Table of contents **Page**

LIST OF TABLES Page

LIST OF FIGURES Page

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANOVA	Analysis of variance
ART	Anti-retroviral Therapy
CBO	Community based organisation
CDC	Centres for Disease Control and Prevention
CI	Confidence Interval
CMD	Chief Medical Director
DHIS	District Health Information System
FHI 360	Family Health International
FSSQ	Functional Social Support Questionnaire
GEE	Generalised Estimating Equations
GF	Global Fund for AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
HRH	Human resources for health
ID	Identification
IQR	Interquartile range
IRB	Institutional Review Board
NARHS	National AIDS and Reproductive Health Survey
NBS	Nigeria Bureau of Statistics
NHREC	Nigeria Health Research Ethics Committee
NIH	United States National Institutes of Health
OR	Odds ratio
PEPFAR	President's Emergency Plan for AIDS Relief
PHSC	Protection of Human Subjects Committee
PLHIV	Persons Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
SIDHAS	Strengthening Integrated Delivery of HIV/AIDS Services
SIV	Simian immunodeficiency virus
SNSSM	Social Networks and Social Support Model
TasP	Treatment as Prevention
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
UNC	University of North Carolina
UNICEF	United Nations Children Education Fund
UNISA	University of South Africa
USA	United States of America
USC	University of California
WHO	World Health Organization

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

The overarching aim of the study was to develop an evidence-based model for revitalising people living with HIV (PLHIV) caregiver social support competencies. The model is necessary to provide a framework for enhancing positive behavioural outcomes of PLHIV. These behavioural outcomes include reduced HIV-related stigma; positive HIV-status disclosure; reduced sexual risk behaviours; and improved adherence to anti-retroviral therapy (ART). The study examined differences between PLHIV who participate in support group activities and those who do not, in terms of the above behavioural outcomes. The researcher also explored reasons for participation and non-participation in support group activities by PLHIV. Using the study findings, the researcher developed a model for revitalising social support competencies of PLHIV caregivers in a bid to enhance positive behavioural outcomes of PLHIV.

This chapter provides a background to the research topic, states the research problem, and explains the purpose and objectives of the study. The chapter also states the significance of the study and defines the key variables in the study. The later sections state the theoretical foundation of the study, describe the research design and methodology, as well as the scope of the study. The final section gives an outline of the structure of the thesis and ends with a conclusion.

1.2 BACKGROUND TO THE RESEARCH PROBLEM

1.2.1 The despair and hope in the fight against HIV/AIDS

1.2.1.1 New infections outstrip treatment scale up

Although there is reason for optimism in the fight against HIV/AIDS, the current gains in prevention and treatment are insufficient to reach the global goal of halving sexual transmission of HIV by end of 2015 (UNAIDS 2012:16). The success in scaling up

ART in resource-limited settings is tempered by continuing high HIV incidence rates, especially in Sub-Saharan Africa. People infected with HIV annually still significantly outnumber annual enrolments on ART (Gupta, Wainberg, Brun-Vezine, Gatell, Albert, Sönnerborg & Nachega 2013:1). In 2012 alone, 2.3 million new HIV infections were recorded while only 1.6 million people were initiated on ART (UNAIDS 2013:8, 50).

1.2.1.2 Treatment for prevention, the ray of hope

Although there is not yet a vaccine for HIV and a cure for AIDS, there is a growing promise of ART in preventing HIV and tuberculosis (TB) transmission. In 2011, researchers reported that in addition to individual health benefits for the treated patient, successful ART decreases the risk of transmitting HIV and TB to others, including reducing the odds of sexual transmission within serodiscordant heterosexual partners (Cohen, Chen, McCauley, Gamble, Hosseinipour, Kumarasamy, Hakim, Kumwenda, Grinsztejn, Pilotto, Godbole, Mehendale, Chariyalertsak, Santos, Mayer, Hoffman, Eshleman, Piwowar-Manning, Wang, Makhema, Mills, deBruyn, Sanne, Eron, Gallant, Havlir, Swindells, Ribaudo, Elharrar, Burns, TTaha, Nielsen-Saines, Celentano, Essex & Fleming 2011:1). This new knowledge represents the biggest breakthrough and optimism so far in the fight against HIV/AIDS. As a result of this scientific milestone, ART has now been adopted as part of HIV prevention, hence the reference to “Treatment for/as Prevention (TasP)” (Nicolas, Sigaloff, Kityo, Mandaliya, Hamers, Bertagnolio, Jordan, Boucher, Rinke & Van de Vijver 2013:1; WHO 2013:1).

1.2.1.3 The value and challenges of adherence to anti-retroviral treatment

While ART for HIV treatment and prevention offers a ray of hope, the potential medical and public health impact of ART greatly depends on the extent to which PLHIV adhere to the prescribed daily dosing regimens of anti-retroviral medicines. ART adherence is needed for suppression of the virus (UNAIDS 2012:32). However, a number of PLHIV enrolled in ART programmes do not adhere to their treatment prescriptions or interrupt their treatment along the way. There is evidence that nearly half of all people who were initiated on ART in 2007 at the same treatment centre in

Malawi were no longer in care five years later (Massaquoi, Zachariah, Manzi, Pasulani, Misindi, Mwagomba, Bauernfeind & Harriese 2009:1). Also, a recent study in Uganda shows that 11% of the PLHIV who enrolled for ART between 2004 and 2012 at a centre that provides free services temporarily discontinued and then resumed ART after at least one year of interruption (Mills, Funk, Kanters, Kawuma, Cooper, Mukasa, Odit, Karamagi, Mweheire, Nachenga, Yaya, Featherstone & Ford 2013:1).

Non-adherence to ART is of great concern because it causes drug resistance, treatment failure and death. In terms of HIV prevention, non-adherence to ART increases the viral load and the risk of person-to-person HIV transmission (Al-Dakkak, Patel, McCann, Gadkari, Prajapati & Maiese 2013:1). Additionally, non-adherence to ART has been associated with risky sexual behaviours. In a study in Atlanta, USA, by Kalichman, Ntseane, Nthomang, Segwabe, Phorano and Simbayi (2010:1), results show that non-adherent men who have sex with men (MSM) are more likely to have more sexual partners and engage in unprotected sex than those who are adherent. Also, there is evidence that ART reinvigorates sexual desires and sexual activity of PLHIV; and that few PLHIV practice safe sex (Dessie & Deresa 2012:1; Kidder, Bachanas, Medley, Pals & Nuwagaba-Biribonwoha 2013:1; Ndziessi, Cohen, Kouanfack, Boyer, Moatti, Marcellin, Laurent, Spire, Delaporte & Carrieri 2013:1). These findings highlight the significance of ART adherence support and sexual behavioural change among PLHIV.

1.2.1.4 The challenges of stigma and non-disclosure

While HIV/AIDS control programmes have implemented a number of innovations to reduce HIV transmission and enhance treatment outcomes, stigma and non-disclosure of positive HIV status remain daunting challenges. Stigma, normally manifested in negative attitudes and beliefs, guilt, shame, fear, silence, and alienation is still high among PLHIV and in communities where they live (Ugarte, Horgberg, Elitte & Essen 2013:2; UNAIDS 2012:78).

1.2.2 The value of social support

1.2.2.1 Social support, stigma reduction and positive HIV status disclosure

Some studies have found that social support helps PLHIV to overcome stigma and disclose their positive HIV serostaus. Researchers in Rwanda (Walstrom, Operario, Zlotnick, Mutimura, Benekigeri & Cohen 2013:7); in Kenya (Sarna, Luchters, Musenge, Okal, Chersich, Tun, Mall, Kingola & Kalibala 2013:11); in South Africa (Madiba & Canti-Sigaqa 2012:5); and in Mozambique (Decroo, Damme, Kegels, Remartinez & Rasschaert 2012:1) report that social support by peers, community health workers, family members and counsellors generally reduces stigma and increases PLHIV's self-efficacy to disclose their positive serostatus. However, in all these studies, the value of social support provided by PLHIV in support groups was not determined.

1.2.3 PLHIV support groups

According to Fanelli and Moyo (2008:2), a PLHIV support group is an association of PLHIV who come together to share and address their common challenges and experiences. While some PLHIV support groups form spontaneously, HIV/AIDS control programmes are increasingly facilitating formation of support groups as a strategy for increasing PLHIV involvement in dispensing HIV/AIDS services. This is premised on beliefs that PLHIV involvement in care and support improves the relevance, acceptability and effectiveness of HIV/AIDS programmes; that PLHIV's actions, messages and reach out to others in their communities can help to create a revolution in people's attitudes and behaviours towards HIV (UNAIDS 2007:1). For example, in an HIV/AIDS project being implemented by Family Health International (FHI 360) in Nigeria, PLHIV are encouraged to form support groups as a mechanism for enhancing social support, addressing stigma and discrimination, and improving ART adherence.

1.2.3.1 Objectives and benefits of support groups

Most HIV/AIDS control programmes encourage and support formation of PLHIV support groups with the objectives to: provide on-going psycho-social support to members; increase public awareness of HIV/AIDS; demonstrate by example that PLHIV can lead healthy and productive lives; and to help in reducing stigma and discrimination associated with HIV (Fanelli & Moyo 2008:3).

Also, HIV/AIDS control programmes facilitate support group activities as a strategy to assure meaningful involvement of PLHIV in providing care and support to peer PLHIV through HIV/AIDS education by “expert patients”, treatment defaulters tracking; ART adherence counselling; and ART adherence monitoring and support. It is generally believed that members of support groups accrue individual, group and community benefits. Individual benefits include on-going supportive and preventive counselling; ART adherence counselling and monitoring; and peer support. Group benefits include psychosocial therapy and experience sharing; while community benefits include community education and sensitisation through music, dance, drama, poetry; and sharing life testimonies (AIDS Information Centre (AIC) 2012:2).

According to Fanelli and Moyo (2008:2), by joining support groups, PLHIV realise that they are not alone in their situations because support groups provide forums in which members share concerns, brainstorm solutions, and share advice. In support groups, PLHIV give and receive emotional, social and spiritual support. Through support groups, PLHIV also develop and sustain positive strategies for living with HIV. Fanelli and Moyo (2008:2) add that support groups are considered effective because members receive first-hand advice, and the lessons and skills that members learn come from peers who are coping with similar circumstances are perceived practical, personal and relevant.

Furthermore, HIV/AIDS control programmes promote participation in support group activities to enhance positive HIV status disclosure. Support group members help each other to think through how to disclose their HIV-positive status to their sexual partners, friends, family members or co-workers by sharing ideas such as what to say, when to disclose and who to disclose to.

Also, support groups are used to enhance a “buddy” system – a method of providing one-on-one support over a long-term period of time. The buddy system is especially effective for people who have recently learnt their HIV-positive status or have commenced ART. PLHIV support groups are often a hub for “buddies”; members serve as buddies and identify buddies who can support them. A buddy’s key role is to offer personal and frequent support to a peer PLHIV by, for example, reminding him or her to take ARV drugs on time or accompanying the peer to the clinic for check-ups.

1.2.3.2 Challenges faced by PLHIV support groups

Despite their perceived benefits, support group activities are not embraced and patronised by all PLHIV. For example, while each ART site supported by the FHI 360 project in Nigeria has a support group affiliated with it, not every enrolled ART client belongs to a support group. From the few studies that have been documented, the major reason why some PLHIV shun support group activities is stigma – fear of being recognised as HIV infected persons. In a qualitative study in South Africa, male PLHIV perceived attending support groups as tantamount to disclosing their positive HIV status to other people (Madiba & Canti-Sigaqa 2012:5). Other reasons include lack of knowledge of associated benefits and a perception that support groups lack skills and resources to provide effective psychosocial or other support needed by PLHIV. This may explain why some studies have found that only about 30% of PLHIV belong to support groups (Walakira, Kaawa-Mafigiri, Byamugisha & Rogers 2012:38).

1.3 STATEMENT OF THE RESEARCH PROBLEM

While various HIV/AIDS programmes have implemented innovative strategies for optimising behavioural outcomes of PLHIV, the value of social support provided by PLHIV to PLHIV is not yet fully understood and optimised. There is no information in the literature on whether participation in support group activities positively influences behavioural outcomes of PLHIV. Although some studies have reported possible health and psychosocial benefits of social support on PLHIV (Kamau, Olsen, Zipp & Clark 2012:7; Sarna et al 2013:11; Walstrom et al 2013:7), these studies did not differentiate social support provided by PLHIV support group members, the “expert patients”, from that provided by other care providers. Consequently, HIV/AIDS control programmes continue facilitating PLHIV support groups without evidence that there is any value in support group participation in terms of enhancing behavioural outcomes of PLHIV and contributing to reducing transmission of HIV. To fill the knowledge gaps, there is need to compare PLHIV who participate in support group activities and those who do not in terms of their behavioural outcomes.

1.4 AIM OF THE STUDY

This study aimed to develop an evidence-based model for revitalising PLHIV caregiver social support competencies.

1.4.1 Objectives of the study

The objectives of the study were to

(i) determine reasons for participation or non-participation in PLHIV support group activities among PLHIV
(ii) determine differences between PLHIV who participate in support group activities and those who do not, in terms of perceived social support, HIV-related stigma, HIV positive status disclosure, sexual risk behaviours and adherence to ART
(iii) use the findings gleaned from the cross-sectional study to develop a model for revitalising PLHIV caregiver social support competencies so as to enhance positive behavioural outcomes of PLHIV

The research questions in this study were:

1. What are the reasons for PLHIV’s participation and non-participation in support groups?
2. Do PLHIV who participate in support group activities differ from those who do not, in terms of socio-demographics, perceived social support, HIV-related

stigma, positive HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment?

3. How can positive behavioural outcomes of PLHIV be enhanced?

1.5 SIGNIFICANCE OF THE STUDY

Given the limited information on whether participating in support group activities enhances the behavioural outcomes of PLHIV, the findings from this study would generate additional knowledge that could be used to fill this gap in literature. If a strong association was found between participation in support group activities and the behavioural outcomes of PLHIV, the findings would be handy in developing a model to enhance positive behavioural outcomes of PLHIV.

The timing of the study was particularly significant, given the ongoing debate about approaches to HIV/AIDS response beyond 2015 – the year the world is expected to have halted and reversed the spread of HIV, and made anti-retroviral treatment accessible to all those who need it. It is unlikely that these goals will be met – hence the need for more evidence to inform strategies in the post 2015 Global Human Development Agenda and the fight against HIV/AIDS in particular.

1.6 DEFINITIONS OF TERMS

1.6.1 PLHIV support group

According to Fanelli and Moyo (2008:2), a PLHIV support group is an association of PLHIV who come together to share and address their common challenges and experiences. For purposes of this study, a PLHIV support group was defined as a formal association of adult PLHIV who met monthly either at a health facility or designated place in their community to discuss issues and carryout activities related to individual, group and community management of HIV/AIDS. A PLHIV support group could be based at a health facility or in the community.

1.6.2 Behavioural outcomes

The American Heritage Dictionary (2014:1) defines behaviour as the actions or reactions of a person or animal in response to external or internal stimuli. *The Gale Genetics Encyclopaedia* (2014:1) defines behaviour as activities and actions towards one another; and an outcome as a change in a target audience's skills, attitudes, knowledge, behaviours, status or condition of life. In the context of this study, the researcher restricted the definition of behavioural outcomes to four changes expected from PLHIV participation in PLHIV support group activities: reduced HIV-related stigma, positive HIV status disclosure, reduced sexual risk behaviour and improved adherence to anti-retroviral treatment.

1.6.3 Social support

Heaney and Isreal, in Glanz, Rimer and Lewis (2002:186) define social support as the aid and assistance exchanged through social relationships and interpersonal transitions. The authors add that social support is the functional content of relationships that can be categorised into four types of supportive behaviour or acts: emotional support, instrumental support, informational support and appraisal support. In this study, the operational definition of social support was the perception of availability of social support by a PLHIV. Respondents were asked questions using the Duke-University of North Carolina Functional Social Support Questionnaire (Broadhead, Gehlbach, deGruy, & Kaplan (1988:1). The Duke-UNC Functional Social Support Questionnaire (FSSQ) is an eight-item instrument to measure the strength of the person's social support.

1.6.4 Stigma

The Centers for Disease Control and Prevention (CDC 2012:1) defines stigma as an attribute that is deeply discrediting and sets the bearer apart from the rest of society, bringing with it feelings of shame and isolation. In this study, two operational definitions of HIV-related stigma were used: i) Internal stigma was defined as negative feelings towards oneself because of their HIV positive status; ii) External stigma was defined as perceptions of being negatively viewed by others because of the person's HIV positive status. HIV-related stigma was measured using a stigma measurement tool that was developed by Berger, Ferrans and Lashle (2001:1). Although the tool had been tested and found reliable and valid, the researcher re-validated it during questionnaire pre-testing and found it satisfactory.

1.6.5 Positive HIV status disclosure

Positive HIV status disclosure was defined as openly acknowledging one's HIV-positive status (UNAIDS 2007:2). For purposes of this study, disclosure meant having revealed one's HIV positive status to a sexual partner/spouse, co-worker, friends or healthcare provider. Positive HIV status disclosure was measured by asking questions about whether PLHIV have disclosed their positive HIV status to the above categories of relations and confidants.

1.6.6 Adherence to anti-retroviral therapy

According to WHO (2013:1), adherence to treatment is the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed treatment. In this study, ART adherence was operationally defined as the extent to which patients acted in accordance with the prescribed interval and dose of their ART regimen.

1.6.7 Sexual risk behaviour

The Unites States National Institutes of Health (NIH 2013:1) defines safe sex as taking steps before and during sex that can prevent one from getting an infection or from infecting one's partner. In the context of this study, sexual risk behaviour was defined as practicing sex that puts the sexual partner at risk of getting infected with HIV. Even though all respondents were HIV positive, risky sexual behaviours expose them to other sexually transmitted infections and to pregnancy, and can aggravate their conditions and treatment options. It also exposes their sexual partners to HIV infection, hence the interest in knowing whether and with whom PLHIV practice unsafe sex.

1.6.8 Social support competencies

To define the concept of social support competencies, we define social skills and social competencies. In his works *Social Skills and Health*, Argyle (2013:48) defines social skills as styles of social behaviour used by interviewers, nurses and others in dealing with the clients. Argyle argues that as with motor skills, some people have more social skills than others and thus are more effective in attaining the desired goals. He adds that when social skills required for performance have been identified, they can be taught through training courses. Argyle contends that in the healthcare professions, technical or medical skills are as important as social skills and urges institutions training healthcare workers to lay more emphasis on imparting social skills on their trainees.

According to Mallinckrodt and Wei (2005:3), ***social competencies*** are skills needed to recruit and maintain satisfying and supportive relationships together with trait-like dispositions that govern use of these skills. Social competencies include social self-efficacy and emotional awareness. Social self-efficacy involves the belief that one can initiate social contact and develop new friendships from initial acquaintances. Persons who lack social self-efficacy believe that close personal relationships are a matter of luck or other factors outside their personal control. Emotional awareness refers to perceptions of attachment to others. It is the ability to communicate one’s feelings and experiences to others. The authors argue that adults with high levels of social self-efficacy and emotional awareness are more likely to solicit social support for themselves or provide it to others. According to Boyatzis (2008:11), a series of longitudinal studies have shown that people’s emotional and social-self efficacy competencies can change through training and education programmes.

From the above two definitions (social skills and social competencies) we can deduce that **social support competence** is the ability to perceive and provide help. This help may be in the form of informational, emotional, appraisal or material support. Both Argyle (2013) and Boyatzis (2008) acknowledge that social support competencies can be acquired.

1.7 THEORETICAL FOUNDATIONS OF THE STUDY

1.7.1 Research paradigm

The researcher used quantitative study methods because the study involved comparing relationships among study variables to answer the question whether PLHIV who participate in support group activities differ from those who do not in terms their socio-demographics, perceived social support, and behavioural outcomes. However, one of the research questions sought to understand reasons for PLHIV participation and non-participation in support group activities. Although questions in this section were structured, there was room for respondents to provide more answers thus allowing triangulation of the responses.

Quantitative study designs are designs that identify variables which can be observed and measured in a predetermined and specific way. The variables are recorded as numbers and statistical methods are used to measure relationships between and among them. Data in quantitative studies are collected using structured questionnaires, are numeric and can be summarised numerically. As the aim in quantitative studies is to compare attributes of different variables, factors unique to individual cases and information about contexts are ignored (Cottrell & McKenzie 2010:4; O'Sullivan, Rassel & Berner 2003:38; University of South California (USC) 2013:1).

1.7.2 Theoretical framework

The researcher based this study on the Social Networks and Support Model. The concept of social support and its benefits to health is articulated by Heaney and Israel, in Glanz, Rimer and Lewis (2002:185-205). According to the authors, there is a link between social support and mental, physical and social health. They argue that social support and social networks are beginning points or initiators of a casual flow towards health. The proponents of the model contend that social support and social networks: (i) enable individuals to cope with stress through increased individual and community resources, and that new contacts and information reduce uncertainty and unpredictability thereby enhancing individuals' problem solving abilities and perceived control; (ii) increase community's ability to garner resources and solve problems. The increase in individual and community resources may have health enhancing effects or diminish negative effects on health due to exposure to stressors; (iii) influence individual behaviour change such as adherence to medical regimens, increase health seeking behaviours, and adoption of preventive health behaviour. These changes result from interpersonal exchanges within social networks.

The researcher used the Social Networks and Social Support theoretical model to presume that by participating in PLHIV support group activities, PLHIV perceive more social support, are enabled to cope with and solve their common problems such as stigma and HIV status disclosure, adopt safer sexual behaviours, and adhere to their anti-retroviral treatment regimens.

1.8 RESEARCH DESIGN

To achieve the research objectives, the researcher conducted the study in two phases using a mix of theory-generation and descriptive designs.

Theory generating: According to Chinn and Kramer (1995:21), a theory is a systematic abstraction of reality that serves some purpose. Researchers contribute to theory development either through generating or testing a theory. Theory-generating-research is designed to discover and describe relationships without imposing preconceived notions of what these phenomena mean. This is usually done through inductive or deductive approaches depending on whether the research is using qualitative or quantitative methods. This study focused on generating theory or a model for revitalising social support competencies among PLHIV caregivers and confidants. This process involved using quantitative methods to determine whether PLHIV who participate in support group activities differ from those who do not in terms of social support, HIV-related stigma, sexual risk behaviour and adherence to ART. The researcher was interested in determining the value of support group participation on PLHIV behavioural outcomes. Findings would then be used to generate a model for enhancing positive behavioural outcomes of PLHIV.

Descriptive study: Descriptive studies are designs which use numbers, percentages and averages, and characteristics of a group of people or some other phenomena. Descriptive studies are undertaken when there is not much information about a phenomenon (Cottrell & McKenzie 2010:8). In this study, the researcher was interested in understanding whether PLHIV who participate in support group activities were different from those who do not in terms of their socio-demographics, perceived social support and behavioural outcomes. The descriptive statistics generated aided in describing similarities and differences between PLHIV who participate in support groups and those who do not in terms of the study variables. A descriptive design also aided respondents in articulating reasons for participation and non-participation in support group activities.

1.8.1 Phase 1 (empirical phase)

To answer the first two research questions in section 1.4.1 above, the researcher used a quantitative methods and a cross-sectional design. Quantitative research is a means for testing objective theories by examining the relationship among variables. Information collected in the course of the study is in a quantified or numeric form. A cross sectional study design is one where data are collected at one specific point in time (Cottrell & McKenzie 2010:9, 192). The researcher preferred a cross-sectional design because time and resources precluded use of other feasible designs. Nevertheless, cross sectional designs also enable determination of current characteristics, attitudes, beliefs and behaviours of the study population (PLHIV), thus the design was appropriate for the objectives of the study.

The study was designed in such a way that adult PLHIV who were initiated on ART between January 1, 2010 and December 31, 2012 and had ever participated in a PLHIV support group meeting were comparable with those who were initiated on ART during the same period but had never attended a support group meeting. The two groups were compared in terms of socio-demographics, perceived social support, HIV-related stigma, positive HIV status disclosure, anti-retroviral treatment adherence and sexual risk behaviours. Furthermore, the researcher explored reasons for PLHIV participation and non-participation in support group activities.

From the study findings, the researcher deduced conclusions on the value of PLHIV participation in support group activities.

1.8.2 Phase 2: Model development

The second phase of the study involved developing an evidence-based model for revitalizing PLHIV caregiver social support competencies. This phase builds on the findings of the first phase, that is, the cross-sectional study. Following guidance from Chin and Kramer (1995:27), a five-step process was used to develop the model. These are:

- Step 1: Concept identification. This was achieved using findings from the cross-sectional study through deductive reasoning.
- Step 2: Concept definition and classification to create conceptual meaning.
- Step 3: Construction of relationship statements.
- Step 4: Description and evaluation of the model.
- Step 5: Operationalising the model.

Details of the above processes are provided in chapters 3, 6 and 7.

1.9 SCOPE OF THE STUDY

This study was confined to analysing associations between participation in PLHIV support group activities and specific behavioural outcomes-HIV-related stigma, HIV status disclosure, sexual risk behaviours and adherence to ART. The study did not attempt to establish whether there are cause-and-effect relationships between and among dependent and independent variables. Findings from the cross-sectional design of the study were used to develop a model for revitalising PLHIV caregiver social support competencies in order to enhance behavioural outcomes of PLHIV.

1.10 STRUCTURE OF THE THESIS

This thesis is presented in eight chapters outlined as follows:

Chapter 1: Orientation to the study

This chapter provides an introduction and background information about the research problem, the aim of the study, the research question and the research objectives. The chapter also defines the key study variables, and highlights the research design and scope.

Chapter 2: Literature review

This chapter includes a review of the literature on epidemiology of HIV/AIDS, the theoretical foundation of the study and provides conceptual as well as operational definitions of the key study concepts. Also in this chapter, the researcher analyses, compares, and synthesises prior research related to the research topic, theory base, and the study variables. This analysis brings out gaps in the existing literature thereby establishing the foundation for the study.

Chapter 3: Methodology

This chapter presents the methodology used in the study including the study design, the study population, respondents sampling, sample size, the data collection instrument, data collection procedure and data analysis. It outlines the process taken in using findings from data analysis to develop a model for revitalising PLHIV caregiver social support competencies so as to enhance behavioural outcomes of PLHIV. The chapter also describes steps taken to ensure internal and external validity of the data collected, reliability of the measures, and how the researcher adhered to the ethical principles concerning studies involving human subjects (Coughlin, Soskolne & Goodman 2009:3).

Chapter 4: Presentation of the research findings

In this chapter, findings from the first phase of the study, the cross-sectional design, are presented and described. The presentation includes both descriptive and inferential statistics. The results are grouped by descriptive characteristics of the sample population, study objectives and research questions.

Chapter 5: Discussion and interpretation of research findings

In chapter 5, the researcher discusses and interprets the findings from the first phase of the study and compares them with findings from related studies cited in the literature reviewed. The interpretation builds a foundation for generating a model for revitalising PLHIV social support competencies so as to enhance positive behavioural outcomes of PLHIV.

Chapter 6: Development of a tentative model

In this chapter, the researcher uses the cross-sectional study findings presented in chapter 4 to develop a tentative model for equipping PLHIV caregivers and confidants, identified by PLHIV as their sources of social support, with social support competencies so as to enhance PLHIV behavioural outcomes.

Chapter 7: Description of the model

Chapter 7 provides a detailed description of the final model for revitalising social support competencies of PLHIV caregivers and confidants so as to enhance positive behavioural outcomes among people living with HIV. The chapter also provides guidelines for operationalising the model in the context of HIV/AIDS care and support.

Chapter 8: Conclusions, limitations and recommendations

In this final chapter, the researcher deduces conclusions of the research in relation to the research question and objectives. The chapter also highlights limitations of the study. The last sections of this chapter present contributions of the study to both the academic world and HIV/AIDS programming.

1.11 CONCLUDING REMARKS

Although scientists have discovered that early initiation of ART decreases the risk of HIV and TB transmission, the medical and public health benefits of ART can only be realised through long-term and continuous adherence. This has not been possible in many countries due to stigma and non-disclosure of positive HIV status. Researchers and public health practitioners continue to explore different interventions to enhance both stigma reduction and positive behavioural outcomes of PLHIV. While some studies have established that there may be protective benefits of social support in reducing stigma and enhancing ART adherence, the effectiveness of social support provided by PLHIV support group members, “the expert patients”, has not been fully studied. This study sought to determine whether PLHIV who participate in support group activities are different from those who do not, in terms of selected behavioural outcomes. The aim of the study was to develop a model for revitalising PLHIV caregiver social support competencies, so as to enhance positive behavioural outcomes of PLHIV.

In this chapter, the researcher provided an orientation to the study, including background to the research topic, the research problem, the purpose and objectives of the study. The chapter also stated the significance of the study and defined the key variables in the study. The next chapter presents a review of the literature.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter, the researcher provided an orientation to the study, including background to the research topic, the research problem, the purpose and objectives of the study. The chapter also stated the significance of the study and defined the key variables in the study. This chapter contains the literature review. According to Cottrell and McKenzie (2010:42), literature review is a written summary of articles, books and other documents, which especially in quantitative research, is used to justify the importance of a study, place the study in historical perspective, refine the research questions, and identify appropriate methodology and instrumentation. A literature review puts one's research into context by showing how it fits in a particular field. It also provides a framework for relating new findings to previous findings in the discussion section of a thesis. Without establishing the state of the previous research, it is impossible to establish how the new research advances the previous research (Blanche, Durrheim & Paiter 2006:40; Randolph 2009:2).

In this chapter, the researcher analyses, compares, and synthesises prior research related to the research topic, question, theory-base and key study variables. This analysis brings out gaps in the existing literature thereby establishing the foundation for the study. The information is organised along the main concepts in the study: social support; PLHIV support groups; HIV-related stigma; HIV status disclosure; adherence to anti-retroviral treatment; sexual risk behaviour and social support competencies.

To obtain the relevant literature, the researcher subscribed to FHI 360's library services email listserv for two monthly updates called "HIV Awareness" and "Global HIV Updates". FHI 360 subscribes to and obtains periodic articles from major HIV/AIDS and public health related journals, including The Journal of International AIDS Society, The American Journal of Public Health, The Lancet, and The New

England Journal of Medicine. The two updates provide monthly compilations of citations and abstracts of articles related to HIV/AIDS prevention, care and treatment from a broad range of publications with a focus on the contexts of developing countries. The researcher selected the articles of interest using key concepts in the study as search words – social support, HIV status disclosure, ART adherence, HIV stigma and sexual risk behaviour. The researcher then requested for full texts of the selected articles from the FHI 360 library every month, and used these to complete the literature review.

2.2 EPIDEMIOLOGY OF HIV/AIDS

2.2.1 Global perspective

For over three decades, the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) commonly referred to as the HIV/AIDS epidemic have been among the defining issues facing scientists, health workers and governments, globally. The Joint United Nations Programme on HIV/AIDS (UNAIDS 2013:8-12, 42) estimates that since the beginning of the epidemic, almost 75 million people have been infected with HIV, about 36 million have died and 35.3 million people were living with HIV at the end of 2012. About 1.6 million people died of AIDS-related illnesses worldwide in 2012 alone.

2.2.2 HIV/AIDS in Africa and Sub-Saharan Africa

Although HIV/AIDS affects all continents, Sub-Saharan Africa remains the most severely affected region accounting for 71% of the PLHIV worldwide. Out of the 35.3 million PLHIV in 2012, about 25 million lived in sub-Saharan Africa. Given that this region accounts for only 10% of the world’s population, this disproportion of the HIV burden is of great concern. In 2012, nine countries in southern Africa accounted for less than 2% of the world’s population but represented 33% of the global HIV infections (DeCock, Jaffe & Curron 2012:1). Sub-Saharan Africa also accounted for 71% of all new infections and more than 90% of the children who acquired HIV infection in 2012 (UNAIDS 2013:4).

2.2.3 HIV/AIDS in Nigeria

According to the 2013 UNAIDS report on the global AIDS epidemic, HIV prevalence in Nigeria is estimated at 3.1% and in 2012, there were 3.4 million PLHIV, of which, 430,000 were children below five years. About 240,000 Nigerians died of AIDS-related illnesses in 2012. Nigeria alone accounts for 30% of the global mother-to-child transmission of HIV (PMTCT) burden (UNAIDS 2012:42). Also, of the estimated 15 million AIDS-caused orphans who live in Sub-Saharan Africa, Nigeria accounts for 2.2 million of them (17%) (UNICEF 2012:4).

2.3 CLINICAL PICTURE/ASPECTS OF HIV/AIDS

2.3.1 Origin and pathogenesis of HIV

Available literature shows that acquired immunodeficiency syndrome of humans is caused by two human immunodeficiency viruses types 1 and 2 (HIV-1 and HIV-2). Both types result from multiple cross-species transmissions of simian immunodeficiency viruses (SIVs) naturally infecting African primates. Scientists have traced the origins of HIV to chimpanzees in Cameroon (CDC 2014: 1; Sharp, Beatrice & Hahn 2011:1). It is believed that genetic changes occurred as the SIV crossed from monkeys to apes and from apes to humans (HIV). How humans acquired the ape precursors of HIV is not known. However, based on the biology of these viruses, transmission is thought to have occurred through cutaneous or mucous membrane exposure to infected ape body fluids. Such exposures most commonly occur in the context of eating bush meat (Peeters, Courgnaud, Abela, Auzel, Pourrut, Bibollet-Ruche, Loul, Liegeois, Butel & Koulagna 2002:3).

HIV pathogenesis has proven to be quite complex and dynamic with most of the critical events (e.g. transmission and the $CD4^+$ T-cell destruction) occurring in mucosal tissues. Although the resulting disease can progress over years, scientists believe that many critical events happen within the first few weeks of infection when most people are unaware that they are infected. These events occur predominantly in tissues particularly along the gastrointestinal tract, where massive depletion of the

$CD4^+$ T cells occurs long before adverse consequences of HIV infection are otherwise apparent (Sharp et al 2011:2-4).

AIDS was first recognised as a new disease in 1981 when increasing numbers of young homosexual men in America succumbed to unusual opportunistic infections and rare malignancies (Greene 2007:2). To date, the disease has become a global pandemic affecting men and women, children and adults, homosexuals and heterosexuals, the rich and the poor.

2.3.2 Modes of transmission

HIV is transmitted from an HIV-infected person to another through body fluids, including blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids and breast milk. These fluids must come in contact with a mucous membrane or damaged tissue or be directly injected into the bloodstream for transmission to possibly occur (CDC 2014:1). HIV spreads by sexual, percutaneous and perinatal routes. However, 80% of adults acquire HIV following exposure during sexual intercourse, thus HIV/AIDS is primarily a sexually transmitted disease (Cohen, Shaw, McMichael & Haynes 2011:2).

2.3.3 Symptomatology

Many people who are infected with HIV do not have any symptoms at all for 10 years or more. Some people who are infected with HIV report having flu-like symptoms two to four weeks after exposure. Other symptoms can include fever, enlarged lymph nodes, sore throat and rash. These symptoms can last from a few days to several weeks. During this time, HIV infection may not show up on an HIV test, but people who have it are highly infectious and can spread the infection to others (CDC 2014:1).

2.3.4 HIV prevention

There are different ways to prevent HIV. As HIV is largely transmitted through sex, limiting the number of sexual partners is one of the most effective tools. Other tools include non-sharing of needles, using condoms correctly and consistently, and using biomedical interventions such as male circumcision, safe injections, safe blood transfusions, and pre-exposure and post-exposure prophylaxis. Recently, anti-retroviral therapy (ART) has been found to be an effective weapon for preventing HIV transmission from an infected to an uninfected sexual partner as well as from an infected mother to a child (Cohen et al 2011:12).

2.3.5 Treatment

Although there is no cure for HIV infection, ART can help PLHIV live long, healthy and productive lives. ART is the combination of several anti-retroviral medicines used to slow the rate at which HIV makes copies of itself in the body. A combination of three or more anti-retroviral medicines is more effective than using just one (monotherapy) to treat HIV/AIDS. The use of three or more anti-retroviral medicines, also commonly referred to as an anti-HIV "cocktail" is currently the standard treatment for HIV infection. So far, this treatment offers the best chance of preventing HIV from multiplying, which allows the body immune system to stay healthy. The goal of ART is to reduce the amount of virus in the body (viral load) to a level that can no longer be detected with current blood tests. Recently, scientists proved that ART is effective in prevention of HIV transmission (Cohen et al 2011:12).

Recent advances in ART for both HIV treatment and prevention have increased interest in psychosocial factors that influence treatment adherence and sexual behaviours of PLHIV. This is because studies have shown that the potential medical and public health impact of ART on reducing HIV incidence greatly depends on the extent to which PLHIV adhere to the prescribed daily dosing regimens of anti-retroviral medicines (UNAIDS 2012:32). The concern is that many patients enrolled for ART programmes in Africa do not adhere to their treatment prescriptions or interrupt their treatment along the way (UNAIDS 2012:56). In terms of HIV prevention, non-adherence to ART leads to a spike in viral load and increases the risk of person-to-person HIV transmission. Additionally, non-adherence to ART has been associated with risky sexual behaviours (Dessie & Deresa 2012; Kidder et al 2013:1; Ndziessi et al 2013:1).

Available literature suggests that HIV-related stigma and non-disclosure of a positive HIV status are the main obstacles to ART adherence and reduction in HIV transmission (UNAIDS 2012: 8-12). Non-disclosure of one's positive HIV status has been associated with internalised stigma. To mitigate these obstacles, researchers and the public health community continue to explore options to optimise treatment adherence and retention in care. Social support interventions are one such strategy.

2.4 SOCIAL SUPPORT NETWORKS

This study was grounded in theory about the relationship between social support and health behavioural outcome as articulated in the Social Networks and Social Support Model (SNSSM) presented by Heaney and Isreal, in Ganz, Rimer and Lewis (2002:185-205). The authors argue that there is a link between social support and mental, physical and social health outcomes. They claim that social support and social networks are a beginning point or an initiator of a casual flow towards better health. The authors postulate that social support and social networks:

i) enable individuals to cope with stress through increased individual and community resources, and that new contacts and information reduce uncertainty and unpredictability thereby enhancing individuals' problem solving abilities and perceived control;

ii) increase communities' abilities to garner resources and solve problems. The increase in individual and community resources may have health enhancing effects or diminish negative effects on health resulting from exposure to stressors;

iii) influence individual behavioural change such as adherence to medical regimens, increased health seeking behaviours, and adoption of preventive health behaviours. These changes come as a result of interpersonal exchanges within social networks.

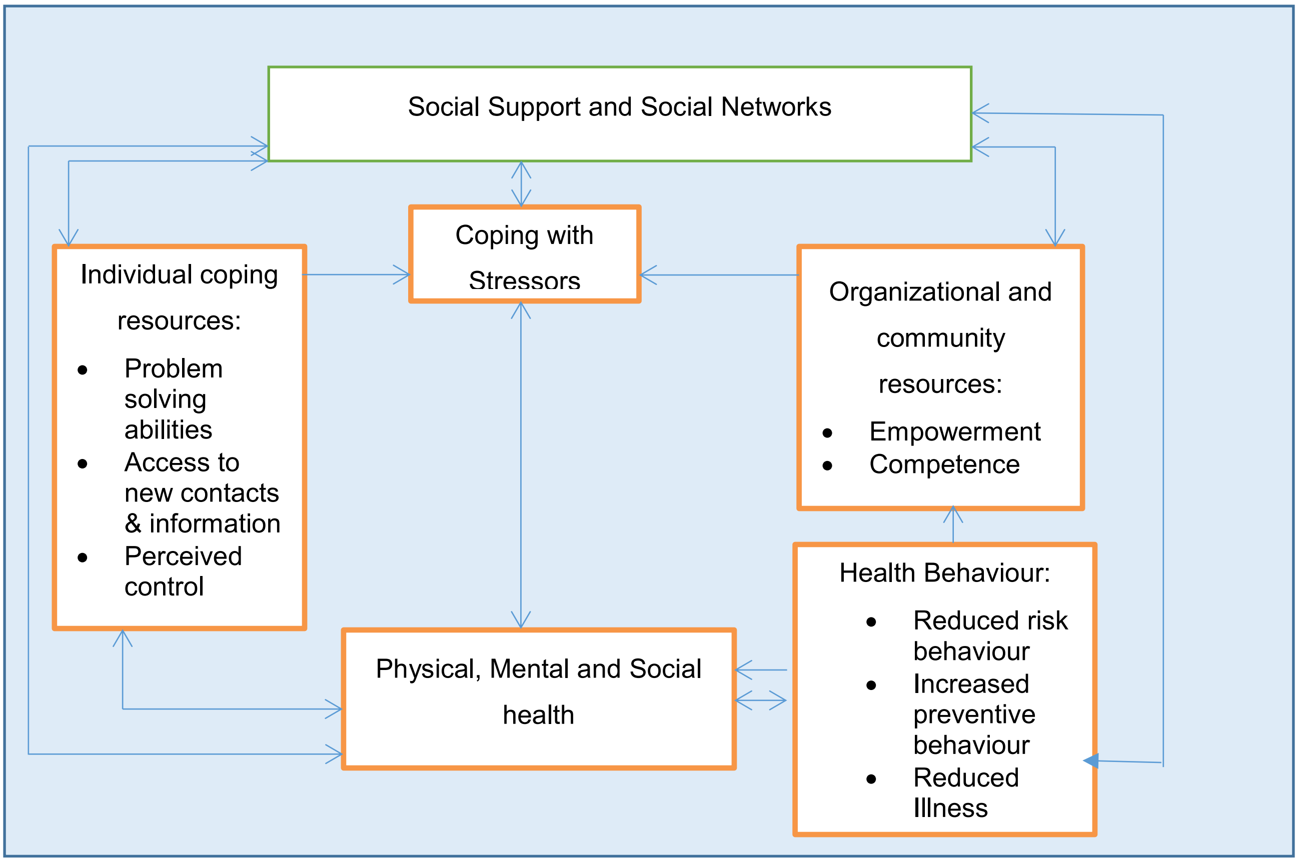


Figure 2.1 The theoretical relationship between social support and health

(Adapted from Heaney and Isreal in Ganz, Rimer and Lewis 2002:190)

The researcher used this theoretical model to presuppose that by participating in support group activities, PLHIV perceive more social support, are enabled to cope with and solve both their individual and common problems such as stigma and HIV status disclosure, adopt safer sexual behaviours, and they adhere to their ART regimens. The cross-sectional study carried out was to determine whether PLHIV who participate in support group activities differ from those who do not in terms of these behavioural outcomes.

2.5 CONCEPTUAL FRAMEWORK OF THE STUDY

Based on the above theoretical framework and the review of the literature, the researcher used the conceptual framework below to highlight the presumed independent and dependent variables in the study. The framework illustrates the assumptions that participating in support group activities yields perceptions of social support, helps PLHIV to overcome HIV-related stigma and disclose their positive HIV status. The researcher further presupposed that participation in support group activities positively impacts on PLHIV's adherence to ART and sexual behaviours. The researcher therefore sought to determine whether PLHIV who participate in support group activities differ from PLHIV who do not participate, in terms of perceived social support, HIV-related stigma, HIV status disclosure, ART adherence, and sexual risk behaviours.

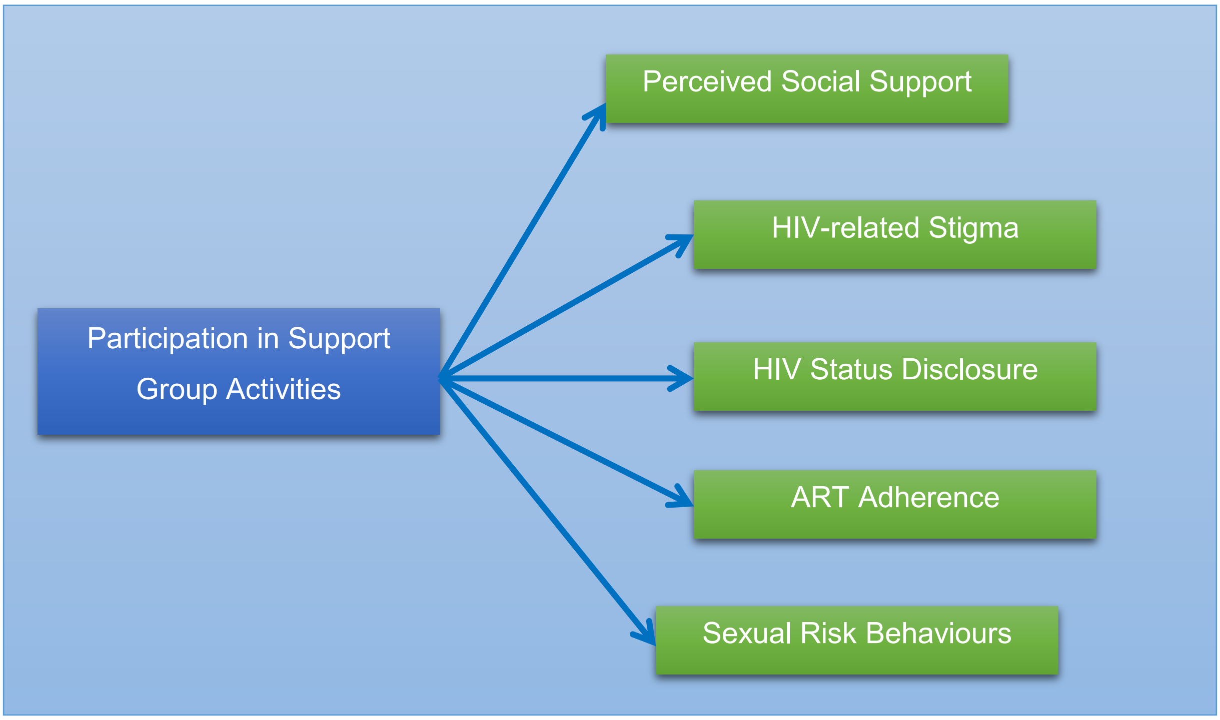


Figure 2.2: Proposed conceptual framework

2.6 SOCIAL SUPPORT

2.6.1 The meaning of social support

The concept of social support is defined differently by different scholars. In their study, Bekele, Rourke, Tucker, Greene, Sobota, Koornstra, Monette, Rueda, Bacon, Watson, Hwang, Dunn and Guenter (2013:6) define social support as supportive functions performed for the individual by significant others, such as family members, friends, and co-workers. Heaney and Isreal, in Ganz, Rimer and Lewis (2002:186) on the hand define social support as the aid and assistance exchanged through social relationships and interpersonal transitions. The duo add that that social support is the functional content of relationships that can be categorised into four supportive acts: emotional support; instrumental support; informational support and appraisal support. Heaney and Isreal argue that social support is different from other functions of social relationships in that social support is always intended to be helpful. This is what distinguishes it from negative interactions. According to Cutrona (1990:4), in order for social support to be beneficial, the social support given by the provider has to match the desires of the recipient. While different authors provide different definitions, the review of the literature highlights one common feature – that social support is assistance received from other people, may be real or perceived by someone in need and is always intended to meet a felt need. Social support comes from many sources: family, friends, organisations and co-workers (Bekele et al 2013:1).

2.6.2 Forms of social support

2.6.2.1 Emotional support

Emotional support is the offering of empathy, concern, affection, love, trust, acceptance, intimacy, encouragement or caring. People who perceive emotional support have beliefs of loving and caring, sympathy, and understanding from their acquaintances. Providing emotional support can let the individuals know that they are valued. Emotional support strengthens the focal individual's feelings of self-worth and belonging, affirming or bolstering their coping efforts (Bekele et al 2013:6; Heaney & Isreal 2002:186; Langford, Bowsher, Maloney & Lillis 2008:31-32; Schaefer, Coyne & Lazarus 1981:1).

In the context of care and support for PLHIV, emotional support is normally provided through sharing experiences, stories and hopes especially by social workers, counsellors or individuals experiencing similar challenges. Sharing experiences is especially helpful for members who have recently learnt of their positive HIV status. According to AIC (2012:1), emotional support promotes positive HIV status disclosure and enhances the psychosocial adjustments (acceptance) of those infected and affected.

2.6.2.2 Instrumental support

According to Heaney and Isreal (2002:186); Langford et al (2008:31) and Schaefer et al (1981:1), instrumental support involves the provision of tangible aid and services that directly assist a person in need. This form of social support encompasses the concrete, direct ways people assist others. Examples of instrumental support include material goods and services. Schaefer and colleagues link emotional support with both informational support and tangible support, particularly when the intent of information or tangible goods is to indicate care and is not done out of a sense of obligation.

In most socially knitted rural communities in Nigeria and Sub-Saharan Africa, customary tangible aid includes contribution of food, money and other material support in times of major life events such as marriage, baptism and death or child birth. With the advent of HIV, this social gesture has been adopted by support groups of PLHIV and includes exchange of nutritious foods and small loans.

2.6.2.3 Informational support

Heaney and Isreal (2002:186) define informational support as the provision of advice, guidance, suggestions and information that a person can use to address problems. Its intent is almost always to give the focal individuals a means to help themselves, for example, when the individual is struggling with a problem or making a decision (Langford et al 2008:31).Like emotional support, informational support comes in the forms of sharing experiences, stories and hopes by people experiencing similar challenges.

In the context of HIV, support groups have become sources of vital information that is beneficial to PLHIV, especially for persons newly diagnosed with the virus. Additionally, a number of HIV/AIDS programmes have empowered PLHIV through training, HIV/AIDS talks, peer education, pre/post-test counselling and testing and adherence support, thereby making them important sources of information support to their fellow PLHIV.

2.6.2.4 Appraisal support

Appraisal support involves the provision of information that is useful for self-evaluation purposes such as constructive feedback, affirmation and social comparison (Heaney and Isreal 2002:186). It is information that is intended to help the focal individuals evaluate their circumstances (Harvey & Alexander 2012:1). Among PLHIV support groups, appraisal support includes assessment of or advice to members concerning their personal lifestyles such as HIV-related internal stigma, positive HIV status disclosure, sexual risk behaviours and adherence to treatment.

2.6.3 Social support and health

Social support has been found to have ties with physical and mental health. People with low social support are at a higher risk of death from a variety of diseases such as cancer and cardiovascular disease (Uchino 2004:16). Also, research has found that people with higher social support have an increased likelihood for survival (Holt-Lunstad, Smith & Layton 2010:1). In a study in rural Uganda by Bolton, Bass, Neugebauer, Verdeli, Loughery, Wickramaratne, Speelman, Ndogoni, and Weissman (2003:1), social support and group therapy significantly reduced HIV and war-induced depression and dysfunction. Social support has also been found to promote psychological adjustment to conditions involving chronic high stress like cancer and coronary artery disease (Turner-Cobb, Gore-Felton, Marouf, Koopman, Israelski & Spiegel 2002:1).

The link between social support and health is explained by the buffering and direct effects hypotheses (Cohen & Wills 1985:1; Harvey & Alexander 2012:4). In the buffering hypothesis, social support protects or buffers people from the bad effects of stressful life events such as death or loss of a job. According to the duo, evidence for stress buffering is found when the correlation between stressful events and poor health is weaker for people with high social support than for people with low social support. Conversely, the weak correlation between stress and health for people with high social support is often interpreted to mean that social support has protected people from stress. According to the authors, in the direct effects hypothesis, people with high social support are in better health than people with low social support, regardless of stress.

Interestingly, providing social support has been associated with health benefits to both the recipient and the provider. In a study by Brown, Nesse, Vinokur and Smith (2003:320), providing instrumental and emotional support to friends, relatives and neighbours was linked to a significant decrease in the risk for morbidity and mortality among those who provide social support. This correlation is particularly important in the context of PLHIV support groups where members are both providers and recipients of social support. However, there is still need to adduce evidence that participating in PLHIV support group activities enhances adoption of positive behaviours among PLHIV.

2.7 SUPPORT GROUPS

2.7.1 Types and functions of support groups

Support groups are forums where people experiencing similar problems or life transitions come together regularly to offer each other support and encouragement. Although social support can often be got from family members and friends, it is recognised that sometimes family members and friends can’t quite understand what it’s like to be in one’s situation, hence the need for persons in similar situations to form support groups (Scholten 2013:1).

The types and functions of support groups tend to follow the circumstances that trigger their formation. For example, support groups for managing chronic conditions arise from prevalence of a chronic disease; situational crises such as death and unemployment. Therefore they emerge to address such situational circumstances; while the need for personal growth and wellness may give birth to related support groups such as weight loss and smoking cession support groups. Support groups also come in a variety of formats, with some having members that meet in person, while others meet through the internet, by telephone or in a physical place. Support groups may be led by professional facilitators such as a nurse, social worker or psychologist; or by group members themselves as is the case with most support groups of PLHIV in Sub-Saharan Africa. Although support groups vary greatly, they have one common characteristic: they are places where people with similar problems share personal experiences, offer one another emotional comfort, and get heard in an atmosphere of acceptance, understanding and encouragement. Support group members share information, resources, practical advice to help one another cope with their situations. By helping others, people in a support group strengthen and empower themselves (Fanelli & Moyo 2008:1; Scholten 2013:1).

2.7.2 People living with HIV (PLHIV) support groups

According to Fanelli and Moyo (2008:2), a PLHIV support group is an association of PLHIV who come together to share challenges and experiences of living with HIV. In some countries such as Uganda, PLHIV support groups are also called post-test clubs. According to AIC (2012:1), a post-test-club is a social support group for all persons who have received counselling and testing for HIV, regardless of the test results. However, post-test-clubs normally transform themselves into small community-based PLHIV support groups as non-HIV positive individuals gradually dropout leaving individuals with a common problem – HIV-positive status.

2.7.3 Objectives of PLHIV support groups

Most HIV/AIDS programmes in Africa encourage and support formation of support groups. Available literature shows that there are a number of reasons that underpin formation of support groups. According to the UNAIDS policy brief on the greater involvement of PLHIV (GIPA), support groups and networks are necessary because there is evidence that involvement of PLHIV in programme development, implementation and policy making improves the relevance, acceptability and effectiveness of HIV/AIDS programmes (UNAIDS 2007:1). Additionally, the recent scale up of ART has made HIV/AIDS a chronic condition requiring lifelong adherence to medication. Consequently, ART programmes in Africa increasingly involve support groups to tap their skills as "expert patients" in ART adherence counselling and support in the wake of scarce trained health workers hence task shifting (Decroo et al 2012:1).

2.7.4 Benefits of PLHIV support groups

PLHIV support groups are the most common and popular ways of providing social support for PLHIV in Nigeria. It is believed that PLHIV who participate in support group activities accrue individual and group benefits. Individual benefits include general supportive counselling and ART adherence counselling. Group benefits include group psychotherapy and experience sharing. Group benefits are often a result of participating in group activities such as community HIV/AIDS education and sensitisation through music, dance, drama, poetry and sharing life testimonies. PLHIV support groups have been instrumental in bringing the reality of HIV/AIDS to the general population and demonstrating by example that PLHIV can lead healthy and productive lives thereby helping to reduce stigma and discrimination associated with HIV (AIC 2012:2; Fanelli & Moyo 2008:2; Madiba & Canti-Sigaqa 2012:1; Walstrom et al 2013:7).

According to Fanelli and Moyo (2008:2), by joining support groups, PLHIV realise that they are not alone in their situations. Support groups provide forums in which members share concerns, brainstorm solutions and give each other advice. By participating in support groups, PLHIV give and receive emotional, social and spiritual support. PLHIV together develop and sustain positive strategies for living with HIV and increasing their knowledge of HIV/ AIDS. The authors argue that support groups are considered an effective source of social support because members receive first hand advice from peers who are coping with similar circumstances and thus the advice received is perceived to be practical, personal and relevant.

Support groups have also been reported to enhance retention in care and adherence to guidelines in the PMTCT context. In a study in Zimbabwe, researchers observed that HIV positive women who participated in “Mother-to-Mother” programmes (support groups) had far higher retention rates at 6–8 weeks (99% vs 50%) and higher adherence to PMTCT guidelines, compared to those who opted not to participate in the programme (Shroufi, Mafara, Saint-Sauveur, Taziwa & Vin˜oles 2013:1). The drawback of this study is that it used a qualitative design, so, the proportions quoted are not expected in qualitative research and therefore cannot be used to assess the difference between the two types of mothers.

While the available literature provides invaluable insights into the objectives and intended benefits of establishing PLHIV support groups, there is no information on studies that have evaluated the benefits of PLHIV participation in support group activities. The works done by Fanelli and Moyo (2008); Madiba and Canti-Sigaqa (2012); and Walstrom et al (2013) did not compare PLHIV who participate in support group activities and those who do not in order to ascertain the differences in their behavioural outcomes. Furthermore, all the three studies used qualitative designs, thus the reported benefits may not be applicable beyond the study respondents. Consequently, there is a gap in knowledge in terms of whether participation in support group activities positively impacts the behaviour outcomes of PLHIV. Moreover, one can argue that the above functions could also be performed by health workers and trained lay volunteers. It is therefore necessary to determine differences between PLHIV who participate in support group activities and those who do not in terms of specific PLHIV behavioural outcomes such as HIV-related stigma, positive HIV disclosure, ART adherence to treatment and sexual risk behaviours. Significant differences would point to effectiveness and value of participation in support group activities.

2.7.5 Participation in PLHIV support groups

Even when most HIV/AIDS programmes in Africa encourage PLHIV to join support groups, not all PLHIV belong to and participate in support group activities. In Uganda, one of the countries where tremendous efforts have been made in the fight against HIV/AIDS, only 30% of PLHIV belong to support groups (Walakira, Kaawa-Mafigiri, Byamugisha & Rogers 2012:38). Additionally, in most support groups, women outnumber men. In other cases, PLHIV who have registered with support groups do not regularly attend monthly support group meetings. The reasons for this poor participation are not fully understood. In a study in South Africa that focused on men who did not participate in support group activities, respondents cited fear to disclose their HIV status as the main reason for non-participation (Madiba & Canti-Sigaqa 2012:5). However, this study did not collect data from women PLHIV and therefore it is not clear whether they hold the same views. Also, the study did not collect the views of PLHIV who belong to support groups to get their reasons for participation. Other studies have found that some PLHIV have access to other sources of ART adherence support interventions such as mobile phone reminders by healthcare givers and support from relatives, as well as HIV self-management training programmes as alternatives to belonging to PLHIV support groups (Tran, Nguyen, Nguyen, Hoang & Hwang 2013:1). Given the low patronage of PLHIV support group activities and the lack of clarity on the reasons for and for non-participation, there was need to explore the underlying reasons as a step towards increasing participation especially if the benefits of participation were found profound.

2.8 HIV-RELATED STIGMA

2.8.1 The meaning of stigma

The CDC (2011:1) defines stigma as an attribute that is deeply discrediting and sets the bearer apart from the rest of society, bringing with it feelings of shame and isolation. In the context of HIV, stigma is both internal and external. Internal or self-stigma involves a negative attitude towards ones-self, including blame, for example, “It is my fault that I am HIV positive” kind of attitude. External stigma consists of negative attitudes expressed towards PLHIV or those associated with them, for example, relatives or health care providers. Expressions of stigma include social rejection, intolerance, avoidance, discrimination, stereotyping and violence (Ugarte et al 2013:2).

2.8.2 Impact of stigma on the fight against HIV/AIDS

While significant progress has been made in averting new HIV infections and in prolonging lives of persons diagnosed with HIV through highly active anti-retroviral therapy, stigma and non-disclosure of positive HIV status continue to thwart efforts to reduce HIV transmission and increasing adherence to ART (UNAIDS 2012:8-12).

2.8.2.1 Stigma and positive HIV status disclosure

Available literature shows that rates of HIV-positive status disclosure remain very low and vary from country to country. Some studies have found that less than 54% of PLHIV disclose their status to their sexual partners (Sarahmona, Golin, Widman, Grodensky, Earp & Suchindran 2013:2). Other studies have reported that most parents of HIV positive children have not disclosed their HIV status to them, yet some of them are becoming sexually active (Fernet, Wong, Richard, Otis, Lévy, Lapointe, Samson, Morin, Thériault & Trottier 2011:1). A recent review of the literature revealed that most HIV-infected children worldwide do not know their HIV serostatus (Pinzo´ n-Iregui, Beck-Sague & Malow 2013:1). A study in Kenya found that only 19% caregivers had disclosed to their children that they (the children) have HIV (John-Stewart, Wariua, Beima-Sofie, Richardson, Farquhar, Maleche-Obimbo, Mbori-Ngacha & Wamalwa 2013:1).

Some researchers have found that non-disclosure of positive HIV status is associated with culture and internalised stigma. In most rural Africa, culture and tradition do not facilitate discussion of sexuality issues among parents and their children, and this inhibits disclosure in cases of positive HIV status (Courtois, Mullet & Malvy 2000:1). A study in Kenya showed that PLHIV with more internalised stigma were also found unlikely to have disclosed their HIV status to their sexual partners (Overstreet, Earnshaw, Kalichman & Quinn 2013:5). Due to the stigma associated with HIV, some HIV positive spouses in discordant relationships do not suggest the use of condoms for fear of being suspected or accused of infidelity (Mfecane 2012:1); couples shun couple HIV testing and counselling for the same reasons; and pregnant women shun PMTCT services for fear of revealing their positive HIV status (Nabusoba 2013:1). As non-disclosure of positive HIV status has also been associated with limited uptake of treatment (Negash & Ehlers 2013:1), this implies that many PLHIV in discordant relationships continue transmitting HIV to their sexual partners and children.

From the available literature, it was apparent that stigma inhibits HIV status disclosure. What was not known was whether PLHIV who participate in support group activities had or experienced less HIV-related stigma and are thus more likely to disclose their HIV positive sero-status than those who do not. The researcher presupposed that since PLHIV who belong to support groups automatically disclose their HIV status to their group members, this action, plus the social support and experience got from other support group members aided them perceive less internal and external stigma and gain efficacy to disclose their HIV status, compared to their counterparts who do not participate in support groups. However, this was to be validated with findings from this study.

2.8.2.2 Stigma, retention in care and initiation of ART

Due to stigma, retention of PLHIV both in pre-ART and post ART care remains significantly suboptimal, even when ART is offered for free. A recent review of literature shows that about two-thirds of patients testing positive for HIV but not eligible for ART are retained in pre-ART care continuously and that some of them do not accept their status because of perceived internal and external stigma. As a result, such PLHIV start ART when their CD4 count is too low to respond positively. In a study in Eastern Uganda, researchers found that 45% of the pregnant women who are diagnosed HIV positive do not enrol for PMTCT or are lost to follow up due to stigma and lack of HIV status disclosure (Lubega, Musenze, Gukiina, Dhafa, Badaza, Bakwesegha & Reynolds 2013:1; Rosen & Fox 2011:1).

2.8.2.3 Stigma, treatment uptake and adherence

Negative attitudes and beliefs within households, workplaces and communities increase internalised self-stigma (guilt, shame and alienation) felt by PLHIV. As a result, many PLHIV remain silent, alienate themselves and avoid taking their anti-retroviral drugs (ARVs) in public or presence of their family members even when they are faced with life-threatening health conditions. Some health workers have found that HIV positive mothers rub codes off their registration cards that would enable health workers to identify HIV exposed infants for appropriate diagnosis and care thereby frustrating paediatric AIDS treatment (Nabusoba 2013:1). In a study in Malawi, mothers reported that they stopped taking their children for treatment because “people call our children ‘Nevirapine babies’ ” (Otergaard & Bula 2010:1). Also, stigma has been identified as one reason for missing medication doses. In a cohort study carried out in Lesotho, Malawi, South Africa, Swaziland, and Tanzania, a significant relationship was found between perceived HIV stigma and self-reported missed doses of anti-retroviral medications (Dlamini, Wantland, Makoae, Chirwa, Kohi, Greeff, Naidoo, Mullan, Uys & Holzemer 2009:1).

On the other hand, low levels of internalised stigma have been found to enhance adherence to ART. In a recent study in rural Nigeria, researchers found a strong association between levels of stigma and adherence to ART. Respondents' with low levels of stigma were significantly more adherents of ART than those with high levels of stigma (Omosanya, Elegbede, Agboola, Isinkaye & Omopariola 2013:3). In another study in Eastern Nigeria (Onyebuchi-Iwudibia & Brown 2013:1), stigma was found to have a strong association with depression. As other studies have found depression associated with non-adherence to ART (Wagner, Goggin, Remien, Rosen, Simoni, Bangsberg & Liu 2011:1), this implies that stigma directly and indirectly impedes adherence to ART.

2.8.2.4 Social support and stigma

There is evidence that social support reduces stigma associated with being HIV positive (Bekele et al 2013:6; Walstrom et al 2013:7; Tsai, Bangsberg, Kegeles, Katz, Haberer, Muzoora, Kumbakumba, Hunt, Martin & Weiser 2013:1). Social support has also been found to aid both stigma reduction and HIV status disclosure. In a study in Uganda that sought to examine the relationship between internalised HIV-related stigma and HIV serostatus disclosure, internalised stigma was negatively associated with HIV serostatus disclosure and the inhibiting effect of stigma was greatest for the most socially distant ties (Tsai et al 2013:1). The gap in these studies is that they do not show whether PLHIV who participate in support group activities differ from those who do not in terms of social support and HIV-related stigma.

2.9 HIV STATUS DISCLOURE

2.9.1 Disclosure in the context of HIV/AIDS

Positive HIV status disclosure is defined as openly acknowledging one's HIV positive status (UNAIDS 2007:2). According to the WHO (2004:1), positive HIV status disclosure motivates sexual partners to seek HIV testing and change behaviour, and this ultimately decreases HIV transmission. In addition, positive HIV status disclosure increases opportunities for social support; access to medical care; discussing and implementing HIV risk reduction with partners; and planning for the future.

Publicly acknowledging one’s HIV-positive status demolishes myths and misconceptions about HIV and PLHIV. It is argued that disclosing one’s positive HIV status can also be an empowering process if it starts by combating internal stigma and shame (UNAIDS 2007:2). Also, some studies have found that mutual disclosure may have a role in supporting ART adherence (Anglemyer, Rutherford, Horvath, Baggaley, Egger & Siegfried 2013:1). Attempts to adopt safer sexual behaviours in marital relationships have been found unsuccessful without HIV status disclosure. In a study conducted in Cape Town, South Africa, HIV positive men belonging to support groups met resistance from their spouses when the men suggested use of condoms before disclosing their positive HIV status (Mfecane 2013:1). This highlights the need for disclosure to enhance adoption of safer sexual behaviours.

Also, from a recent review of the literature on studies in both developing and developed country settings, HIV status disclosure to sexual partners was found associated with positive outcome, including increased social support, acceptance, kindness, decreased anxiety and depression, and strengthening of relationships (Krauss, Letteney, Anniek, De Baets, Baggaley & Okero 2013:1). In separate studies carried out in Ethiopia and Zimbabwe, women who disclosed their HIV positive to their sexual partners were almost five times more likely to participate in PMTCT programmes than their counterparts (Sendo, Cherie & Tadese Asfaw Erku 2013:1; Shroufi et al 2013:1). Another study in France found that non-disclosure of positive HIV status was independently associated with non-optimal PMTCT- late initiation of ART, detectable viral load at delivery and lack of neonatal prophylaxis (Jasseron, Mandelbrot, Dollfus, Trocme, Tubiana, Teglas, Faye, Rouzioux, Blanche & Warszawski 2013:1).

2.9.2 Barriers and rates of HIV status disclosure

The major barrier to positive HIV status disclosure is stigma and fear of negative reactions from sexual partners. In a qualitative study aimed to assess HIV knowledge, disclosure and sexual risk among pregnant women and their partners in rural South Africa, respondents cited fear of embarrassment being seen at ART clinics or taking ARVs (Shikwane, Villar-Loubet, Weiss, Peltzer & Jones 2013:8).

However, while fear of negative outcomes is the major reported barrier to HIV status disclosure (Malaju & Alene 2013:1), some studies have found that most individuals who disclose their positive HIV status report experiencing positive social outcomes, including support and understanding from their partners (WHO 2004:2).

Despite the known benefits, positive HIV disclosure remains suboptimal in many developing countries. In a cross-sectional study among HIV positive pregnant women in northern Tanzania, only 41% had disclosed their positive HIV status to their sexual partners (Kiula, Damian & Msuya 2013:1) while in a different study in South Africa, the rate was 45% (Shikwane et al 2013:8). Even in developed countries such as United States, HIV status disclosure challenges are still prevalent. In a five year study among HIV positive pregnant women in Texas, positive HIV status disclosure occurred in over 90% of women with a serodiscordant partner, but in 68% of women with partners whose HIV status was unknown (Nacius, Levison, Minard, Fasser & Davila 2013:1). A study in France found that only 15% of HIV pregnant women of Africa origin had disclosed their status to their partners (Jasseron et al 2013:1). Given the world’s commitment to eliminate mother-to-child transmission of HIV and to empower pregnant women to have an individualised HIV-disclosure plan to disclose their status to their sexual partners, HIV status disclosure is critical for male involvement, support and success.

While the reviewed studies provide insights into the significance of positive HIV status disclosure, none of them collected data on and compared HIV status disclosure rates between PLHIV, including HIV positive pregnant women who participate in support group activities and those who do not. Comparing positive HIV status disclosure rates among HIV positive women, who participate in support group activities and those who do not, would show a glimpse into the value of participation in support group activities. This would galvanise or downplay the value of participating in PLHIV support group activities on positive behavioural outcomes PLHIV.

2.10 SEXUAL RISK BEHAVIOUR

2.10.1 The meaning of sexual risk behaviour

CDC (2012:1) defines sexual risk behaviours as sexual actions that can result in unintended health outcomes such as sexually transmitted infections or unwanted pregnancy. The Unites States National Institutes of Health (NIH 2013:1) defines safe sex as taking steps before and during sex that can prevent one from getting an infection, or from infecting one's sexual partner. Safer sexual behaviour therefore refers to practices that reduce the risk of infection with or spreading sexually transmitted infections, including HIV. It encompasses both having protected sex and refraining from risky sexual behaviours. Safer sex behaviour change therefore refers to the adoption of safer sexual practices.

Risky sexual behaviour embodies practices that lead to sex that increases one's risk of contracting or spreading sexually transmitted infections, including HIV (CDC 2007:1). Examples of risky sex include: unprotected sexual intercourse – sex without barrier contraceptives such as a condom; early sexual activity – below age 18; multiple sexual partners; casual sex; extramarital sex; and sex with high risk partners (persons who have multiple sexual partners, intravenous drugs users, commercial sex workers and men who have sex with men)

Sexual behaviour change is complex; it involves knowledge, motivations and choices, which are influenced by socio-cultural norms, as well as risk assessment in relation to immediate benefits and future consequences. It also involves both rational decision making, along with impulsive and automatic behaviour (Marteau, Hollands & Fletcher 2012:1). Consequently, sexual risk behaviour change requires tested and multiple interventions.

2.10.2 Sexual risk behaviours among PLHIV

Researchers have found that HIV transmission can be halted through behaviour modifications. According to a study by Hallett, Aberle-Grasse, Bello, Boulos, Cayemittes, Cheluget, Chipeta, Dorrington, Dube, Ekra, Garcia-Calleja, Garnett, Greby, Gregson, Grove, Hader, Hanson, Hladik, Ismail, Kassim, Kirungi, Kouassi, Mahomva, Marum, Maurice, Nolan, Rehle, Stover and Walker (2006:1), changes in sexual risk behaviours was associated with declines in HIV prevalence in Kenya, Uganda, Tanzania and Haiti.

Also, some studies show that non-adherence to treatment increases the viral load and the risk of person-to-person HIV transmission (Enriquez & McKinsey 2011:1). Additionally, non-adherence to ART has been associated with risky sexual behaviours. In a study in Atlanta, USA by Kalichman et al (2010:1), results show that non-adherent men who have sex with men (MSM) are more likely to have a greater number of sex partners and engage in unprotected sex than those who are adherent to ART. Also, there is evidence that ART reinvigorates sexual desires and sexual activity of PLHIV; and that few PLHIV practice safe sex. In an observational cohort study among PLHIV in Uganda, 56% reported sexual transmission risk behaviour at least once. (Dessie & Deresa 2012:1; Kidder et al 2013:1; Ndziessi et al 2013:1; Siedner, Musinguzi, Tsai, Muzoora, Kembabazi, Weiser, Bennett, Hunt, Martin, Haberer, & Bangsberg 2013:1). These findings provide further support for provision of ART, along with interventions to promote long-term adherence, to reduce HIV transmission in HIV.

Studies have also shown that sexual risk behaviour among PLHIV is associated with individual psychosocial wellbeing. In a prospective cohort study among PLHIV in the Kilimanjaro region of Tanzania, researchers found that post-traumatic stress over time coincided with increases in unprotected sex among PLHIV (Pence, Whetten, Shirey, Yao, Thielman, Whetten, Itemba & Maro 2013:1). This highlights the need for psychosocial interventions such as social support to reduce HIV transmission risk behaviours among PLHIV.

2.10.3 Social support and sexual risk behaviour

Studies have found an association between social support for PLHIV and reduction in risky sexual behaviours. In a prospective cohort study conducted in Mombasa, Kenya, researchers found that PLHIV who received community-based positive prevention reported reduced risky sexual behaviours compared with those who did not receive the support (Sarna et al 2013:11). The challenge with this study is that the social support was provided by community health workers, not PLHIV themselves, so, its findings could not be used to assess the role of support groups in enhancing behaviour change among PLHIV.

2.11 ANTI-RETROVIRAL TREATMENT ADHERENCE

2.11.1 The meaning of anti-retroviral treatment adherence

According to the WHO (2013:1), adherence to treatment is the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed treatment. Adherence may be measured using either process-oriented or outcome-oriented definitions. Outcome-oriented definitions use the end-result of treatment such as cure rate as an indicator of success. Process-oriented indicators make use of intermediate variables such as appointment-keeping or pill counts to measure adherence. The point that separates adherence from non-adherence would be defined as that situation in the natural history of the disease making the desired therapeutic outcome likely (adherence) or unlikely (non-adherence) to be achieved.

ART adherence also depends on the defined adherence threshold (Nachega, Buchan, Orbinski, Attaran, Singh, Rachlis, Wu, Cooper, Thabane, Wilson, Guyatt & Bangsberg 2006:1). Different ART programmes have different thresholds, from the previous 24 hours up to 365 days, and may include one week, one month, three months or a full year. However, most programmes use missing at least three doses in the past 30 days as a measure of treatment default.

ART adherence is particularly important because unlike other chronic diseases, the rapid replication and mutation rate of HIV means that very high levels of adherence (≥95%) are required to achieve durable suppression of viral load (WHO 2013:1). Good adherence is a decisive factor in anti-retroviral treatment success (Walensky, Paltiel Losina, Morris, Scott, Rhode, Seage & Freedberg 2010:1)

Non-adherence to ART is also known as treatment default. Treatment default is defined as a situation where a patient discontinues treatment even if the person resumes treatment at a later stage or will be lost from follow-up (Mills, Funk, Kanters, Kawuma, Cooper, Mukasa, Odit, Karamagi, Mwehire, Nachenga, Yaya, Featherstone & Ford 2013:1). Treatment default is of concern to ART programmes because it increases toxicity, treatment failure, morbidity, costs and deaths (Al-Dakkak et al 2013:1).

Despite interventions in ART adherence support, recent studies have reported low adherence rates. According to the WHO (2013:1), approximately one third of PLHIV consistently take their medication as prescribed. In a recent cross-sectional study on HIV infected adults attending an ART clinic in Nigeria, results showed a high non-adherence rate of 85.1%, while a similar study in Ghana put non-adherence to ART at 38%. A near perfect adherence level of >95% is required for the effective suppression of HIV/AIDS virus. Stigma and non-positive HIV status disclosure are among the commonest reported factors for non-ART adherence (Monjok, Smesny, Okokon, Osaro Mgbere & Essien 2010:1; Obirikorang, Selleh, Abledu & Fofie 2013:1; Okoronkwo, Okeke, Chinweuba & Iheanacho 2013:1; Yahaya, Jimoh & Balogun 2010:1).

2.11.2 Social support and anti-retroviral treatment adherence

The terminal nature of HIV has been a source of profound despair and stress. In order to mitigate the impact of this stress on PLHIV, HIV prevention and care programmes have sought ways of improving the mental state of patients; at the forefront of this, is the role of social support in coping with HIV. Reducing stress is important in HIV/AIDS control because high levels of stress or depression have been found to impede treatment adherence (Obirikorang et al 2013:1; Walstrom et al 2013:7)

A number of studies have reported an association between social support and optimal adherence to ART (Franke, Kaigamba, Socci, Hakizamungu, Patel, Bagiruwigize, Niyigena, Walker, Epino, Binagwaho, Mukherjee, Farmer & Rich 2012:1; Huntley, Araya & Salibury 2012:1; Kamau et al 2013:7, Decroo et al 2012:1; Tomori, Kennedy, Brahmbhatt, Wagman, Mbwambo, Likindikoki & Kerrigan 2013:1). Conversely, other studies have identified psychosocial factors such as lack of social support and poor mental health status as important barriers to optimal ART adherence (Huynh, Kinsler, Cunningham & Sayles 2013:1).

2.11.3 The value of social support provided by PLHIV support groups

While a number of studies report benefits of integrating social support measures in the control of HIV/AIDS, there is a gap in the knowledge regarding the value of PLHIV participation in support group activities. There is no information in the literature on whether PLHIV who participate in support group activities are different from those who do not in terms of perceived social support, HIV-related stigma, HIV disclosure, adherence to ART and sexual risk behaviours. In a study involving 602 adult PLHIV in Ontario, Canada (Bekele et al 2013:6), perceived social support was found to have significant direct effects on physical and mental health. However, although related, the study by Bekele and his colleagues is different from the concluded study because the perceived social support was from interventions meant to address social needs such as unemployment and housing, not participation in support group activities. Also, the study population was different – mainly gay men, lesbians, and alcoholics living in Canada, whereas the concluded study focused on PLHIV in Nigeria most of whom are of heterosexual orientation. The study findings were thus bound to be different.

In a qualitative study done in Rwanda (Walstrom et al 2013:7), although support group members reported that participating in the support group activities led to positive changes in mental health, positive HIV status disclosure, ART adherence and sexual risk behaviours, the support group activities were facilitated by para-professionals trained in trauma counselling, not PLHIV themselves. In a typical PLHIV support group in Nigeria and Africa, the leaders are PLHIV themselves, and services such as peer education, adherence counselling and adherence support are provided by PLHIV themselves. So, there was bound to be differences between the support groups studied by Walstron and his colleagues and those studied by the researcher.

In a study conducted in Mozambique, Decroo et al (2012:1) report increased ART adherence among PLHIV supported by peer PLHIV in a community setting. Selected

PLHIV who had been on ART and known to be adherent; “the expert patients” facilitated ART refill in communities rather than the usual facility-based drug refill administered by pharmacists. However, the “expert patients” were remunerated by the sponsoring project as a part of “task shifting” initiative and thus were not supporting their peers for reciprocal social support. Moreover, the ART adherence support was not rendered in a support group setting; hence the observed ART adherence cannot be associated with participation in support group activities.

Furthermore, in the study in Kenya (Sarna et al 2013:11) where researchers found that community-based positive prevention, including counselling and social support lead to increased positive HIV status disclosure and adherence to ART, the associated support services were provided by community health workers, not support group members. In another study in Kenya where social support was found to be associated with ART adherence (Kamau et al 2012:7), the social support was also not provided by PLHIV but by integrated treatment services providers, including programme nurses.

While the above studies contribute to our understanding that social support has a role to play in HIV/AIDS care and support, there is a gap in the literature concerning the relationship between participation in PLHIV support group activities and perceived social support as well as whether PLHIV who participate in support group activities differ from those who do not, in terms of perceived social support, HIV-related stigma, HIV status disclosure, sexual risk behaviours and adherence to ART. This information was vital in demonstrating the value of participating in support group activities.

2.11.4 Social support competencies

To define the concept of social support competencies, we define social skills and social competencies. In his works *Social Skills and Health*, Argyle (2013:48) defines social skills as styles of social behaviour used by interviewers, nurses and others in dealing with the clients. Argyle argues that as with motor skills, some people have more social skills than others and thus are more effective in attaining the desired goals. He adds that when social skills required for performance have been identified, they can be taught through training courses. Argyle contends that in the healthcare professions, technical or medical skills are as important as social skills and urges institutions training healthcare workers to lay more emphasis on imparting social skills on their trainees.

According to Mallinckrodt and Wei (2005:3), ***social competencies*** are skills needed to recruit and maintain satisfying and supportive relationships together with trait-like dispositions that govern use of these skills. Social competencies include social self-efficacy and emotional awareness. Social self-efficacy involves the belief that one can initiate social contact and develop new friendships from initial acquaintances. Persons who lack social self-efficacy believe that close personal relationships are a matter of luck or other factors outside their personal control. Emotional awareness refers to perceptions of attachment to others. It is the ability to communicate one’s feelings and experiences to others. The authors argue that adults with high levels of social self-efficacy and emotional awareness are more likely to solicit social support for themselves or provide it to others. According to Boyatzis (2008:11), a series of longitudinal studies have shown that people’s emotional and social-self efficacy competencies can change through training and education programmes.

From the above two definitions (social skills and social competencies) we can deduce that **social support competence** is the ability to perceive and provide help. This help may be in the form of informational, emotional, appraisal or material support. Both Argyle (2013) and Boyatzis (2008) acknowledge that social support competencies can be acquired.

2.12 CONCLUSION

From the available literature covering both theory and empirical studies, there is evidence that social support enhances mental and physical health. However, there is no information on whether PLHIV who participate in support group activities differ from those who do not in terms of perceived social support, HIV-related stigma, HIV status disclosure, ART adherence and sexual risk behaviour. Examining these differences is important in determining the value of participation in PLHIV support groups.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The previous chapter provided the literature review where the researcher analysed, compared and synthesised prior research related to the research topic, question, theory-base and concepts in the study. The analysis brought out gaps in the existing literature thereby strengthening the foundation for the study. This chapter describes the operational framework used for data collection and analysis as well as in developing a model for revitalising PLHIV caregiver social support competencies so as to enhance positive behavioural outcomes of PLHIV. The later sections of the chapter describe how the researcher assured internal and external validity of the data as well as how ethical issues inherent in research among vulnerable populations (PLHIV) were addressed.

3.2 RESEARCH AIM AND OBJECTIVES

The aim of this study was to develop an evidence-based model for revitalising PLHIV caregiver social support competencies. The study objectives were to

(i) determine reasons for participation or non-participation in support group activities among PLHIV
(ii) determine differences between PLHIV who participate in support group activities and those who do not participate
(iii) use the findings gleaned from the cross-sectional study to develop a model for revitalising PLHIV caregiver social support competencies

3.3 RESEARCH DESIGN

A research design is a strategic framework for action that serves as a bridge between research questions and the implementation of the research. It provides a plan that specifies how the research is going to be executed in such a way that it answers the research question (Blanche et al 2006:33). In order to answer the above research questions, the researcher used a mix of theory-generating and descriptive designs.

The study was conducted in two phases. Phase one entailed a cross sectional study to determine the differences between PLHIV who participate in support group activities and those who do not in terms of social support, HIV-related stigma, sexual risk behaviours, positive HIV status disclosure and adherence to ART, as well as understanding the reasons for PLHIV participation and non-participation in support groups. In the second phase of the study, the researcher used findings and conclusions from this cross-sectional study, through deductive reasoning, to define the main concept, which is the first step in theory or model development. The model development process continued following all the five steps as proposed by Walker and Avant (1995:38).

3.3.1 Theory generation

Researchers contribute to theory development either through generating or testing a theory (Chinn & Kramer 1995:21). Theory generating research is designed to discover and describe relationships without imposing preconceived notions of what these phenomena mean. This may be through an inductive or deductive approach depending on whether one is using qualitative or quantitative methods. This study focused on generating theory or a model for revitalising social support competencies among PLHIV caregivers and confidants. This process involved deducing conclusions on the value of PLHV participation in support groups based the differences between PLHIV who participate in PLHIV support groups and those who do not. It also involved exploring reasons for PLHIV participation and non-participation in support group activities. The findings from the cross-sectional study fed into developing the model for revitalising PLHIV caregiver competencies.

3.3.1.1 Stages of theory generation

According to Chinn and Kramer (1995:27), there are four processes in theory generation: creating a conceptual meaning; structuring and conceptualising theory; generating and testing theoretical relationships; and deliberate application of theory. The aim of this study was to develop a model for revitalising PLHIV caregiver social support competencies. The researcher used the above processes as a foundation for developing the model.

3.3.1.2 Reasoning strategies

In addition to the above four processes of theory generation, the researcher followed reasoning strategies suggested by Walker and Avant (1995:38) as well as Chinn and Kramer (2008:181) to develop the model for revitalising PLHIV caregivers social support competencies. This enabled formulation of local arguments for exploration and description of the phenomena under study; the value of support group participation in enhancing positive behavioural outcomes of PLHIV. The aim of studying the phenomena was to develop an evidence-based model for revitalising PLHIV caregiver social support competencies so as to enhance positive behaviour outcomes of PLHIV. The strategies include analysis, synthesis, derivation, induction and deduction.

Analysis

The Merriam-Webster Dictionary (2015) defines analysis as the identification or separation of ingredients of a substance. On the other hand, Mouton and Marais (1996:45) refer to analysis as taking a whole and breaking it into parts so that the interrelated constructs that are relevant to the understanding of the main concept are isolated. In this study, “analysis” of responses from study participants was done to answer the first two research questions − determining reasons for PLHIV participation and non-participation in support group activities; and determining the differences between PLHIV who participate in support group activities and those who do not in terms of their behavioural outcomes. Analysis was also used in identification and classification of the main concept, *revitalising social support competencies*.

Synthesis

The Merriam-Webster Dictionary (2015) defines synthesis as the composition or combination of parts or elements so as to form a whole. Mouton and Marais (1996:46) state that synthesis takes place after analysis and is necessary to combine the concepts that have been identified so that a whole can be formed. In this study, synthesis was used to draw conclusions and recommendations from data from the cross-sectional study, as well as in exploring related concepts and combining them to identify the main concept; revitalising social support competencies.

Derivation

The Merriam-Webster Dictionary (2015) defines derivation as the formation of a word from another word or base. In this study, derivation of the main concept was done by defining different concepts, identifying essential and related concepts or attributes, and synthesising the related concepts.

Inductive reasoning

In inductive reasoning relies on observing multiple particular instances and combining those particulars into a larger whole. It is moving from a specific to a general (Chinn & Kramer 1995:65). In this study, inductive reasoning was applied when structuring and relating concepts derived from the main concept.

Deductive reasoning

In deductive reasoning, prepositions or assertions of relationships are interrelated in a consistent way. It is reasoning from the general to the particular (Chinn & Kramer 1995:67). Based on the findings from the first phase of this study, the researcher used deductive reasons to draw conclusions on the value of PLHIV participation in support groups and how this could impact on PLHIV behavioural outcomes. Using data from the first two research questions, the researcher was able to narrow down to a specific concept which later formed the basis for developing a model for revitalising PLHIV caregiver social support competencies.

3.3.2 Descriptive design

Descriptive designs use numbers, percentages or averages, and characteristics of a group of people or some other phenomena. Descriptive studies are undertaken when there is not much information about a phenomenon. (Cottrell & McKenzie 2010:8). In this study, the researcher was interested in understanding whether PLHIV who participate in PLHIV support group activities were different from those who do not, in terms of their behavioural outcomes. This was achieved by generating descriptive and inferential statistics on the two study groups. This information was necessary to answer the research question: whether PLHIV who participate in PLHIV support group activities differ from those who do not, in terms of behavioural outcomes. A descriptive design also aided respondents in articulating reasons for participation and non-participation in support group activities.

3.4 RESEARCH METHOD

Phase 1

The first phase of the study used a cross-sectional design to determine whether PLHIV who participate in support group activities differ from those who do not in terms of their socio-demographics, perception of social support and their behavioural outcome, including *HIV-related stigma, positive HIV status disclosure, sexual risk behaviours and adherence to ART*. This phase also explored reasons for PLHIV participation and non-participation in support group activities.

This phase covered two objectives:

(i) to determine reasons for participation or non-participation in support group activities among PLHIV

(ii) to determine differences between PLHIV who participate in support group activities and those who do not participate

The first objective was achieved through including structured questions in the questionnaire. The questions required respondents to state reasons why they or do not participate in support group activities. The second objective was pursued by comparing PLHIV who participate in support group activities and those who do not in terms of their behavioural outcomes as stated in section 1.4.1. To do the comparison, the researcher carried out a quantitative study.

The researcher largely used a quantitative method because this study involved comparing study groups on specific study variables to answer the research question: whether PLHIV who participate in support group activities differ from those who do not in terms of socio demographics, perceived social support, HIV-related stigma, positive HIV status disclosure, sexual risk behaviour, and adherence to ART. The drawback of using quantitative methods is that the study may miss contextual details that can only be obtained through qualitative methods.

Additionally, the researcher used a cross-sectional design. A cross-sectional design is one where data are collected at one specific point in time (Cottrell & McKenzie 2010:9, 192). The researcher preferred a cross-sectional design because time and resource constraints precluded a longitudinal design. The drawback of using a cross-sectional design is that as time passes, the values of the obtained results could change in either a positive or negative direction. Despite this drawback, a cross-sectional design enables determination of current characteristics, attitudes, beliefs and behaviours of the study population. In this study, the researcher was interested in comparing specific behavioural outcomes of PLHIV who participate in support groups and those who do not.

3.4.1 Population

In research, population means the target group under investigation; the total set of units in which the investigator is interested; or the larger set from which the sample is drawn (Cottrell & McKenzie 2010:124; O'Sullivan et al 2003:134; USC 2013:17).

In this study, the population was all PLHIV aged 18 and above. It included both PLHIV who participate in PLHIV support group activities and those who do not.

Target population: This represents units in a population that conform to a set of specifications such as the people living in a given location at a particular time (Cottrell & McKenzie 2010:124; O'Sullivan et al 2003:134). According to Burns and Grove (2005:225), a target population is the entire set of individuals who meet the sampling (inclusion) criteria. In this study, the target population were: adult PLHIV (18 years and older); receiving ART services at hospitals supported by FHI 360; enrolled for ART between January 1, 2010 and December 31, 2012; and still in care. Having a specific short reference period was intended to enable the researcher improve comparability of respondents. People who had enrolled more than three years before the period covered by the study and those who had enrolled less than 12 months prior to the study were excluded from the study to avoid a possibility of bringing into the study respondents who are substantially different. The researcher chose a three-year period so as to include enough study population to get the required sample size per site. Also, selecting respondents who had been on ART for at least one year was meant to study only those PLHIV who had had sufficient exposure to demonstrate any differences in the study variables across the comparative groups.

Accessible population: According to Cottrell and McKenzie (2010:124), accessible population is the same as study population. It includes individuals in the population who are accessible to the researcher. In this study, the study population included all PLHIV aged 18 and above who were enrolled in ART between January 1, 2010 and December 31, 2012 and are still in care at the sampled sites, irrespective of where they were first initiated on ART provided they were accessible for interviews. These included those who were members of support groups and those who were not, women and men.

Sampling refers to a process through which a manageable number of respondents are selected to participate in the study. It is a process of selecting a sample population that is considered representative of the population to whom results will be generalised or transferred (Cottrell & McKenzie 2010:124; USC 2013:17). In this study, the researcher used a multistage probability sampling method to select sites and respondents to participate in the study.

3.4.2 Sampling

3.4.2.1 Sampling procedure

Sampling frame: This refers to an accurate list of all sampling units in the study population from which the sample is actually drawn (Bruce, Pope & Stanstreet 2010:143; Cottrell & McKenzie 2010:127; O'Sullivan et al 2003:125). In this study, three sampling frames were used to select study sites and respondents:

i. A list of all supported comprehensive care hospitals (ART sites) supported by FHI 360 in 15 states that had: at least 200 patients enrolled in ART, active support groups, and were providing ART services since at least January 1, 2010. This list had 60 hospitals with 47,695 PLHIV on ART. Hospitals in two states were excluded – Borno state, due to insecurity, and Edo state, because it was not directly supported by FHI 360 as at the time of the study.
ii. Lists of all adult PLHIV enrolled in each of the sampled hospitals between January 1, 2010 and December 31, 2012. Only ID numbers were extracted by persons privy to the registers. These lists had 10,080 patients altogether.
iii. Lists of PLHIV who were on list # ii above and were scheduled for ART refill at each of the sampled hospitals during the anticipated period of data collection. On these lists, there were 5,443 PLHIV.

Out of the 60 hospitals that met the inclusion criteria, that is, had been providing comprehensive HIV/AIDS services at least since January 1, 2010; had at least 200 PLHIV on ART at the time of the study; and had an active PLHIV support group; the researcher randomly selected 30 hospitals. This was done by writing the names of all the hospitals on 60 pieces of paper, folding the papers, putting all the folded papers in a container, shaking the container to thoroughly mix the folded papers and randomly picking 30 of them. Limiting the number of study sites to 30 was based on time and resource constraints within which this study had to be completed. The 30 hospitals were distributed in 10 states of which, 2 are in the North central, 2 in North East, 2 in the Southeast, 3 in the South-south and 1 in the Southwest geopolitical zones of the country.

Once a hospital was sampled, IDs of all adult PLHIV who were enrolled on ART between January 1, 2010 and December 31, 2012; were still in care at the sampled sites irrespective of where they were initiated on ART; and were scheduled for ART refill within the 30-45 days period of data collection were selected. This constituted the site sampling frame. From each site sampling frame, a simple random sample of up to 70 PLHIV were picked using STATA software version 12 to participate in the study.

3.4.2.2 Sample size

In order to ensure adequate power to detect differences between PLHIV who participate in support group activities and those who do not, the researcher calculated the minimum sample size required using the formula:

$$n = D\frac{\left[\sqrt{2P(1-P)}Z_{1-\alpha} + \sqrt{P_1(1-P_1)+P_2(1-P_2)}Z_{1-\beta}\right]^2}{\Delta^2}$$

Where:

n= minimum sample size required; D = design effect; P = (P1 + P2) / 2; Δ = |P2 – P1|

$Z_{1-\alpha}$ = the z-score corresponding to the probability with which it is desired to be able to conclude that an observed change of size (P2 - P1) would not have occurred by chance; and $Z_{1-\beta}$ = the z-score corresponding to the degree of confidence with which it is desired to be certain of detecting a change of size (P2 − P1) if one actually occurred. The researcher used $\alpha = 0.05$ ($Z_{1-\alpha} = 1.96$) $\beta=0.20$ ($Z_{1-\beta}=0.842$).

The researcher calculated sample sizes for two different dependent variables for which data was available (adherence to ART and sexual risk behaviour) using STATA software (StataCorp. 2011). The researcher then adjusted the estimates for clustered-data design effects and loss to follow-up. The larger of the two sample sizes was then selected for this study.

When considering the first behavioural outcome (dependent variable), differences between PLHIV who participate in support group activities and those who do not in terms of adherence to ART, a proportion of PLHIV who participated in support groups and adhered to anti-retroviral treatment of 47% (Walakira et al 2012:1)were assumed. As there was no data on treatment adherence among PLHIV in support groups in Nigeria, an estimate of 47% from the Uganda study was used. The settings in sub Saharan Africa tend to be similar. Assuming that the proportion of sampled subjects who participate in PLHIV support group activities lies between 0.33 and 0.67, a total sample size of up to 405 would be required to have 80% power to detect a 15% lower ART adherence rate among PLHIV who do not participate in support groups (using a two-sided type 1 error rate of 5%). The researcher assumed a moderate within-hospital correlation of 0.05 among members of each group and a correlation of 0.025 between-group members. This led to a design effect of approximately 1.15 with a cluster size of 16. With this, the researcher estimated that he needs to enrol 405*1.15 = 466 PLHIV, or approximately 16 from each of the 30 clusters, to achieve the desired power for outcome one.

When considering the second behavioural outcome (dependent variable) along with differences between PLHIV who participate in PLHIV support group activities and those who do not in terms of adopting safer sex practices, a proportion of PLHIV who adopt safer practices of 80% was assumed. This was informed by the Botswana study where 80% of interviewed support group members reported condom use across partner types over a period of 3 months, and 80% reported having sex with only one sexual partner over the past 3 months (Kalichman et al 2007:1). In the absence of any other information on sexual practices of PLHIV in support groups, the researcher used the above two indicators (number of sexual partners and condom use) as a composite indicator for sexual risk behaviours among PLHIV in PLHIV support groups. For this behavioural outcome, a difference of 8 percentage points was deemed a meaningful difference.

Assuming that the proportion of sampled subjects who participate in PLHIV support groups lies between 0.33 and 0.67, a total sample size of 1,080 was deemed required to have 80% power to detect an 8% lower rate of safer sex practices among

PLHIV who do not participate in PLHIV support groups (using a two-sided type 1 error rate of 5%). Further, assuming a moderate within-hospital correlation of 0.05 among members of each group and a correlation of 0.025 between-group members led to a design effect of approximately 1.5 with a cluster size of 54 respondents Based on this, the researcher estimated that he needs to enrol 1,080*1.5 = 1,620 PLHIV, or approximately 54 in each of the 30 clusters to achieve the desired power for outcome two.

Comparing the two, outcome two yielded the larger sample size. Further accounting for 15% non-response, the researcher planned to enrol 1,620*0.85 = 1,906 total respondents, approximately 64 respondents for each of the 30 sites. This was further rounded off to 70 participants per site.

3.4.3 Data collection

3.4.3.1 Data collection approach and method

Given the sensitivity of the information to be collected, the researcher used self-administered questionnaires to collect data from respondents. This was because the information to be collected was largely on private and sensitive issues hence the need for a tool that allows anonymity so as to increase accuracy and response rate. Self-administered questionnaires minimise interviewer bias since the respondent independently answers questions and feels more anonymous (Bruce et al 2010: 165; Cottrell & McKenzie 2010:197). The major drawbacks of using self-administered questionnaires were that it provided no room for probing and the researcher could not return to the respondent in cases where some questions were found not answered.

In order to expedite the data collection exercise, the researcher hired 15 research assistants. Their terms of reference were: liaising with authorised FHI 360 and hospital staff to develop respondents' sampling frames; obtaining permission from Chief Medical Directors of the 30 sampled hospitals; working with pharmacists to identify sampled respondents (using IDs only); obtaining informed consent; providing instructions for filling the questionnaire; receiving completed questionnaires; and returning completed questionnaires to the researcher.

The researcher and all research assistants completed an online research ethics training course developed by FHI 360’s Office of International Research Ethics (see annexe D). Assistants were required to present certificates from the organisation as proof of completion of the course and attainment of the 80% pass mark in the online examination. The assistants were drawn from a pool of fresh graduates attached to FHI 360 state offices as volunteers or interns. Before commencing the data collection exercise, all research assistants received a briefing from the researcher with special emphasis on seeking informed consent, preserving confidentiality of all information from respondents and adhering to all other provisions of the approved research protocol. The researcher had a telephone conference with each research assistant and together, went through the questionnaire and the informed consent document (see annexe E) to ensure that they understood the provisions of the entire tool and its administration process so as to apply them appropriately. The researcher kept telephone and email contacts of all research assistants through which he passed on instructions, responses to questions and updates. The assistants also had access to the researcher through similar means.

3.4.3.2 Development and testing of the data collection instrument

With the aim of ensuring use of reliable and valid measures for the key study variables, the researcher adopted instruments or relevant items thereof that had been validated in similar contexts. In order to measure social support, the researcher used the Duke-University of North Carolina Functional Social Support Questionnaire (FSSQ) (Broadhead et al 1988:1). The tool was tested as a measure of perceived social support among HIV-infected adults in rural Rwanda, and its validity and reliability found favourable (Cronbach's alpha coefficients ≥0.75 or above) for the scales overall and across subgroups of gender, literacy and mode of ART delivery (Epino, Rich, Kaigamba, Hakizamungu, Socci, Bagiruwigize & Franke. 2012:1). When rev-validated during questionnaire pre-testing, the selected items had a Cronbach’s coefficient Aplpha of 0.82.

For HIV-related stigma, the short version of the stigma measurement tool developed by Berger, Ferrans and Lashley (2001:1) was used. The tool had been tested and found reliable and valid with Cronbacj Coeffient Alpha of more than 0.75 on all dimensions. When re-validated during questionnaire pre-testing, the selected items had a Cronbach’s coefficient Alpha of 0.80 for internal stigma and 0.92 for external stigma.

For ART adherence, the researcher adopted measures that were validated by Gagne and Naccache (2003:1).and found to have a Cronbach’s Coefficient Alpha of 0.89, hence perceived to be reliable.

For questions requiring socio-demographic information as well as questions on HIV status disclosure and sexual risk behaviour, the researcher reviewed several tools used for similar studies and adopted relevant items and measures that had been validated in the HIV/AIDS and African contexts. In particular, items were extracted from the questionnaire used by ORC Macro in carrying out Demographic and Household Surveys in various countries in Sub-Saharan Africa. The adopted instruments/items were combined into one questionnaire with different sections (Annexe F).

Questionnaire pre-testing: The researcher pre-tested the questionnaire in four hospitals involving at least five respondents in each. The pre-testing exercise was limited to non-sampled hospitals so as to avoid bias at the time of actual research. Two sites for questionnaire pre-testing were from the north (Bauchi and Adamawa states) while the other two were from the south (Edo and Bayelsa states). A total of 30 respondents with similar characteristics as the study population completed the pre-test questionnaires.

The researcher, assisted by one colleague experienced in research methods and HIV programming as well as a biostatistician reviewed the tool and the pre-test data, in order to check for comparability of responses from different respondents. This review enabled identification and revision of unclear terms in the tool, clarification of ambiguous items, and removal of questions deemed unnecessary. During the process, the researcher: (i) noted that some questions with “skip to” options had not been properly aligned-this was corrected; (ii) rearranged sections by moving socio-demographic information questions from section 2 to section 1; (iii) corrected questions on adherence to reflect the two types of regimen in force among clients in FHI 360 supported sites (two doses or one dose); (iv) re-arranged the flow of questions about disclosure beginning with questions for married persons and then for the unmarried. This was to enable unmarried persons easily detect and skip questions not relevant to them.

Also, based on pre-test feedback from both the respondents and volunteer research assistants, the researcher ensured that all research assistants had enough pens for respondents to use; introduced “other” as an option response to some questions; and dropped the requirement for respondents to sign the informed consent document as respondents felt it would compromise their anonymity and confidentiality.

Cronbach’s Alpha: One of the common reliability checks used in statistical analysis is Chronbach’s alpha. It determines the internal consistency or average correlation of items in a research instrument to gauge its reliability (Blanche et al 2006:152-154). Its value ranges from 0 (no internal consistency) to 1 (maximum internal consistency). The higher the score, the more reliable the tool is. Alpha values greater than 0.75 are considered reliable. Although the researcher adopted items for measuring social support, stigma and ART adherence rates derived from tools whose reliability had been tested and validated, items for measuring internal stigma, external stigma and social support were re-validated during the pre-test of the questionnaire. The measures were found to have good internal consistency (Cronbach’s alpha $\geq$0.75): external stigma (0.92); internal stigma (0.80) and social support (0.82).

3.4.3.3 Characteristics of the data collection instrument

The researcher assembled a data collection questionnaire by adopting instruments and items validated and used in similar settings as well as developing additional questions to enlist responses peculiar to this study. The questionnaire consisted of items grouped around 12 themes. These included questions on respondents’ socio-demographic data (adopted from ORC Macro); support group participation (developed by the researcher); social support (adopted from the Duke UNC FSSQ (Epino et al 2012:1); sexual risk behaviours and positive HIV status disclosure (adopted from ORC Macro’s DHHS tools); internal and external HIV-related stigma (adopted from Berger et 2001:1); adherence to ART (adopted from Gagne & Naccache 2003:1); and post-test counselling (developed by the researcher).

Socio-demographic data questions

Questions enlisting participants’ socio-demographic data were developed by the researcher guided by information from the literature review and the research objectives. Questions in this section covered common socio-demographic parameters, including sex, age and education. Others were source of income, religion and marital status of respondents. Questions in this section were meant to describe the characteristics of the sample and make comparisons to assess whether PLHIV who participate in support group activities differ from those who do not in terms of these characteristics.

PLHIV support group participation questions

Questions in this section were meant to assess whether a respondent: (i) was a member of a PLHIV support group; (ii) had ever participated in support group activities; (iii) regularly participated in support group activities; and (iv) frequently participated in support group activities. The section also had questions for respondents to give reasons for their support group participation or non-participation choices. This set of questions was necessary to determine why some PLHIV join and participate in support group activities while others do not. The questions on duration and frequency of support group participation were meant to help in determining if participation had a dose effect. This was done by evaluating whether the greater the number of sessions attended, the stronger the relationship with the dependent variables. All questions in this section were developed by the researcher and pre-tested before data collection.

Social support questions

In this study, social support was defined as a perception by a PLHIV that he/she can get social support. Respondents were asked questions using the Duke-University of North Carolina Functional Social Support Questionnaire (Broadhead et al 1988:1). The Duke-UNC Functional Social Support Questionnaire (FSSQ) is an eight-item instrument that measures the strength of a person’s social support. Responses to each question were scored on a 1 to 5 scale. “As much as I would like” received a score of 5 and “Much less than I would like” received a score of 1. The scores from all eight questions were summed (maximum 40) and then divided by 8 to get an average score. The higher the average score, the greater was the perceived social support.

Epino et al (2012:1) examined the reliability and construct validity of the Duke-UNC Functional Social Support Questionnaire which was used to assess perceived social support among HIV-infected adults in rural Rwanda. The authors also studied whether the scale reliability differed by gender, literacy status, or ART delivery strategy. The tool performed well in the study population. Reliability was favourable (Cronbach's alpha coefficients ≥0.75 or above) for the scale’s overall and across subgroups of gender, literacy, and mode of ART delivery. The scale also demonstrated good convergent, discriminant, and known-group validity.

Additionally, respondents were asked to rank their sources of social support. The options were support group/member; family member; co-worker; health provider; and other (specify). Responses from this question were needed to reveal the sources of social support for respondents who indicated receiving it and to corroborate responses from the FSSQ and other questions.

Sexual risk behaviour questions

Questions in this section were meant to inform the researcher whether PLHIV practice risky sex that may increase HIV transmission, and whether the sexual behaviours of PLHIV who participate in support group activities differ from those who do not. Safer sexual behaviour was defined *as not practicing sex that puts one’s* *sexual partner at the risk of getting infected with HIV*. Even though all respondents were HIV positive, risky sexual behaviours expose them to other sexually transmitted infections and to pregnancy, and can aggravate their conditions and treatment options. It also exposes their sexual partners to HIV infection, hence the interest in knowing whether and with whom PLHIV practice unsafe sex. Sexual risk behaviour was measured by asking questions that required respondents to indicate whether in the past 12 months, they had or had not been involved in known risky sexual practices such as:

- Sex with sexual partners outside marriage/cohabitation
- Transaction/sex with commercial sex workers
- Unprotected sex without knowledge of the HIV serostatus of the partner
- Sex without a condom
- Sex with multiple and concurrent partners

In the first four questions, respondents were expected to say Yes or No. Response values were summed up to get the total number of Yes and No answers per group. These scores were compared among PLHIV who participate in support groups and those who do not. The last question in this section required indicating absolute numbers. Respondents putting a number other than zero were regarded as practicing unsafe sexual behaviour and the degree of risk was deemed to vary with the number.

Positive HIV status disclosure questions

In this study, disclosure was defined as having revealed one’s HIV positive status to a sexual partner/spouse, HIV positive child (by parents or caregivers), and co-worker, friends or healthcare provider. HIV status disclosure was measured by asking questions about whether PLHIV had disclosed their HIV positive status to the above categories of relations and confidants. Respondents who answered in affirmative to the questions were considered to have disclosed, while those who answered in negative were considered as not having disclosed. In addition, respondents were asked questions related to disclosure to their sexual partners (for sexually active respondents) or to any other person (friend, family member, support group member, co-worker, etc.) for non-sexually active respondents. These additional questions were needed to examine who PLHIV had disclosed to as this has significance in terms of reducing HIV transmission. For example, PLHIV disclosure to their sexual partners is more important than disclosing to co-workers.

Internal and external HIV-related stigma questions

In this study, two dimensions of HIV-related stigma were measured: (i) Internal stigma, defined as negative feelings towards oneself because of their HIV positive status; (ii) External stigma, defined as perceptions of being negatively viewed by others because of the person’s HIV positive status. The researcher selected relevant items from a stigma measurement tool that was developed, tested, and found reliable and valid with a large, diverse sample of people with HIV (Berger et al 2001:1). During data analysis, items in each subscale (internal and external stigma) were coded and scored. Scores for subscales were obtained by simply adding raw values for individual items.

ART adherence questions

Treatment adherence was measured by asking respondents to report: (i) the number of anti-retroviral doses missed in the past three days; (ii) the number of days, in total, respondents missed taking one or more of their anti-retroviral doses in the past seven days; (iii) whether or not in the past 30 days, respondents had missed taking at least three doses of their treatment for any reason. These questions were adopted from a tool developed and validated by Gagne and Naccache (2003:1). On the first question, respondents were asked to indicate by Yes or No for the question whether on any of the past three days they had missed their morning/lunch or evening/dinner doses (for those not yet on fixed dose combinations) or their daily dose (for those on fixed dose combinations). After coding, these values were summed up to get the total number of doses missed in the past three days, divided by the expected number of doses, and multiplied by 100 to get the adherence score. These scores were compared among PLHIV who had ever participated in support groups and those who had never.

On the second question, respondents were asked to state the number of days, in total, they had missed taking one or more of their anti-retroviral doses in the past seven days, using numeric numbers from zero to seven. The third set of questions required respondents to recall whether in the past one week, month or year they had missed taking their doses for at least three days, one week or month respectively. These questions were used to assess and compare retention in treatment among the two categories of respondents.

Post-test counselling questions

Questions in this section were meant to assess whether the differences in the availability and quality of post-test counselling correlate with support group participation choices. These questions were developed by the researcher.

3.4.3.4 Data collection process

After training and briefing the 15 research assistants, the researcher assigned each of them specific sites. The case load per assistant was between 1 and 3 sites. This was based on the assistants' area of residence vis-à-vis the number of sampled sites in the location/ state as well as the terrain. The first task for the research assistants was to obtain permission from Chief Medical Directors of the 30 sampled hospitals. This was done by physically delivering a letter from the researcher seeking permission to carry out the study in the site (see annexe B). To the letter, certificates of ethics clearance from UNISA and the Nigeria Health Research Ethics Committee (see annexes A and C) were attached.

Having obtained permission from the Chief Medical Directors, the research assistants liaised with authorised FHI 360 and hospital staff to develop respondents' sampling frames. The assistants submitted extracted sampling frames to the researcher who worked with the biostatistician to generate a simple random sample for each site using STATA software version 12. On each clinic day during the nine weeks period from February 24 to April 30, 2014, research assistants worked with pharmacists to identify eligible respondents from the sample list (using IDs only).

Research assistants used the daily site appointment dairies as well as sampled IDs to pre-select respondents expected to come for ART refill that day. Research assistants then provided the ID numbers of all expected and eligible respondents to the pharmacists. The pharmacists identified clients on the sample list for each day by comparing the numbers on the patient folders or pharmacy order forms, and requested them to meet with the research assistants.

Research assistants met the referred clients and sought their consent to participate in the study. This was done by either reading or providing the informed consent form to each eligible respondent. Research assistants provided questionnaires, envelopes and pens to selected and consenting respondents; provided instructions for filling the questionnaire; and received completed questionnaires on the same day. When the exercise was concluded, each research assistant packaged and returned completed questionnaires to the researcher by courier.

The researcher maintained overall responsibility for the study to ensure that all procedures were followed in accordance with the approved study protocol. The researcher kept in touch with all research assistants by phone, asked questions on how they were following the established procedures and provided guidance where necessary. The researcher paid unannounced visits to two sites randomly selected to ensure that all the precautions were being taken to achieve a hitch free study. Data collection began on February 24, 2014 and had been completed by April 30, 2014. Different sites had different schedules, but on average, it took six weeks to meet all the respondents sampled at each site.

3.4.3.5 Data management and analysis

Guided by the principles of conducting research among vulnerable populations, the researcher instituted stringent data management measures to ensure that the entire research process upholds the rights, privacy and confidentiality of respondents. In order to ensure privacy and confidentiality of the respondents, obtaining informed consent and administration of the survey tools were carried out in discrete rooms prearranged with management of the sampled hospitals. Also, research assistants ensured that respondents filled the questionnaires at their respective hospitals because it was deemed that carrying questionnaires to their homes or other places would compromise the respondents' confidentiality.

No personal identifiers such as name, address, telephone, hospital identification, national identifications or passport numbers were documented on the survey tools. This was done to ensure that data are not identifiable with a particular individual respondent. All research assistants returned the completed questionnaires in sealed parcels addressed directly to the researcher thereby limiting access by parties not privy to the study. All persons who had a role to play in the data collection and analysis processes were trained in research ethics with emphasis on preserving respondents' confidentially and anonymity.

Three persons who had experience in using the Microsoft Excel application were hired as data entry clerks. The biostatistician and the researcher directly supervised the data entry process which took place within the researcher's office building. The biostatistician developed an excel template for data entry and ensured accuracy of the dataset by instituting quality assurance measures, including double entry, audit trails, verification checks and appropriate data cleaning procedures. Data that differed during double entry were cross-checked against the questionnaires concerned. Data entry lasted for two weeks and took place in a room exclusively used by the engaged data entry clerks so as to limit access to the respondents' information by other parties.

After data entry, the biostatistician exported the data into Stata® version 12 (StataCorp, College Station, TX) software for cleaning and analysis. The analysis was done from her office and ensured that no unauthorised persons had access to the datasets kept on her computer. All data collection tools and consent forms were kept under lock and only accessible by the biostatistician and the researcher.

Descriptive statistics were used to summarise socio-demographic and other descriptive variables of the study participants. Outputs of this analysis include frequency tables, graphs and charts that show comparisons of the two study groups in terms of age, sex, religion, source of income, marital status and education levels. Other descriptive variables include year of initiation on ART, membership in support groups, participation in PLHIV support group activities, and types of support groups by location.

Chi-square test was performed to evaluate differences in categorical variables: differences between PLHIV who participate in support group activities and those who do not in terms of socio-demographics, positive HIV status disclosure, adherence to ART and sexual risk behaviours. Perceived social support and HIV-related stigma scores were not normally distributed, thus median scores of internal and external stigma, and social support were summarised and used in the analysis. In addition, Mann-Whitney-U test and Kruskal Wallis tests were used to compare stigma and social support scores of PLHIV who participate in support groups and those who do not. Also, Spearman's correlation analysis was used to assess correlations among continuous variables − HIV-related stigma, perceived social support and cumulative ART adherence.

Generalised Estimating Equations (GEE) were performed to account for clustering. Separate GEE models were used to assess crude and adjusted associations between study groups, socio-demographics and the key outcomes. Odds ratios were estimated along with 95% confidence intervals. The internal consistency of stigma and social support scales were assessed using Cronbach's alpha. A *P*-value <0.05 was considered statistically significant.

3.4.4 Data analysis and statistics generated

The researcher used Stata® version 12 (StataCorp, College Station, TX) (Statacorp. 2012) software to analyse the data. The data analysis process begun with coding the questionnaire and developing an excel template for data entry. The template had fields for all questions and codes to aid data entry and worksheets labelled by state. The researcher engaged three data entry clerks who were trained and supervised by the biostatistician. After data entry, the biostatistician exported the data into STATA software, and cleaned it before actual analysis began.

3.4.4.1 *Descriptive statistics*

Univariate analysis was done to calculate descriptive statistics and generate frequencies and distributions of all variables of interest. Respondents' socio-demographic information: sex, highest level of education, source of income, religion, and marital status were summarised in percentages.

Age of respondents and monthly attendance of support group meetings were summarised using mean (standard deviation). Monthly attendance of support group meetings in the past 12 months was categorised into two groups: 1-5 times and 6-12 times.

The researcher summarised responses to the question on "Year of ART initiation" to show the proportions of respondents who were initiated each year from 2010-2012. Also, responses to questions on support group participation (YES/NO), positive HIV status disclosure, and sexual risk behaviour variables were summarised in percentages.

In order to analyse responses to questions about stigma, the researcher summarised mean scores of internal and external stigma, and aggregated the scores from either group to obtain the overall HIV-related stigma score. Also, mean scores of social support were generated from responses from all respondents. Stigma and social support scores were tested for normality using Shapiro-Wilk test. All descriptive data is presented in the next chapter (chapter 4) using tables, graphs and charts.

3.4.4.2 *Inferential statistics:*

Bivariate analysis

Chi-square tests were performed to determine differences between PLHV who participate in support group activities and those who do not in terms of socio-demographics, HIV status disclosure, adherence to ART and sexual risk behaviours. Measures for these variables could allow bivariate analysis. This was done by:

- Cross tabulating socio-demographics and study group.
- Cross tabulating HIV status disclosure-related variables and study group. This was done for both “currently married” and “not currently married” respondents.
- Cross tabulating sexual risk behaviour variables and study group.

ARV doses missed were summed up to determine respondents’ cumulative adherence. This was categorised into two groups i.e. cumulative adherence >95% and cumulative adherence <95%.The categorised adherence variable was cross tabulated with the study groups to assess whether PLHV who participate in support groups are more likely to adhere to ART than those who do not.

Mean scores of internal and external stigma as well as social support were summarised. The Student’s t-test and Analysis of Variance (ANOVA) were used to compare PLHIV who participate in support groups and those who do not in terms of the two continuous variables (stigma and social support). This entailed assessing differences between the two study groups in terms of their socio-demographics, stigma scores and social support scores. Pearson’s correlation analysis was used to assess associations among the continuous variables.

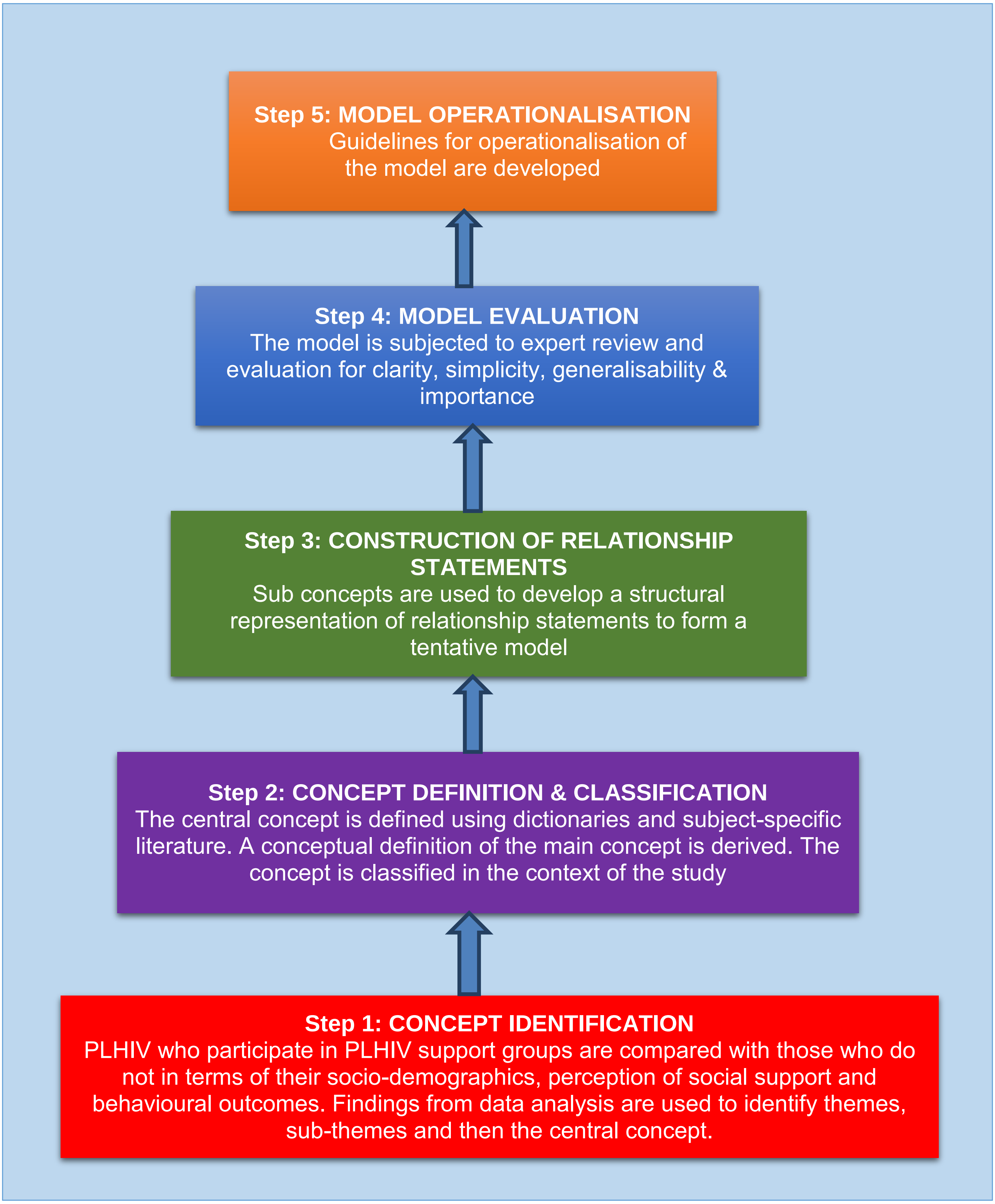
Multivariable analysis

Generalised Estimating Equations (GEE) were performed to account for clustering. Given the research questions, support group participation was the key independent variable. Hence, univariate and multivariable GEE models were fitted for the five outcomes namely: HIV status disclosure, sexual risk behaviour, adherence to anti-retroviral treatment, perceived social support and HIV-related stigma. GEE models were used to assess crude and adjusted associations between study groups, socio-demographics and the five outcomes.

In addition, binomial distributions were specified for HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment, while identity link function was specified for perceived social support and HIV-related stigma. Odds ratios were estimated along with 95% confidence intervals. The internal consistency of stigma and social support scales were assessed using Cronbach's alpha. All tests were two-sided and statistical significance was set at P-value <0.05.

Phase 2: Model development

Phase two aimed at achieving the third objective of the study: to use the findings from the first phase to develop a model for *revitalising PLHIV caregiver social support competencies so as to enhance positive behavioural outcomes of PLHIV.* Since model development follows the same process as theory development, the researcher followed the five-step process described by Chinn and Kramer (1995:79-124). This process is illustrated in figure 3.1 below.



Step 5: MODEL OPERATIONALISATION
Guidelines for operationalisation of the model are developed

Step 4: MODEL EVALUATION
The model is subjected to expert review and evaluation for clarity, simplicity, generalisability & importance

Step 3: CONSTRUCTION OF RELATIONSHIP STATEMENTS
Sub concepts are used to develop a structural representation of relationship statements to form a tentative model

Step 2: CONCEPT DEFINITION & CLASSIFICATION
The central concept is defined using dictionaries and subject-specific literature. A conceptual definition of the main concept is derived. The concept is classified in the context of the study

Step 1: CONCEPT IDENTIFICATION
PLHIV who participate in PLHIV support groups are compared with those who do not in terms of their socio-demographics, perception of social support and behavioural outcomes. Findings from data analysis are used to identify themes, sub-themes and then the central concept.

Figure 3.1: Five steps of model development

Step 1: Identifying the main concept

This was achieved using findings and conclusions from the cross-sectional study carried out in phase 1. The researcher found that PLHIV who participate in support group activities were more likely to portray positive behavioural outcomes than those who do not. The researcher therefore concluded that there is value in PLHIV participation in support group activities in terms of enhancing their behavioural outcomes. The study also found that apart from support group participation, PLHIV have other sources of social support or caregivers. These include healthcare workers, family members and co-workers. However, not all PLHIV caregivers are fully competent when it comes to providing effective social support to PLHIV. Providing social support to PLHIV requires confidence, proficiency in social communication skills, and ability to provide effective counselling. Through deductive reasoning, the researcher identifies revitalizing PLHIV caregiver social support competencies as the main concept in the model to be developed. This step was followed by steps 2-5 to conclude the process of model development.

Step 2: Definition and classification of central and related concepts

In accordance with guidelines by Chinn and Kramer (1995:79-123), after identifying the main concept, the next step is to define the main concept using dictionaries and subject-specific literature. In this step, essential and related attributes were identified and a model case was written. A conceptual definition of the main concept, revitalising social support competencies, was then identified. Lastly, the concepts were classified in the context of the study following a survey list developed by Dickoff, James and Wiedenbach (1968:422). The classification titles are: agent, recipient, procedure, dynamics, context and terminus. This process is articulated in chapter 6, sections 6.3.2-3.

Step 3: Initial model description and construction of relationship statements

The researcher used the following six questions as suggested by Chinn and Kramer (1995:115-120) to describe the components of the tentative model for revitalising PLHIV caregiver social support competencies as presented in chapter 6.

- **What is the purpose of the model?**

This question addresses why the researcher developed the model and reflects the context and situations to which the model can be applied. The purpose of the model for revitalising PLHIV caregiver social support competencies is described in chapter 7, section 7.3.

- **On what assumptions is the model built?**

This question addresses the basic truths that underlie theoretical reasoning. The assumptions of the model or the external factors which must hold for it to achieve its purpose are provided in chapter 7, section 7.4. The assumptions of the model also represent the environment in which it is to be operationalised. This is illustrated in figure 7.1 of chapter 7.

- **What are the concepts of the model?**

This question identifies the ideas that are structured and related within the model. The main concepts as derived from the processes of identifying essential and related attributes as well as through the reduction process are described in chapter 7 and illustrated in the pillars of the model in figure 7.1.

- **How are the concepts defined?**

This question clarifies the meaning for concepts within the model. The dictionary and conceptual definitions or meanings of the concepts in the model are provided in chapter 6, section 6.3.4.

- **What is the nature of relationships of concepts in the model?**

This question addresses how concepts are linked. The manner in which the concepts are linked to each other, as well as the relationships between them are described in chapter 7, section 7.7. These relationships are further illustrated in the structure of the model in figure 7.1. The relationships are explained in the context of the study to make the model meaningful and practical.

- **What is the structure of the model?**

This question addresses the overall form of the conceptual interrelationships. From relating the concepts of the model, the overall organisation and composition of the model emerges and is described in chapter 7, section 7.8.

Step 4: Evaluation of the model

The model was critically evaluated with the help of a panel of experts, who included experts in HIV/AIDS care and support as well as in research. The following questions proposed by Chinn and Kramer (1995:128-130) were used:

- **How clear is the model?**

The clarity of the model reflects how understandable the model is and how consistently the ideas are conceptualised. The clarity of the model for revitalising PLHIV caregiver social support competencies is described in chapter 7, section 7.11.1.

- **How simple is the model?**

The model is analysed in relation to its descriptive ability as well as its ability to explain or predict phenomena. It is evaluated according to the difficulty versus the straightforwardness of the concepts and relationships. This evaluation is presented in chapter 7, section 7.11.2.

- **How general is the model?**

The overall purpose and scope of the model was investigated to determine whether he model can be applied to other areas and situations. This determination is laid out in chapter 7, section 7.11.3.

- **How accessible is the model?**

The model was evaluated on how it is accessible as well as the extent to which empiric indicators for the concepts can be identified and how attainable the projected outcomes of the model are after it has been operationalised. The accessibility of the model for revitalising social support competencies is described in chapter 7, section 7.11.4.

- **How important is the model?**

This pertains to the usefulness of the model. This is detailed in chapter 7, section 7.11.5.

3.5 INTERNAL AND EXTERNAL VALIDITY OF THE STUDY

Validity means following a logical procedure to answer a research question. Internal validity refers to the evidence that a specific independent variable, not something else, caused the change in the dependent variable. On the other hand, external validity refers to the appropriateness of extending or generalising research findings to a group beyond that involved in the study, or the extent to which the results of a study are generalisable or transferable (Faryadi 2012:1; O'Sullivan et al 2003:57-62; USC 2013:15).

The use of a cross-sectional design to assess the association between participation in PLHIV support group activities and the behavioural outcomes specified in the study at a point in time limits the degree to which the research findings can be generalised. In order to mitigate this shortcoming of the design method, the researcher ensured validity of the data collected through following strict random selection of study sites and respondents; selecting an adequate sample size; and pre-testing the questionnaire before use.

Reliability is the degree to which a measure yields consistent results. It is the quality of measurement. If the measuring instrument (questionnaire) is reliable, then administering it to similar groups would yield similar results. Reliability is a prerequisite for validity. An unreliable indicator cannot produce trustworthy results (Faryadi 2012:1; USC 2013:15). With the aim to ensure reliability of the measures, the researcher adopted tools and items that had been validated in the African and HIV/AIDS contexts. For questions developed by the researcher, reliability was ensured through pre-testing, careful review of responses from the pre-testing exercise and making appropriate adjustments to improve the quality of responses.

3.6 ETHICAL CONSIDERATIONS

3.6.1 Ethical issues related to sampling

Ethical considerations related to sampling were made at two levels; selection of study sites and selection of study respondents. At both stages, the main considerations were fairness and randomness.

Selection of study sites: The researcher adhered to the inclusion and exclusion criteria set out in the research proposal. Sites inclusion criteria were: (i) supported by FHI 360; (ii) have at least 200 patients enrolled in ART; (iii) have an active PLHIV support group; (iv) having been providing ART services since at least January 1, 2010. Sites in Borno state were excluded due to insecurity. At the time of the study, the state was under a state of emergency. Exactly 60 sites met the above criteria and each of them had an equal chance of being selected in a sample of 30. A simple random sample of 30 sites was then drawn as described in section 3.3.1.2 above.

Selection of respondents: The inclusion criteria for respondents were: (i) enrolled in ART at one of the sampled sites; (ii) having enrolled for ART between January 1, 2010 and December 31, 2012; (iii) aged 18 years and above; (iv) still in care (not lost to follow up); and (v) on appointment for ARV refill within the data collection period for the site.

Confidentiality: After obtaining permission from managers of the sampled hospitals, research assistants worked with hospital records staff authorised to access ART patients' registers and obtained patients' ID numbers (not names). These ID numbers were then traced in the ARV refill appointment dairies for the nine-week data collection period. This gave IDs of all PLHIV who enrolled for ART during the reference period, were still in care at the sampled sites, and were expected to turn up for ARV refills during the nine-week period of planned data collection. Sampling frames for each site were then developed and forwarded to the researcher who worked with the biostatistician to draw a simple random sample of 70 PLHIV for each site using STATA software version 12. Each person on the sampling frame had an equal chance of being selected. Persons below 18 years were excluded because they were perceived unable to give informed consent.

3.6.2 Ethical considerations related to data collection

As this was a research involving human subjects, the researcher sought and obtained ethical clearance from the Higher Degrees Committee of the Department of Health Studies at UNISA before administering the questionnaire. Additionally, the researcher sought clearance from the National Health Research Ethics Committee of the Nigeria Federal Ministry of Health. Furthermore, the researcher obtained permission from Chief Medical Directors (CMDs) of all sampled hospitals before data was collected from their sites. Given that the researcher was to collect data from sites supported by FHI 360, ethical approval was also sought and obtained from the FHI 360 Protection of Human Subjects Committee (PHSC) at the organisation's headquarters in North Carolina, USA.

Prior to each ART clinic day, research assistants provided hospital pharmacists with IDs of the sampled patients. This was preceded by explanation of the purpose of the study with emphasis on the need to maintain anonymity and confidentiality of respondents. On the ART clinic day, pharmacists matched these IDs with those on pharmacy order forms presented at the pharmacy by all patients in need of ARV refill. The pharmacists then privately requested the clients on the sample list to meet the research assistants in designated rooms for information about a study. The pharmacists told the potential respondents that "there are researchers present doing a research study that you may qualify for; if you would like further information about the study, I can arrange for the researchers to speak with you; would you like for me to do this, so you can find out more about the study?"

As the respondents (PLHIV) are considered vulnerable population, care was taken to ensure that they are not stigmatised by participating in the study. The research assistants met the referred patients in pre-arranged rooms (for privacy), explained what the study was about, assured them of anonymity and confidentiality, and sought their consent to participate in the study. Research assistants respected the opinions and rights of clients who did not wish to participate in the study and assured them that their decision would not affect their access to services at the hospital. Individuals who could not read and write in English (about 1% of the target respondents) were excluded from the study.

After obtaining informed consent, research assistants provided sealable envelopes and pens for respondents to fill the questionnaires at the hospital as taking the questionnaires home or outside the pre-arranged rooms could compromise respondents' confidentiality. Respondents put completed questionnaires in envelopes and either dropped them in a box at a designated place or handed them over to the research assistants. No personal identifiers such as name, address, telephone, hospital identification, national identification or passport number were documented on the survey tools. The assistants returned the completed questionnaires in big sealed packages to the researcher for coding, data entry, cleaning and analysis.

The major outputs from the first phase of the study were findings related to the research questions. The researcher used the findings to distil the main concept in the study. This process is described in detail in chapter 6, section 6.3.1. The main concept and sub-concepts provided the foundation for developing a model for enhancing behavioural outcomes of PLHIV in the second phase of the study.

3.7 CONCLUSION

This chapter described the research design and methodology used by the researcher to answer the research questions. The choice of the study design, sampling procedures, instrument, measures and statistical analyses were largely informed by the review of literature and the researcher considered them justified and right for the study. The chapter also details the processes undertaken to develop a model for revitalising PLHIV caregiver social support competencies so as to enhance positive behaviours of PLHIV. The process of model development is informed by findings from the first phase of the study.

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

In chapter 3, the researcher presented the design and methodology used in this study, as well as the ethical considerations made during sampling, data collection and data analysis. In this chapter, findings from the study are analysed, presented and described. The presentation includes both descriptive and inferential statistics. The results are grouped according to (by) descriptive characteristics of the sample population, the research objectives and research questions.

The aim of this study was to develop an evidence-based model for revitalising PLHIV caregiver social support competencies so as to enhance positive behavioural outcomes of PLHIV. The study objectives were: (i) to determine reasons for participation or non-participation in support group activities among PLHIV; (ii) to determine differences between PLHIV who participate in support group activities and those who do not participate; (iii) to use the findings gleaned from the cross-sectional study to develop a model for revitalising PLHIV caregiver social support competencies.

4.2 RESEARCH RESULTS

4.2.1 Descriptive statistics of the study participants

A total of 2,100 PLHIV (70 per site) were sampled to participate in the study. Out of these, 1,713 (82%) completed and returned the questionnaires to their respective research assistants, while 387 did not. The majority of the PLHIV who did not fill and return the questionnaires were persons who missed their appointments for ARV refill during the data collection period (331/387 (86%). The 387 non-respondents also included 35 sampled respondents enrolled for ART at Bichika General Hospital in

Adamawa state who could not be reached because the hospital temporarily closed after a terrorist attack during the research period. The 387 non-respondents also include 21 PLHIV who could not read and write in English.

Out of the 1,713 questionnaires that were returned, 1,676 (98%) were fairly complete and were included in data analysis. As the required sample size was 1,906 after adjusting for design effect and non-response, this study reached 88% of the set sample size. With 1,713 respondents, the study exceeded the threshold of 1,620 respondents that were required to achieve the desired power.

4.2.1.1 Socio-demographic characteristics of the sample

Respondents' socio-demographic characteristics are summarised in table 4.1 below.

Table 4.1: Socio-demographic characteristics of the sample (n=1,676)

Characteristics	Frequency (n=1,676)	Valid percentage
Gender		
Female	1,111	66
Male	532	32
Age category		
18-30	411	25
31-44	848	51
45-80	385	23
Education		
Completed primary	580	35
Completed secondary	737	44
Tertiary	267	16
Religion		
Christianity	1,288	77
Islam	356	21
Traditional	15	1
Source of income		
Farming	306	18
My spouse	102	6
Office work	272	16
Trading/business	844	50
Unemployed	62	4
Marital status		
Currently married	947	57
Living with a sexual partner	29	2
Single	332	20
Widowed/separated	365	22

[The totals do not add up to 100% because some respondents did not respond to some questions]

Sex of respondents

Out of the 1,676 respondents, 1,111 (66%) were females, 532 (32%) males, while 33 (0.2%) did not indicate their sex. The finding that 66% of the respondents were female is in line with the UNAIDS report which states that the number of women living with HIV in Sub-Saharan Africa is twice as high the number of HIV positive men of the same age group (UNAIDS 2013:17).

Age of respondents

The median age of respondents was 37 years (IQR 31-44 years). Approximately 51% of the respondents (848/1,676) were in the 31-44 years age bracket; 75% (1,259/1,676) of respondents were below 45 years, while only 23% (385/1,676) were aged 45 years and above. This finding confirms that HIV is more prevalent in the sexually active population group (CDC 2013:1).

Education levels of respondents

Two thirds (60%) of respondents (1,004/1676) had completed at least secondary level education, while 580/1,676 (35%) had only completed primary education. A small proportion of respondents (16% (267/1,676) had completed tertiary education. These statistics generally reflect the education levels of the Nigerian population whose literacy rate is estimated at 72% (Nigeria Bureau of Statistics (NBS) 2010:20).

Religion of respondents

Christians constituted the majority of respondents (77%) followed by Muslins (21%) and others (1%). Although the Nigerian population is estimated to be comprised 50% Christians predominantly in the south and 50% Muslims predominantly in the north, the majority of FHI 360 supported hospitals and thus the target respondents were from predominately Christian states in the southern and eastern parts of the country. This may be the reason the majority of respondents were Christians.

Respondents' occupation/sources of income

The majority of the respondents were businessmen/women (50%) followed by farmers (18%) and office workers (16%). Six percent (6%) of the respondents indicated that they depend on their spouses for income, while 4% indicated that they are unemployed. This data relatively mirrors the major sources of livelihoods in Nigeria. Over the years, the country's dependency on oil has relegated farming to a less prominent source of livelihoods as the majority of the population have found other opportunities fuelled by the huge national annual oil revenues (NBS 2010:12).

However, studies have also found that persons who earn their livelihoods from off-farm businesses also tend to be occupational migrants workers, a category of Most-At-Risk Population, thus susceptible to HIV infection (National HIV/AIDS and Reproductive Health Survey (NARHS) 2013:10).

Marital status

The majority of the respondents were married (57%). Twenty-nine respondents (2%) were living with sexual partners although not married, while 22% and 20% were widowed, separated, divorced and single respectively.

4.2.1.2 Year of ART initiation

Responding to the question on year of initiation on ART, 636 (38%) of the respondents indicated that they had initiated ART in 2010, 488 (29%) in 2011 and 552 (33%) in 2012. This shows that between 2010 and 2011 there was a decline in initiation of new PLHIV on ART at hospitals supported by FHI 360 in Nigeria, but initiation picked again in 2012. This finding corresponds with the events of the times. In 2010, the project implemented by FHI 360 was closed and a new one began in 2011. Due to uncertainty in continued funding, several supported hospitals reduced the number of PLHIV initiated on treatment during the transition period.

Table 4.2: Proportions of respondents who initiated ART in 2010, 2011 and 2012

Year of initiation on ART	Frequency	Valid percentage
2010	636	38
2011	488	29
2012	552	33
Total	**1,676**	**100**

4.2.1.3 ART initiation and PLHIV support group enrolment

The researcher was interested in knowing whether PLHIV who initiate ART also enrol in support groups around the same time. This would point to the value and effectiveness of post-test counselling, which in an ART setting includes encouraging PLHIV newly initiated on ART to join support groups for ART adherence support. Table 4.3 below shows a comparison between when PLHIV initiated ART and when they enrolled in support groups. Generally, the results show that over 60% of PLHIV initiated on ART and enrolled in PLHIV do so within or around the same period. This cuts across the three years. Year of support group enrolment is represented by the four bars with each colour representing one of the years from 2010 to 2014.

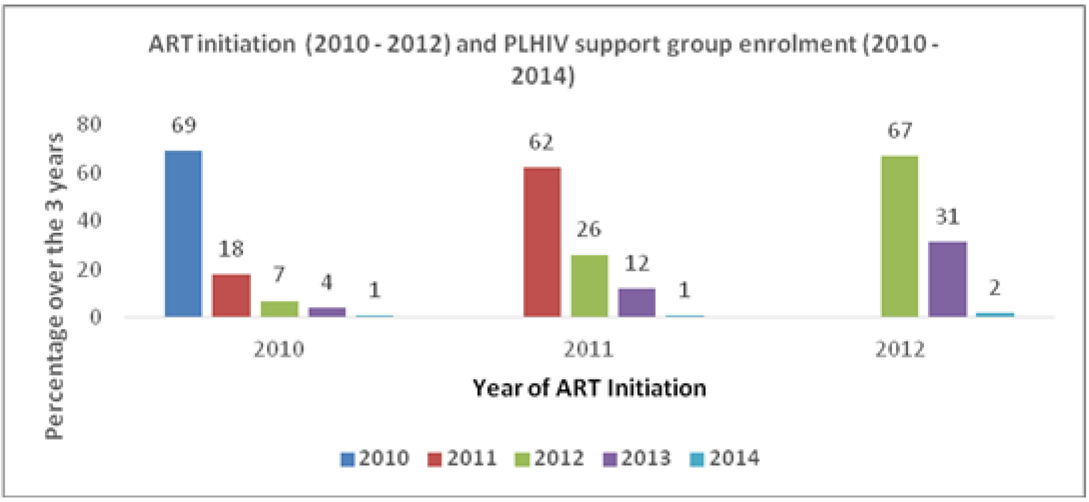


Figure 4.1: Proportion of PLHIV who initiate ART and enrol in PLHIV support groups in the same year

4.2.1.4 Membership and participation in PLHIV support groups

In order to measure participation in support group activities, respondents were asked to indicate whether they were members of a support group or had ever participated in support group activities. In response to these questions, 33% indicated that they were members of a support group, 8% had been members but had left, 6% had ever participated in support group activities but had never been members, while 53% had never participated. As participation in support group activities was defined as both being a member and having ever participated in support group activities, 47% of respondents were considered to have ever participated in support group activities against 53% who had never. This shows that the study sample was comprised approximately two equal study groups.

The finding that only 33% of PLHIV belong to support groups is consistent with an earlier study in Uganda, which put the figure at 30% (Walakira et al 2012:38). This finding (low patronage of support groups) is also related to the finding in this study which shows that only 16% consider support group members as their major source of social support.

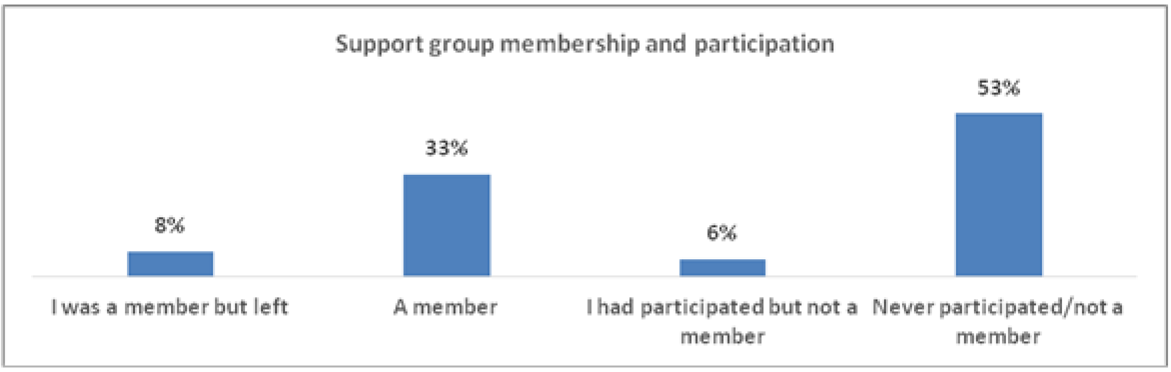


Figure 4.2: Proportion of PLHIV who belong to and participate in support group activities

4.2.1.5 Frequency of participation in PLHIV support group activities

The key independent variable in this study was participation in support group activities. The researcher was also interested in knowing whether PLHIV who participate do so frequently and whether this has any dose effect on their behavioural outcomes. Respondents were asked to indicate their frequency of participation in monthly support group activities over the past 12 months. Responses were categorised in 1-5 (low participation) and 6-12 (high participation). This categorisation was meant to help in determining whether participation in support group activities had a dose effect. This was done by evaluating whether the greater the number of sessions attended, the stronger the relationship with the dependent variables. Out of those who had ever participated in support group activities, 63% had attended at least six monthly support group meetings in the previous 12 months while 37% had attended less than half of the sessions. This shows that the majority of respondents who were participating in support group activities did so frequently.

4.2.1.6 Facility versus community-based PLHIV support groups

Respondents who belonged to or participated in support group activities were asked to indicate the location of their support groups. Figure 4.3 below shows that the majority (90%) of support groups are located within hospitals and that just 10% of them are community-based. This is despite of FHI 360's past three year efforts of relocating support groups from hospitals to communities aimed to enhance stigma reduction and community-based care of PLHIV.

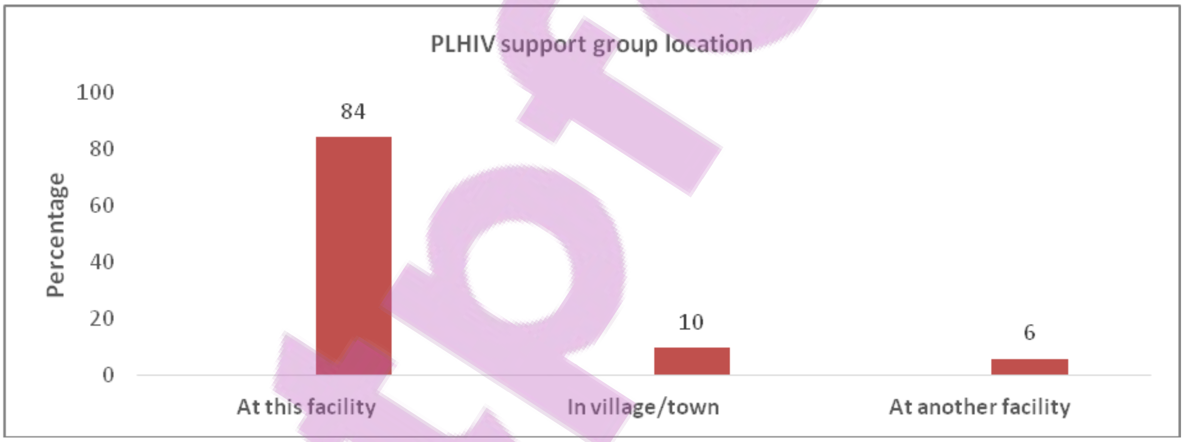


Figure 4.3: Location of PLHIV support groups patronised by respondents

4.2.2 Findings by objectives of the study and research questions

4.2.2.1 Objective 1

To examine differences between PLHIV who participate in support group activities and those who do not in terms of their socio-demographics, perceived social support and behavioural outcomes

Differences between PLHIV who participate in support group activities and those who do not in terms of socio-demographics

The researcher was interested in knowing whether PLHIV who participate in activities differ from those who do not in terms of socio-demographics. This was needed to shed light, on which socio-demographic characteristics may influence the decision to participate or not participate in support group activities. The information would confirm or refute the assumption that at baseline (HIV diagnosis and initiation on ART), there is no difference in the socio-demographics of PLHIV who chose to join support group activities and those who do not.

Table 4.3: Socio-demographic characteristics of respondents by study group

Variable	**Support group participation**				**P-value**
	NO		**YES**		
	Frequency	**Valid %**	**Frequency**	**Valid %**	
Gender					
Female	611	55	500	45	**0.029**
Male	262	49	270	51	
Age category					
18-30	248	60	163	21	**<0.001**
31-44	430	51	418	54	
45-80	192	50	193	25	
Education					
Completed primary	305	53	275	47	0.748
Completed secondary	374	51	363	49	
Tertiary	141	53	126	47	
Marital status					
Currently married	467	49	480	51	**<0.001**
Living with sex partner	15	52	14	48	
Single	195	59	137	41	
Widowed/separated	209	57	156	43	
Religion					
Christianity	685	53	603	47	**0.034**
Islam	193	54	163	46	
Traditional	3	20	12	80	
Source of income					
Farming	154	49	158	51	0.067
My spouse	60	59	42	41	
Office work	140	51	132	49	
Trading/business	441	52	403	48	
Unemployed	42	68	20	32	

The findings above indicate that PLHIV who participate in support group activities and those who do not differ significantly according to levels of education (*p*=0.748) and source of income (*p*=0.067), but differed in marital status (*p*=<0.001), age (*p*=<0.001), sex (*p*=0.029) and religion (*p*=0.034). People who were not married (single, widowed, separated or divorced) were less likely to participate in support group activities than those who were married or living with a sexual partner (37% vs 67%). PLHIV support group participation was similar among respondents aged 31-44 (49%) and those aged 45-80 (50%) However, people aged below 30 years were less likely to participate in support group activities than those between 31 and 44 years as well as those over 45 years (21% vs 54% vs 25%). Despite there being more HIV positive women than men, men were more likely to participate in PLHIV support group activities than women (51% vs 45%); and persons who practiced traditional religion were more likely to participate in support group activities than those who practiced Christianity and Islam (80% vs 47% vs 46%).

Do PLHIV who participate in support group activities differ from those who do not on perceived social support?

Perception of social support among all respondents

Respondents were asked a range of questions concerning their perception of different dimensions of social support. Their responses are summarised in table 4.5 below:

Table 4.4: Respondents' perceptions of social support

Perceptions of social support	Much less than I would like n (%)	Less than I would like n (%)	Some, but would like more n (%)	Almost as much as I would like n (%)	As much as I would like n (%)
I have people who care about what happens to me	107 (7%)	95 (6%)	189 (12%)	298 (18%)	932 (58%)
I get the love and affection I need	81 (5%)	103(6%)	212 (13%)	425 (27%)	772 (48%)
I get chances to talk to someone about problems at work or with my housework or my life	151 (9%)	162 (10%)	263 (16%)	442 (28%)	578 (36%)
I get chances to talk to someone I trust about my personal or family problems	135 (8%)	148 (9%)	221 (14%)	464 (29%)	631 (39%)
I get chances to talk about money matters	223 (14%)	180 (11%)	258 (16%)	326 (21%)	588 (37%)
I get invitations to go out and do things with other people	102 (6%)	111(7%)	156 (10%)	347 (22%)	873 (55%)
I get useful advice about important things in life	53 (3%)	75 (5%)	171 (11%)	395 (25%)	903 (57%)
I get help when I am sick in bed	138 (8%)	109 (7%)	186 (12%)	330 (21%)	845 (53%)

More than half of the respondents reported that they have people who care about what happens to them (58%) --"as much social support as they would like" (the highest score): get invitations to go out and do things with other people (55%); get useful advice about important things in life (57%); and get help when sick in bed (53%). Generally, perceived social support was high among all respondents (32/40 score = 80%), implying that most PLHIV have access to sources of social support.

Respondents' socio-demographics and perceived social support

The median perceived social support score was significantly higher amongst males [33 (27-37)] than females [32 (26-37)] (*p*=0.028). Also, the median perceived social support scores differed significantly from respondents' educational status (32, 32 and 34) for respondents who completed primary, secondary and tertiary education respectively, *p*<0.001). In terms of marital status, perceived social support median scores were highest amongst married respondents [33 (28-37] and lowest among windowed [30 (24-35)] and source of income. The median scores of perceived social support by socio-demographics are summarised in table 4.5 below.

Table 4.5: Median scores of perceived social support by socio-demographics

Variable	Median (IQR)	P-value
Support Group Participation		
Non-participation	31 (26–37)	0.159
Participation	32 (27–37)	
Frequency of participation		
1-5 times	31.90 (6.92)	0.192
6-12 times	31.08 (7.37)	
Year of ART initiation		
2010	32 (27–37)	0.356
2011	32 (26–37)	
2012	32 (27–36)	
Gender		
Female	32 (26–37)	**0.028**
Male	33 (27–37)	
Education		
Completed primary	32 (26–37)	**<0.001**
Completed secondary	32 (27–37)	
Tertiary education	34 (29–38)	
Age Category		
≤30	32 (26–37)	0.136
31-44	32 (27–37)	
44-80	32 (27–37)	
Source of Income		
Office work	34 (28–38)	**0.004**
Spouse	31 (26–36)	
Farming	31 (27–37)	
Trading	32 (26–36)	
Unemployed	33 (26–39)	
Marital status		
Currently married	33 (28–37)	**<0.001**
Living with sexual partner	30 (26–34)	
Single	32 (26–37)	
Widowed	30 (24–35)	

PLHIV support group participation and perception of social support

In order to ascertain whether there are differences in perception of social support among the two study groups, median scores of respondents who participate in support group activities were compared with those of respondents who do not. PLHIV who participate in support group activities had a median score of 32 (27-37), while those who do not had a median score of 31 (26-37) as shown in figure 4.4. below.

This aggregate score of all respondents was 32 (27-37) out of the maximum possible score of 40. This implies that there is no significant difference between PLHIV who participate in support groups and those who do not in terms of perceived social support (*p=0.28*). Generally, perceived social support was high among all respondents (32/40 = 80%), implying that most PLHIV have access to social support.

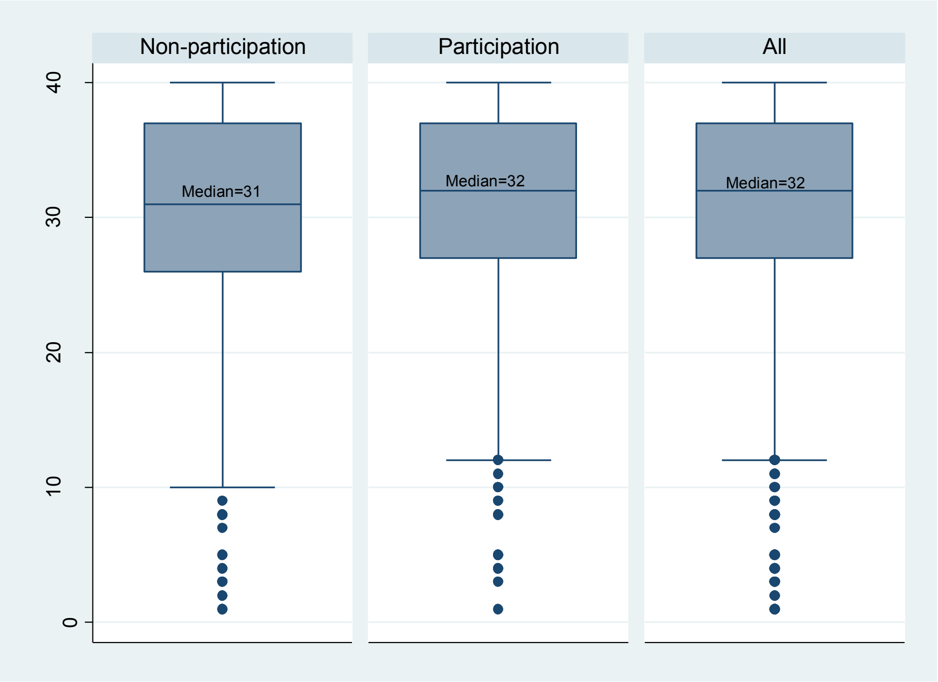


Figure 4.4: Respondents' PLHIV participation and social support median scores

Respondents ranking of their sources of social support

The graph below shows how respondents ranked their sources of social support on a scale of 1 to 5 – where 5 was the highest and 1 the lowest. The results show that

66% of the respondents highly rated health workers as their source social support while 36% rated family members and 16% rated support group members. Workmates were rated at 13%. This finding implies that even PLHIV who do not participate in support group activities, accessing social support is not a challenge.

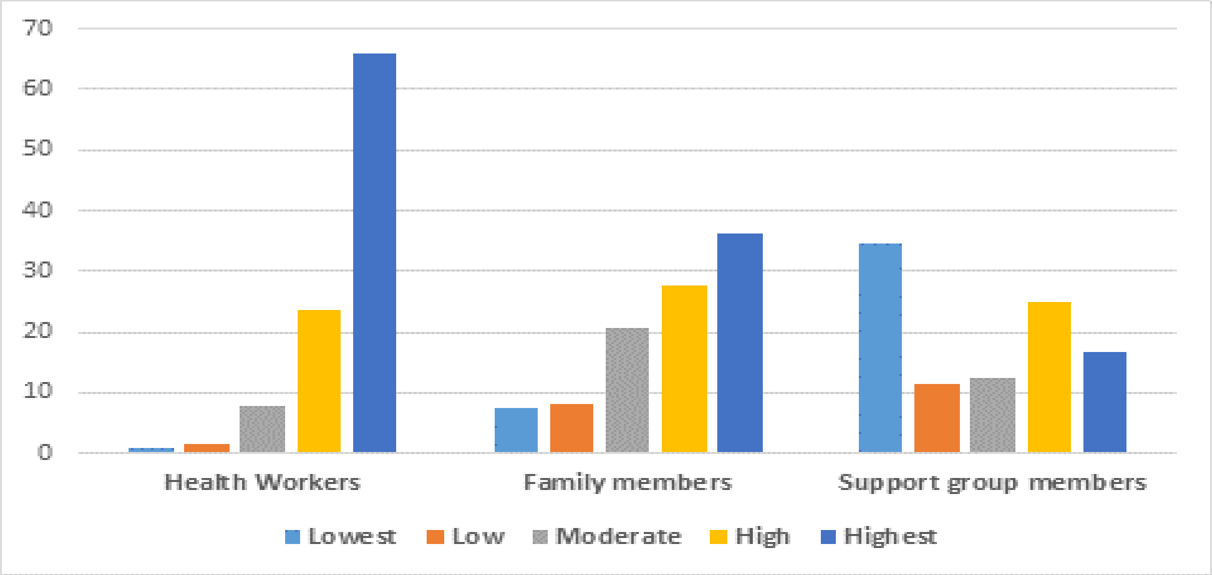


Figure 4.5: Respondents ranking of their sources of social support

Do PLHIV who participate in support group activities differ from those who do not on HIV-related stigma?

Respondents' perception of internal stigma

Respondents were asked questions meant to measure their internal and external stigma. On the internal stigma scale, more than half of the respondents reported that: they worked hard to keep their HIV status a secret (41% agree and 30% strongly agree); telling someone they have HIV is risky (45% agree, 24% strongly agree); they worry that people who know their HIV status would tell others (38% agree, 18% strongly agree). On the other hand, more than 50% of the respondents reported that: they do not feel guilty because they have HIV (31% disagree, 24% strongly disagree); disagree that people's attitudes about HIV and PLHIIV make them feel worse about themselves (38% disagree, 22% strongly disagree) The 50% also disagree that since learning that they have HIV, they feel isolated from the rest of the world (45% disagree, 26% strongly disagree). Respondents' scores on the internal social stigma scale are summarised in table 4.6 below.

Table 4.6: Respondents' perceptions of internal stigma

Perceptions of internal stigma	**Agree**	**Strongly Agree**	**Disagree**	**Strongly disagree**
I feel guilty because I have HIV	529 (32%)	215 (13%)	505 (31%)	405 (24%)
People's attitudes about HIV and people living with HIV make me feel worse about myself	506 (31%)	159 (10%)	627 (38%)	365 (22%)
Since learning that I have HIV, I feel isolated from the rest of the world	347 (21%)	118 (7%)	743 (45%)	435 (26%)
Telling someone I have HIV is risky	739 (45%)	391 (24%)	340 (21%)	178 (11%)
I work hard to keep my HIV status a secret	669 (41%)	495 (30%)	318 (19%)	170 (10%)
I feel I am not as good a person as others because I have HIV	324 (20%)	110 (7%)	728 (44%)	477 (29%)
I worry that people who know I have HIV will tell others	632 (38%)	302 (18%)	458 (28%)	253 (15%)

Respondents' perception of external stigma

In terms of external stigma, over 50% of respondents disagreed with the statements that people they care about stopped calling after learning they have HIV (36% disagree, 16% strongly disagree), and that their friends abandoned them after learning that they have HIV (34% disagree, 16% strongly disagree). There were no significant differences in the respondents' views concerning the rest of the elements on the external stigma scale. Responses concerning participants' perception of external stigma are summarised in table 4.7 below:

Table 4.7: Respondents' perceptions of external stigma

Perceptions of external stigma	Agree	Strongly agree	Not applicable	Disagree	Strongly disagree
I have been emotionally hurt by how people reacted to learning I have HIV	483 (29%)	179 (11%)	380 (23%)	400 (24%)	209 (13%)
People seem afraid of me once they learn I have HIV	365 (22%)	138 (8%)	442 (27%)	467 (28%)	235 (14%)
People I care about stopped calling after learning I have HIV	239 (15%)	81 (5%)	458 (28%)	591 (36%)	270 (16%)
My friends abandoned me after learning that I have HIV	243 (15%)	87 (5%)	483 (30%)	555 (34%)	269 (16%)
Some people who know I have HIV have grown more distant	292 (19%	93 (6%)	445 (27%)	555 (34%)	250 (15%)
I regret having told some people that I have HIV	362 (22%)	182 (11%)	411 (25%)	490 (30%)	188 (12%)
As a rule, telling others that I have HIV has been a mistake	427 (26%)	176 (11%)	398 (24%)	465 (28%)	175 (11%)

Respondents' socio-demographics and perceived stigma

Total HIV-related stigma scores based on the sex and educational status were not significantly different among respondents, but were different for respondents' age, source of income and marital status. The median stigma score was significantly higher amongst respondents younger than 30 years [31 (24–37)] than older respondents [28 (21-35)], ($p<0.001$). The median stigma score was highest amongst respondents living with sexual partners but not married [33 (IQR 26 -38)] and lowest among married respondents [28 (21-34] $p=0.034$. Respondents' socio-demographics and total stigma median scores are summarised in table 4.8.

Table 4.8: Respondents' socio-demographics and overall stigma mean scores

Variable	Median (IQR))	P-value
Support group participation		0.882
Non-participation	29 (IQR 21–35)	
Participation	28 (IQR 22–35)	
Frequency of participation	22 (IQR 29–36)	0.919
1-5 times	28 (IQR 22–35)	
6-12 times		
Year of ART initiation		0.166
2010	29 (22–35)	
2011	28 (20–35)	
2012	29 (21–35)	
Sex		0.057
Female	29 (22–36)	
Male	28 (20–34)	
Education		0.078
Completed primary	28 (21–36)	
Completed secondary	29 (22–35)	
Tertiary education	28 (20–34)	
Age category		**<0.001**
≤30	31 (24–37)	
31-44	28 (21–35)	
44-80	28 (21–34)	
Source of income		**0.001**
Office work	28 (21–34)	
Spouse	27 (20–33)	
Farming	31 (23–37)	
Trading	28 (21–36)	
Unemployed	31 (23–37)	
Marital status		**0.003**
Currently married	28 (21–34)	
Living with sexual partner	33 (26–38)	
Single	29 (23–37)	
Widowed	30 (22–37)	

Comparison of stigma scores among the two study groups

Responses to both categories of questions (related to internal and external stigma) were scored and the median scores of PLHIV who participate in PLHIV support groups were compared with those of PLHIV who do not. Median scores of internal stigma were significantly lower amongst PLHIV who participate in PLHIV support group activities [16 (14-19)] than those of PLHIV who had never participated in support group activities [18 (15-20)] (*p*=<0.001). Median scores of external stigma of PLHIV who participate in support group activities [14 (10-18)] were almost similar with scores of PLHIV who do not [14 (9-17)], (*p*=0.250). Overall internal stigma [17 (14-20)] was higher than overall external stigma [14 (9-17)] amongst all respondents (figure 4.6). Total median stigma scores (internal plus external) of respondents who participate in support group activities [28 (22-35)] and those who do not [29 (21-35)] were not significantly different (*p*=0.88).

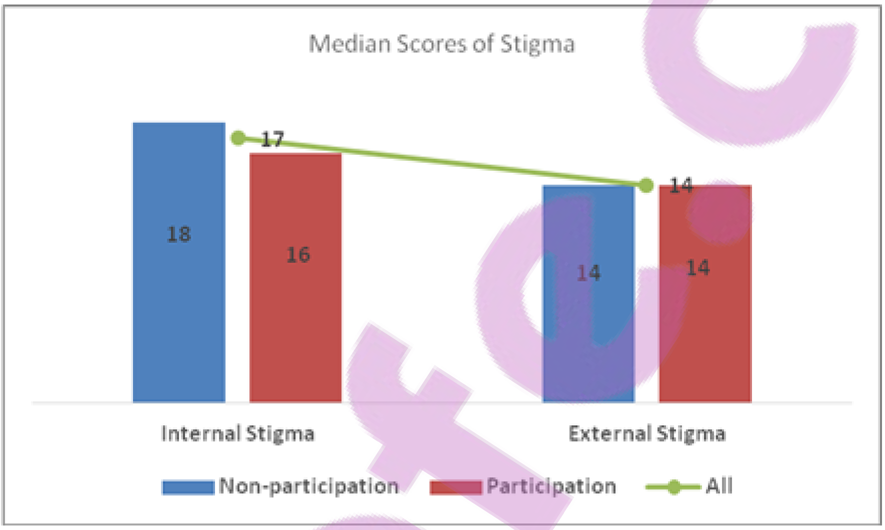


Figure 4.6: Respondents' mean stigma scores

Do PLHIV who participate in support group activities differ from those who do not – on HIV status disclosure?

Respondents' socio-demographics and positive HIV status disclosure

Overall, positive HIV status disclosure to sexual partners and/or relatives amongst all respondents (both married and not married) was 78% (1,032/1,325). Positive HIV status disclosure significantly differed by respondents' socio-demographics; sex (*p*=<0.001), year of ART initiation (*p*=<0.001), age (*p*=<0.001), level of education (*p*=0.015), marital status (*p*=<0.001) and source of income (*p*=<0.001).

Disclosure of positive HIV status to sexual partners among respondents who were married and those who were not married was 92% and 51% respectively, and overall disclosure was highest amongst currently married (92%) and lowest amongst single respondents (47%). This implies that married PLHIV are more likely to disclose their positive HIV status to their sexual partners than those who are not married. Disclosure of positive HIV status to relatives and friends amongst respondents who were not married was 41% (figure 4.7).

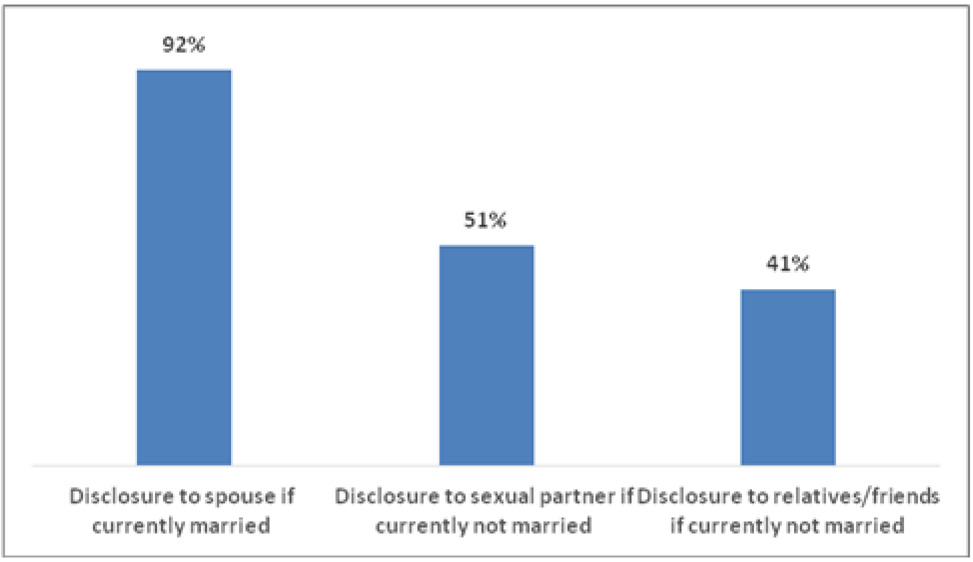


Figure 4.7: Respondents marital status and positive HIV status disclosure

Overall disclosure significantly decreased every successive year of ART initiation (82%, 79% and 72% in 2010, 2011 and 2012 respectively; *p*=0.001). Males were more likely to disclose their positive HIV status than females (83% vs 76%) and older PLHIV were more likely to disclose their positive HIV status than younger PLHIV.

Table 4.9: Respondents' socio-demographics and HIV disclosure

Variable	Over all disclosure		P-value
	YES	NO	
Year of ART initiation			**0.001**
2010	395 (82%)	85(18%)	
2011	313 (79%)	84 (21%)	
2012	324 (72%)	124 (28%)	
Gender			**.001**
Female	645 (76%)	208 (24%)	
Male	370 (83%)	74 (17%)	
Age category			**0.001**
≤30	248 (73%)	93 (27%)	
31-44	528 (77%)	154 (23%)	
44-80	242 (85%)	43 (15%)	
Education			**0.015**
Completed primary	357 (79%)	95 (21%)	
Completed secondary	440 (74%)	151 (26%)	
Tertiary education	187 (83%)	37 (17%)	
Marital status			**<0.001**
Currently married	792 (92%)	65 (8%)	
Living with sexual partner	20 (77%)	6 (23%)	
Single	121 (47%)	134 (53%)	
Widowed	99 (53%)	88 (47%)	
Source of income			**<0.001**
Office work	192 (83%)	38 (17%)	
Spouse	85 (91%)	8 (9%)	
Farming	191 (79%)	50 (21%)	
Trading	497 (75%)	162 (25%)	
Unemployed	23 (55%)	19 (45%)	

Comparison of positive HIV status disclosure rates among the two study groups

Overall disclosure was significantly higher amongst respondents who had participated in support group activities (81%) than those who had never participated (75%) (*p*=0.005). Frequency of attending support group meetings did not have a dose effect on positive HIV status disclosure (*p*=0.316). Table 4.10 below summarises positive HIV status disclosure rates among PLHIV who participate in support group activities and those who do not. It also shows disclosure rates among PLHIV who frequently attend support group meetings and those who attend less frequently.

Table 4.10: Respondents' disclosure of positive HIV by participation status

Variable	Overall disclosure YES	 NO	P-value
Support Group Participation			
Non-participation	510 (75%)	172 (25%)	**0.005**
Participation	522 (81%)	121 (19%)	
Frequency of participation			
1-5 times	153 (78%)	44 (22%)	0.316
6-12 times	265 (81%)	61 (19%)	

Do PLHIV who participate in support group activities differ from those who do not participate on adherence to anti-retroviral treatment?

Respondents' socio-demographics and ART adherence

Respondents' responses to questions about adherence to ART were scored to measure their rates of adherence. Respondents who scored $\geq$95% were considered adherent while those who scored below 95% were considered non-adherent. Overall, 1,559 (93%) of the respondents were found adherent and 117 (7%) not adherent. Generally, there was no significant difference between respondents' socio-demographics and their rates of adherence to ART except for marital status. 'Respondents' self-reported adherence was highest amongst married respondents (93%) and lowest amongst respondents living with sexual partner but not married (79%). Table 4.11 below summarises respondents' socio-demographics and ART adherence.

Table 4.11: Respondents' socio-demographics and ART adherence

Variable	Adherence YES	Adherence NO	
Gender			
Female	1038 (93%)	73 (7%)	0.325
Male	490 (92%)	42 (8%)	
Age Category			
≤30	378 (92%)	33 (8%)	0.194
31–44	798 (94%)	50 (6%)	
44–80	353 (92%)	32 (8%)	
Education			
Completed Primary	537 (93%)	43 (7%)	0.761
Completed secondary	688 (93%)	49 (7%)	
Tertiary Education	246 (92%)	21 (8%)	
Marital status			
Currently married	884 (93%)	63 (7%)	**0.014**
Living with sexual partner	23 (79%)	6 (21%)	
Single	314 (95%)	18 (5%)	
Widowed	335 (92%)	30 (8%)	
Source of income			
Office work	255 (94%)	17 (6%)	
Spouse	92 (90%)	10 (10%)	0.255
Farming	291 (93%)	21 (7%)	
Trading	790 (94%)	54 (6%)	
Unemployed	54 (87%)	8 (13%)	
Year of ART initiation			
2010	596 (94%)	40 (6%)	
2011	455 (93%)	33 (7%)	0.512
2012	508 (92%)	44 (8%)	

Comparison of ART adherence rates among the two study groups

Adherence to ARVs amongst PLHIV who participated in support group activities was reported by 745/788 (95%) respondents while adherence among PLHIV who never participated in support group activities was reported by 814/888 (92%) respondents. Among respondents who reported non-adherence to ART, 74/117 (8%) had never participated in support group activities compared to just 43/117 (5%) non-adherent PLHIV who participated in support group activities. These findings suggest that PLHIV who participate in support group activities significantly differ from those who do not in terms of adherence to ART (p=0.021). The frequency of attending support group activities has no association with ART adherence (*p*=0.461) and so does the year of ART initiation (*p*=0.512).

Table 4.12: Respondents' PLHIV support group participation and ART adherence

Variable	Adherence YES	 NO	P-value
Support group participation			**0.021**
Non-participation	814 (91.67)	74 (8.33)	
Participation	745 (94.54)	43 (5.46)	
Frequency of participation			0.461
1–5 times	227 (95.38)	11 (4.62)	
6–12 times	391 (96.54)	14 (3.46)	
Year of ART initiation			0.512
2010	596 (93.71)	40 (6.29)	
2011	455 (93.24)	33 (6.76)	
2012	508 (92.03)	44 (7.97)	

Do PLHIV who participate in support group activities differ from those who do not participate on sexual risk behaviours?

Respondents' sexual risk behaviours

A total of 1,031 respondents answered the question on whether they had a regular sexual partner (spouse or co-habiting partner). Out of this number, 789 (77%) responded in the affirmative, while 242/1,031 (23%) reported that they had no sexual partner. This implies that a significant majority of PLHIV live with their sexual partners. Respondents were also asked a question on whether they had had sex with a person who was not their regular sexual partner in the past 12 months. Out of the 1,108 respondents who answered this question, 201/1,108 (18%) responded in the affirmative and a significant majority (898/1108) or 72% had not had sex with someone other than their sexual partners. The researcher was also interested in knowing with whom the PLHIV who reported sex outside marital/co-habitation relationships were having sex. This would shed light on their risky sexual behaviours. Out of the 201 who reported having had sex with a person who was not their spouse or co-habiting partner, 118 (59%), 47 (23%) and 9 (4%) had had it with boyfriend/girlfriends, casual sexual partners and commercial sex partners respectively (figure 4.8).

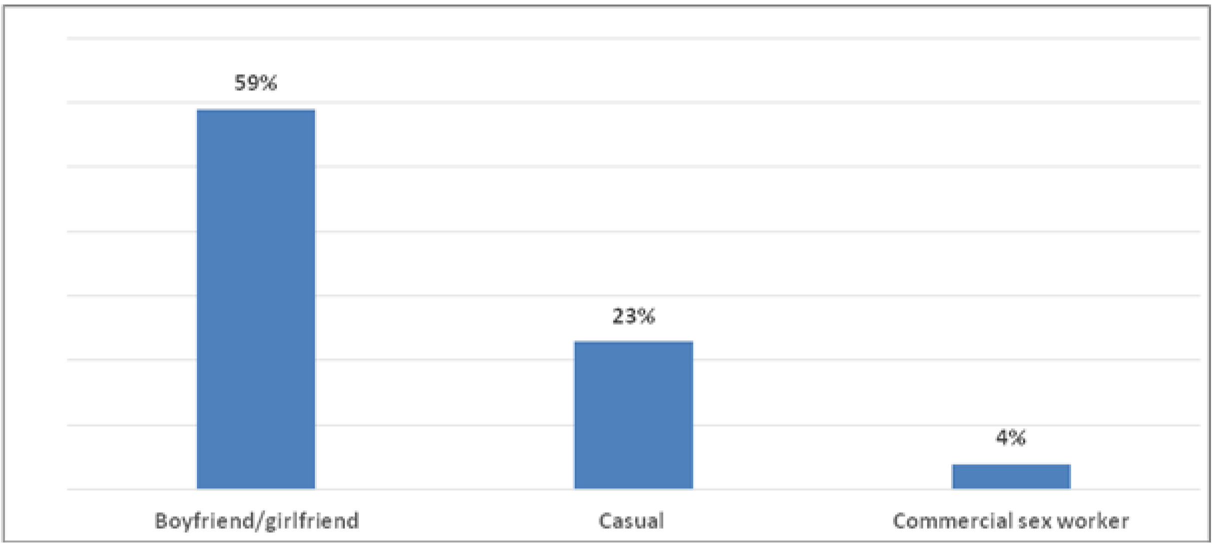


Figure 4.8: Types of sexual partners other than respondents' spouses

Furthermore, 64% of the 201 respondents (129/201) reported to have had sex with more than one sexual partner who was not their spouse or co-habiting partner. Sex without a condom was reported by 32% while 20% reported having sex with commercial sex workers (figure 4.9).

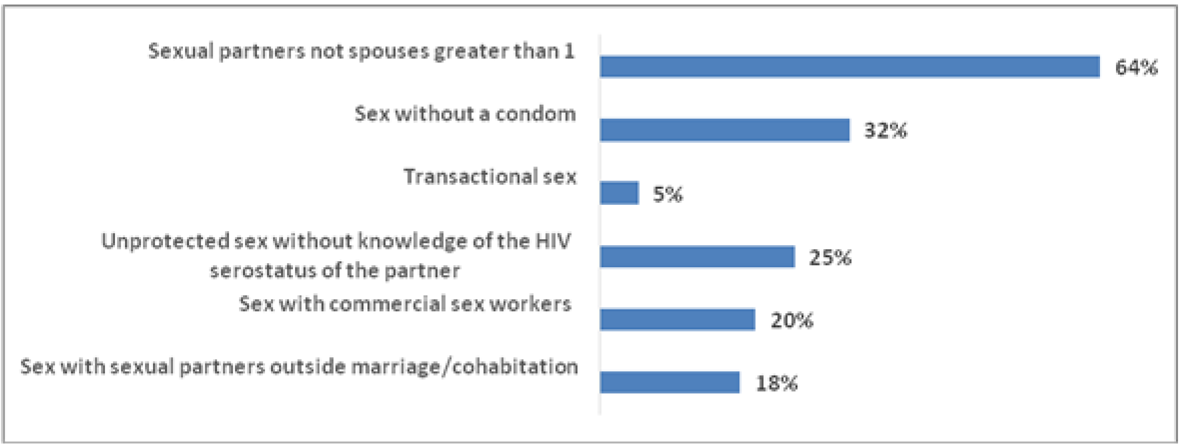


Figure 4.9: Respondents' risky sexual practices

Respondents' socio-demographics and sexual risk behaviours

Respondents were asked different questions to assess their sexual risk behaviours. When their responses were analysed, 29% of the respondents were found to have practiced risky sexual behaviours in the past 12 months. Respondents' sexual behaviours significantly differed by all the analysed socio-demographics except sex and level of education.

Sexual risk behaviour significantly increased with each subsequent year of ART initiation (25%, 27% and 36% in 2010, 2011 and 2012 respectively, p<0.001). Sexual risk behaviour was higher amongst females (30%) than males (27%), but this finding was not statistically significant (p=0.231). Younger PLHIV (<30 years) (40%) were more likely to engage in risky sexual practices than PLHIV in the 31-44 (28%) and 45-80 (22%) age brackets (*p*=<0.001). Respondents who were single were also more likely to practice risky sexual behaviours than those who were married or living with a sexual partner (*p*=<0.001). Comparably PLHIV who were unemployed as well as those who derived livelihoods from trading and farming were more likely to practice risky sex than their counterparts in other occupations (*p*=<0.011). Differences in sexual risk behaviour by respondents' socio-demographics are summarised in table 4.13.

Table 4.13: Respondents' socio-demographics and sexual risk behaviours

Variable	**Total sexual risk behaviour** **NO RISK**	 **YES RISK**	**P-value**
Gender			
Female	646 (70%)	278 (30%)	0.231
Male	351 (73%)	130 (27%)	
Age category			
≤30	213 (60%)	140 (40%)	**<0.001**
31–44	534 (72%)	206 (28%)	
44–80	248 (78%)	70 (22%)	
Education			
Completed Primary	337 (70%)	159 (32%)	0.144
Completed Secondary	448 (71%)	187 (29%)	
Tertiary Education	172 (75%)	57 (25%)	
Marital status			
Currently married	792 (84%)	148 (16%)	**<0.001**
Living with sexual partner	17 (68%)	8 (32%)	
Single	77 (33%)	159 (67%)	
Widowed	131 (56%)	103 (44%)	
Source of income			
Office work	179 (74%)	62 (26%)	**<0.011**
Spouse	90 (89%)	11 (11%)	
Farming	183 (69%)	220 (31%)	
Trading	499 (69%)	220 (31%)	
Unemployed	21 (51%)	20 (49%)	

Comparison of sexual risk behaviours of the two study groups

When sexual risk behaviours of the two study groups were compared, overall sexual risk behaviour was higher among PLHIV who had never participated in support group activities [31%; (233/419)] than those who had participated [27%; (186/419)], showing that there is a significant difference between the two groups (*p*=0.045). There is no difference between PLHIV who frequently attend support group meetings than those who attend less frequently (28% vs. 25%; p=0.498). See table 4.14.

Table 4.14: Respondents' PLHIV support group participation and sexual risk behaviours

Variable	Total sexual risk behaviour		P-value
	NO RISK	YES RISK	
Support group participation			
Non-participation	507 (69%)	233 (31%)	**0.045**
Participation	511 (73%)	186 (27%)	
Frequency of participation			
1–5 times	152 (75%)	52 (25%)	0.498
6–12 times	258 (72%)	101 (28%)	

4.2.2.2 Objective 2

To explore reasons for participation or non-participation in support groups among PLHIV

Reasons for participation in PLHIV support group activities

As indicated in section 4.3.1.4 above, approximately 47% of respondents had ever participated in support group activities. For those who participated, the main reasons were: getting advice from others (51%), sharing experiences (48%), and seeking help (31%); (See Table 4.15). These reasons rhyme with three dimensions of social support – emotional, instrumental and informational support (Heaney & Isreal 2002:186).

Table 4.15: Respondents' reasons for participating in PLHIV support groups

Reasons for participation	Frequency	Valid percentage
To share experiences	378	48%
Seek help	244	31%
Get advice from others	402	51%

Reasons for non-participation in PLHIV support group activities

Findings from this study indicate that the majority (53%) of the respondents do not belong to and have never participated in support group meetings. The reasons given for non-participation include lack of time (35%), lack of information about benefits of PLHIV support groups (29%), not wanting others to know the respondent's positive HIV status (14%), lack of transport (6%) and having other sources of support (5%). (See table 4.16)

Table 4.16: Respondents' reasons for non-participation in PLHIV support group activities

Reasons for non-participation	Frequency	Valid percentage
I do not have time to attend support group meetings	312	35%
Have no information about benefits of support groups	258	29%
I do not want others to know my status	121	14%
Distance/financial constraints	49	6%
I get support from other people	46	5%

4.2.2.3 Correlation analysis

HIV-related stigma scores, social support scores and cumulative adherence were tested for significant relationships using Spearman's correlation analysis. Correlation coefficients among HIV-related stigma, social support and adherence are shown in Table 4.17 below.

Results show that there was no correlation between adherence and stigma (*r*=0.04), though the finding was not significant (*p*=0.10). Results also suggest that there is a significant but weak negative correlation between social support and stigma (*r*=-0.08, *p*<0.001), and a weak positive correlation between adherence and social support (*r*=0.08, *p*<0.001). Correlation analysis was only limited to continuous variables.

Table 4.17: Correlation coefficients amongst selected variables

Variables	Stigma	Social support	Adherence
Stigma	1.0000		
Social support	**r=-0.08 p<0.001**	1.0000	
Adherence	r=- 0.04 p=0.0988	**r=0.08 p<0.001**	1.0000

4.2.2.4 Multivariable analysis

The results presented above were from univariate and bivariate analyses - mainly done to assess whether one independent variable is associated with one dependent variable. With the aim to examine relationships between and among more than two study variables, the researcher carried out multivariable analyses. The results are summarised below.

Crude and adjusted associations between respondents' socio-demographics, support group participation and social support

Table 4.18: Crude and adjusted associations between respondents' socio-demographics, support group participation and social support

Variable	**Univariate**		**Multivariable**	
	Coefficient (95% CI)	**p-value**	**Coefficient (95% CI)**	**P-value**
Support group participation				
Non-participation*				
Participation	0.41 (-0.3, 1.14)	0.77	-0.09 (-0.85, 0.67)	0.823
Gender				
Female*				
Male	0.91 (0.122, 1.69)	**0.024**	0.16 (-0.70, 1.03)	0.713
Age category				
≤30*				
31-44	0.58 (-0.32, 1.48)	0.207	0.24(-0.74 , 1.22)	0.633
45-80	0.83 (-0.23, 1.89)	0.125	0.43(-0.79 , 1.64)	0.490
Education				
Primary*	1		1	
Secondary	0.55 (-0.26, 1.37)	0.183	0.28 (-0.60, 1.16)	0.530
Tertiary	2.31 (1.22, 3.40)	**<0.001**	1.73 (0.44, 3.02)	**0.009**
Sources of income				
Office Work*				
Spouse	-1.68 (-3.40, 0.04)	0.056	-1.22 (-3.13 , 0.68)	0.207
Farming	-1.83 (-3.05, -0.60)	**0.004**	-0.53 (-1.94, 0.87)	0.456
Trading	-1.88 (-2.91, -0.85)	**<0.001**	-0.66 (-1.82 , 0.50)	0.265
Unemployed	-0.62 (-2.72, 1.47)	0.560	0.82 (-1.41, 3.04)	0.473
Marital status				
Currently married*				
Living with sexual partner	-2.82 (-5.61, -0.03)	0.048	-2.96 (-5.84 , -0.09)	**0.043**
Single	-1.06 (-1.99, -0.13)	**0.026**	-1.34 (-2.43, -0.32)	**0.011**
Widowed	-2.76 (-3.67, -1.85)	**<0.001**	-2.54 (-3.56 , -1.51)	**<0.001**

**reference category*

Univariate and multivariable Generalised Estimating Equations (GEE) models were fitted to identify factors associated with respondents' perceived social support. Results are shown in Table 4.18 above. While in the univariate analysis gender, educational status, sources of income and marital status significantly predicted perceived social support, only educational status and marital status remained significantly associated with perceived social support in the multivariable model. Just like in the univariate analysis, support group participation was not associated with perceived social support (*p*=0.823).

Crude and adjusted associations between respondents' socio-demographics, support group participation, social support, HIV status disclosure and overall HIV-related stigma

Table 4.19: Crude and adjusted associations between respondents' socio-demographics, support group participation, social support, HIV status disclosure and overall HIV-related stigma

Variable	Univariate		Multivariable	
	Coefficient (95% CI)	*P*-value	Coefficient (95% CI)	P-value
Support group participation				
Non-participation*				
Participation	-0.08 (-0.99, 0.83)	0.861	-0.23 (-1.29, 0.82)	0.665
Gender				
Female*				
Male	-0.94 (-1.92, 0.03)	0.057	0.03 (-1.16, 1.22)	0.963
Age category				
≤30*				
31-44	-2.24 (-3.35, -1.14)	**<0.001**	-2.67(-4.00, -1.34)	**<0.001**
45-80	-2.57 (-3.87, -1.26)	**<0.001**	-2.91 (-4.62, -1.20)	**0.001**
Education				
Primary*				
Secondary	0.64 (-0.39, 1.66)	0.223	0.68(-0.55 , 1.91)	0.276
Tertiary	-0.90 (-2.26, 0.460	0.194	-0.13 (-1.94, 1.68)	0.888
Sources of income				
Office Work*				
Spouse	-0.67 (-2.81, 1.46)	0.536	0.02 (-2.50,2.54)	0.991
Farming	2.38 (0.85, 3.91)	**0.002**	3.04 (1.08 , 5.01)	**0.002**
Trading	0.67 (-0.61, 1.96)	0.304	0.51 (-1.10, 2.11)	0.539
Unemployed	2.40 (-0.19, 4,99)	0.069	0.95 (-2.32, 4.22)	0.568
Marital status				
Currently married*				
Living with spouse	3.73 (0.26, 7.200	**0.035**	2.20 (-1.62, 6.02)	0.258
Single	1.86 (0.68, 3.04)	**0.002**	1.17 (-0.43, 2.76)	0.152
Widowed/ Separated	1.40 (0.26, 2.53)	**0.016**	1.49 (-0.24, 3.22)	0.090
Social support	-0.10 (-0.16, -0.04)	**0.001**	-0.05 (-0.12, 0.02)	0.188
Overall disclosure				
No*				
Yes	-0.36 (-1.64, 0.93)	0.587	1.12 (-0.33, 2.58)	0.131

**reference category*

Univariate and multivariable Generalised Estimating Equations (GEE) models were fitted to identify factors associated with respondents' HIV-related stigma. Results are shown in Table 4.19 above. While in the univariate analysis age, sources of income, marital status and social support significantly predicted HIV-related stigma, only age and sources of income remained significantly associated with HIV-related stigma in the multivariable model. Like in the univariate analysis, support group participation was not associated with overall HIV-related stigma (p=0.665).Also, social support and positive HIV status disclosure were not found associated with overall HIV-related stigma. This finding contradicts an earlier study (Bekele et al 2013:6) which reports a relationship between social support and physical and mental health.

Crude and adjusted associations between respondents' socio-demographics, support group participation, social support, HIV stigma and positive HIV status disclosure

Table 4.20: Crude and adjusted associations between respondents' socio-demographics, support group participation, social support, HIV stigma and positive HIV status disclosure

Variable	Univariate		Multivariable	
	Odds ratio (95% CI)	**P-value**	**Odds ratio (95% CI)**	**P-value**
Support group participation				
Non-participation	1		1	
Participation	1.45 (1.12, 1.89)	**0.005**	1.30 (0.93, 1.80)	0.120
Gender				
Female	1		1	
Male	1.61 (1.20, 2.16)	**0.001**	1.16 (0.80, 1.69)	0.441
Age category				
≤30	1		1	
31–44	1.29 (0.95, 1.73)	0.099	0.68 (0.46, 1.01)	0.058
45–80	2.11 (1.41, 3.16)	**<0.001**	0.86 (0.49, 1.49)	0.581
Education				
Primary	1		1	
Secondary	0.78 (0.58, 1.04)	0.088	0.94 (0.64, 1.38)	0.766
Tertiary	1.34 (0.88, 2.04)	0.166	2.09 (1.16, 3.76)	**0.014**
Sources of income				
Office Work	1		1	
Spouse	2.10 (0.94, 4.70)	0.070	0.98 (0.39, 2.45)	0.966
Farming	0.76 (0.47, 1.21)	0.240	1.31 (0.70, 2.46)	0.395
Trading	0.61 (0.41, 0.90)	**0.012**	0.91 (0.54, 1.51)	0.708
Unemployed	0.24 (0.12, 0.48)	**<0.001**	0.59 (0.25, 1.40)	0.234
Marital status				
Currently married	1		1	
Living with spouse	0.27 (0.11, 0.71)	**0.007**	0.26 (0.09, 0.74)	**0.016**
Single	0.07 (0.05, 0.11)	**<0.001**	0.07 (0.05, 0.11)	**<0.001**
Widowed/ Separated	0.09 (0.06, 0.14)	**<0.001**	0.09(0.06, 0.15)	**<0.001**
Social support	1.02 (1.00, 1.04)	**0.005**	1.02 (0.99, 1.04)	0.089
Overall HIV-related stigma	0.99 (0.98, 1.00)	0.415	1.01 (0.99, 1.03)	0.117

Univariate and multivariable Generalised Estimating Equations (GEE) models were fitted to identify factors associated with respondents' positive HIV status disclosure to sexual partners and or relatives. Results are shown in Table 4.20 above. While in the univariate analysis PLHIV gender, age, sources of income and marital status as well as support group participation and social support significantly predicted HIV-disclosure, only education and marital status remained significantly associated with HIV disclosure in the multivariable model. PLHIV support group participation and social support were not associated with HIV status disclosure after adjusting for other variables (p=0.120 and p=0.089 respectively). Just like in the univariate analysis, overall stigma was not associated with positive HIV status disclosure. This finding contradicts an earlier study (Wastrom et al 2013:7) which reports a relationship between social support, HIV status disclosure and mental health.

Crude and adjusted associations between respondents' socio-demographics, support group participation, HIV stigma, positive HIV status disclosure, ART adherence and sexual risk behaviour

Table 4.21: Crude and adjusted associations between respondents' socio-demographics, support group participation, HIV stigma, positive HIV status disclosure, adherence and sexual risk behaviour

Variable	**Univariate**		**Multivariable**	
	Odds ratio (95% CI)	**P-value**	**Odds ratio (95% CI)**	**P-value**
Support group participation				
Non-participation	1		1	
Participation	0.79 (0.63, 0.99)	0.046	0.97(0.68, 1.38)	0.872
Gender				
Female	1		1	
Male	0.86 (0.67, 1.10)	0.231	1.30 (0.88,1.93)	0.191
Age category				
≤30	1		1	
31–44	0.58 (0.45, 0.77)	**<0.001**	0.64 (0.41, 0.99)	**0.044**
45–80	0.43 (0.31, 0.60)	**<0.001**	0.63 (0.36, 1.10)	0.106
Education				
Primary	1		1	
Secondary	0.88 (0.68, 1.14)	0.345	0.59 (0.39, 0.88)	**0.010**
Tertiary	0.70 (0.49, 1.00)	0.050	0.49 (0.26, 0.92)	**0.027**

Variable	Univariate		Multivariable	
	Odds ratio (95% CI)	P-value	Odds ratio (95% CI)	P-value
Sources of income				
Office Work	1		1	
Spouse	0.35 (0.18, 0.70)	**0.003**	0.49 (0.20, 1.24)	0.133
Farming	1.29 (0.88, 1.91)	0.194	1.36 (0.71, 2.61)	0.354
Trading	1.27 (0.91, 1.77)	0.151	0.97 (0.55, 1.69)	0.903
Unemployed	2.75 (1.40, 5.41)	**0.003**	0.59 (0.18, 1.89)	0.376
Marital status				
Currently married	1		1	
Living with spouse	2.52 (1.07, 5.94)	**0.035**	2.11 (0.71,6.25)	0.180
Single	11.05 (7.99, 15.28)	**<0.001**	9.42 (5.70, 15.56)	**<0.001**
Widowed/ Separated	4.21 (3.08, 5.75)	**<0.001**	4.18 (2.45, 7.14)	**<0.001**
Overall HIV-related stigma	1.01 (1.00, 1.03)	**0.019**	1.01 (0.99, 1.03)	0.516
Overall disclosure				
No	1		1	
Yes	0.04 (0.03, 0.05)	**<0.001**	0.07 (0.05, 0.11)	**<0.001**
Adherence				
Non-Adherent	1		1	
Adherent	0.66 (0.44, 0.99)	0.045	0.56 (0.31, 1.02)	0.058

Univariate and multivariable Generalised Estimating Equations (GEE) models were fitted to identify factors associated with respondents' sexual risk behaviours. Results are shown in Table 4.21 above. While in the univariate analysis age, sources of income, marital status, HIV-related stigma and HIV status disclosure significantly predicted sexual risk behaviour, only age, education, marital status and positive HIV status disclosure remained significantly associated with sexual risk behaviour in the multivariable model. This finding supports an earlier finding, which reports an association between positive HIV status disclosure and sexual risk behaviour (Mfecane 2013:1). However, the finding contradicts an earlier report that non-adherence to ART is associated with risky sexual behaviours (Kalichman et al 2010:1)

PLHIV support group participation, HIV stigma and ART adherence were not associated with sexual risk behaviour after controlling for other variables (p=0.872, 0.516 and 0.058 respectively).

Crude and adjusted associations between respondents’ socio-demographics, support group participation, HIV stigma, positive HIV status disclosure, and ART adherence

Table 4.22: Crude and adjusted associations between respondents’ socio-demographics, support group participation, HIV stigma, positive HIV status disclosure, and ART adherence

Variable	Univariate		Multivariable	
	Odds ratio (95% CI)	P-value	Odds ratio (95% CI)	P-value
Support group participation				
Non-participation	1		1	
Participation	1.58 (1.07, 2.32)	**0.022**	1.71 (1.08, 2.72)	**0.022**
Gender				
Female	1		1	
Male	0.82 (0.55, 1.22)	0.326	0.67 (0.41,1.11)	0.122
Age category				
≤30	1		1	
31–44	0.59 (0.45, 0.77)	**<0.001**	1.37 (0.77, 2.42)	0.283
45–80	0.43 (0.31, 0.60)	**<0.001**	1.03 (0.52, 2.07)	0.925
Education				
Primary	1		1	
Secondary	1.12 (0.74, 1.72)	0.589	0.97 (0.58, 1.63)	0.906
Tertiary	0.94 (0.54, 1.61)	0.817	0.88 (0.40, 1.88)	0.734
Sources of income				
Office work	1		1	
Spouse	0.61 (0.27, 1.39)	0.241	0.45 (0.17, 1.24)	0.122
Farming	0.92 (0.48, 1.79)	0.814	0.71 (0.30, 1.68)	0.435
Trading	0.98 (0.56, 1.71)	0.931	0.75 (0.36, 1.57)	0.452
Unemployed	0.45 (0.18, 1.10)	0.079	0.59(0.15, 2.31)	0.445
Marital status				
Currently married	1		1	
Living with spouse	0.27 (0.11, 0.70)	**0.006**	0.23 (0.08 , 0.63)	**0.044**
Single	1.24 (0.72, 2.13)	0.429	1.74 (0.78 , 3.86)	0.174
Widowed/ Separated	0.80 (0.51, 1.25)	0.323	0.73 (0.37, 1.46)	0.381
Overall HIV-related stigma	0.99 (0.97, 1.01)	0.396	1.00 (0.98, 1.03)	0.994
Overall disclosure	1		1	
No	0.92 (0.55, 1.54)	0.754	0.99 (0.53, 1.86)	0.976
Yes				

Univariate and multivariable Generalised Estimating Equations (GEE) models were fitted to identify factors associated with respondents' adherence to ARVs are shown in table 4.23 above. While in the univariate analysis age, marital status and support group participation significantly predicted ART adherence, only support group participation and marital status remained significantly associated with ART adherence in the multivariable model. Respondents who had participated in PLHIV support group activities [OR=1.71 (95%C.I; 1.08, 2.72) were two times more likely to adhere to their ARV medication than those who had never participated. This finding is consistent with findings in earlier studies (Obirikorang et al 2013:1; Walstrom et al 2013:7).Respondents living with sexual partners but not married [OR=0.23 (95% C.I; 0.08, 0.63)] were less likely to adhere to their ARV medication than those who were married.

Internal consistency and reliability of stigma and adherence measures

Although the researcher adopted items for measuring social support, stigma and ART adherence from tools, whose reliability had been tested and validated, items for measuring internal stigma, external stigma and social support were re-validated during the pre-test of the questionnaire. The measures were found to have good internal consistency (Cronbach's alpha $\geq$ 0.75) as indicated in table 4.23 below.

Table 4.23: Cronbach's alpha for stigma and ART adherence measures

Construct	Cronbach's Coefficient Alpha
Internal stigma	0.80
External stigma	0.92
Social support	0.82

4.3 OVERVIEW OF THE RESEARCH FINDINGS

The above results indicate that 47% of PLHIV has ever participated in support group activities, while 53% has never. They also show us that PLHIV aged 30 years and above are more likely to participate in support group activities than those aged below 30 years; that male PLHIV are more likely to participate in support group activities than female PLHIV. Also, results show that PLHIV engaged in business and farming are more likely to participate in support group activities than PLHIV engaged in others sources of livelihoods; and that levels of education and source of income are not predictors of participation in support group activities. Most PLHIV patronise hospital-based than community-based support groups.

The results of univariate analysis indicate that PLHIV who participate in support group activities differ from those who do not, in terms of HIV-related internal stigma, positive HIV status disclosure, sexual risk behaviours, and ART adherence. The two groups do not differ, in terms of perceived social support.

4.4 CONCLUSION

This chapter presented results of both descriptive and inferential statistics carried out using data from respondents. Descriptive statistics showing socio-demographic and other descriptive characteristics of the respondents were presented using frequency tables and bar graphs. Also, the chapter presented the results from comparisons of the two study groups on *socio-demographics, perceived social support, HIV-related stigma, positive HIV status disclosure, sexual risk behaviour and ART adherence.* The analysis was done using various statistical methods. The findings show that PLHIV who participate in support group activities differ from those who do not as a result of HIV-related internal stigma, positive HIV status disclosure, ART adherence and sexual risk behaviours. However, the two study groups do not differ in terms of socio-demographics, perceived social support and external stigma. The findings also show that PLHIV obtain social support from family members, healthcare workers and co-workers rather than just from PLHIV support groups. In the next chapters, the researcher will discuss these findings, make conclusions regarding the research questions and provide recommendations.

CHAPTER 5

DISCUSSION AND INTERPRETATION OF STUDY FINDINGS

5.1 INTRODUCTION

The previous chapter covered findings from the cross-sectional study. In this fifth chapter, the researcher discusses and interprets the study findings and compares them with findings from related studies cited in the literature reviewed.

5.2 RESEARCH DESIGN AND METHOD

In order to answer the first two research questions, the researcher used a quantitative cross-sectional design to determine reasons for PLHIV participation and non-participation in support groups and to compare specific behavioural outcomes of PLHIV who participate in support group activities and those who do not. Findings from this cross-sectional study were used to develop an evidence-based model for revitalising PLHIV caregiver social support competencies.

5.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

5.3.1 Socio-demographic characteristics of respondents

Sex of respondents

Data analysis shows that 66% (1,111/1,643) of the respondents was female. Since respondents were randomly selected, this means that more female than male Nigerians are infected with HIV. This finding is consistent with the UNAIDS report which states that the number of women living with HIV in Sub Saharan Africa is two times that of HIV positive men of the same age group (UNAIDS 2013:17). It is therefore not surprising that the majority of respondents were female. Since the sample was drawn from PLHIV on ART, this also indicates that more females than male are on ART. Again, this corroborates earlier reports, which show that more women than men are enrolled on ART. According to UNAIDS (2014:48), in most regions, including Sub Saharan Africa, HIV treatment coverage for men is lower than that for women. The UNAIDS report indicates that in low and middle income countries, 57% of treatment eligible men received anti-retroviral therapy in 2012, compared to 73% of treatment-eligible women.

Age of respondents

Analysis of the respondents' age shows that 75% (1,259/1,676) of all respondents was below 45 years. This finding supports earlier study, which shows that HIV is more prevalent in the youthful and more sexually active population group (CDC 2013:1). The finding is also consistent with the national trend of HIV distribution in Nigeria as reported in the NARHS (2013:10). The report shows that HIV infection in Nigeria affects mostly people in the 15-49 years bracket. The NARHS report (2013:10) reveals that while the national HIV prevalence was 3.4%, HIV prevalence was highest among the 35-39 years age group (4.4%).

Respondents' education

Two thirds (60%) of respondents (1,004/1676) had completed at least secondary level education, and slightly above one third (35%) or 580/1,676 had only completed primary education, implying that at least 95% of the respondents had completed primary education. The high literacy rate was also demonstrated by the fact that over 95% of the respondents was able to complete the self-administered questionnaire, which was in English. This high literacy rate is consistent with Nigeria Bureau of Statistics' report of 2010, which states that 72% of adult Nigerians are able to read and write in both their local languages and English (NBS 2010:20).

In terms of HIV vulnerability, this finding is consistent with other studies, which show that persons with education above primary level are more likely to indulge in risky sexual behaviours than their counterparts with lower education. In Nigeria, the National HIV/AIDS and Reproductive Health Survey done in 2012 reports that HIV prevalence was generally higher among respondents with primary and secondary education (4.0%) and lowest among respondents who had Qur'anic education only (2.4%) (NARHS 2013:10).

Respondents' religion

Christians constituted the majority of respondents (77%), followed by Muslims (21%) and others (1%). This statistic is inconsistent with national socio-demographics, which indicate that the country's population is almost equally divided between Christians and Muslims. Although the Nigerian population is believed to be equally divided between Christians and Muslims (50%:50%), the majority of FHI 360 supported hospitals and thus the target respondents were from predominately Christian states in the southern and eastern parts of the country, hence the reason the majority of respondents were Christians.

Respondents' occupations

The majority of respondents were businessmen/women (50%) followed by farmers (18%) and office workers (16%). This data relatively reflects the major sources of livelihoods in Nigeria. Over the years, the country's dependency on oil has relegated farming to a lesser prominent source of livelihoods as the majority of the population found other opportunities availed by the huge national annual oil revenues (NBS 2010:12). Consequently, Nigerians from the oil-rich southern states are richer than their counterparts in other regions of the country. However, this imbalance has costs. The National HIV/AIDS and Reproductive Health Survey indicates that HIV prevalence was higher among the wealthier (3.7%) than the poorer (2.9%), (3.5%), and was highest in the South-South region (5.5%). Studies have also found that persons who earn their livelihoods from businesses tend to be occupational migrant workers and more likely to engage in risky sex and thus susceptible to HIV infection (Lurie, Williams, Zuma, Mkaya-Mwamburi, Garnett, Sturm, Sweat, Gittelsohn & Karim 2003:1). This information is corroborated by findings from the present study.

Respondents' marital status

Respondents who were married accounted for 57% of all respondents (947/1,673). Twenty nine respondents (2%) were also living with sexual partners although not married. This finding is consistent with recent studies which show that married couples and persons in stable relationships account for the highest percentage of new HIV infections (Uganda AIDS Commission 2012:2). This finding highlights the significance of positive HIV status disclosure.

5.3.2 Respondents' participation in support group activities

At least 33% of respondents indicated that they were members of a PLHIV support group, 8% had been members but had left, 6% had ever participated in PLHIV support group activities but had never been members while 53% had never participated in PLHIV support group activities. As participation in support group activities was defined as both being a member and having ever participated in PLHIV support group activities, 47% of respondents were considered to have ever participated in PLHIV support group activities against 53% who had never. This shows that the study sample was comprised approximately two equal study population groups.

The finding that only 33% of PLHIV belonged to PLHIV support groups is not significantly different from an earlier study in Uganda, which put the figure at 30% (Walakira et al 2012:38). The finding, which shows low patronage of PLHIV support groups by PLHIV, is also related to another finding in this study, which shows that only 16% consider PLHIV support group members as their major source of social support. This implies that apart from PLHIV support groups, PLHIV have access to other sources of social support and care.

5.3.3 PLHIV's socio-demographics and support group participation

This study sought to establish whether PLHIV who participate in support group activities differ from those who do not in terms of their socio-demographic characteristics. Analysis of data from the study shows that there is no significant difference between PLHIV who participate in support group activities and those who do not in terms of their levels of education (*p*=0.748) and sources of income (*p*=0.067), but differed in marital status (*p*=<0.001), age (*p*=<0.001), sex (*p*=0.029) and religion (*p*=0.034).

People who were not married (single, widowed, separated or divorced) were less likely to participate in support group activities than those who were married or living with a sexual partner (37% vs 67%). PLHIV support group participation was similar among respondents aged 31-44 (49%) and those aged 45-80 (50%), however, people aged below 30 years were less likely to participate in support group activities than those between 31 and 44 years as well as those over 45 years (21%vs 54% vs 25%). Despite there being more HIV positive women than men, men were more likely to participate in support group activities than women (51% vs 45%); and persons who practiced traditional religion were more likely to participate in support group activities than those who practiced Christianity and Islam (80% vs 47% vs 46%).

The above findings indicate that education and income status are not predictors of participation in PLHIV support group activities. This may be attributed to the high levels of literacy and incomes in Nigeria, which make the population almost homogeneous in terms of the two parameters.

The finding that married PLHIV are more likely to participate in support group activities than PLHIV who are not married may be related to time constraints. At least 35% of respondents who do not participate in support group activities cited lack of time as the main reason. Given that single, divorced or windowed PLHIV tend to shoulder more household responsibilities than their married counterparts who share the load with their partners, it is possible that their non-participation in support group activities is associated with this factor.

The revelation that people aged below 30 years were less likely to participate in support group activities than those of higher age is consistent with young people's health seeking behaviour (Babatunde, Tawab, Geibel, Kalibala, Okal, Mane, Sohaba, Walker & Green 2014:4). Generally, social norms stigmatise young people and inhibit their health seeking behaviour. For example, society does not expect unmarried youths to be infected with sexually transmitted infections such as HIV or to be pregnant. Because of this, young people generally shun places where sexual reproductive health services are provided. This may explain why young PLHIV shun support groups which tend to be patronised by older people. This is the main reason some programmes have responded to this challenge by establishing youth friendly service centres.

The finding that despite there being more HIV positive women than men, men were more likely to participate in support group activities than women (51% vs 45%) is a reflection of gender issues in Sub-Saharan Africa. Generally, African men have more “free” time and money than women. Given that 41% of respondents who do not participate in support group activities cited time and money (transport) constraints, it is possible that this is the reason fewer women than men can afford to participate in support group activities.

5.3.4 Participation in PLHIV support group activities and PLHIV behavioural outcomes

5.3.4.1 PLHIV support group participation and perceived social support

The researcher was interested in establishing whether PLHIV who participate in support group activities differ from those who do not in terms of perceived social support. The study compared social support median scores of PLHIV who participate in support group activities and those who do not. PLHIV who participate in support group activities had a median score of 32 (27-37), while those who do not had a median score of 31 (26-37). The aggregate score of all respondents was 32 (27-37) out of the maximum possible score of 40. This implies that there is no significant difference between PLHIV who participate in support group activities and those who do not in terms of perceived social support (*p=0.28*). Generally, perceived social support was high among all respondents (32/4 =80%), implying that most PLHIV have access to social support.

Also, although only 33% of respondents reported that they belong to a PLHIV support group, 80% of respondents perceived that they receive adequate social support. This finding is consistent with responses to the question that asked respondents to rank their sources of social support. The majority ranked health workers (66%) and family members (36%) above PLHIV support groups (16%), implying that even for PLHIV who do not participate in PLHIV support group activities, accessing social support is not a challenge. This finding tells us that PLHIV support group participation is not associated with perceived social support among PLHIV. Results from multivariate analysis also tell us that social support is not a predictor of HIV-related stigma and positive HIV status disclosure. This contradicts earlier findings in a study by Bekele et al (2013:6), which show that social support has a significant direct effect on physical and mental health. The possible explanation for the contradiction may be the social-cultural differences in the communities where the studies were carried out. It is generally believed that the extended family system in Africa and thus in Nigeria is a stronger source of social support compared with the family system in Canada. It is therefore possible for PLHIV in Nigeria to discount the value of PLHIV support group participation than PLHIV in Ontario Canada because the former are more likely to depend on their families for social support than the latter.

5.3.4.2 PLHIV support group participation and HIV-related stigma

Median scores of internal stigma were significantly lower amongst PLHIV who participate in support group activities [16 (14-19)] than those of PLHIV who had never participated [18 (15-20)] (*p*=<0.001). This finding is consistent with earlier studies, which report an association between support group participation and reduced HIV-related stigma (Walstrom 2013:1).

On the other hand, median scores of external stigma of PLHIV who participate in support group activities [14 (10-18)] were almost similar to scores of PLHIV who do not [14 (9-17)], (*p*=0.250). Overall internal stigma [17 (14-20)] was higher than overall external stigma [14 (9-17)] amongst all respondents (figure 4.6). Total median stigma scores (internal plus external) of respondents who participate in support group activities [28 (22-35)] and those who do not [29 (21-35)] were not significantly different (*p*=0.88).

Possible explanation for this could be that, while it is possible for an individual to overcome self or internal stigma through interventions such as counselling and disclosure, the individual has no control over external stigma because it is exerted by other people. Also, participation in PLHIV support group activities automatically leads to one's HIV status being known, thus opening up for public judgement and perceptions, which may increase the individuals' external stigma. Moreover, HIV-related stigma and discrimination persist as major obstacles to an effective HIV response in all parts of the world, with national surveys finding that discriminatory treatment of PLHIV remains common in multiple facets of life (UNAID 2014:12).

5.3.4.3 PLHIV support group participation and HIV status disclosure

Disclosure was significantly higher amongst respondents who had participated in support group activities (81%) than those who had never participated (75%) (*p*=0.005). This finding is consistent with previous findings which state that belonging to support group activities enhances PLHIV's self-efficacy to disclose their positive HIV status to their sexual partners. In a qualitative study done in Rwanda (Walstrom et al 2013:1), support group members reported that participating in the support group activities led to positive changes in mental health, positive HIV status disclosure, ART adherence and sexual risk behaviours. However, the support group activities had been facilitated by para-professionals who had been trained in trauma counselling rather than PLHIV themselves.

Frequency of attending support group meetings did not have a dose effect on positive HIV status disclosure (*p*=0.316). The possible explanation for this is that, because PLHIV who participate in PLHIV support group activities inevitably disclose their status to other members, disclosure becomes a one-off event and cannot have any association with the frequency of PLHIV support group participation.

5.3.4.4 PLHIV support group participation and adherence to ART

The study sought to determine whether PLHIV who participate in support group activities differ from those who do not in terms of ART adherence. Study findings indicate that PLHIV who participate in support group activities significantly differ from those who do not in terms of adherence to ART (p=0.021). However, the frequency of attending support group activities has no association with ART adherence (p=0.461) and so does the year of ART initiation (p=0.512).

The finding that support group participation is associated with ART adherence is consistent with previous findings, which indicate that generally, social support from peers, family members or health workers increased ART adherence (Kamau et al 2012:7; Sarna et al 2013:11; Walstrom et al 2013:1). The novel finding from this study is that social support from PLHIV peers, through a support group mechanism, has value in terms of ART adherence. This finding is also consistent with the Meaningful Involvement of PLHIV (MIPA) principle, which is premised on the belief that participation of PLHIV in HIV/AIDS prevention, care and treatment enhances PLHIV behavioural outcomes.

5.3.4.5 PLHIV support group participation and sexual risk behaviours

The researcher was interested in establishing whether PLHIV who participate in support group activities differ from those who do not in terms of sexual risk behaviour. Analysis of data collected from respondents shows that overall sexual risk behaviour was higher among PLHIV who had never participated in support group activities [31%; (233/419)] than those who had participated [27%; (186/419)] implying that there is a significant difference between the two study groups (p=0.045). This finding is related to an earlier study in Kenya, which found an association between social support for PLHIV and reduction in risky sexual behaviours. In a prospective cohort study conducted in Mombasa, Kenya, researchers found that PLHIV who received community-based positive prevention reported reduced risky sexual behaviours compared with those who did not receive the support (Sarna et al 2013:11). The difference between the two studies is that in the Kenya study, social support was provided by community health workers, not PLHIV themselves. This study therefore confirms the valuable contribution of support group participation to enhancing positive living and reduction in HIV transmission. However, further analysis shows that there is no difference between PLHIV who frequently attend support group meetings and those who attend less frequently (28% vs. 25%; p=0.498).

5.3.5 Reasons for and non-participation in PLHIV support group activities

5.3.5.1 Reasons for participation in PLHIV support group activities

As indicated in section 4.3.1.4 above, approximately 47% of respondents belonged to or had ever participated in support group activities. For those who participated, the main reasons were getting advice from others (51%), sharing experiences (48%) and seeking help (31%). These reasons rhyme with three dimensions of social support: emotional, instrumental and informational support (Heaney & Isreal 2002:186). The reasons given are also consistent with a report by Fanelli and Moyo (2008:2), which states that PLHIV support groups provide forums in which members share concerns, brainstorm solutions, give each other advice and encourage one another to live positively with HIV.

5.3.5.2 Reasons for non-participation in PLHIV support group activities

Findings from this study indicate that the majority (53%) of the respondents do not belong to and have never participated in support group activities. The reasons for non-participation include lack of time (35%), lack of information about benefits of support groups (29%), fear of disclosure (14%), lack of transport (6%) and having other sources of support (5%).

Some of these reasons for non-participation are similar to findings of a previous study in South Africa, where the major reasons for non-participation in support groups were given as: i) perception that attending support group activities would be disclosing their positive HIV status to other people; ii) lack of knowledge of associated benefits; and iii) perceptions that support groups lack skills and resources to provide effective psychosocial or other support needed by PLHIV (Madiba &

Canti-Sigaqa 2012:5). This implies that while participation in support group activities is associated with less internal stigma, external stigma is an obstacle to support group participation. Popularising support group activities and increasing participation would most likely reduce HIV-related internal and external stigma.

5.4 CONCLUSION

In this chapter, the researcher has interpreted study findings and compared them with those of similar studies done before. While there are similarities in some, there are also contradictions with some findings reported in the literature reviewed.

Since it has been widely accepted that after diagnosis PLHIV suffer from stress brought about by feelings of shock, anger, and fear of being stigmatised or not knowing what will happen in the future (WHO 2013 1), and since social support has been found to enable PLHIV to overcome this stress and enhance their self-efficacy to face the challenges of living with HIV, in the future, HIV/AIDS programmes need to emphasise social support enhancing interventions in their packages. HIV-related fear and stigma inhibit uptake of, and adherence to treatment (Dlamini et al 2009:1; Omosonya et al 2013:1; Onyebuki-Iwudibia & Brown 2013:1; Wagner et al 2011:1), and therefore must be addressed in order to enhance positive outcomes of PLHIV.

In this study, the researcher found that apart from support group participation, PLHIV have other sources of social support or caregivers. These include healthcare workers, family members and co-workers. However, not all PLHIV caregivers are fully competent when it comes to providing effective social support to PLHIV. Providing social support to PLHIV requires confidence, proficiency in social communication skills, and ability to provide effective counselling.

While the findings in this study underscore the importance of support group participation and therefore the need for improving their social support competencies, PLHIV are only one source of social support for peer PLHIV. Although they have an important role to play in positively influencing their behaviour outcomes, individual PLHIV cannot be sources of the social support they themselves need. The researcher therefore recommends a model for revitalising social support competencies of all the major PLHIV caregivers identified by respondents in this study, including PLHIV, but for the benefit of their peers. The model recognises that these caregivers are already providing some social support, but puts more emphasis on the quality aspects, hence the focus on revitalising social support competencies in order to enhance its effectiveness. In the next two chapters, the researcher used the findings presented in chapter 4 and discussed in this chapter 5 to develop a model for revitalising PLHIV caregiver social support competencies in order to positively enhance behavioural outcomes of PLHIV.

CHAPTER 6

A CONCEPTUAL FRAMEWORK FOR DEVELOPING A MODEL FOR REVITALISING SOCIAL SUPPORT COMPETENCIES OF CAREGIVERS OF PEOPLE LIVING WITH HIV

6.1 INTRODUCTION

In chapters 4 and 5, the researcher reported, discussed and compared the research findings with the literature. The major highlights of the research findings are that participation in support group activities is associated with positive PLHIV behavioural outcomes; and that support groups are not the only source of social support for PLHIV. In this chapter, the researcher uses the findings to develop a framework for a model for equipping PLHIV caregivers and confidants, identified by PLHIV as their sources of social support, with competencies for enhancing PLHIV social support and behavioural outcomes. The model is intended to serve as a resource for revitalising social support competencies of support group members, family members, workmates and health workers – to enable them provide effective care and support necessary for enhancing behavioural outcomes among PLHIV. The model development process follows five steps suggested by Chin and Kramer (1995:27).

6.2 THE MAIN FINDINGS

With PLHIV support group participation defined as both being a member and ever to have participated in PLHIV support group activities, 47% of respondents reported to have at one time participated in support group activities against 53% who had never. The reasons given for non-participation include lack of time (35%), lack of information about benefits of support groups (29%), not wanting others to know the respondent’s positive HIV status (14%), lack of transport (6%), and having other sources of support (5%). The study found that there is no significant difference between PLHIV who participate in support group activities and those who do not, in terms of perceived social support ($p=0.28$).

Generally, perceived social support was high among all respondents (32/40 score = 80%), implying that most PLHIV have access to sources of social support. Also, apart from support group participation, study respondents indicated that they have other sources of social support. These include health workers, peers in workplaces and family members. When asked to rank their sources of social support, the majority of respondents ranked health workers (66%) and family members (36%), above PLHIV support groups (16%), implying that even PLHIV who do not participate in support group activities do not find challenges in accessing social support.

A comparison of the two study groups indicates significant differences in terms of HIV-related stigma, positive HIV status disclosure, sexual risk behaviour and ART adherence. PLHIV who participated in support group activities are more likely to have less HIV-related stigma, disclose their positive HIV status, adopt safer sexual behaviour, and adhere to their anti-retroviral treatment than those who do not participate.

The researcher concluded that although participation in support group activities is valuable in terms of enhancing PLHIV behavioural outcomes, other sources of social support are equally important in enhancing PLHIV behavioural outcomes. The study findings demonstrated the need for a multifaceted response to enhance greater and broader PLHIV behavioural outcomes. The multifaceted response ought to integrate approaches for enhancing social support to PLHIV, including families, co-workers, health workers, PLHIV support groups and other confidants of PLHIV. *Oxford Dictionaries Language Matters* (2015) defines a confidant as a person with whom one shares a secret or private matter, trusting them not to repeat it to others. Therefore, throughout this model, sources of social support as cited by PLHIV are categorised as “caregivers and confidants”.

6.3 CLARIFYING THE CONCEPTS

6.3.1 Identification of the main concept

The researcher used the study findings in chapter 4 to identify the main concept as *revitalising social support competencies.* The researcher found that PLHIV who participate in support group activities were more likely to portray positive behavioural outcomes than those who do not. The researcher therefore concluded that there is value in PLHIV participation in support group activities in terms of enhancing their behavioural outcomes. The study also found that apart from support group participation, PLHIV have other sources of social support or caregivers. These include healthcare workers, family members and co-workers. However, not all PLHIV caregivers are fully competent when it comes to providing effective social support to PLHIV. Providing social support to PLHIV requires confidence, proficiency in social communication skills, and ability to provide effective counselling. Through deductive reasoning, the researcher identifies revitalizing PLHIV caregiver social support competencies as the main concept in the model to be developed. The researcher believes that revitalising social support competencies would assist PLHIV caregivers and confidants to provide effective care and support to PLHIV, thereby enhancing positive behavioural outcomes of PLHIV. In the following sections, the identified concept, “revitalising social support competencies” is defined and classified for clarity.

6.3.2 Process of defining the main concept, “revitalising social support competencies”

In order to clearly define the central concept in terms of its attributes (main features, elements), each sub-part is defined. Dictionary definitions are used to define each word in the concept, *revitalising social support competencies*. Following dictionary definitions, subject literature is searched to place the concept in its appropriate context. In this step, words are defined in reverse sequence to make sure that there is “parsimony of effort and detail”, as well as logical development of the pertinent description (Wandelt & Stewart 1975:66-67). With the aim to avoid bias or distortion of the understanding or perception of the true nature of the concept, the literature search is extended beyond the field of health to psychology, anthropology and community development.

Walker and Avant (1995:38) contend that it is important to further distinguish between the *essential* and *related* attributes of a concept; that attributes should identify the theoretical meaning of the central concept as clearly and concisely as possible. Chinn and Kramer (1995:94) state that listing defining attributes of the concept aids one in isolating specific phenomena as differentiated from other similar ones. Essential and related criteria are therefore determined and employed to form the foundation of the model case description.

6.3.3 Classification of the main concept

The researcher's mental map is informed by Dickoff, James and Wiedenbach (1968:422) survey list. This is used to classify concepts of the model.

The aspects of the survey list include the recipient, the agent, the context, the procedure, dynamics, the context and the terminus. In the proposed model, the aspects are as follows:

1. The **recipients** are the PLHIV caregivers and confidants. These include health workers, support group members, family members, and co-workers. These are persons a PLHIV is likely to disclose personal information such as HIV status to. According to the findings of this study, these are the main sources of social support for PLHIV.

2. The **agents** of change are the HIV/AIDS programmes involved in strengthening health and community systems for enhancing effectiveness of HIV/AIDS interventions. These programmes use trained professionals (staff and consultants) to facilitate the desired change in social support competencies.

3. The **procedure** is the process that HIV/AIDS programmes need to follow in order to revitalise social support competencies among PLHIV caregivers and

other confidants. This procedure involves restoring social support confidence in PLHIV caregivers/confidants, enhancing their proficiency in social communication, building their abilities to provide effective counselling and social support. As well, the procedure involves encouraging them to revive, embrace and utilise social networks so as to provide comprehensive and sustainable help.

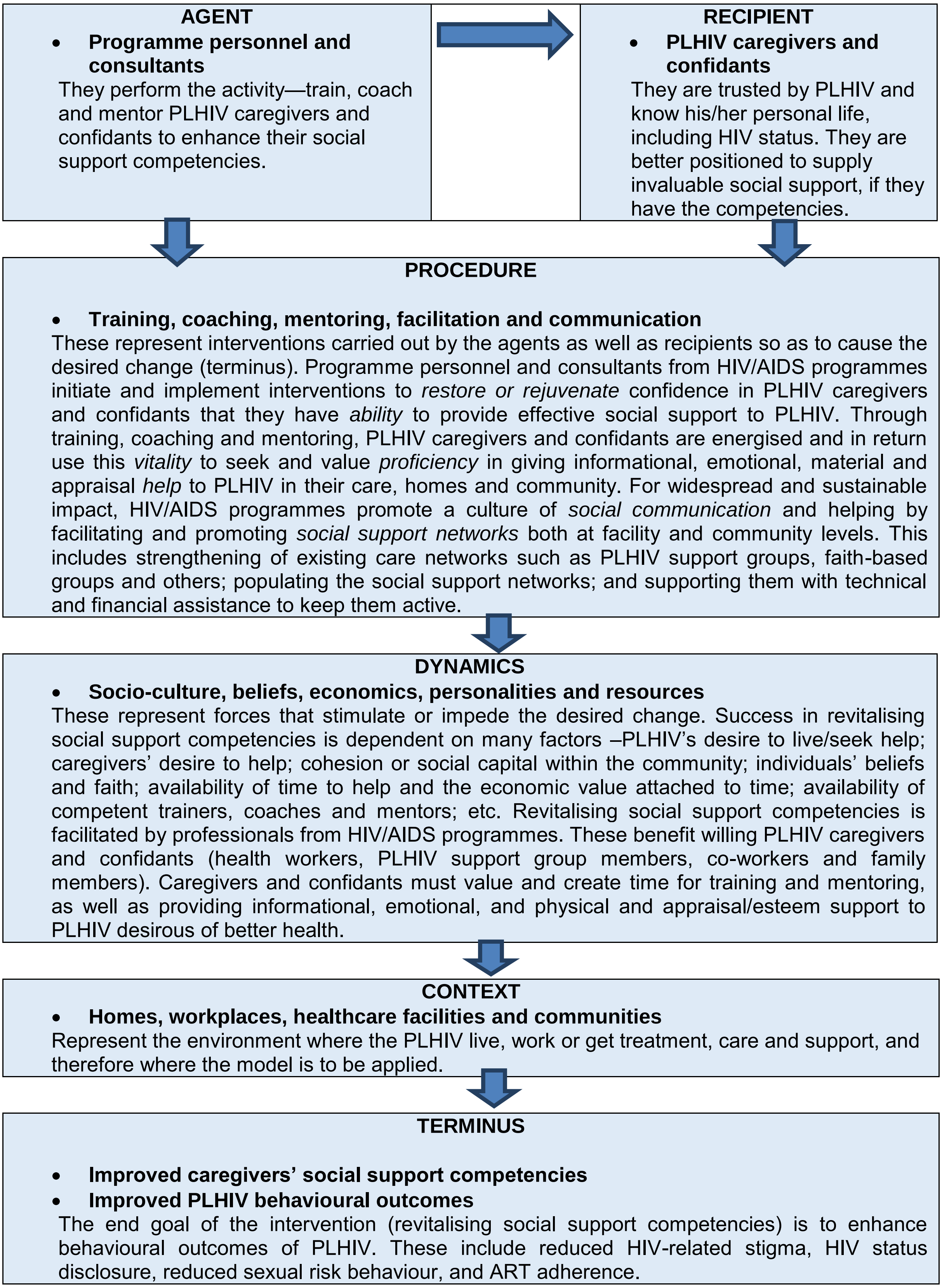
4. The **dynamics** are the catalysts and impediments that determine the success of the interventions. They represent forces that stimulate or impede the desired change. Success in revitalising social support competencies is dependent on many factors – PLHIV's desire to live/seek help; caregivers' desire to help; cohesion or social capital within the community; individuals' beliefs and faith; availability of time to help and the economic value attached to time; availability of competent trainers, coaches and mentors; etc. Revitalising social support competencies is facilitated by professionals from HIV/AIDS programmes.

   These benefit willing PLHIV caregivers and confidants (health workers, PLHIV support group members, co-workers and family members). Caregivers and confidants must value and create time for training and mentoring as well as providing informational, emotional, and physical and appraisal/esteem support to PLHIV in need of better health.

5. The **context** is the community where PLHIV live. This includes health facilities where they obtain healthcare, PLHIV workplaces and PLHIV homes.

6. The **terminus** or end goal of the activity is to enhance PLHIV's behavioural outcomes. This is facilitated by the social support perceived and received from caregivers and confidants.

The above concepts are interconnected. Figure 6.1 below illustrates the researcher's thinking-map in terms of the six features of the classified list.



AGENT

- **Programme personnel and consultants**

They perform the activity—train, coach and mentor PLHIV caregivers and confidants to enhance their social support competencies.

RECIPIENT

- **PLHIV caregivers and confidants**

They are trusted by PLHIV and know his/her personal life, including HIV status. They are better positioned to supply invaluable social support, if they have the competencies.

PROCEDURE

- **Training, coaching, mentoring, facilitation and communication**

These represent interventions carried out by the agents as well as recipients so as to cause the desired change (terminus). Programme personnel and consultants from HIV/AIDS programmes initiate and implement interventions to *restore or rejuvenate* confidence in PLHIV caregivers and confidants that they have *ability* to provide effective social support to PLHIV. Through training, coaching and mentoring, PLHIV caregivers and confidants are energised and in return use this *vitality* to seek and value *proficiency* in giving informational, emotional, material and appraisal *help* to PLHIV in their care, homes and community. For widespread and sustainable impact, HIV/AIDS programmes promote a culture of *social communication* and helping by facilitating and promoting *social support networks* both at facility and community levels. This includes strengthening of existing care networks such as PLHIV support groups, faith-based groups and others; populating the social support networks; and supporting them with technical and financial assistance to keep them active.

DYNAMICS

- **Socio-culture, beliefs, economics, personalities and resources**

These represent forces that stimulate or impede the desired change. Success in revitalising social support competencies is dependent on many factors –PLHIV's desire to live/seek help; caregivers' desire to help; cohesion or social capital within the community; individuals' beliefs and faith; availability of time to help and the economic value attached to time; availability of competent trainers, coaches and mentors; etc. Revitalising social support competencies is facilitated by professionals from HIV/AIDS programmes. These benefit willing PLHIV caregivers and confidants (health workers, PLHIV support group members, co-workers and family members). Caregivers and confidants must value and create time for training and mentoring, as well as providing informational, emotional, and physical and appraisal/esteem support to PLHIV desirous of better health.

CONTEXT

- **Homes, workplaces, healthcare facilities and communities**

Represent the environment where the PLHIV live, work or get treatment, care and support, and therefore where the model is to be applied.

TERMINUS

- **Improved caregivers' social support competencies**
- **Improved PLHIV behavioural outcomes**

The end goal of the intervention (revitalising social support competencies) is to enhance behavioural outcomes of PLHIV. These include reduced HIV-related stigma, HIV status disclosure, reduced sexual risk behaviour, and ART adherence.

Figure 6.1: Structural representation of concepts

(Adapted from Dickoff, James and Wiedenbach 1968)

6.3.4 Definition of concepts

A concept is a term or label that describes a phenomenon or group of phenomena (Meleis 2007:11). The researcher uses the study findings in chapter 4 to identify the main concept. This is then defined using a three-step method as suggested by Wandelt and Stewart (1975:64-68). The intention of identifying the main concept is to uncover its authentic meaning (McKenna 1997:62). This is achieved by exploring three types of definitions. The first exploration is by using dictionary definitions of the concept. This is followed by an all-inclusive contextual definition in line with the context of the research [the value of PLHIV support group participation in enhancing behavioural outcomes of PLHIV]. After this step, attributes of the definitions are reduced to essential and related criteria. This leads to the third step of defining the concepts using the *for-instance definition.* This is executed in form of a model case comprising all attributes of a perfect representation of the concept. Finally, a conceptual definition is developed and this forms the basis of developing the model. The steps are summarised below.

Table 6.1: Steps for defining the main concept

Step 1	Dictionary definitions of the concept
Step 2	Contextual definition of the concept
Step 3	Model case/*for-instance* definition of the concept

6.3.4.1 Dictionary definitions of the main concept

In an effort to consider its different features, dictionary definitions are used to define or locate the various usages of *revitalising social support competencies*. Glossaries of the specific discipline are taken into account to consider different aspects (Wandelt & Stewart 1975:66). The concept is defined by considering all the words it comprises.

a) Definition of *revitalising*

The concept revitalising comprises a collection of sub-components, namely *re-, vital, vitality, vitalise and -ing*

- According to *The Cambridge Advanced Learner's Dictionary Online* (2015), the prefix ***re-***means "do again" or "returning something to its original state". *The Longman Dictionary of Contemporary English Online* (2015) defines re- as "again", "again in a better way", or "back to a former state". *The Chambers 21st Century Dictionary Online* (2015) defines re- to mean "again" or "again and in a different way". From the above definitions, the related concepts from the prefix "re-" are "again", "return", and "back". According to the Oxford Dictionaries.com (2015), "again" means returning to a previous position or condition. On the other hand, "return" means going back to a particular situation while "back" means to return to an earlier or normal position or condition.
- According to *The Cambridge Advanced Learner's Dictionary Online* (2015), the concept ***vital*** means necessary for the success or continued existence of something; extremely important. *The Longman Dictionary of Contemporary English Online* (2015) states that vital means extremely important and necessary for something to succeed or exist. On the other hand, *The Chambers 21st Century Dictionary Online* (2015) indicates vital to mean essential or of the greatest importance. All the above definitions related to "significance" and "importance". So, "re-vital" means bringing back something important.
- ***Vitality*** is defined by *The Chambers 21st Century Dictionary Online* (2015) as the ability to stay alive or the state of being alive, while *The Cambridge Advanced Learner's Dictionary Online* (2015) defines vitality as energy and strength. *The Longman Dictionary of Contemporary English Online* (2015) defines vitality as great energy and eagerness to do things. All of the dictionary definitions above relate to "liveliness" and "energy". *The Merriam-Webster Dictionary* (2015) defines vitality as the peculiarity distinguishing the living from the non-living.
- According to *The Cambridge Advanced Learner's Dictionary Online* (2015), ***revitalise*** means to give new life, energy, activity, or success to something, while *The Merriam-Webster Dictionary* (2015) defines the concept as to make someone or something active, healthy or energetic again. *The Oxford*

Dictionaries Language Matters (2015) defines revitalise as imbuing something with new life and vitality.

- *The New Oxford Dictionary Online* (2015) defines ***–ing*** as a suffix denoting something involved "in action" or "its result" or "a verbal action relating to an occupation". *The Cambridge Advanced Learner's Dictionary Online (2015)* indicates that -ing is a suffix used to form the present participle of regular verbs e.g. walk-ing, play-ing or read-ing.

Considering the above dictionary definitions, one could state that *revitalising* means the act of bringing back necessary life or energy into something.

b) Definition of social support

Social support is defined by looking for dictionary meanings of the words *social* and *support*.

- *The Cambridge Advanced Learner's Dictionary Online* (2015) defines the concept ***social*** as activities in which one meets and spends time with other people or an occasion when members of a group or organisation meet informally. On its part, *The Oxford Dictionaries Language Matters* (2015) defines social as activities with others. According to *Dictionary.com* (2015), social refers to friendly companionship or relations, or living in companionship with others or in a community, rather than in isolation. From the above dictionary definitions, social means being connected with others.

- The concept of **support** is defined by *Dictionaries.com* (2015) as to maintain (a person, family etc.) by supplying with things necessary for existence or provide for. *The Cambridge Advanced Learner's Dictionary Online* (2015) states that the term support means to encourage, help, provide and accept. As a verb, support is defined as to help someone emotionally or in a physical way. On its part, *The Longman Dictionary of Contemporary English Online* (2015) defines support as helping someone by being sympathetic and kind to them during a difficult time in their life.

From the above dictionary definitions, social support may mean being connected to others to give or receive help.

c) Definition of competence

The Chambers 21st Century Dictionary Online (2015) explains that the term ***competence*** is derived from the Latin word *competere,* meaning "to meet" (for instance, expectations or standards) and "to be sufficient" (have enough, adequate). *The Cambridge Advanced Learner's Dictionary Online* (2015) defines competence as the ability to do things well, while *The Longman Dictionary of Contemporary English Online* (2015) refers to competence as skills needed to do a particular job.

6.3.4.2 Pertinent subject definitions of the main concept

The concept definitions are now presented by employing meanings specific to the subject of study – the value of PLHIV support group participation by PLHIV, with regard to their behavioural outcomes. One of the objectives of this study was to use the findings to develop a model for revitalising PLHIV caregiver socials support competencies so as to enhance behavioural outcomes of PLHIV. The subject definitions of the concepts are meant to aid this process. Each phrase is defined in reverse sequence and the description from the preceding words forms a part of the description of a succeeding phrase as recommended by Wandelt and Stewart (1975:74). This results in a final definition that follows a methodical evolution. In this way, the intent of the study is indicated in a coherent manner. In line with this approach, the concept *"competence"* is defined first, followed by *"social support competence"* and lastly, *"revitalising social support competencies."*

a) Contextual definition of competence

The researcher was interested in determining the value of support group participation by PLHIV, with regard to their behavioural outcomes. Simply put, this study sought to establish whether there is value in support group participation by PLHIV. The researcher was interested in knowing whether PLHIV have any information, skills, knowledge or material or emotional support they obtain from participating in support group activities which could in turn aid them to improve their behavioural outcomes.

In his work entitled concepts of competence, Eraut (2012:1) defines competence as the ability to perform tasks and roles to the expected standard. He further notes that competence is a personal capability or characteristic. This definition raises two contextual questions: Does participation in PLHIV support group activities enable a PLHIV gain more ability to cope with challenges associated with living with HIV? Does participation in support group activities enhance members' ability to help themselves and their peers in coping with living with HIV? From the findings presented in chapter 4, participation in support group activities enhances PLHIV's competencies to cope with HIV, although support group participation is not the only source of the required competencies.

Boyatzis (2008:1) defines competence as a capability or ability. He argues that competencies:

- can be developed in adults or can be learnt
- are a set of related but different sets of behaviour organised around an underlying construct called intent, and that intent predicts effectiveness
- are a behavioural approach to emotional, social and cognitive intelligence
- are a behaviour manifestation of talent
- drive performance
- are a critical differentiator of performance

In Jirasinghe and Lyons (1996:22), Boyatzis describes several important features of competence, namely:

- A *competence* can be a motive, trait, skill, aspect of one's self-image or social role, or a body of knowledge, which a person uses in his daily life.
- A *competence* may exist within an individual at various levels, with motives and traits at the unconscious level, and skills at the behavioural level.

- A *competence* is context dependent, i.e. given a different organisational environment; competencies may be evident through different specific actions.

In order to further understand the definitions above, we look at what the terminologies in the definition mean.

- *Behaviour*: a generic term covering acts, activities, responses, operations, or in short, any measureable response of an individual
- *Knowledge:* the body of information possessed by a person
- *Skill:* the capacity to carryout complex, well-organised patterns of behaviour, in order to achieve a given goal
- *Motive:* a characteristic of a cause the cause of an individual's behaviour
- *Trait is* any enduring characteristic of an individual that can serve an explanatory role in accounting for the observed regularities and consistencies in behaviour. It does not constitute the regularities themselves. A trait therefore is a hypothesised, underlying component of a person's behaviour.
- *Ability:* the quality that enables a person to perform a particular act at a specified time (Jirasinghe & Lyons 1996:24).

Furthermore, the definitions above have generated two other main concepts: behaviour capability and performance, which too need to be defined.

- *Behaviour capability:* According to Glanz, Rimer and Lewis (2002:171), the concept of behaviour capability maintains that if a person is to perform a particular behaviour, he or she must know what the behaviour is (knowledge of the behaviour) and how to perform it (skills), and that this distinguishes between learning and performance because a task can be learnt and not performed. Performance presumes learning and thus there is need for revitalising social support through training and performance management. This definition underscores the importance of developing a model for revitalising social support competencies.
- *Performance: The BusinessDictionary.com* (2015) defines performance as the accomplishment of a given task measured against pre-set known standards of

accuracy, completeness, cost and speed. Maximum performance is believed to occur when the person’s capability or talent is consistent with the needs of the job demands and the organisational environment (Boyatzis 2008:6).

b) Contextual definition of social support competencies

With the aim to define the concept of social support competencies, we first define social support, social competencies and social skills. Heany and Isreal in Glanz, Rimer and Lewis (2002:187) define **social support** as the aid and assistance exchanged through social relationships and interpersonal transactions. The authors argue that social support is always intended by the supplier to be helpful and this distinguishes it from intentional negative interactions such as angry criticism and undermining. Hunt (2011:182) defines social support as verbal and non-verbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one’s life experience. On his part, Gottlieb (2000:28:7) defines social support as a process of interaction in relationships which improves coping, esteem, belonging, and competence through actual or perceived exchange of physical or psychological resources.

According to Mallinckrodt and Wei (2005:3), ***social competencies*** are skills needed to recruit and maintain satisfying and supportive relationships together with trait-like dispositions that govern use of these skills. Social competencies include social self-efficacy and emotional awareness. Social self-efficacy involves the belief that one can initiate social contact and develop new friendships from initial acquaintances. Persons who lack social self-efficacy believe that close personal relationships are a matter of luck or other factors outside their personal control. Emotional awareness refers to perceptions of attachment to others. It is the ability to communicate one’s feelings and experiences to others. The authors argue that adults with high levels of social self-efficacy and emotional awareness are more likely to solicit social support for themselves or provide it to others.

According to Boyatzis (2008:11), a series of longitudinal studies have shown that people's emotional and social-self efficacy competencies can change through training and education programmes.

In his works *Social Skills and Health*, Argyle (2013:48) defines **social skills** as styles of social behaviour used by interviewers, nurses and others in dealing with the clients. Argyle argues that as with motor skills, some people have more social skills than others and thus are more effective in attaining the desired goals. He adds that when social skills required for performance have been identified, they can be taught through training courses. Argyle contends that in the healthcare professions, technical or medical skills are as important as social skills and urges institutions training healthcare workers to lay more emphasis on imparting social skills on their trainees.

From the above two definitions (of *social competencies* and *social skills*), we can deduce that **social support competence** is the ability to perceive and provide help. This help may be in the form of informational, emotional, appraisal or material support. Both Argyle (2013) and Boyatzis (2008) acknowledge that social support competencies can be acquired. This underscores the need for a model to revitalise the required competencies to boost social support in HIV/AIDS care and support. The two authors also suggest that social support competencies are needed by both the providers and recipients because unsociable behaviour on the part of a recipient may render the person ignored, neglected, or forgotten with sarcasm.

c) Contextual definition of revitalising social support competencies

Having given the subject definitions of competencies and social support competencies, there is need for a subject definition of revitalisation in order to fully define the concept of "revitalising social support competencies".

The concept of revitalisation is as old as many disciplines and was first defined many centuries ago. The concept has been applied in sociology, anthropology, religion, politics, psychology, physical planning, community development and other disciplines. Callahan (2012:1) defines revitalisation as a term used in community development and physical planning meaning to rebuild, to rejuvenate, to reinvent, to revive, or to regenerate. In his works entitled *Theory of Revitalisation Movement*, an American anthropologist Wallace (1956:1) defines revitalisation as a process of adaptation and transformation. He calls it changes that communities or cultures go through to overcome dissatisfaction revitalisation movements. According to him, a revitalisation movement is a deliberate, organised, conscious effort by members of a group to create a new culture. In the context of anthropology, such movements lead to social reforms, for example, religious revivals or people's revolutions and the motive is always constructing a more satisfying social or cultural system. Wallace contends that revitalisation is a step-wise process that begins with a steady state and ends with a steady state as illustrated below:

- a steady state
- a period of individual stress
- a period of socio-cultural distortion
- a period of revitalisation
- a steady state

Within the revitalisation period, six major processes occur: (1) "maze way" reformulation, (2) communication to others, (3) organisation of followers, (4) adaptation to contention and conflict, (5) socio-cultural transformation, and (6) routinisation of the new socio-culture system. This leads to a steady state again.

Revitalisation is also used in politics, strategy development and community development. According to the *Neighbourhood Revitalisation Initiative* of The Office of Urban Affairs, The White House (2015:1), revitalisation means catalysing change. The Office of Urban Affairs uses the concept in its strategy for catalysing change in slum communities to improve people's living conditions – to empower neighbourhoods in distress, generate local action to transform themselves into neighbourhoods of opportunity and hope.

Still in the discipline of community development, Mitchell-Brown (2013:6) defines revitalisation as a process of mobilising, developing and utilising social capital -the extent to which members of a community can work together effectively to develop and sustain strong relationships, solve problems, and collaborate to accomplish collective goals. He uses the concept in the context of bringing back vitality in declining suburban neighbourhoods in USA by mobilising and using community social capital.

When put in the perspective of HIV/AIDS care and support, the concept – revitalising social support competencies means rekindling confidence, skills and knowledge of providing care and social support to PLHIV. In the context of this study, this revitalisation is necessary among PLHIV caregivers and confidants, including healthcare workers, family members, support group members and co-workers. To provide effective and holistic care for PLHIV, health facilities need to re-emphasise integration of both medical and social skills among healthcare workers. Families of PLHIV need help to rejuvenate their social care skills and communities of PLHIV need to take or have a fresh look at how they can support one another.

The analysis of the above definitions of "revitalising social support competencies" as found in the dictionaries and subject related literature is now concluded. The following step involves examining the essential and related attributes of the concept.

6.3.4.3 Reduction process of the identified attributes

In this section, defining attributes (main features and elements) are identified and reduced to the essential and related attributes of the central concept, as contextualised within the scope of the study. Each criterion that contributed to the conceptualisation of the main concept, "revitalising social support competencies" is bolded in both dictionary and subject definitions. Criteria with similar meaning are clustered together to form a list of essential criteria to include in the definition of "revitalising of social support competencies as well as other related criteria (see tables 6.1–6.7). This is done to arrive at the final definition of the central concept "revitalising social support competencies". The final definition includes all the important characteristics. All the individual concepts that constitute the main concept, as identified from dictionaries and subject-specific literature are listed.

Based on a recommendation by Mckenna (1997:63), the “test for necessity” and the “test for sufficiency” are conducted as part of the process of defining attributes of the main concept. The test for necessity is done by taking each defining attribute, then taking effort to identify and isolate any contrary example of the concept that does not incorporate the specific attribute. If the defining attribute also applies to the contrary example, then this is considered as an imprecise attribute of the concept and is thus deleted from the list. The test for sufficiency is conducted by considering the complete list of attributes. If a contrary case is identified, then an essential attribute has been omitted.

Listed attributes are further reduced to “essential” and “related” criteria. Essential criteria represent the criteria that “must be present in order for the concept to exist” (Wood 2002:167). Related criteria further elucidate the essential criteria. According to McKenna (1997:62), it is better to identify three or four defining attributes that characterise the concept well, than to have too many attributes, which will be combined to form the final list of the criteria that make up the concept – “revitalising social support competencies”. These criteria are utilised to constitute the basis for the model case to give rise to the final concept definition. For the identified main concept, “revitalising social support competencies”, we identify attributes of each of the sub concepts. The attributes of the concept, “revitalising”, are listed in the table below.

Table 6.2: Attributes of the concept revitalise

- Reinvigorate
- Re-energise
- Regenerate
- Revive
- Renew
- **Restore**
- Revivify
- Rejuvenate
- Reanimate
- Resuscitate
- Refresh
- Stimulate
- Catalysing change
- Breathe new life into
- Give new life, energy, activity, or success to something
- Make someone or something active, healthy or energetic again
- As imbuing something with new life and **vitality**

Based on the list of attributes of the concept, *"revitalising",* indicated in table 6.2 above, the researcher generates a list of essential and related attributes as presented in table 6.3 below.

Table 6.3: Essential and related criteria of the concept revitalising

Essential criteria	Related criteria
• Restore	• rejuvenate • revive • bring back a previous right, practice, custom, or situation • return someone or something to a former condition, place, or position • restore to a condition characteristic of a younger state • make someone or something look or feel younger, fresher, or more lively • restore to life or consciousness • give new strength or energy to
• Vitality	• the strength and vitality required for sustained physical or mental activity • the state of being strong and active; energy • regain life, strength • new life

Definition of "revitalising": Restoring energy or new life into something.

The attributes of the concept, "*social support*," are listed in the table below.

Table 6.4: Attributes of the concept social support

Social communication
Social relationships
Interpersonal transactions
Uncertainty reduction
Enhanced control
Physical help
Psychological help
Financial help
Information help
Networking
Interaction
Belonging
Exchange
Help
Aid
Assist
Exchange of physical or psychological resources

Based on the list of attributes of the concept "social support" indicated in Table 6.4 above, the researcher generates a list of essential and related attributes as presented in Table 6.5 below.

Table 6.5: Essential and related criteria of the concept social support

Essential criteria	Related criteria
Social communication	• social reciprocity • social interaction • joint sharing of experiences and emotions
Help	• aid • help, typically of a practical nature • to help, assist, or support someone or something in the achievement of something • to make it easier for someone to do something by offering one's services or resources • assisting someone to do something • providing assistance
Assist	• to help (someone), typically by doing a share of the work or proving money

Definition of social support: An act and process involving social communication and physical helping or assistance to share or ease the recipient's burden

The following table outlines attributes of the concept competence:

Table 6.6: Attributes of the concept competence

Capability **Ability** **Proficiency** Accomplishment Expertise Adeptness Skills Prowess Mastery Talent To meet expectations Ability to do things well Ability to do something successfully or efficiently

Based on the list of attributes of the concept, *competence,* indicated in Table 6.6 above, the researcher generates a list of essential and related attributes as presented in table 6.7 below.

Table 6.7: Essential and related criteria of the concept competence

Essential criteria	Related criteria
Ability	• possession of the means or skill to do something • talent, skill, or proficiency in a particular area
Proficiency	• a high degree of skill; expertise.

Definition of competence: A skill required to succeed or excel.

The individual concepts of revitalising, social support and competencies have been defined by listing all their attributes and reducing them to essential and related criteria. In the next analysis, the criteria are combined to form a final list of essential attributes for the whole concept, "revitalising social support competencies" (table 6.8). These attributes are evident in all instances of revitalising social support competencies in the context of HIV/AIDS care and support. They define the required actions in order for PLHIV to perceive and receive sufficient social support to enhance their positive behavioural outcomes. They also reflect the dynamic nature of social support strategies and the supportive role of caregivers, confidants and healthcare professionals that are central in enhancing positive behavioural outcomes of PLHIV.

Table 6.8: Essential and related criteria of the concept revitalising social support competencies

Essential criteria	Related criteria
Restore	• the action of returning something to a former owner, place, or condition • making someone or something look or feel younger, fresher, or more lively • revive • rejuvenate
Vitality	• passion • the state of being strong and active • energy • the strength and vitality required for sustained physical or mental activity • power, vigour, life
Ability	• possession of the means or skill to do something • talent, skill, or proficiency in a particular area • capacity; capability; potential
Help	• to make it easier for someone to do something by offering one's services or resources • aid • intervention • the provision of money, resources, or information to help someone • the action of helping someone with a job or task
Social communication	• joint sharing of experiences and emotions
Proficiency	• a high degree of skill • expertise, know-how • ability to meet performance standards

The concept, “revitalising social support competencies”, has been reduced to its essential and related criteria. The researcher now states the final conceptual definition.

6.3.4.4 Relating and structuring concepts: A concept map

The above reduction process of the identified attributes has generated the essential criteria of the concept, “revitalising social support competencies”, within the context of HIV/AIDS care and support. The next step is to formulate a conceptual definition of revitalising social support competencies, which is then evaluated according to the criteria suggested by Morse, Mitchman, Hupcey and Tason (1996:390). In this section, the concepts are given structural form to clarify their relationship by means of a symbolic representation as suggested by Chinn and Kramer (1995:116) (see figure 6.3). “Revitalising social support competencies” signifies several interdependent processes which should be simultaneously facilitated for better outcomes.

Revitalising competencies entails ***restoring confidence*** among PLHIV caregivers and confidants (health workers, PLHIV support groups, co-workers and family members) that they have or can easily acquire the skills and knowledge to provide effective social support to PLHIV. This involves correcting the existing unsatisfactory beliefs, behavioural and practices. Through expert interventions, the confident but experienced PLHIV caregivers and confidants are energised and enabled to acquire ***proficiency in social communication*** (listening and providing adequate information). Expert intervention also enables PLHIV caregivers and confidants to gain ***abilities and vitality in providing effective counselling and social support*** to PLHIV. This is achieved through expert training, coaching, mentoring, retraining, redirection and redevelopment of PLHIV support groups, health workers, family members of PLHIV co-workers. In order for the social support to be more effective and benefit more PLHIV, a revival of social support networks both at facility and community levels is facilitated. This involves strengthening of existing care networks such as PLHIV support groups, faith-based groups and others; popularising the social support networks; and supporting them with technical and financial assistance to keep them active. This enhances access to ***comprehensive and sustainable help***. PLHIV are empowered to confidently disclose their positive HIV status, overcome HIV-related stigma, adopt safer sexual behaviours and adhere to their ART. Revitalising social support competencies enhances PLHIV ***behavioural outcomes***.

The mental map illustrated in figure 6.3 below is informed by the findings of the first phase of the study and the researcher's perception of the change that would result from implementing the model for revitalising caregiver social support competencies.

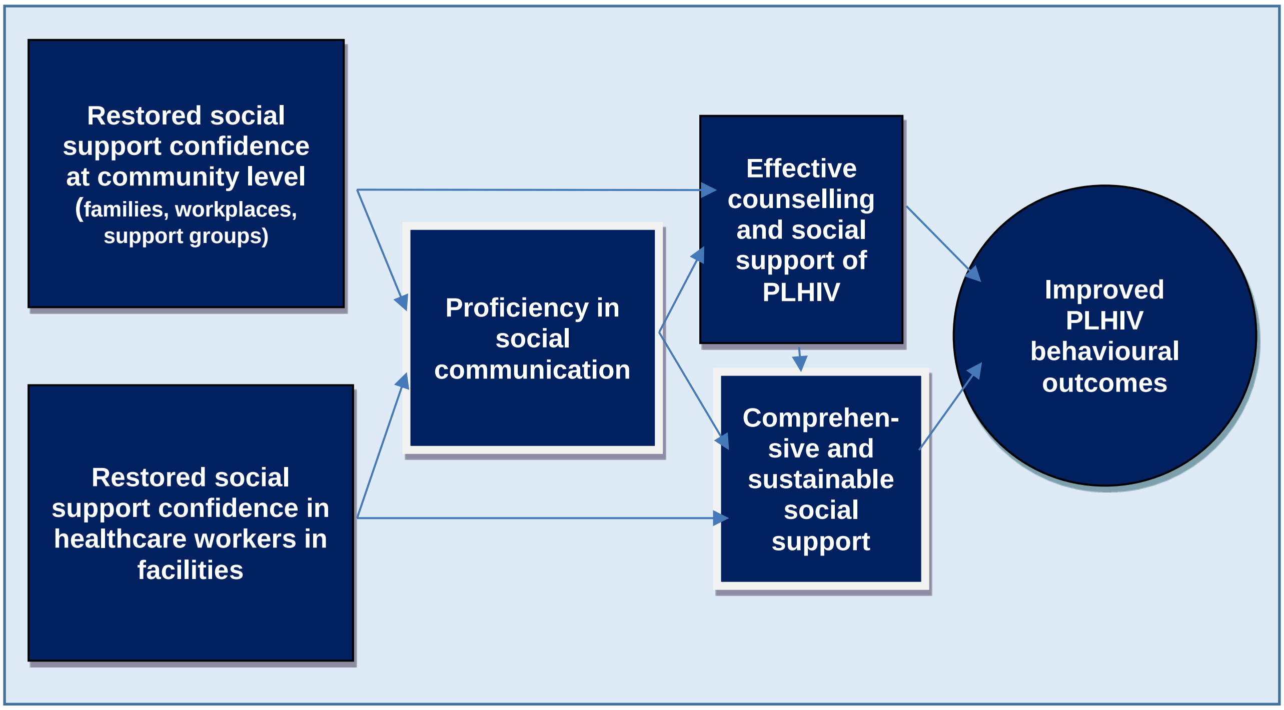


Figure 6.3: The researcher's mental map of the benefits of the model

Based on the study findings, participation in support group activities has a positive value on PLHIV behavioural outcomes. The study also suggests that apart from PLHIV support group peers, PLHIV have other sources of social support. These include health workers, peers in workplaces and family members. The researcher therefore visualises that PLHIV would have access to all-round social support if all their caregivers and confidants (at home, in workplaces, in communities and healthcare facilities) were helped to revitalise (acquire or improve) their competencies in providing social support to PLHIV. This stimulates the researcher to conceive a model to achieve this.

The researcher's mental map for building the model is thus premised on beliefs that IF the social support competencies of PLHIV caregivers and confidants in the communities where they live or work were revitalised, THEN, these PLHIV caregivers and confidants (health workers, family members, support group members and co-workers) would be more competent and effective in providing the required social support to PLHIV. The all-round social support would positively enhance PLHIV behavioural outcomes, including reduced HIV-related stigma, positive HIV status disclosure, reduced sexual risk behaviour and ART adherence. The researcher’s mental map is illustrated in figure 6.3 above.

6.3.4.5 The model case

The model case below contains all the essential and related attributes of the main concept. The purpose of the model is to provide a better understanding of the concept. An example of a real-life situation is given in order for the reader to gain a better understanding of the meaning of the concept, “revitalising social support competencies”.

Kate, Winfred, and Arthur are my cousins. Their dad is my uncle. He is a well-off man having served in government as a District Commissioner for many years. My cousins are much older than me, and I respect them. In fact, while I am an undergraduate student living at the University, I often visit my cousin Kate over the weekends for a change on diet and replenishment of pocket money. Kate is married to Robert, an economist who has held several expatriate jobs in Eastern and Southern Africa. Later when I begin working, my close friend at the workplace is Mary. We knew each other from high school days. Coincidentally, Mary is also a close friend of Kate.

Whenever Kate, Arthur and I meet, we confide in each other and discuss issues pertaining to our businesses, jobs or property. However, we live an urban capitalistic life where everyone is busy striving to survive in the city. So, we really never have time to listen and offer social help to each other when needed. Also, due to the ever eroding African extended family system, we are rarely available to help each other even when one of us faces a stressful event, except in cases of death. In fact, outsiders may not believe that we have such close social ties, yet are so apart. This ever-growing social distance is also true in the family of Robert and Kate. Arthur and Winfred are businessmen and they too, spend many days away from their families.

As an employee of an international organisation, Robert often travels on business for several days. It is perhaps this staying away from his wife Kate that tempts him to indulge in extramarital sex. As time goes by, Robert presents with symptoms of diabetes (blurred vision, weight loss, fatigue and always thirsty), in fact, while with the family on a holiday in Mombasa, he becomes seriously ill and is admitted at Nairobi Hospital. On discharge, Robert continues to take his diabetes prescription drugs daily. However, Robert's health continues to deteriorate. He was diagnosed with HIV, but has not disclosed this to anyone. Since his family is convinced he has diabetes and is on treatment, many of us do not suspect that he had another illness. Also, because we do not often talk about our personal lives, no one *cares* to ask Robert what the matter is exactly (*insufficient social communication)*.

Before long, Kate too becomes ill and presents with symptoms of HIV/AIDS. However, she does not suspect that she could be infected with HIV, so she continues treatment for apparent opportunistic infections such as fever, diarrhoea, cough, skin rash and others. Even with this development, Robert fears to disclose his positive HIV status to his wife and his *family members* because he thinks they may not offer any help *(does not perceive support from family and friends)*. Being a Christian couple, Kate believes her husband is faithful. Even when she sees Robert taking daily medication (anti-retroviral treatment (ART), she is convinced he is treating his diabetes. Moreover, in those days, many people could not differentiate anti-retroviral drugs from other drugs.

With time, Kate's health continues to deteriorate. I have graduated and I am working with an organisation that is implementing an HIV/AIDS prevention, care and treatment programme. One day, I visit Kate in the hospital and I am shocked that Kate has all the symptoms of AIDS. She is emaciated and is wasting away. I (*family member)*_don't get the courage (*feel incompetent*) to ask whether she has or would be interested in taking an HIV test. Kate too does not feel confident to discuss her illness and the possible options with me. However, I know Mary is very close to her and being a lady, she would probably discuss with Kate and chart a course of action. Indeed, Kate confides in Mary that she would like to take an HIV test but was afraid of knowing her status in case she is HIV positive. In the ensuing *social communication*, Mary discloses to Kate that she had been HIV positive for many years, was on anti-retroviral treatment, felt healthy and lived a normal life. She puts to use her counselling *competencies* and convinces Kate to take an HIV test. The test confirms my fears, Kate is HIV positive.

A few days later, Kate confides in me that she had tested HIV positive, and requested that I work with Mary to inquire whether and how she could be enrolled on ART at the nearest ART site. Shocked and panicky, I ask the doctor on the ward (who already knew Kate's HIV status) on the best course of action. He advises that we do a CD4 cell count test to establish whether Kate is eligible for initiation on ART. The hospital does not provide CD4 laboratory test services, so, we have to mobilise money and obtain the services from a private laboratory in town. Apparently, the doctor does not explain *(insufficient social communication competencies)* the meaning of HIV positive test results to Kate. He reckons that is the work of the counsellors, but there was none on duty that moment. Mary and I are unable (*are incompetent*) to counsel and convince Robert (*informational support*) to also take the HIV test. We also feel it would be devastating to Arthur and Winfred (Kate's brothers). So, we decide not to disclose Kate's positive HIV status to them. We call two friends (also related to Kate), Mark and Nick and we borrow money from them for the CD4 test, but we do not disclose the purpose for which we wanted it. Eventually, the duo visit Kate at her hospital bed and recognise that she had AIDS. While Mark understands the natural history of AIDS and encourages Kate to request for more laboratory tests, Nick, who is Kate's nephew, breaks down uncontrollably. We do not how know how to *help* or *assist* him.

After two days, the CD4 test results are out and Kate's CD4 count is just 100 copies/ml. Mary and I now realise how unprepared *(lack social support competencies)* we are to disclose the low CD4 test results to Kate. All the same, we agree to just tell her (*no counselling knowledge and skills*) and ask the doctor to initiate her on ART immediately. Back to her hospital bed, we break the news to Kate. She sobers up, looks in our faces and says, "Robert has betrayed me". "I have always seen him with drugs similar to what the doctor has given me today but he always claimed they were for treating diabetes". Unfortunately, Kate reacts to the ART and dies a few weeks later.

At Kate's burial, Robert breaks down and regrets that he could have saved Kate's life had he gotten help *(social support)* on how to manage his own illness. During the same event, I overhear Roberts' colleagues saying that even when they have known for some time that Robert is living with HIV, none of them had the courage and skills *(feels confident)* that he/she is competent to help him in coping with the illness. After Kate's death, Mary discloses to me that she too is living with HIV. Like Robert, she is afraid of disclosing her positive HIV status to her husband. Equipped with basic counselling skills acquired from a training organised by my workplace, this time I feel confident that I can help Mary. Moreover, the death of Kate remains so painful to me and makes me resolve to do whatever is in my means not to lose another significant other to AIDS – I am convinced that I could have saved Kate's life had I acquired social support competencies earlier. This motivates me to seek more social support skills (*proficiency*) every time an opportunity arises. I also resolve to save Mary and Robert's lives.

Besides Robert and Mary, I know a few more people living with HIV (PLHIV) whom the project I am working for is supporting, to enhance community-based care and support for PLHIV. The PLHIV had themselves formed a PLHIV support group. I encourage Mary to join the group to *rejuvenate* her social support skills, and she agreed. A few months later, Mary confides in me that she felt *energised* and empowered to manage her own HIV situation and even help other PLHIV. She has got enormous *informational, emotional*, and even *material help* from her colleagues in the PLHIV support group. Mary and I agree that we invite her family members to one of our project-funded training sessions in HIV/AIDS care and support. The training targets PLHIV family members. At the end of the training, Mary's sister gives a testimony and praises the project for "enabling them *to acquire social communication skills essential* in caring for their family members when they fall sick". She pledges to extend her *help* and *aid* to her neighbours who may have PLHIV.

Despite some convincing by Mary and me, Robert refuses to join the PLHIV support group, presumably due to stigma. Determined to save his life and others like him, I convince my project manager to roll-out our workplace HIV/AIDS programme to his organisation. We resolve to equip all employees in this organisation with skills for caring and supporting PLHIV in their workplace, including HIV disclosure, stigma reduction and non-discrimination as well as ART adherence counselling and support. Months later, we learn from the Human Resources Manager that Robert had publicly disclosed his positive HIV status and he had been seen taking his ARVs consistently (we *had restored his confidence* about his ability to live positively with HIV).

Encouraged by the benefits from *Revitalising Social Support Competencies* in Mary's PLHIV support group, family and Robert's workplace, I convince my Project Manager to target health workers in a few health centres in the district. Here, the training focuses on integrated medical and social skills in patient care (*revitalising social support competence among healthcare workers)*. The target health workers include doctors, nurses, midwives, laboratory scientists and pharmacists – all of whom interface with PLHIV at different service delivery points.

A few years later, Mary and Robert are living "normal" lives. Mary works for a charity organisation that cares for people with disabilities in Amherst, Massachusetts. She has disclosed her positive HIV status to her employers and receives all the necessary emotional, financial and appraisal care, and support to continue living positively. Robert has since remarried and together with his HIV positive wife are running a vibrant consultancy firm. During their "free" time, they volunteer to share their experiences (*social communication*) with church and community-based PLHIV support groups in their neighbourhoods so as to *revive as many of such social networks* as possible to enhance effective care and support to PLHIV and orphans and vulnerable children.

As a result of my project's deliberate efforts to *rejuvenate* social support competence in workplaces, PLHIV families, health facilities and among PLHIV support groups, both Robert and Mary have disclosed their positive HIV status to their spouses, have reportedly abandoned living risky sexual lives, are no longer stigmatised by their positive HIV status and are adhering to their ART treatment. They exhibit ***positive behavioural outcomes****.*

6.4 CONCLUSION

In this chapter, the researcher described the process of developing a model for revitalising PLHIV caregiver social support competencies so as to enhance behavioural outcomes of PLHIV. A systematic analysis and synthesis of the definitions of the concept, “revitalising social support competencies” was performed, resulting in the final conceptual definition. In chapter 7, the researcher will describe the model in detail, providing visual representation and relationship statements of the identified related concepts. Guidelines for operationalising the model will also be provided.

CHAPTER 7

DESCRIPTION OF THE FINAL MODEL FOR REVITALISING SOCIAL SUPPORT COMPETENCIES TO ENHANCE POSITIVE BEHAVIOURALAL OUTCOMES AMONG PEOPLE LIVING WITH HIV

7.1 INTRODUCTION

In chapter 6, the researcher presented a framework for developing a model to revitalise social support competencies in PLHIV caregivers and confidants, in order for them to be able to provide effective social care and support to PLHIV. Chapter 7 provides a detailed representation of the model. The chapter also provides guidelines for operationalising the model in the context of HIV/AIDS care and support.

7.2 OVERVIEW OF THE MODEL

The model to revitalise PLHIV caregiver social support competencies is premised on the cross-sectional study findings, which affirm the value of PLHIV support group participation in enhancing positive behavioural outcomes of PLHIV. However, the findings also suggest that PLHIV obtain social support from varied sources, including PLHIV support groups, family members, co-workers and health workers. PLHIV use this social support from various sources to address their holistic needs. The model is the researcher's recommended framework for enhancing behavioural outcomes of PLHIV through a combination of interventions on modifiable factors associated with PLHIV behavioural outcomes.

The model seeks to **restore confidence** in PLHIV caregivers and confidants, and equip them with skills and knowledge to enhance their **proficiency in social communication.** The interventions include training, coaching and mentoring of PLHIV family members, healthcare workers, workmates and peer PLHIV support group members. The change is facilitated by experts namely, staff and consultants from HIV/AIDS programmes. Proficiency in social communication enhances **abilities** and **vitality** of PLHIV caregivers and confidants in providing effective counselling and social support to PLHIV. Social support may be in the form of informational, emotional, material and other forms of help needed by PLHIV to cope with living with HIV. Replication of the interventions on a wider scale enables PLHIV to access **comprehensive and sustainable help**. The ultimate goal is to enhance behavioural outcomes, thereby contributing to the reduction in HIV transmission and improvements in the wellbeing of PLHIV.

7.3 PURPOSE OF THE MODEL

In explaining the purpose of the model, it is important to elucidate how it is applied. This highlights the circumstances and specifications under which it is applied, as well as who executes it (Chinn and Kramer 1995:106). The purpose of this model is to describe a theoretical frame of reference for revitalising social support competencies among PLHIV caregivers and confidants in order for them to be able to provide effective care and support to PLHIV in their care. The assistance of trained and skilled programme experts will be secured. Through this model, PLHIV caregivers and confidants will have their confidence **restored**, their **proficiency** in **social communication** enhanced, and their **abilities and vitality** to provide effective counselling as well as comprehensive and sustainable **help** to PLHIV with diverse needs facilitated. While focus is on PLHV's behavioural outcomes, the model underscores the need to care for caregivers. Thus, in the model, PLHIV act as both recipients and providers of social support.

The model is meant to serve three main objectives:

- To empower all PLHIV caregivers and confidants to actively contribute to enhancing positive behavioural outcomes of PLHIV. Empowering all caregivers and confidants entails equipping them with skills and information related to PLHIV care and support.
- To enhance PLHIV access to holistic care. Holistic care means addressing the physical, psychosocial, spiritual, and material and other care needs of PLHIV

- To increase demand for, and utilisation of HIV/AIDS services through strengthened health facility and community systems. Uptake and utilisation of HIV prevention, treatment and care services is critical in enhancing PLHIV’s behavioural outcomes.

7.4 ASSUMPTIONS OF THE MODEL

Chinn and Kramer (1995:115) define assumptions as the basic principles that serve as the foundation of the model. This refers to other conditions necessary, in addition to the suggested interventions for the model to yield the expected outcomes. Assumptions can also be associated with relationship statements that give reference to the values underlying the model. In order to perceive the significance of the model, it is essential to make the assumptions clear. This also helps in the process of reviewing the model.

7.4.1 Revitalising competencies

PLHIV family members, workmates, healthcare workers and PLHIV support group members have a responsibility to care and support PLHIV in their purview. However, many of them often perceive themselves as ill-equipped to provide the necessary social care and support. The assumption is that external assistance in building their confidence and competencies for providing social support to PLHIV would enable them to comfortably and confidently provide the necessary social support.

Through awareness creation, training, coaching and mentoring, PLHIV caregivers and confidants will have their confidence **restored** and their courage strengthened to face the challenge. Intervention by programme experts will also enable PLHV caregivers and confidants enhance their **proficiency** in **social communication** (listening and providing more information to PLHIV). The interventions will also enable PLHIV caregivers and confidants affirm their worthiness and commitment to take responsibility for their actions. The restored confidence and capabilities in social communication will grow their **abilities and vitality** to sustainably provide multiple forms of **help** to PLHIV with diverse needs facilitated.

7.4.2 People living with HIV

The PLHIV who constituted the study population reported that they derive social support from multiple sources, including peer support group members, family members, workmates and health caregivers. However, it is recognised that an individual PLHIV is central in assuring effective care. All interventions whether social or medical support depend on the cooperation and participation of the individual PLHIV. The model assumes that PLHIV will be active agents of the desired change namely, positive behavioural outcomes. This calls for the individual PLHIV's interest, motivation and self-efficacy. Moreover, experts recommend transformative approaches that empower PLHIV to become change agents (UNAIDS 2007:18).

7.4.3 Caregivers and confidants of people living with HIV

PLHIV who participated in the study cited multiple sources of social support, including peer PLHIV support group members, family members, workmates and health caregivers. The model assumes that these PLHIV caregivers and confidants will be interested in revitalising their social support competencies and using the competencies to offer the needed help to PLHIV. While some caregivers such as health workers may be legally and ethically obliged to care for PLHIV as part of their work responsibilities, workmates, family members and peer PLHIV support group members are not legally obliged to care for PLHIV and they can only do so out of their goodwill. Moreover, the study also found that HIV-related stigma is still widespread and inhibits PLHIV from seeking care and PLHIV caregivers and confidants from providing care to PLHIV. Revitalising their social support competencies is therefore necessary to motivate both parties to take action.

7.4.4 Environment

In addition to social care and support, the environment in which the care is provided also impacts on PLHIV behavioural outcomes. While the model prioritises PLHIV social support, the role of governments in ensuring an uninterrupted supply of ARVs is critical for the success of the model. Also, the supply of other commodities such as condoms and drugs for treating opportunistic infections must be assured for effective

HIV/AIDS prevention, care and treatment. Additionally, providing holistic care requires deploying more human and other resources at different levels of care. The model assumes that governments will live to their responsibilities by availing and increasing the necessary human and other resources in health facilities to supplement effective social support provided by PLHIV caregivers and confidants and match the stimulated demand for HIV/AIDS care and treatment.

7.5 CONTEXT OF THE MODEL

The contexts represented by the model for revitalising social support competencies includes ART sites in Nigeria, various workplaces where there are PLHV, families with PLHIV and facility or community-based PLHIV support groups. The study was carried out in Nigeria at ART sites supported by the Strengthening Integrated Delivery of HIV/AIDS Services (SIDHAS) project implemented by FHI 360. The SIDHAS project aims to enhance accessibility, quality, and integration and host government (federal and state) ownership of a comprehensive HIV/AIDS response in 15 states in Nigeria. The supported ART sites provide comprehensive HIV/AIDS services to the population from their catchment communities. The services include HIV testing and counselling (HTC), prevention of mother-to-child transmission of HIV (PMTCT), ART, care and support for PLHIV.

To enhance retention in care and adherence to ART, healthcare workers provide adherence counselling to all HIV positive patients before initiating them on ART. Adherence counsellors continue to sensitise both pre-ART and ART patients about the benefits of **PLHIV support group participation** and encourage them to become members so as to benefit from continuous adherence support, positive prevention and care services. PLHIV support group members meet at least once a month and participate in activities related to positive prevention, stigma reduction and group psychosocial therapy. Not all PLHIV enrolled in care participate in support group activities.

Also, ART adherence has generally been sub-optimal, implying that there could be deficiencies in competencies of health workers and support group members in terms of ART adherence-related counselling and social support. Although PLHIV cited workplaces and families as other sources of social support, there are no known programmes targeting PLHIV families and workplaces to enhance their social support and care skills for PLHIV. The purpose of the model is to revitalise social support competencies of all individuals and groups with whom PLHIV live, work or confide, and thus are well positioned to positively enhance their behaviour outcomes.

7.6 THEORETICAL DEFINITIONS OF THE CONCEPTS OF THE MODEL

In chapter 6, key concepts in the model were identified and defined. This was an effort to create conceptual meanings. In this section, the process continues by clarifying and explaining the structure of the model. This procedure precedes development of relationship statements. The application of the concepts in a particular context requires description in relation to the theory so as to convey their essential meaning. The concept definitions provided in chapter 6 are repeated to ensure continuity of the model description. The main concept identified in this model is revitalising social support competencies. The essential attributes identified are: ***restoration of confidence***; ***proficiency in social communication***; ***enhanced counselling abilities and vitality***; and ***sustainable comprehensive help*** to PLHIV.

7.6.1 Revitalising social support competencies

This is the main concept in the model. It can be conceptually defined by stating four interdependent processes, which should be simultaneously facilitated. *Restoration of confidence* among PLHIV caregivers and confidants entails providing information on the basic social support skills needed and their significance in improving PLHIV behavioural outcomes. In the African culture, the weak and vulnerable have always leaned on family members (extend family system) and the community to overcome challenges of life. However, the strength of this system is threatened by globalisation and “modernisation”. Reawakening families and communities of their responsibility towards their significant others living with HIV is aimed at rebuilding conscience and confidence among PLHIV caregivers and confidants. Aside rebuilding confidence, the model proposes interventions by programme experts to enable PLHV caregivers and confidants *enhance their proficiency in social communication* (listening and giving more information to PLHIV). This enhances rapport between the parties thereby enabling the client (PLHIV) to freely disclose more information necessary for the caregiver to provide effective social care and support. Enhancing proficiency in social support communication also entails training caregivers and confidants on listening and responding skills. Additionally, the model recognises the need for programme experts to improve *abilities and vitality* of PLHIV caregivers in *providing effective counselling and social support* to PLHIV. This is done through training mentoring and coaching. Mainstreaming of social support and counselling in facility, community and home-based care for PLHIV vitalises the need for social support competencies among all PLHIV caregivers and confidants and assures PLHIV on *comprehensive and sustainable help*.

7.6.2 Restoration of confidence

The concept restoration of confidence can be defined as a process of bringing back a feeling of self-efficacy or self-assurance arising from the appreciation of one's own capability. It can be viewed as the revival of a firm trust, a feeling of certainty, and a sense of reliance. Restoring confidence brings courage, boldness and development of a realistic concept of self. PLHIV caregivers and confidants often lack confidence, which results in a feeling of incompetence. Through facilitating a process of reflective action on African cultural values as well as professional ethics (on part of healthcare workers), PLHIV caregivers and confidants can rebuild and restore their confidence in providing social care and support to PLHIV. This enables them to develop a sense of responsibility and ability to cope with the stress that comes with caring for a PLHIV.

7.6.3 Proficiency in social communication

This refers to skills or expertise in listening and providing information in a social setting. In the context of care and support for PLHIV, it involves listing to the needs of PLHIV and providing appropriate response aimed at alleviating the challenges faced by the clients. PLHIV caregivers and confidants need to be proficient social communicators so as to influence PLHIV to adopt positive health behaviour. The model presupposes that proficiency in social communication can be learnt through intervention by experts.

7.6.4 Counselling and social support abilities and vitality

Just like proficiency in social communication, PLHIV caregivers and confidants need to improve their counselling and social abilities and vitality so as to passionately influence PLHIV to cope with challenges of living with HIV. The model proposes intervention by experts to rejuvenate or to build these skills in PLHIV caregivers and confidants.

7.6.5 Assuring comprehensive and sustainable help to PLHIV

In addition to imparting counselling and social support skills in PLHIV caregivers and confidants, these skills need to be mainstreamed in facility, workplaces, community and home-based care and support for PLHIV. This helps to vitalise the need for social support competencies among all PLHIV caregivers and confidants and assures more PLHIV of comprehensive and sustainable help.

7.6.6 Programme experts

In this model, programme experts are skilled professionals who have expertise in HIV/AIDS counselling and social communication. They are also proficient in training, mentoring and coaching. Additionally, they are knowledgeable in basic principles of HIV/AIDS prevention, care and treatment. These may be employees of government or Non-Governmental Organisations (NGOs) or consultants. They use this expertise to enable PLHIV caregivers and confidants become more knowledgeable about HIV/AIDS, the needs of PLHIV and how to efficiently help PLHIV positively enhance their behavioural outcomes.

7.7 RELATIONSHIP BETWEEN CONCEPTS

According to *The Free Dictionary.com (2015),* a relationship is a tendency for two values or variables to change together, in either the same or opposite way. Relationship statements, describe, explain or predict the nature of interactions between concepts of a theory or model (Chinn and Kramer 1995:96). To enable PLHIV caregivers and confidants revitalise their social support competencies, it is essential that the *restoration of confidence* occurs first. Confidence is attained by facilitating feeling of certainty that they can cope with helping PLHIV in their purview (their families, workplaces, healthcare facilities and communities). This results in PLHIV caregivers and confidants' perceived self-efficacy to handle challenges of caring for PLHIV with confidence and boldness.

After regaining confidence, PLHIV caregivers and confidants are facilitated to enhance their *proficiency in social communication* − listening and giving more information to PLHIV with stamina and enthusiasm. This builds rapport between the parties thereby enabling the client (PLHIV) to freely disclose more necessary information for the caregiver to provide effective social care and support.

Confidence and proficient social communication contribute to PLHIV caregivers and confidants' *abilities and vitality to provide more effective counselling and social support* to PLHIV. This is reinforced by expert intervention from programme personnel and consultants. Strong relationships between PLHIV and their caregivers and confidants spur positive perceptions about HIV/AIDS and self-efficacy to live normal and fulfilling lives.

Positive outcomes from intervening in individual cases motivate HIV/AIDS programmes to mainstream social support and counselling in facility, community and home-based HIV care and support activities. This vitalises the need for social support competencies among all PLHIV caregivers and confidants and assures PLHIV on *comprehensive and sustainable help*. The end result is improved PLHIV behavioural outcomes.

7.8 STRUCTURAL DESCRIPTION OF THE MODEL

The previous section explained relationships between concepts. This section describes the structural form of the model. The structural pattern of the model assists in understanding relationships between the concepts, their preferred sequence of occurrence and how they interact (Chinn & Kramer 1995:112). The model is premised both on the findings of the study and the researchers' deductive reasoning which leads to identification of the interventions required for the model to be effective. The researchers' reasoning is based on literature and experience implementing HIV/AIDS programmes.

The starting point of the proposed model is the grey colour at the bottom of the model (see figure 7.1). It depicts lack of confidence, skills, information, openness, support, trust, knowledge, encouragement, and so forth. PLHIV do not seek and perceive social support. PLHIV caregivers do not feel confident and competent to provide effective social support. There is thus limited communication between the parties.

In order to change the status-quo, the model proposes intervention by programme experts (HIV/AIDS programme personnel and consultants). The aim is to revitalise social support competencies among PLHIV caregivers and confidants. This is realised through assessing PLHIV needs and caregiver confidence and competence gaps. It is followed by implementing tailored interventions (facilitation, training, mentoring and coaching), then promoting and mainstreaming counselling and social support in all HIV/AIDS care, treatment and support programmes. This expert intervention is depicted by the blue colour illustrated as the foundation of the model.

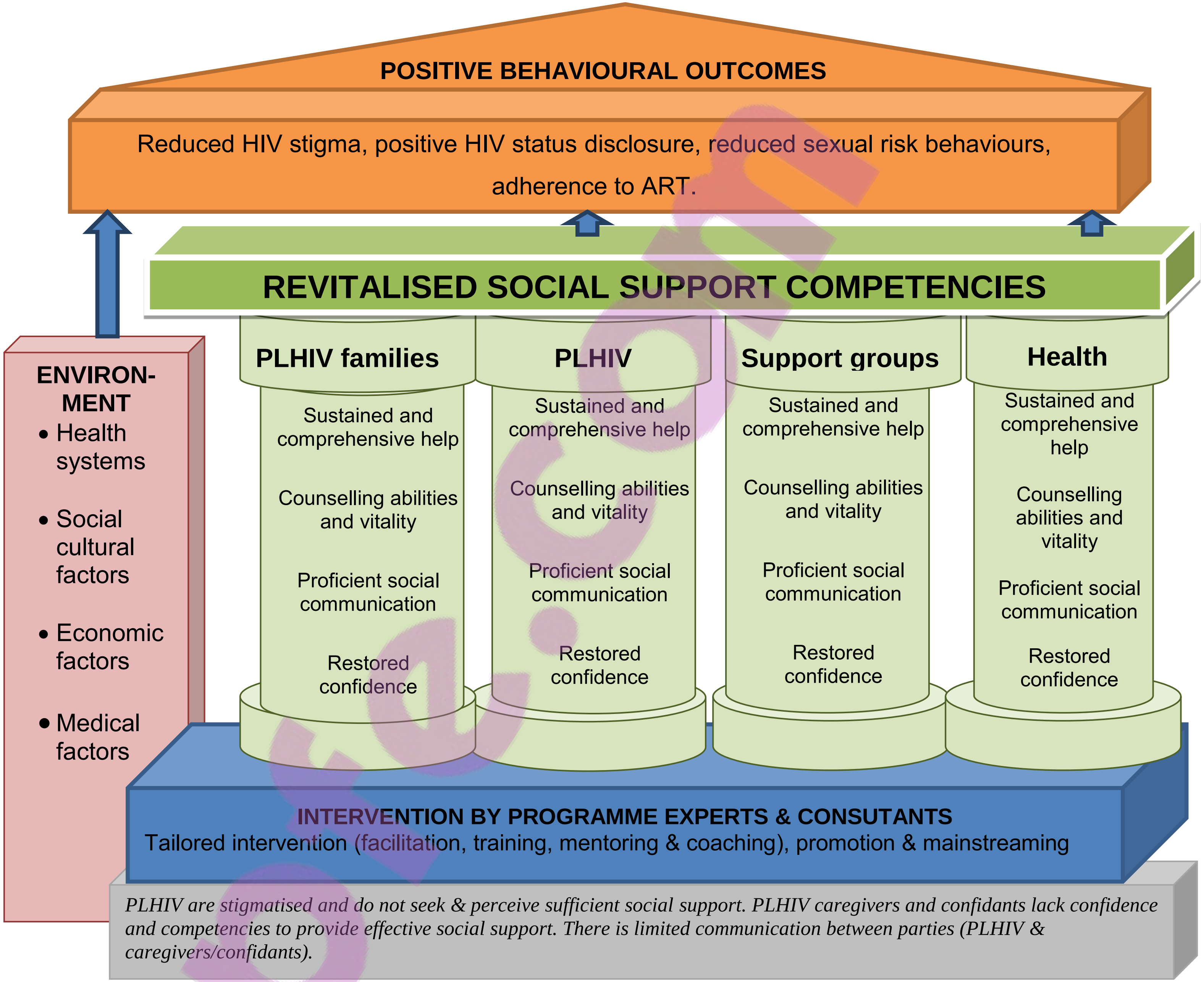


Figure 7.1: Structural description of the model to revitalise social support competencies

Based on the study finding that PLHIV derive social support from family members, workmates, health workers, and peer PLHIV support group members, the model is built on four pillars each representing the cited source of social support. Therefore, programme expert interventions target the four pillars simultaneously. The intervention in form of facilitation, training, mentoring and coaching of PLHIV caregivers and confidants enables them to “see” and use their capabilities. Their confidence is restored, they become proficient in social communication and they acquire abilities and vitality to effectively and passionately provide counselling and social support to PLHIV in their purview. With these interventions mainstreamed in HIV/AIDS programmes, social support competencies among PLHIV caregivers and confidants are revitalised and they become able to provide sustainable and comprehensive help. There is a ray of hope, and this is reflected by the green colour.

Assuming that the other factors in the environment (social cultural factors, economic factors, health systems and medical factors remain favourable, revitalising social support competencies leads to improved PLHIV behavioural outcomes – reduced HIV stigma, positive HIV status disclosure, reduced sexual risk behaviour and adherence to ART. These are the expected fruits of the proposed model and are depicted by the orange colour.

7.10 OPERATIONALISATION OF THE MODEL

The proposed guidelines for operationalising the model are aimed at making it achieve three main objectives:

- To empower all PLHIV caregivers and confidants to actively contribute to enhancing positive behavioural outcomes of PLHIV. Empowering all caregivers and confidants entails equipping them with skills and information related to PLHIV care and support.
- To enhance PLHIV access to holistic care. Holistic care means addressing the physical, psychosocial, spiritual and other care needs of PLHIV.
- To increase demand for and utilisation of HIV/AIDS services through strengthened health facility and community systems. Uptake and utilisation of

HIV prevention, treatment and care services is critical in enhancing PLHIV's behavioural outcomes.

The intervention by programme experts is in three phases: the initial phase, the intervention phase and the sustenance phase.

7.10.1 Initial phase

This phase constitutes a diagnosis of the gaps and the needs be addressed in the intervention phase. It involves assessment of the factors underlying deficiencies in confidence and competencies for providing social support to PLHIV. A critical assessment of PLHIV caregivers and confidants' perceptions and capabilities to meet PLHIV social support needs is critical for developing an effective model of interventions. Also in this stage, programme experts determine strengths and weaknesses in PLHIV caregivers and confidants.

7.10.2 Intervention phase

During this phase, programme experts develop and implement strategies for addressing the gaps identified in the initial phase. This involves multifaceted activities necessary to generate outcomes. The model is premised on a belief that a multifaceted response by diverse confident and competent caregivers will have the greatest and broadest impact on PLHIV behavioural outcomes. The interventions or responses are organised along three variables: community-based PLHIV care systems strengthening, health facility-based PLHIV care systems strengthening, and PLHIV families' empowerment. The researcher argues that when the three variables (sets of interventions) are present or implemented in combination, they are expected to result in the desired outcomes.

The sets of interventions aim to achieve five intermediate objectives which lead to achieving the three main objectives and then the desired outcome: improved PLHIV behavioural outcomes.

Intermediate Objective 1: PLHIV caregivers and confidants gain confidence in their ability to provide effective social support to PLHIV.

Interventions: The above intermediate objective will be achieved through:

- Listening carefully to the concerns and perceptions of PLHIV caregivers and confidants with regard to providing social support to PLHIV
- Conveying enthusiasm and a sense of self-efficacy to provide effective social support to PLHIV
- Encouraging caring relationships, which enable both PLHIV and caregivers and confidants to develop a feeling of self-worth
- Promoting positive values, attitudes and behavioural, as well as an open climate for the exchange of ideas

In this phase, programme experts have an important task of assisting both parties to maintain open communication to enhance a caring relationship.

Intermediate Objective 2: To promote acquisition of skills and proficiency in social communication, counselling and social support among active PLHIV caregivers.

Interventions:

Programme experts identify and promote attributes related to the goal of revitalising social support competencies among active but ill-equipped caregivers.

- Introduce the concepts of effective social communication, counselling, and social support
- Review perceptions, beliefs, values and traits of participating PLHIV caregivers and confidants
- Create awareness of factors that facilitate a change in feelings, thoughts and behavioural
- Support willingness to acquire or improve competencies in social communication, counselling and social support

- Ensure adequate counselling of every PLHIV before and after initiation of ART
- Facilitate adherence counsellors to identify potential barriers and facilitators of behavioural change among PLHIV (including safe sex, disclosure and treatment adherence) and work with each individual to reduce the barriers and reinforce the facilitators of the desired change
- Engage treatment buddies in counselling and supporting PLHIV
- Provide ongoing treatment adherence counselling and support – counselling should not be a one-off event
- Practice skills with trainees (PLHIV caregivers and confidants)

Intermediate Objective 3: To empower PLHIV households for effective social care and support

In this study, 36% of respondents cited family members as their source of social support. This reinforces old knowledge that many Africans rely on the traditional extended family system to meet their social, material and psychosocial needs. However, with the devastation caused by HIV/AIDS in Sub-Saharan Africa, this system is overstretched and unable to handle the multiple challenges associated with PLHIV care and support (UNAIDS 2007). The proposed model therefore involves skilling and tooling PLHIV households to enable them become effective PLHIV care givers.

Interventions:

- Engage community volunteers to reach households in communities covered by HIV/AIDS programme to increase awareness about HIV/AIDS and the needs of PLHIV
- Hold anti-stigma and anti-discrimination campaigns by addressing factors that fuel stigma at household level
- Encourage PLHIV to disclose their positive HIV status to their family members so that family members provide them with timey social care and support
- For PLHIV who consent, engage trained lay counsellors to support them in disclosing their positive HIV status to their family members

- Advocate recruitment and training of family members/relations of PLHIV as adherence support counsellors
- Support PLHIV households to meet materials needs of PLHIV and other household members. Interventions may include livelihoods training and other targeted household economic strengthening support mechanisms

Intermediate Objective 4: To empower PLHIV workmates for effective social care and support

At least 13% of respondents cited workplaces as their source of social support. Additionally, 96.2% of the respondents reported that they are employed implying that they spend a significant part of their day time at the workplace with their co-workers. Like in the family context, the model proposes skilling and tooling workmates of PLHIV to enable them become active and effective caregivers.

Interventions:

- Engage community volunteers to reach all workplaces in communities covered by HIV/AIDS programmes to increase awareness about HIV/AIDS and the needs of PLHIV
- Hold anti-stigma and discrimination campaigns by addressing factors that fuel stigma in workplaces
- Encourage PLHIV to disclose their positive HIV status to their employers and workmates
- Reach out to employers and ministries, departments and agencies responsible for labour affairs to advocate development and implementation of HIV/AIDS workplace policies
- For PLHIV who consent, deploy trained lay counsellors to support PLHIV in disclosing their positive HIV status to their employers and workmates
- Advocate recruitment and training of PLHIV workmates as adherence support counsellors
- Advocate insurance companies to include HIV/AIDS treatment just like any other chronic illness

Objective 5: To improve the quality of PLHIV care and support services in health facilities.

Recent advances in sciences have made HIV/AIDS one of the chronic diseases which if well managed can enable PLHIV live long, healthy and productive lives. This requires strengthening health systems especially assuring competent human resources for health to provide high quality care and support and assure that PLHIV remain in care.

Interventions:

- Advocate for an increase in the number of Human Resources for Health (HRH) in health facilities and communities that can provide professional care for PLHIV and to reduce HIV-related stigma
- Integrate HIV/AIDS among other services provided by health facilities as compared to establishing parallel HIV/AIDS centres. This would increase the number of health workers skilled in managing HIV/AIDS and reducing HIV-related stigma
- Improve quality of care and treatment services through continuous medical education for health workers using up to date guidelines, promoting operations research and integrating findings in HIV/AIDS programming

7.10.3 The sustenance phase

Revitalising social support competencies is a process and its sustenance is critical for sustainable social support to PLHIV. Programme experts must adopt intervention strategies that live beyond a single intervention programme. Examples are training of trainers, capacitating community-based trainers and selecting willing and committed PLHIV caregivers. Additionally, programme experts need to strengthen local PLHIV support groups and networks.

Intermediate Objective 1: To strengthen community-based organisations (CBOs), PLHIV support groups and networks

Findings from this study show that participation in PLHIV support group activities benefits PLHIV in terms of reducing their HIV-related internal stigma, reducing their sexual risk behaviour, enhancing positive HIV status disclosure and improving ART adherence. The proposed model therefore recommends strengthening CBOs, PLHIV support groups and PLHIV networks to sustain the revitalised social support competencies.

Interventions:

- Intensify post-test counselling for all PLHIV to appreciate the importance of positive living especially adherence to ART and safer sexual behavioural
- During post-test counselling, encourage all PLHIV to join support groups and highlight the benefits of PLHIV support group participation. From the study findings, 29% of the respondents were not aware of the existence or benefits of PLHIV support groups
- Decentralise PLHIV support groups to reduce transport costs of attending group meetings
- As much as possible, train and involve all willing PLHIV in HIV/AIDS service delivery; PLHIV may be engaged as peer educators, mentor mothers, adherence counsellors, lay counsellors, data entry clerks, contact trackers, and referral coordinators/facilitators
- HIV/AIDS programmes should strengthen the organisational and technical capacities of PLHIV support groups and other CBOs in which PLHIV are members. Organisational development interventions could include training and mentoring on governance, leadership, planning, financial management, resource mobilisation, and sustainability, innovation, learning and reporting. Technical capacity building interventions for strengthening PLHIV support groups should include behavioural change communications, HIV status disclosure skills, and adherence counselling and support

7.11 EVALUATION OF THE MODEL

Chinn and Kramer (1995:134-137) provide a framework for evaluating models. Model evaluation helps in clarifying how well a model relates to theory, research or practice.

The proposed model has been scrutinised by colleagues familiar with model development and HIV/AIDS care and support, in addition to guidance from my academic supervisor. All revision and suggestions have been incorporated to refine the model.

7.11.1 Clarity of the model

Chin and Kramer (1995:127) recommend that evaluating the model should consider two major factors: (i) semantic clarity and consistency (ii) structural clarity and consistency. Clarity refers to how understandable the model and its description are to readers or potential users. Consistency refers to conformity with standard processes or procedures for the sake of logic, accuracy, or fairness. To achieve semantic clarity and consistency, the researcher has endeavoured to construct definitions of concepts in a logical or sequential manner from the identification of the main concept, to its attributes, throughout theoretical definitions and in structuring of the model. Clarity was lacking in the initial model proposed by the researcher. However, the model has now become more lucid through the interventions proposed in each intermediate objective. No unimportant concepts have been introduced to create unnecessary complexity.

7.11.2 Simplicity of the model

According to Chin and Kramer (1995:124), simplicity refers to the complexity of the structural components and relationships between concepts. In this model, the essential and related attributes are derived from the main concept thus are closely related. In order to keep the model simple, it has been illustrated using a simple structure that can be easily understood.

7.11.3 Generality of the model

Chinn and Kramer (1995:132) assert that it is essential that a model be broad and wide in scope and thus applicable in an array of situations. This model has been developed to revitalise social support competencies in multiple settings: workplaces, families, health facilities and communities.

Also, although it is intended for use in HIV/AIDS control programmes, it can be applicable to other situations where there is a feeling of incompetence and need for enhancing efficiency and productivity in providing social or healthcare services.

7.11.4 Accessibility of the model

Accessibility addresses the extent to which empiric indicators for the concepts can be identified and how attainable the projected outcomes of the model are after it has been operationalised (Chinn & Kramer 1995:129-136). These two factors are dependent on the scope and specificity of the model. The accessibility of the model has been ensured by the provision of clear definitions of concepts, built on the essential criteria. The model can be accessible to different types of empirical testing, making it easy for a skilled experienced programme expert to design intervention programmes to enhance revitalisation of competence in different situations.

7.11.5 Importance of the model

The model described above is the researcher's recommended framework for positively enhancing behavioural outcomes of PLHIV through revitalising social support competencies of their caregivers and confidants. The model is premised on the study findings, which affirm the value of PLHIV support group participation but also suggest that PLHIV obtain social support from varied sources, including PLHIV support groups, family members, co-workers and health workers. The model is therefore important since it is a tool to enhance comprehensive care and support of PLHIV and ultimately their behavioural outcomes. The fact that it is also applicable in other settings other than HIV/AIDS programmes increases its level of importance.

7.12 CONCLUSION

Overall, this chapter has given a detailed description of the model for revitalising social support competencies among PLHIV caregivers and confidants and its operationalisation. The description has covered the process of identifying the main and related concepts and how these concepts are related to develop a model. It also covers the overview, purpose, context, assumptions of the model.

The theoretical definitions of concepts, construction of relationship statements and structural description of the model are also addressed in the chapter. The latter sections of the chapter provide guidelines for the operationalisation of the model and its evaluation using the five criteria set by Chinn and Kramer (1995:122-137). In Chapter 8, the focus will be on the conclusions, limitations and recommendations of this study.

CHAPTER 8

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

8.1 INTRODUCTION

In the previous three chapters, the researcher discussed the findings of the study and presented a model for revitalising PLHIV caregiver social support competencies so as to improve positive behavioural outcomes of PLHIV. In this final chapter, the researcher presents conclusions drawn from findings of the study in relation to the research objectives and questions. The chapter also highlights limitations of the study. The last sections of the chapter present recommendations for the academic world and for improving HIV/AIDS programming in Sub-Saharan Africa.

The aim of this study was to develop an evidence-based model for revitalising PLHIV caregiver social support competencies so as to enhance positive behavioural outcomes of PLHIV. The study objectives were to: i) determine reasons for participation or non-participation in support group activities among PLHIV; ii) determine differences between PLHIV who participate in support group activities and those who do not participate; and iii) use the findings to develop a model for revitalising PLHIV caregiver social support competencies and enhance positive behavioural outcomes of PLHIV.

The research questions in this study were: (i) What are the reasons for PLHIV's participation and non-participation in support groups ?; (ii) Do PLHIV who participate in support group activities differ from those who do not – in terms of socio-demographics, perceived social support, HIV-related stigma, HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment? Iii) How can behavioural outcomes of PLHV be enhanced?

8.2 CONCLUSIONS

Based on the study findings, the researcher concludes that PLHIV who participate in PLHIV support group activities differ from those who do not – in terms of internal HIV-related stigma, HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment; but there is no difference between the two groups in terms perceived social support and some socio demographics. The findings suggest that participating in support group activities is valuable to PLHIV in terms of enhancing their positive behavioural outcomes. The following section presents conclusions by study objectives.

8.2.1 Objective 1: To determine reasons for participation or non-participation in support group activities among PLHIV

The researcher tabulated reasons given by respondents for participating or not participating in support group activities. For respondents who had ever participated in support group activities, the main reasons for participation were: getting advice from others (51%); sharing experiences (48%); and seeking help (31%). For respondents who had never participated in support group activities, the major reasons were lack of time (35%); lack of information about benefits of support groups (29%); and not wanting others to know the respondent's positive HIV status (14%). The researcher concludes that generally, most PLHIV perceive and appreciate the benefits of support group participation, but some PLHIV's participation is constrained by time, lack of information about benefits of PLHIV groups and stigma. If HIV/AIDS programmes decentralised support groups to communities where PLHIV live, created more awareness about the benefits of participating in support groups and intensified stigma reduction campaigns, more PLHIV would join and participate in support group activities.

8.2.2 Objective 2: To determine differences between PLHIV who participate in support group activities and those who do not participate – in terms of socio-demographics, perceived social support, HIV-related stigma, HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment

This objective was achieved by conducting a study using a cross-sectional design. Data were collected from individuals who had ever participated in support group activities and those who had never participated. The questions asked were related to respondents' socio-demographics and the study variables. Percentages, means and median scores of responses from the two groups were compared. The findings revealed that:

- There was no significant difference between PLHIV who participate in support group activities and those who do not in terms of their levels of education (*p*=0.748) and sources of income (*p*=0.067); but respondents differed in marital status (*p*=<0.001), age (*p*=<0.001), sex (*p*=0.029) and religion (*p*=0.034). The researcher therefore concludes that socio-demographic characteristics are not a predictor of support group participation.

- Median scores of perceived social support for PLHIV who participate in support group activities and those of PLHIV who do not were not significantly different (32 (27-37) vs (31 (26-37). The aggregate score of all respondents was 32 (27-37) out of the maximum possible score of 40. This implies that there is no significant difference between PLHIV who participate in support group activities and those who do not – in terms of perceived social support. The researcher concludes that generally, whether PLHIV participate in support group activities or not, they have almost equated access to social support and from multiple sources.

- Median scores of HIV-related internal stigma were significantly lower amongst PLHIV who participate in support group activities [16 (14-19)] than those of PLHIV who had never participated [18 (15-20)] (*p*=<0.001). However, the reverse was true with external stigma and total median stigma scores (internal plus external stigma). Respondents who participate in support group activities [28 (22-35)] and those who do not [29 (21-35)] were not significantly different (*p*=0.88).The researcher concludes that participating in support group activities may reduce internal stigma but not external stigma. External stigma requires changes in how the community or society perceives HIV/AIDS and PLHIV and can thus be effectively addressed through community-focused anti-stigma interventions.

- Positive HIV status disclosure was significantly higher amongst respondents who had ever participated in support group activities (81%) than those who had never participated (75%) (*p*=0.005). This implies that PLHIV who participate in support group activities are more likely to disclose their positive HIV status than those who do not. The researcher concludes that PLHIV who participate in support group activities differ from those who do not – in terms of positive HIV status disclosure; there is an association between support group participation and positive HIV status disclosure.

- PLHIV who participate in support group activities significantly differ from those who do not – in terms of adherence to ART (*p*=0.021). This finding is consistent with previous findings, which revealed that generally, support from peers, family members or health workers increased ART adherence (Kamau et al 2012:7; Sarna et al 2013:11; Walstrom et al 2013:1). The researcher concludes that support group participation is valuable in terms of enhancing ART adherence. PLHIV who participate in support group activities are more likely to adhere to their ART than those who do not participate.

- Overall sexual risk behaviour was higher among PLHIV who had never participated in support group activities [31%; (233/419)] than those who had participated [27%; (186/419)] (*p*=0.05). The researcher concludes that there is a significant difference between PLHIV who participate in support group activities and those who do not – in terms of their sexual risk behaviour.

PLHIV who participate in support group activities are more likely to adopt safer sexual behaviour than those who do not participate.

8.2.3 Objective 3: To use the findings to develop a model for revitalising PLHIV caregiver social support competencies so as to enhance behavioural outcomes of PLHIV

This objective was met by developing and describing a framework for revitalising PLHIV caregivers social support competencies so as to enhance positive behavioural outcomes of PLHIV. The findings from the cross-sectional study suggest that support group participation is valuable in terms of reducing HIV-related internal stigma, enhancing positive HIV status disclosure and safer sexual behaviour, as well as improving ART adherence among PLHIV. The study did not find any association between support group participation and perceived social support or reduction in HIV-related external stigma. Furthermore, the study found that there are more PLHIV who obtain social support from health workers and family members than those who obtain it from support groups. The proposed model therefore emphasises the importance of revitalising social support competencies among family members, healthcare workers, workmates and support group members in order to assure PLHIV holistic care and support.

Based on the study findings, the researcher has identified the main and related concepts and related these concepts to develop a model for revitalising PLHIV caregiver social support competencies. In the previous chapter, an overview, purpose, context, assumptions of the model were given. The theoretical definitions of concepts, construction of relationship statements and structural description of the model were also addressed. The chapter also provided guidelines for the operationalisation of the model and its evaluation using the five criteria set by Chinn and Kramer (1995:122-137).The model is handy for use by HIV/AIDS programmes interested in positively enhancing behavioural outcomes of PLHIV.

The overall conclusion is that all the three study objectives were met.

8.3 LIMITATIONS OF THE STUDY

This study was limited to establishing whether there is an association between participation in support group activities and specific PLHIV behavioural outcomes: HIV-related stigma, positive HIV status disclosure, sexual risk behaviour and adherence to anti-retroviral treatment. The study did not seek to establish whether there are cause-and-effect relationships between support group participation and the defined behavioural outcomes. It is therefore possible that the observed associations are caused by other factors exclusively or in tandem with support group participation.

This first phase of the study used a cross-sectional design. This was due to time and resource constraints. While the information obtained may be correct as at the time of the study, as time passes, the values of the obtained results could change in either positive or negative directions. A longitudinal study design that monitors behaviours of the two study groups is needed to provide more information about behaviour changes that occur over time.

The researcher relied on self-reports to measure PLHIV sexual risk behaviour and adherence to ART. Participants in both study groups reported high rates of adherence to ART – 95% and 92% among PLHIV who participate in support group activities and those who do not, respectively. These rates are quite high compared to those reported in the literature by other studies. Systematic reviews show that on average, adherence among PLHIV on ART is below 80%, and around a quarter of patients interrupt treatment for a median of 150 days (Mills, Nachega & Ford 2013:3). This means that some respondents could have over reported their ART adherence – this is inherent in self-behaviour reporting. To overcome this challenge, some authors have recommended multiple approaches in ART adherence monitoring (Mills et al 2013:1). However, the self-report method has also been found well correlated with viral load suppression and is particularly recommended for resource-limited settings because of its low cost (Simoni, Kurth & Pearson 2006:1). This study could not use multiple approaches due to time and resource constraints.

Only PLHIV who could communicate in English were included in the study. Moreover, the self-administered questionnaire was in English, thus there was some level of bias in selection of respondents. Also, some questionnaires that were incomplete, and possibly due to limited English language literacy, some were discarded. This could have skewed findings of the study in favour of English literate respondents.

Selection of sites was limited to FHI 360 supported states and hospitals in the southern and eastern parts of the country. Moreover, the three states supported by FHI 360 in the northern region could not be selected due to insecurity. At the time of the study, Borno, Yobe and Adamawa states were under a state of emergency imposed by the Nigeria government as part of a counter-offensive against the *Boko Haram* terrorists. Besides, people from the selected states are predominantly Christians. It is therefore possible that the observed behavioural outcomes are not generalisable in the Muslim dominated northern and western states of Nigeria.

8.4 RECOMMENDATIONS

8.4.1 Recommendations for improving HIV/AIDS programming

Based on the study findings, the researcher makes the following recommendations for improving HIV/AIDS programming in Nigeria and Sub-Sahara Africa in general:

Data from the study shows that 66% (1,111/1,643) of the respondents were female implying that more women than men in Nigeria are living with HIV. However, the study also revealed that despite there being more HIV positive women than men, men were more likely to participate in support group activities than women (51% vs 45%). Also, according to the UNAIDS report (2012:4), 57% of treatment eligible men were on ART in 2012, compared to 73% of treatment-eligible women. This highlights the gender related challenges in HIV/AIDS management especially in Sub-Saharan Africa. To address the inherent gender issues, HIV/AIDS programmes should integrate gender in HIV prevention, care and treatment programmes to reduce women vulnerability to HIV infection and enhance more male involvement in the fight against the scourge.

Findings from this study indicate that the majority (53%) of the respondents do not belong to, and have never participated in support group meetings. The reasons for non-participation include lack of time (35%); lack of information about benefits of support groups (29%); and stigma (not wanting others to know the respondent's positive HIV status (14%). It is possible that some of the respondents who said they do not have time to attend support group activities said so because they do not appreciate the value of participation. Given the findings of this study, which show that participation in support group activities enhances PLHIV positive behavioural outcomes, HIV/AIDS programmes should popularise support groups and step up efforts to reduce stigma and discrimination against PLHIV. Post-test counselling and decentralisation of support groups from health facilities to communities may help.

The researcher recommends that new HIV/AIDS programmes adopt and test the proposed model for revitalising social support competencies among various PLHIV caregivers and confidants. This could be done through operations research using specific, easy to test research questions and hypotheses. This recommendation is based on the findings of this study, and some previous studies, which highlight the need for a combination of care interventions, including PLHIV self-care, care and support by PLHIV family members, health workers, colleagues in the workplace and community care providers in order to address the holistic needs of the PLHIV and enhance their behavioural outcomes. The model is also informed by other health behaviour models and theories such as the Health Beliefs Model, the Social Networks and Social Support Model and the Social Cognitive Theory.

8.4.2 Recommendations for further studies

The study findings indicate that people who were not married (single, widowed, separated or divorced) were less likely to participate in support group activities than those who were married or living with a sexual partner (37% vs 67%). The researcher did not delve into establishing reasons for this difference. Future studies should explore reasons (why) married PLHIV are more likely to participate in support group activities than unmarried PLHIV.

The study also found that people aged below 30 years were less likely to participate in support group activities than those between 31 and 44 years as well as those over 45 years (21% vs 54% vs 25%); implying that older PLHIV are more likely to participate in support group activities than younger people. More studies are needed to establish the reasons for this variation.

As indicated in the limitations section, this study was limited to finding whether there was an association between support group participation and the PLHIV behavioural outcomes considered under this study. This was achieved using a cross-sectional study design. The researcher recommends that a study using a randomised controlled trial using a prospective cohort design be carried out to establish whether there are cause-and-effect relationships between support group participation and the defined behavioural outcomes.

Furthermore, this study did not account for possible intermediations of some of variables in the conceptual model. There is therefore need for a study design that looks at the possible values of stigma reduction and positive sexual disclosure on ART adherence and sexual risk behaviour.

8.5 PERSONAL REFLECTIONS

This chapter brings to an end a journey that I conceived seven years but began three years ago. While pursuing my Master in Public Health at the University of Massachusetts, Amherst, one of my lecturers, Professor Ann Carry interested me in pursuing a doctoral degree and even offered me a position of a Tutorial Assistant in her department. However, due to financial constraints, I turned down her offer because the earnings from tutorship could not support me and my family. Even when I declined the offer, I could not lull my disquietude over the idea. So, in 2012, I enrolled for this doctoral program with UNISA.

While I had done some research before and completed two dissertations as part of my masters programmes, completing this doctoral thesis has been both challenging and rewarding. The research proposal module exposed me to more concepts and complex research design processes, and literally forced me to read more than 200 journal articles in order to understand my research topic and refine the study methodology. With guidance from my able professor, I finally overcame the challenges.

Equally challenging were data analysis and model development. To surmount these, I engaged services of a biostatistician and read several tresses that had involved model development. Access to the UNISA online library was a big relief to me. Overall, the extensive reading, the late night sleeping, and the back and forth with my supervisor have made me a better scholar and given me more insights into the research topic than I had before. Most importantly, the study findings and the recommendations make me proud of this academic milestone. It has been a worthwhile undertaking.

8.6 CONCLUDING REMARKS

Recent advances in anti-retroviral treatment have made HIV/AIDS a manageable chronic disease when patients are initiated early and they strictly adhere to treatment prescriptions. Major benefits of adherence to ART, including optimal treatment outcomes and reduction in HIV transmission are now widely recognised by the medical and public health communities. Based on previous studies which suggest that social support is associated with improved physical and mental wellbeing of PLHIV, different programmes have adopted PLHIV support groups and Meaningful Involvement of PLHIV as some of the strategies to enhance ART adherence and treatment outcomes.

Prior to this study, there was no information linking support group participation and positive behavioural outcomes of PLHIV. This study reveals that there is no association between support group participation and perceived social support. However, the findings indicate that PLHIV obtain social support from varied sources, including family members, health workers and support group participation. The study findings also suggest that participation in support group activities is valuable in terms of HIV-related internal stigma, positive HIV status disclosure, sexual risk behaviour and adherence to ART.

Based on these findings, a framework or model for revitalising social support competencies is recommended to enable PLHIV caregivers and confidants effectively meet the holistic needs of PLHIV and positively enhance their behavioural outcomes.

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ANNEXES

UNISA university of south africa

UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

HSHDC/302/2014

Date: 30 January 2014 Student No: 5130-823-1

Project Title: The value of support group participation by people living with HIV on behavioural outcomes for people living with HIV in Nigeria.

Researcher: Simpson Tumwikirize

Degree: D Litt et Phil Code: DPCHS04

Supervisor: Dr S Mokoboto-Zwane
Qualification: PhD
Joint Supervisor: -

DECISION OF COMMITTEE

Approved ☑ **Conditionally Approved** ☐

LRoets

Prof L Roets
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

for **Prof MM Moleki**
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

December 11, 2013

The Chief Medical Director/Officer

Dear Sir/Madam,

RE: Permission to conduct research in your hospital

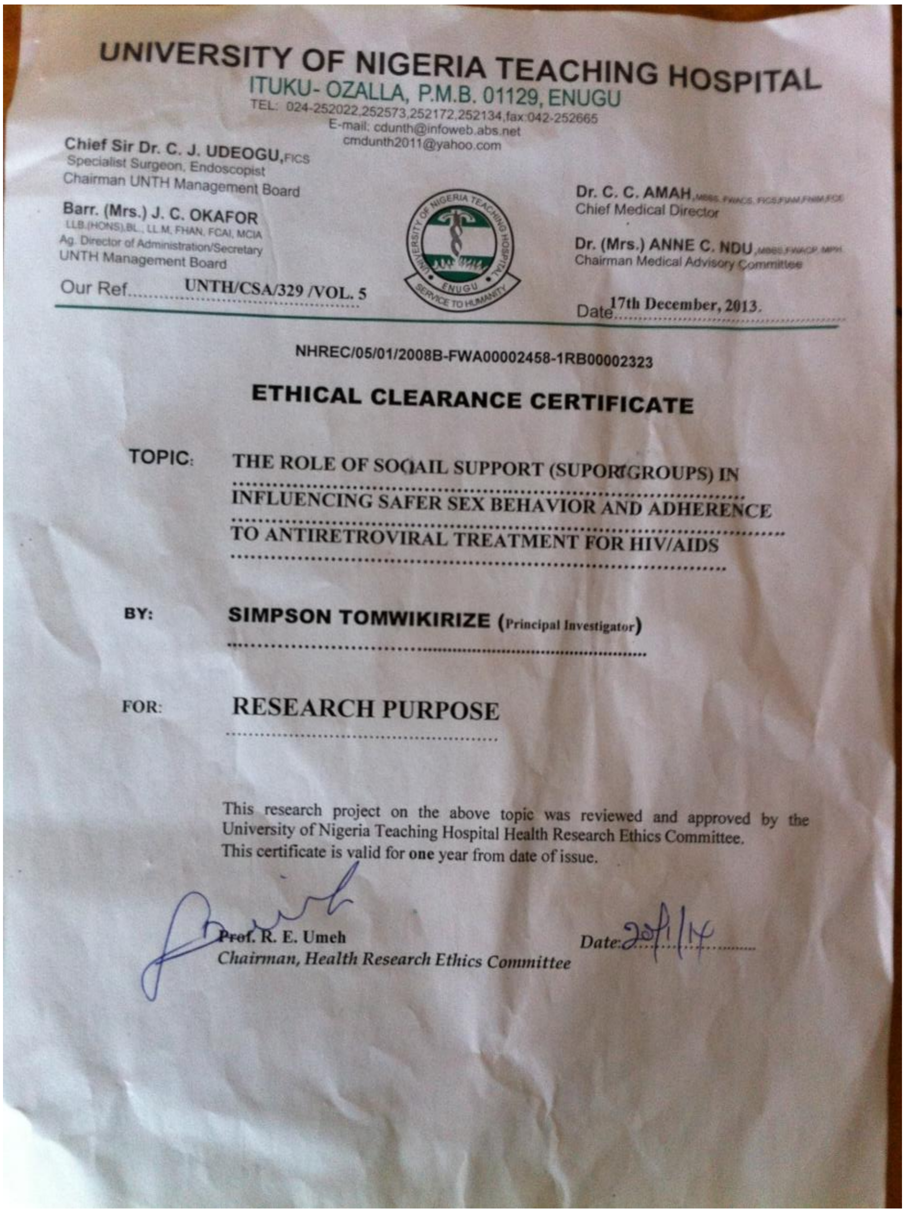
My name is Simpson Tumwikirize, a staff member of FHI 360 and a doctoral student at the University of South Africa. I am the principal researcher in this study. We are carrying out a study that is meant to help us better understand the value of PLHIV support group participation by PLHIV with regards to their behavioural outcomes, as well as establishing reasons underlying their participation choices. The findings will help us develop better programmes to improve HIV/AIDS prevention, care, and treatment. The findings that are of practical significance will be shared with the leadership of FHI 360 for possible integration into the project plans and implementation. We would like to have your permission to interview some of your clients.

Your hospital has been randomly selected to participate in this study. The information collected will be used strictly for academic and programming purposes and will never be used against your hospital. The information got from respondents will be kept confidential. Respondents are requested not to write their names, ID numbers, or any other personal information or that of your hospital on the questionnaire. After filling out the questionnaire, a respondent will put it in the provided envelope and seal it. Our research assistant will collect all the envelopes and hand them over to us unopened.

We will protect information about respondents and their taking part in this research to the best of our ability. We will not use their names in any reports. We will not tell their partners or peers or friends about their participation. Sampled respondents are free to decide if they want to be in this research or not, without any fear of victimization or reprisals. There is no payment for participating in this study. Respondents may ask for clarifications from research assistants on questions they do not understand.

This research has been reviewed and approved by the Institutional Review Board of FHI 360, the Federal Ministry of Health and the Department of Higher Degrees, University of South Africa. If you have any questions or concerns about how your clients are being treated, you may contact *Mr. Y Aminu, National Health Research Ethics Committee, FMOH Federal Secretariat Complex, Shehu Shagari Way, Garki Abuja. P.M.B. 083 Garki Abuja. Tel: +234-9-523-8367. Email: deskofficer@nhrec.net*

Simpson Tumwikirize



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Chief Medical Director

Dr. (Mrs.) ANNE C. NDU, MBBS,FWACP, MPH
Chairman Medical Advisory Committee

Our Ref........UNTH/CSA/329 /VOL. 5

Date 17th December, 2013.

NHREC/05/01/2008B-FWA00002458-1RB00002323

ETHICAL CLEARANCE CERTIFICATE

TOPIC: THE ROLE OF SOCIAIL SUPPORT (SUPORTGROUPS) IN INFLUENCING SAFER SEX BEHAVIOR AND ADHERENCE TO ANTIRETROVIRAL TREATMENT FOR HIV/AIDS

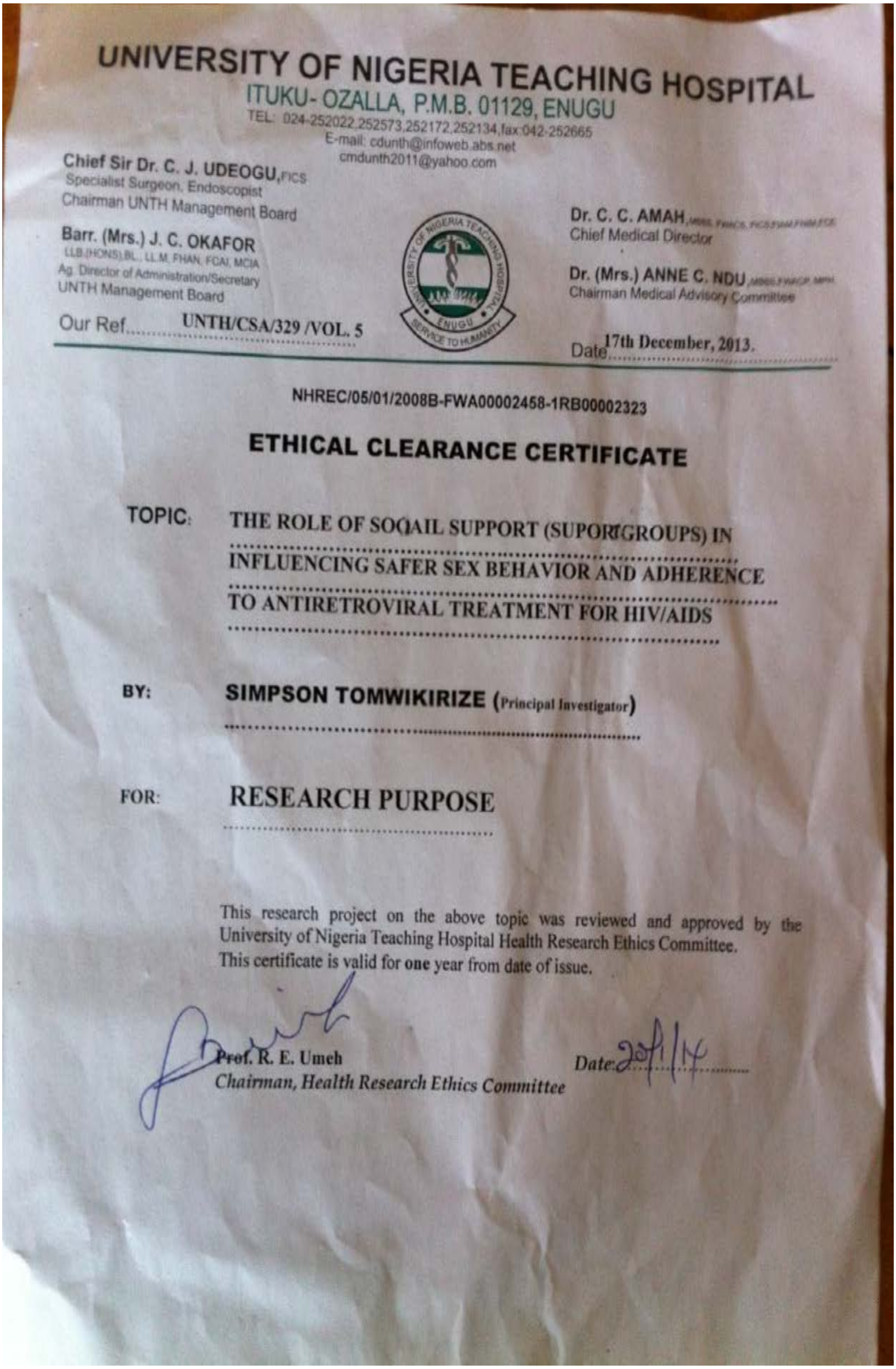
BY: **SIMPSON TOMWIKIRIZE** (Principal Investigator)

FOR: RESEARCH PURPOSE

This research project on the above topic was reviewed and approved by the University of Nigeria Teaching Hospital Health Research Ethics Committee. This certificate is valid for **one** year from date of issue.

Prof. R. E. Umeh
Chairman, Health Research Ethics Committee

Date: 20/1/14



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ETHICAL CLEARANCE CERTIFICATE

TOPIC: THE ROLE OF SOCIAIL SUPPORT (SUPORTGROUPS) IN INFLUENCING SAFER SEX BEHAVIOR AND ADHERENCE TO ANTIRETROVIRAL TREATMENT FOR HIV/AIDS

BY: **SIMPSON TOMWIKIRIZE** (Principal Investigator)

FOR: RESEARCH PURPOSE

This research project on the above topic was reviewed and approved by the University of Nigeria Teaching Hospital Health Research Ethics Committee.
This certificate is valid for **one** year from date of issue.

Prof. R. E. Umeh
Chairman, Health Research Ethics Committee

Date: 20/1/14

THE SCIENCE OF IMPROVING LIVES

FHI 360

certifies that

Simpson Tumwikirize

has completed the

RESEARCH ETHICS TRAINING CURRICULUM

On August 1, 2013

Informed Consent Form

Title: The Value of Support Group Participation by People Living with HIV on Behavioural Outcomes for People Living with HIV in Nigeria.

Sponsor: Privately sponsored.

Principal Investigator: Simpson Tumwikirize

Address: FHI 360, Plot 1073, J. S. Tarka Street, Area 3, Garki, Abuja, Nigeria.
+234 7055883462

Introduction

We are requesting you to take part in a study that is meant to help us better understand the value of PLHIV support group participation by PLHIV, with regards to their behavioural outcomes, as well as establishing reasons underlying their participation choices. The findings will help us build better programs to improve HIV/AIDS prevention, care, and treatment. We want to be sure that you understand the purpose and your responsibilities in this study before you decide if you want to participate. Please ask us to explain any words or question that you may not understand.

Information About the Study

Your hospital and you have been chosen by chance to be in this study. You will be requested to complete the questionnaire by yourself. You will answer the questions on your own; no one will see what you have written. It will take about 30 minutes to complete the questionnaire.

The information collected will be used strictly for academic and programming purposes and will never be used against you or this hospital. This study and the information collected are NOT for providing services or treatment. The information you give us will be kept confidential. After filling out the questionnaire, put it in the provided envelope and seal it in complete privacy. Our research assistant will collect all the envelopes and hand them over to us unopened.

Possible Risks

The possible risk in this study is discomfort in answering some sensitive questions about your private life. You may fear that other people will find out about your information. This will not happen because your name is not written on any of the study documents so no one will know what you have said. To keep your responses anonymous and confidential, do not write personal identifiers such as name, address, telephone, hospital identification, national identifications or passport number on this document. We will protect information about you and your taking part in this research to the best of our ability. We will not use your name in any reports. We will not tell your partner or friends bout your participation.

Possible Benefits

There are no direct benefits to you as an individual but results from the study will be used by agencies and public health professionals to plan better HIV/AIDS prevention and treatment programmes. Findings from this study will be shared with the leadership of FHI 360 for use in future programs.

If You Decide Not to Be in the Study

If you decide not to participate, your decision will not affect the health care you would normally receive at this hospital.

Confidentiality

We will protect information about you and your taking part in this study to the best of our ability. We will not use your name in any reports. We will not tell your partner or peers or friends about your participation.

Payment

There is no payment for participating in this study. It is purely voluntary.

If You Have a Questions about the Study

If you have any questions about the study, call the Principal Researcher on 07055883462 between 8.00am qnd 10.00pm.

Your rights as a Participant

This study has been reviewed and approved by the Institutional Review Board of FHI 360, the Department of Higher Degrees, University of South Africa, the National Health Ethics Committee and the Chief Medical Officer (CMD) of your hospital. If you have any questions or concerns about how you are being treated by the study or your rights as a participant you may contact:

Mr. Y Aminu, National Health Ethics Committee, FMOH Federal Secretariat Complex, Shehu Shagari Way, Garki Abuja. P.M.B. 083 Garki Abuja. Telephone +234-9-523-8367. Email: deskofficer@nhrec.net

VOLUNTEER AGREEMENT

Your consent to participate is implied by your decision to complete this questionnaire

RESEARCH ASSISTANT

I certify that the nature and purpose, the potential benefits and possible risks associated with participating in this study have been explained to the respondent.

____

Signature of Research Assistant Date

QUESTIONNAIRE

Instructions: Before you begin answering questions, read the entire informed consent document provided by the research assistant. If you need help to understand the meaning of any question, contact the research assistant. Read all instructions on how to answer questions in each section. After answering all the questions, put all papers in the provided envelope. Our research assistant will collect all the envelopes and hand them over to us.

Q #	**Question**	**Response category**	**Skip to**
SECTION 1: Circle your chosen answer. Write answers for questions 2 & 3			
01	Sex	1= Male 2= Female	
02	When were you born?	Year of birth ………………	
03	What is your age in years?	……………………………..	
04	What is the highest level of school you completed?	1= Some primary 2= Completed primary 3= Some secondary 4= Completed secondary 5= Tertiary education	
05	What is your source of income?	1= Office work 2= Trading/ business 3= Farming 4= My spouse 5= Other (specify)………….	
06	What is your religion?	1 = Christianity 2= Islam 3 = Traditional 4 = No religion 5= Others (specify) ………	
07	What is your marital status now?	1=currently married 2=divorced 3=widowed 4=separated 5= Single 6=living with sexual partner but not married	
	SECTION 2: Circle your chosen answer		
08	In which year did you begin antiretroviral treatment (ARVs) for AIDS?	1 =2010 2 =2011 3 =2012	
09	Have you ever participated in an HIV/AIDS support group meeting/activity?	1=Yes 2=No	
10	Are you a member of an HIV/AIDS support group?	1=Yes 2=No 3= I was but left the group	

11	If you answered Yes in question 9, in which year did you participate in PLHIV support group meetings for the first time?	1 =2010 2 =2011 3 =2012 4=2013 5=2014	
12	If you are a member of or have ever participated in an HIV/AIDS support group meeting, what are the reasons why you chose to join the group or participate in its meetings **(circle all that are applicable)**	1=To share experiences 2=To seek help from others 3=To get advice from others 4= Others (specify -------------------------------------- -------------------------------------- --------------------------------------	
13	If you are a member of an HIV/AIDS support group or have ever participated in its meetings, how many times have you attended monthly support group meetings in the past 12 months? Choose you answer from [0,1,2,3,4,5,6,7,8,9,10,11,12] and write it the box on the right		
14	If you are a member of an HIV/AIDS support group, where is your supported group located?	1= At this hospital 2= At another hospital 3= In my home village/town 4= Other (specify)-------------	
15	If you are **NOT** a member of an HIV/AIDS support group or was but have left the group, what are the reasons why you chose NOT to join or to leave the support group **(circle all that are applicable)**	1= Have no information about benefits of support groups 2= I do not want others to know my HIV status 3= I do not have time to attend support group meetings 4= I get support from other people 5=Other (specify) -------------------------------------- -------------------------------------	

SECTION 3: This section consists of a list of some things that other people do for us or give us that may be helpful or supportive.

16a. On a scale of 5 to 1 where 5 is the highest and 1 is the lowest, indicate where you get the most support/help (all forms) related to managing your HIV/AIDS situation [Use 5, 4, 3, 2 , 1 to rank the choices in the box on the right]

Source of social support	***Rank (5,4,3,2,1)***
Health workers	
Support group members	
Family members	
Co-workers/Friends	
Others (specify)------	

For the next questions in this section, please read each statement carefully and place an 'X' in the column that is closest to your situation. Give only 1 answer per row.

	5	4	3	2	1
	As much as I would like	Almost as much as I would like	Some, but would like more	Less than I would like	Much less than I would like
16b. I have people who care about what happens to me.					
17. I get the love and affection I need					
18. I get chances to talk to someone about problems at work or with my housework or my life					
19. I get chances to talk to someone I trust about my personal or family problems					
20. I get chances to talk about money matters					
21. I get invitations to go out and do things with other people					
22. I get useful advice about important things in life					
23. I get help when I am sick in bed					

SECTION 4: C<u>ircle</u> your chosen answer. <u>Write</u> a number for question 27			
24	In the past 12 months, have you had sex with anyone?	1.=Yes 2= No	**If No, skip to 39**
25	Do you have a spouse or co-habiting partner (a sexual partner that you live with or have sex with regularly)?	1=yes 2=No	
26	In the last 12 months, have you had sex with a person who is **<u>NOT</u>** your spouse or co-habiting/regular partner?	1= Yes 2= No	**If No, skip to 31**
27	If you answered Yes in question 26, How many?	-------------------------------------	
28	If you answered Yes in question 26, What are the relationships with the persons you had sex? (**<u>Circle all that are applicable</u>**)	1= Boyfriend/Girlfriend 2= Casual acquaintance 3= Commercial Sex Worker 4= Others (specify)-------------- -------------------------------------	
29	If you answered Yes in question 26, Did you use a condom?	1= Yes 2= No	
30	During the past 12 months, did you ever have sexual intercourse with a person who was not your regular sexual partner ***without*** using a condom?	1= Yes 2=No	
Section 5: This section is for respondents who are currently married or have regular sexual partners. If you are one, <u>circle</u> your chosen answer			
31	The last time you had sex with <u>your spouse/regular sexual partner</u>, did you and your partner use a condom?	1= Yes 2=No	**If No, skip to 34**

32	Who suggested using a condom that time?	1= Myself 2= My partner 3= Joint decision	
33	What is the main reason you or your spouse/regular sexual partner used condom the last time you had sex? **(circle all that are applicable)**	1= To prevent pregnancy 2= To prevent HIV 3= Partner insisted 4= Others (specify) …………	
34	If you answered NO to question 31, what was the main reason you or your spouse/regular sexual partner did **NOT** use a condom the last time you had sex? **(circle all that are applicable)**	1= Never heard of condom 2= Partner objected 3 = Don't like them 4 = Desired the pregnancy 5= For religious reasons 6= Condom not available 7= Others (specify) …………	
35	In general, with what *frequency* did you or your spouse/regular sexual partner use a condom every time you had sex in the past 12 months?	1= Every time 2= Almost every time 3 = Sometimes 4 = Never	
SECTION 6: Circle the answer of your choice			
36	In the past 12 months, have you **given** money or gifts in exchange for sex?	1= Yes 2= No	
37	In the past 12 months, have you **received** money or gifts in exchange for sex?	1= Yes 2= No	If Q36=NO & Q37 =NO, skip to Q39
38	The last time you gave or received money or gift for sex; did you or your partner use a condom?	1= Yes 2= No	
SECTION 7: Circle your chosen answer			
39	Have you told anyone about your HIV status?	1=Yes 2=No	**If no, skip to 41**
40	***Answer Q40- Q42 if you are currently married*** If you are currently married, have you disclosed your positive HIV status to your spouse?	1= Yes 2= No 3= I am not married	
41	If you are currently married, do you know the HIV status of your spouse?	1=Yes 2=No 3= I am not married	
42	If you are currently married and have never disclosed your HIV status to your spouse, would you go with your spouse if he/she suggested that you go for couple counseling and testing for HIV?	1= Yes 2= No 3= Not applicable	
43	***Answer Q43- Q45 if you are currently not married*** If you are currently **not married** and have had a sexual relationship in the past 12 months, have you disclosed your positive HIV status to your last sexual partner?	1= Yes 2= No 3= Not applicable	

44	If you are currently **not married** and have had a sexual relationship in the past 12 months, do you know the HIV status of your last sexual partner?	1= Yes 2= No 3= Not applicable	
45	If you are currently **not married** and have not had a sexual relationship in the past 12 months, have you disclosed your positive HIV status to a friend, relative, or family member?	1= Yes 2= No 3= Not applicable	
46	If you are currently **not married** and have never disclosed your HIV status to your sexual partner, would you go with him/her if he/she suggested that you go for counseling and testing for HIV?	1= Yes 2= No 3= Not applicable	

SECTION 8: The questions in this section ask about your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please circle your choice for each question

47	I feel guilty because I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
48	People's attitudes about HIV and people living with HIV make me feel worse about myself	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
49	Since learning that I have HIV, I feel isolated from the rest of the world	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
50	Telling someone I have HIV is risky	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
51	I work hard to keep my HIV status a secret	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
52	I feel I am not as good a person as others because I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	
53	I worry that people who know I have HIV will tell others	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree	

SECTION 9: Questions in the next section assume that you have told other people that you have HIV, or that others know. If this is not true, choose “Not applicable”. Otherwise circle your chosen answer

54	I have been emotionally hurt by how people reacted to learning I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	

55	People seem afraid of me once they learn I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
56	People I care about stopped calling after learning I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
57	My friends abandoned me after learning that I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
58	Some people who know I have HIV have grown more distant	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
59	I regret having told some people that I have HIV	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
60	As a rule, telling others that I have HIV has been a mistake	1=Strongly Disagree 2=Disagree 3=Agree 4=Strongly Agree 5=Not applicable	
	SECTION 10: <u>Circle</u> your chosen answer		
61	How many antiretroviral doses do you take a day?	1. One dose 2. Two doses	If you take one dose a day, SKIP to Q65
62	**Answer Q62 if you take two doses a day** Did you miss your antiretroviral dose **<u>yesterday</u>** for:	Morning/Lunch YES NO Evening/Super YES NO	
63	**Answer Q63 if you take two doses a day** Did you miss your antiretroviral dose **<u>the day before yesterday</u>** for:	Morning/Lunch YES NO Evening/Super YES NO	
64	**Answer Q64 if you take two doses a day** Did you miss your antiretroviral dose **<u>3 days ago</u>** for:	Morning/Lunch YES NO Evening/Super YES NO	

65	**Answer Q65 if you take one dose a day** Did you miss your antiretroviral dose:	Yesterday YES NO The day before yesterday YES NO Three days ago YES NO	
66	In the past 7 days, how many times, in total, did you miss taking one or more of your antiretroviral doses? (If you haven’t missed any, write down the number "0")		
67	In the past one month, have you missed taking your ARVs doses for at least three (3) days due to any reason?	1= Yes 2= No	
SECTION 11: Circle your chosen answer.			
68	In the past one week, have you stopped taking your ARVs for three consecutive days due to any reason?	1= Yes 2= No	
69	In the past one month, have you stopped taking your ARVs for a whole week (7 consecutive days) due to any reason?	1= Yes 2= No	
70	In the past one year, have you ever stopped taking your ARVs for a whole month (30 consecutive days) due to any reason?	1= Yes 2= No	
SECTION 12: Circle your chosen answer			
71	At the time you were tested for HIV or were told your results, did any counselor discuss with you anything about enrolling in care [e.g. where to enroll, why to enroll and when to enroll]?	1=Yes 2= No	
72	At the time you were tested for HIV or were told your results, did any counselor discuss with you anything about joining support group activities [e.g. where to join, why to join and when to join]?	1=Yes 2= No	
END. THANKS VERY MUCH			