait for the others to start.

Training evaluation

Note to facilitator: The last activity of the training is to ask participants to evaluate it. You can compile a form before hand with questions what you want them to evaluate/answer or you can write down the questions on blackboard and give them papers to answer. Explain for them that the aim of evaluation is to improve for future trainings therefore they should be honest and objective.

APPENDIX 8: TRAINING WORKSHOPS PROGRAMS

Workshop program for PLWHA (21- 23 July 2010)

Day1	Day2	Day3
08H00-08H30 Welcome	08H00-08H30 Day1 – Review	08H00-08H30 Day2 – Review
08H30-10H30 Introduction	08H30-10H30 Stigma in the family/house holds	08H30-10H00 Positive living with HIV/AIDs
Break	Tea	Break
11H00-13H00 Naming the problem Naming stigma through pictures Our own experiences as stigmatized	11H00-13H00 Group work: How to reduce stigma in the family Feedback	11H00-13H00 PLWHA can lead long and full lives - Discussion - Course evaluation - Closing remarks
Lunch	Lunch	Lunch
14H00-15H00 Group work: Effects of stigma on different groups PLWHA Family Community	14H00-15H00 How to protect ourselves and others against stigma - Group work - Discussion	

TRAINING WORKSHOP PROGRAM FOR COMMUNITY LEADERS

Workshop program for community leaders (27-29 July 2010)

Day1	Day2	Day3
08H00-08H30 Welcoming remarks Introduction <ul style="list-style-type: none"> • Expectations • Ground rules • Logistics • Objectives 08H30-10H30 Training introduction What is stigma, causes and effects	08H00-08H30 Day 1 review (Participant) 08H30-10H30 Caring for PLWHA in the family Affects of HIV on the family Brainstorming : <ul style="list-style-type: none"> • Immediate effects • Longer term effects • Effects on PLWHA 	08H00-08H30 Day 2 review (Participant) 08H30-10H30 PLWHA have rights too! Discussion : <ul style="list-style-type: none"> • Rights • Responsibilities
Break	Tea	Break
11H00-13H00 Our own experiences as stigmatizing others. (sharing in pairs) Report back (participants) Stigma in different contexts Group work <ul style="list-style-type: none"> • Stigma in family • Neighbors stigmatizing neighbors • Stigma in the community 	11H00-13H00 Group work : What practical things can we do to support PLWHA family members? Report back: Participants Feedback : facilitator	11H00-13H00 Brainstorming: Moving to action Workshop evaluation Closing remarks
Lunch	Lunch	Lunch
14H00-15H00 Report back (participants) More understanding less fear Knowledge assessment Feed back (facilitator)	14H00-15H00 Community support for PLWHA Discussion Mobilizing community support Group work	14H00 Departure
Break	Break	
15H30-16H30 Assessing fears about HIV/AIDS (Sharing in pairs) Feed back (facilitator)	15H30-16H30 Report back : participants	

APPENDIX 9: NAMIBIAN MAP INDICATES 13 REGIONS OF THE COUNTRY

Namibia
Administrative Regions 2003

