

**A CASE STUDY OF THE
FLYING ANGELS HIV SUPPORT GROUP
FOR PEOPLE LIVING WITH HIV AND AIDS
IN NG'OMBE COMPOUND, LUSAKA, ZAMBIA**

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Declaration

I the undersigned hereby declare that the work contained in this thesis is my own original work and has not previously in its entirety or in part been submitted at any university for a degree

Signature:

Date:

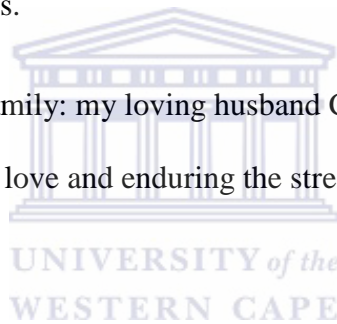


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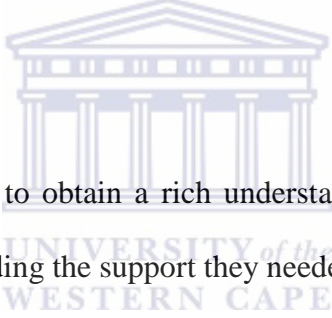
The support from my mentors, Dr Peter Chungulo and Mr John Banda, and encouragement from my colleagues, Mrs Anayawa Siamianze and Ms Concilia Muhau who contributed to the successful completion of my Thesis.

I am particularly indebted to my family: my loving husband Chabala, our children Kaluba and Kapambwe for their unconditional love and enduring the stress my absence created.



ABSTRACT

HIV support groups have been widely adopted as part of care and support interventions in Zambia, yet there is very little research on the effectiveness of these groups in meeting the needs of the PLWHIV from the perspective of those who join them. This case study looks at a selected support group for People Living with HIV and AIDS (PLWHIV) facilitated by the Flying Angels, a faith based non-governmental organization established in 2007 by the Living Assemblies of God Church, in Ng'ombe Township, Lusaka. The Support Group brings together around eighty young and old, married and single, men and women living with HIV and AIDS, to share experiences and find ways of coping with their situation.



The qualitative case study sought to obtain a rich understanding of the experiences of members with a view to understanding the support they needed, the aspects of the support group that are relevant and effective to their situation, and which are not. In-depth interviews and focus group discussions methods were used to collect data. Discussion and interviews were audio-taped. Audio-recordings were translated during transcription, data organized, coded and thematically analysed.

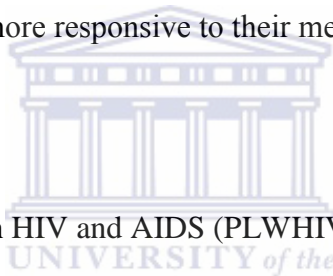
The Flying Angels HIV Support Group (hereafter referred to as the Support Group) could be considered as a success in that it had a sizeable and sustained membership over time. Involvement of members in the running of the Support Group was key to the success of the Group as was the combination of instrumental, emotional and informational support provided. However, the Support Group also had limits, especially in its ability to address

the economic marginalisation of its members and its ability to provide a platform to access a wider range of services. The diverse needs of PLWHIV outweigh the capacity of a single support group's assistance, necessitating establishment of meaningful linkages for "wraparound" support services. Economic empowerment for PLWHIV in support groups is critical.

Effective and functional support groups have potential to complement health facilities in providing health services for PLWHIV. It is hoped that the findings of this study will contribute to further understanding the functioning of HIV support groups in order to seek better ways of making them more responsive to their members' needs.

Ten Keywords:

Support Groups; people living with HIV and AIDS (PLWHIV); opportunistic co-infection; experiences; Ng'ombe compound; Zambia; faith-based organizations.



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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
CBO	Community Based Organization
CDC	Center for Diseases Control
CG ID	Caregiver Identity
FNDP	Fifth National Development Plan
FGD PID	Focus Group Discussion Participant's Identity
HBC	Home Based Care
HIV	Human immunodeficiency virus
NAC	National AIDS Council
NSA	Network Support Agents (PLWHIV trained to support others)
NZP+	Network for Zambian People Living with HIV
OVC	Orphans and Vulnerable Children
PLWHIV	People Living with HIV
SGM ID	Support Group Member Identity
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNECA	United Nations Economic Commission for Africa
WHO	World Health Organization
ZDHS	Zambia Demographic Health Survey

CHAPTER 1 – INTRODUCTION

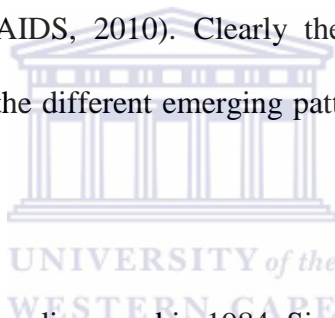
1.1 Introduction to the Study

This is a descriptive study of experiences and perceptions of a faith-based HIV Support Group through the eyes of its founders, facilitators and members. The HIV support group is facilitated by the Flying Angels, a community based non-governmental organization in Ng'ombe Township, Lusaka, Zambia. The organization was selected because it operates an organized Support Group since 2007 under the Living Assemblies of God Church for about 80 young and old, married and single, men and women with HIV and AIDS. The members of the Support Group are joined together by their common interest in a safe environment for sharing experiences and ways of coping with their situations. The study followed a qualitative methodology involving in-depth interviews with the founders, facilitators and members of the Support Group. Although available reports about the performance of support groups indicate that they contribute to positive living for PLWHIV, there is little reporting of lived experiences and more profound changes arising for their members.

1.2. Background to the Problem

HIV and AIDS is a problem that has affected nearly everyone either through infection or being affected. According to the UNAIDS 2010 Global Report, in 2009, there were 33.3 million people infected with the Human Immunodeficiency Virus (HIV) and 2.6 million AIDS-related deaths were reported (UNAIDS, 2010). Sub-Saharan Africa alone accounted for 67% (28.6 million) of the new infections and 72% (1.8 million) of the

deaths (UNAIDS, 2010). Although Africa has been the most severely impacted by the pandemic, infection rates in other regions particularly in Eastern Europe and Central Asia have continued to climb (UNAIDS, 2010). A steady worldwide decrease in AIDS-related deaths, from the peak of 2.1 million in 2004 to an estimated 1.8 million in 2009 was reported by UNAIDS (2010) which attributed the change to increased efforts aimed at prevention and treatment. North America and Western and Central Europe, recorded a decline in deaths due to AIDS soon after antiretroviral therapy was introduced in 1996. In Asia and Central and South America, the number of deaths stabilized, but there was no indication of decline at the time of the report in 2010, whereas deaths continued to increase in Eastern Europe (UNAIDS, 2010). Clearly the above data suggest some positive gains, and also highlight the different emerging patterns in the different regions of the world.



The first case of HIV in Zambia was diagnosed in 1984. Since then, the epidemic has not shown any downward trend. Over 900,000 people are estimated to be living with HIV and AIDS in Zambia, of which nearly 80,000 are newly infected (NAC, 2010). The impact of the Human Immunodeficiency Virus (HIV) in Zambia has compounded the country's high disease burden. According to the Zambia Demographic and Health Survey (ZDHS) of 2007, out of a total population of 11.7 million, the HIV prevalence rate for the adult population stood at an average of 14.3%. This represented 16% of the total adult female and 12% of adult male population in 2007 (NAC, Zambia Country Report, 2010). HIV prevalence in urban areas was twice that of rural areas (20% versus 10%,

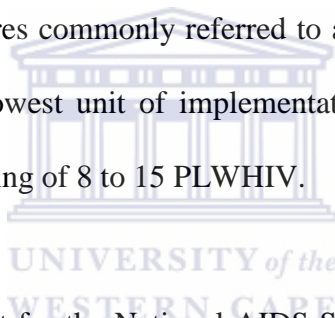
respectively). The differentials by province range from the highest prevalence rate in Lusaka (21%) to the lowest prevalence in North-Western and Northern provinces (7%).

The introduction of Antiretroviral Treatment (ART) in Zambia has helped to improve the lives of People Living with HIV (PLWHIV). In Zambia about 283,863 people were reported to be on ART at the end of 2009 (MoH, 2009). However, as much as ART has prolonged lives of individuals adhering to treatment guidelines, people on ART still face challenges in their day to day lives as a result of not only being HIV positive but also being on medication. This was highlighted by the Central Statistics Office (CSO, 2009) and the 2007 Zambia Demographic Health Survey (ZDHS) which found that many challenges exist which restrict PLWHIV's equitable access to goods and services essential for their well-being. This is especially so in context of the health system's difficulty to cope with the high number of patients and an underlying human resource for health (HRH) shortage (NAC, 2007). As a result, some patients are discharged prematurely from hospitals into the care of their families who are assisted by volunteer caregivers who provide care and support to these patients under the home based care (HBC) model. Caring labour in households and families has always been necessary to maintain families, but it has been additionally stretched by the HIV/AIDS pandemic (Ogden, Simel and Caren, 2004.)

1.2.1. HIV/AIDS Support Groups

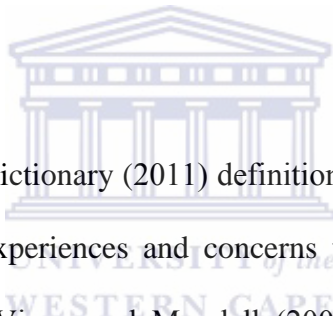
HIV/AIDS support groups are meant to play a pivotal role as far as care and support for PLWHIV is concerned. In the Zambian context, the National AIDS Council (NAC, 2002)

documented that HIV/AIDS support groups for PLWHIV in Zambia began in 1991 when a group of HIV-positive individuals joined together for mutual support and to offer HIV-prevention messages to the public. In so doing they formed the Positive and Living Squad (PALS) which later pioneered the formation of the Network for Zambian People Living with HIV/AIDS (NZP+). The Network promotes HIV/AIDS education, voluntary counseling and testing, positive living through behaviour change and home-based care; they also help establish anti-AIDS clubs; however, the focus is on activities that can improve the livelihood of their members through partnerships with micro-finance institutions, agricultural projects and skills training (NAC, 2002). The network is organized in decentralized structures commonly referred to as District Chapters, who do the actual implementation. The lowest unit of implementation in districts is a support group at community level comprising of 8 to 15 PLWHIV.



The Impact Mitigation Assessment for the National AIDS Strategic Framework (NASF) 2011-2015 (NAC, 2010) revealed that there were substantial numbers of PLWHIV at community level accessing care and support through HIV support groups, as evidenced by 50,000 PLWHIV registered with 3,500 support groups affiliated to NZP+ at the end of 2008 (NAC, 2010). The 2006 Joint Annual Programme Review published by National AIDS Council (NAC), United States President's Emergency Plan for AIDS Relief (PEPFAR) and Churches Health Association of Zambia (CHAZ) (2007) indicates that the recorded number of PLWHIV enrolled in support groups in Zambia had increased from 12,995 males enrolled in 2005 to 20,112 males enrolled in 2006. The number of females enrolled increased from 13,239 in 2005 to 29, 645 in 2006.

The Network for Zambian People Living with HIV/AIDS (NZP+) defines a support group as a group formed by people who come together to find solutions to their common problem. The organization elaborates the purpose of support groups as being ‘the provision of a safe and conducive social space for PLWHIV, enabling positive living’ (NZP+, undated: 5). Support groups, NZP+ notes, provide an atmosphere in which experiences can be shared and coping skills can be developed. Although support groups are diversely defined, the definition and purpose of support groups articulated by NZP+ will be adopted for the purposes of this study, which focuses on experiences of members of one such group in Zambia.



The Merriman-Webster Medical Dictionary (2011) definition of a support group is: ‘... a group of people with common experiences and concerns who provide emotional and moral support for one another’. Visser and Mundell (2008: 66), citing Schopler and Galinsky (1993) refer to support groups as ‘groups of people with some pressing common concern coming together on a regular basis, often face-to-face, to contribute personal experiences and engage in the development of a cohesive, supportive system’. In the context of HIV, support groups are ‘opportunities that can provide recently diagnosed women a safe environment to talk about the virus, share their experiences, learn from the stories of other infected individuals and access information’ (Visser, Mundell, de Villiers, Sikkema and Jeffery, 2005:335).

1.3. Study Setting

The study was conducted in Ng'ombe Township, one of Lusaka's poorest and most densely-populated communities. The Township's catchment population was estimated at 42,383 for the year 2011 (Ng'ombe Health Center, 2011). Ng'ombe Township was purposively selected for a number of reasons. The Township has a dense population that is served by a clinic that is poorly staffed. The economic status of many of the residents is categorized as being poor. High levels of HIV and TB prevalence are attributed to poverty, theft and prostitution. In response to the situation, HIV and TB support groups have been formed by different stakeholders in the community.

The extent of support group formation in the area is not known as information on this is not systematically collated by the formal local health system. However, one of the better known groups is that of the Flying Angels HIV Support Group, catering specifically for PLWHIV on anti-retroviral treatment. The Flying Angels Support Group operates under the auspices of the Life Assemblies of God Church's Community Outreach Ministry. The church has branches in Kasama and Nakonde, in the Northern Province of Zambia and two branches in Lusaka Province. The church supports the functioning of the HIV Support Group through caregivers working at the local church-run hospice. These caregivers provide a counseling and home visiting service. Apart from the hospice, the church also runs a fee-paying out-patients unit for general cases to which the HIV Support Group is attached, a community primary education school and a private school for secondary education. Registered PLWHIV are exempt from the service fee at both the

out-patients unit (K50 per consultation) and the school (K150 per child per term). The earnings are used to support the running of the hospice and the school. According to the pastor, the 'Flying Angels' name was adopted following a 'divine instruction' to help the school children under the church 'to fly over their difficulties.'

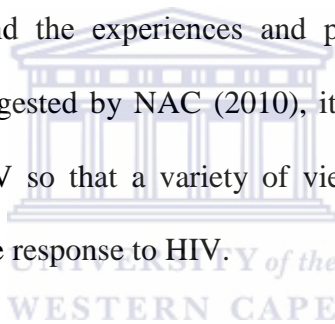
The Flying Angels HIV Support Group started operating in 2007. It was established by a volunteer doctor who saw the need to follow up patients in their homes following the increase in numbers not adhering to anti-retroviral and tuberculosis treatment. The Flying Angels HIV Support Group is run by a newly constituted nine member Executive Committee elected to represent the more than eighty members belonging to the HIV Support Group. The Support Group members meet regularly to share experiences and learn from one another. The members also receive free food supplements from donations to the church, free education for their children and free medical attention from the Flying Angels Hospice OPD.

1.4. Problem Statement and Rationale (Purpose) for the Study

The 2013 Millennium Development Goal progress report for Zambia shows that HIV incidence remains high throughout Zambia, and is rising alarmingly among young people. This will continue exerting pressure on care and support services which should be accessible to everyone living with and affected by HIV and AIDS. One such avenue of access is a 'Support Group' model for supporting PLWHIV, to serve as a platform to voice the many challenges they face (WHO, 2000). Although available reports about the performance of support groups indicate that they contribute to positive living for

PLWHIV, there is little reporting of lived experiences and more profound changes arising for their members; nor is there systematic evidence to show that support groups indeed do address the diversity of needs of, for example, men as opposed to women. It can also be argued that members stop participating in support groups because of unmet needs. While there are factors impeding individual continued participation in support groups, it can be argued that PLWHIV participate in support groups primarily to get food and material support without which they would not survive.

In the light of the above reasons, it was considered important to conduct a study in Ng'ombe Township to understand the experiences and perspectives of members of PLWHIV support groups. As suggested by NAC (2010), it is important at all times to seek the perspectives of PLWHIV so that a variety of viewpoints and experiences is gathered and used to strengthen the response to HIV.



CHAPTER 2 - LITERATURE REVIEW

The chapter presents and discusses information gathered through a literature review to provide context for the study. Both the indexed and grey literature was sourced. Key words used to access the literature included ‘people living with HIV and AIDS (PLWHIV); opportunistic co-infection; experiences; faith-based organizations and Zambia’. Databases searched included Escobar, Google scholar and PubMed. The topic under study was explored from different angles which include needs and experiences of PLWHIV, role and impact of support groups and functioning of support groups: enabling and disabling factors.

1.1. Needs and experiences of People Living with HIV and AIDS

The needs of people living with HIV/AIDS identified in the literature cover a broad spectrum, from help to deal with stigma and discrimination, inadequate access to health and social services, and greater involvement in local governance, community and business development opportunities. In a study conducted in Kenya, Shacham, Reece, Ong'or, Omollo, Monahan, and Ojwang (2008) observed that PLWHIV face different forms of distress either perpetuated by others, individual negative feelings or socio-economic factors. Chileshe and Bond (2010) demonstrate this when they cite the distressful situation of a 21 year-old woman who missed the opportunity to get support because she refused to accept her HIV status and later relocated from town to the village to start a life with her mother's mother whom she did not know well. The Chileshe and Bond (2010) study was conducted in rural Zambia. In contrast, they demonstrated that cases that linked up with a PLWH support group, and were relatively open about having HIV plus having close relatives who advocated for openness about HIV status, helped

individuals to overcome the stigma and disclosure barriers. People with HIV need support to help them cope with the general challenges of poverty as well as the HIV specific challenges that they face including stigma and discrimination (Mundell et al, 2012).

The formation of support groups for PLWHIV and their frequent orientation towards income generation activities flows from the constraints experienced in the everyday lives of PLWHIV. Chileshe and Bond (2010) note the importance of food to PLWHIV. Even in instances where ART is freely available, fear of taking medications on an empty stomach dissuades PLHIV from taking their treatment (Unge et al., 2008). Household food insecurity especially for poor households can result from the family members' withdrawal of their labour to care for the patient when affected by HIV (Roberts, 2008).

According to Mbonu, Borne and Vries (2009), HIV stigma, a major determinant of health-seeking behaviour for PLWHIV, can also be a manifestation of PLWHIV internal reactions to living with the HIV as much as it relates to reactions of society including health professionals. Mbonu et al's (2009: 208) study findings "show that PLHIV make different healthcare-seeking choices as a result of stigmatising themselves." These include self-medication for quick relief of immediate signs and symptoms of illness, consulting traditional healers to hear 'what they want to hear,' and also seek "God's intervention" for miracles in impossible situations. In cases of factors external to PLWHIV, the authors observed that as a result of distant location of a clinic, people who were unable to pay for transportation faced difficulty to go to the clinic or other facilities

for required services (Mbonu et al, 2009: 203). In addition, clinic user fees are also an economic barrier especially for the poor (Mbonu et al, 2009).

Other needs of PLWHIV include adequate access to and appropriate reproductive health care services, involvement in local governance mechanisms for multi-sectoral response, and inclusion in livelihood and business development services (National AIDS Council, 2010).

With respect to stigma, PLWHIV face many challenges either as a result of their own perceptions or by others. Mbonu et al (2009) showed that some families with an HIV positive relative feared being themselves isolated by others. Some examples of stigmatizing behaviours include hiding PLWHIV, isolating PLWHIV in their homes (Mwinituo and Mill, 2006), or even abandoning their bodies in mortuaries after death (Campbell et al., 2007). The study by Mbonu et al (2009), also revealed that stigma has been associated with low uptake and adherence to ART, especially where people do not obtain healthcare and information for fear of people knowing their status. The authors further stated that stigmatization can lead to ‘restriction of job opportunities and loss of employment resulting in economic implications for PLHIV thus they hide their HIV status’ (Mbonu et al, 2009: 205) to safeguard their jobs.

A study to explore gender differences in experiences of ART services in South Africa revealed that societal norms contributed to delayed decisions to draw on available social support by men after testing HIV positive (Schneider, Govender, Harris, Cleary, Moshabela and Birch, 2012). The study revealed that because HIV positive men were

more likely to be seen as social failures than women, they tended to experience higher levels of non-disclosure and self-stigma perpetuated by this type of gender norming (Schneider et al., 2012: 820). Visser et al (2005) have observed that the epidemic of stigma, discrimination, blame and denial has frustrated efforts to overcome the spread and impact of HIV/AIDS.

Despite PLWHIV's disclosure of their HIV status playing a critical role in their care and treatment, Miller and Rubin (2007) found that women did not disclose their status for fear of being sent away by their spouses. However, disclosure of one's status was highlighted as one among other needs which included information about living positively (treatment, condom use), and encouraging others to test for HIV, dealing with stigma and discrimination, planning their children's support, mentioned by women living with HIV who participated in Visser et al's (2007) action research on the development of a structured HIV support group for women.

1.2. The Roles and Impact of Support Groups

WHO (2000) notes that HIV support groups have been a phenomenon in countries across the income spectrum from the United States of America, Britain, Germany, India, South Africa and Brazil, principally to fight against discrimination to which people infected with HIV are subjected. There are various kinds of care and support models around the world, depending on the purpose and target audience for the support (Skovdal, Magutshwa-Zitha, Campbell, Nyamukapa, and Gregson, 2013). Examples include Treatment Adherence Support Groups, Bereavement Support Groups, Farmers

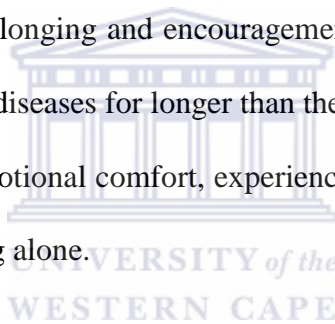
Association and HIV Support Groups. The social support they provide could be emotional (esteem, concern, affect), informational (suggestions advice, information), instrumental (assistance in money, labour or time) or appraisal (feedback, affirmation) in nature (Roberts, 2008: 90-91), “all obtainable through a feedback mechanism from a primary group that is health protective during times of stress” (Cassel, 1976: 5)

Social Support theory as explained by Caplan (1974: 4) holds that it “helps the individual to mobilize his psychological resources and master his psychological, emotional burdens; they share his tasks; and they supply him with extra supplies of money, materials, tools, skills, and cognitive guidance to improve his handling of his situation.” Social support also appears to have a stress buffering function, reducing psychological distress during times of threat or demand. This argument resonates with Maslow’s hierarchy of needs theory which states that the human needs are released and satisfied successively from a lower level (basic physiological needs) to higher level (emotional) needs (Maslow, 2002).

A recent study by Mundell et al (2013) which sought to explore the experiences and consequent life changes in a women’s HIV support group, revealed improved mental well-being, positive lifestyle changes, and being more comfortable talking about HIV. The women’s stories of how they gained confidence and knowledge about HIV and healthy living, including coping with the diagnosis, were indicative of the positive impact of the support group.

In Uganda, the Ministry of Health noted that psycho-social support attempts to address stigma, discrimination and denial of infection, and known causes of delays in diagnosis, treatment and care for both people in pre- and post-HIV test groups (MOH Uganda, 2006).

Support groups also provide PLWHIV a space for openness, opportunity to meet peers who serve as role models in accepting their status, live positively, adhere to treatment and “live well” (Skovdal et al, 2013: 5). This resonates with the findings of the study by Mundell et al (2012), which showed that women living with HIV who participated in a support group found a sense of belonging and encouragement from others (role models) who had lived and coped with the diseases for longer than themselves. Similarly, Roberts (2008:90) points out that some emotional comfort, experienced in support groups, can be derived from the sense of not being alone.



Support group participation also has material benefits. In Zambia, support group members have reported receiving *chitenge* (women’s traditional wraps), T-shirts, protective clothing, and bicycles (CARE Zambia, 2010 STAMPP Annual Report).

A study to evaluate the meaningful involvement of PLWHIV in Uganda also showed that by serving as role models and offering encouragement, Network Support Agents (NSAs) or PLWHIV trained to support others contributed to “an increase in the disclosure of HIV status to the family members and the community members” (Kim, Kalibala, Neemac, Lukwagod and Weisse 2011:6), which enabled information sharing on how to cope with

issues of denial, stigma, and discrimination and fear arising from the uncertainty of living with the virus. This in turn enables individuals to seek appropriate services assuring continuum of care (Kim et al 2011:7). Correspondingly, PLWHIV's desire to receive support from family, friends and work colleagues was the most common reason for disclosing one's status (Ssali, Atuygabe, Timwine, Segujja, Nekesa, Nannungi, and Ryan, 2010). To put it differently, support groups give the members an opportunity to share strategies to help them handle their stressful situations (Bengtsson and Bengtsson, 2005).

Support groups have also been known to assist in mobilizing communities for different reasons which are not limited to connecting PLWHIV to information and other services through informal referral systems. An evaluation of the Networks Project in Kampala Uganda, which trained group members to serve as Network Support Agents (NSAs) to deliver HIV services targeting reducing stigma, showed an increase in patient volumes which was attributed to the referral system operated by the NSAs (Kim et al, 2011: 7). The authors highlighted voluntary counseling and testing; and accessing antiretroviral medicines and septrin (cotrimoxazole) as areas of greatest impact. Network Support Agents (NSA) in Uganda mobilized PLWHIV to use existing services at health facilities as well as "wraparound" services (or services which are customized to the individuals' needs) provided by other community-based and non-governmental organizations (Kim et al, 2011). This enabled coordinated referrals from homes to health facilities and other community organizations.

The Zambian NAC (2002) Report sums up its findings from Focus Group Discussions (FGD) that persons living with HIV/AIDS participated in activities that included counseling, HIV/AIDS awareness and prevention, a demonstration of positive living, networking, advocacy, stigma reduction, voluntary counseling and testing, home-based care, succession planning and life skills training.

1.3. Functioning of Support Groups: Enabling and Disabling Factors

In Zimbabwe, men in support groups were less likely than women to disclose their HIV status as openness was perceived by their community to be a stereotypical female trait (Skovdal et al, 2013: 5). This was revealed when the women living with HIV in a female support group tended to characterize groups responding to HIV as females spaces where openness to discuss HIV was a norm.

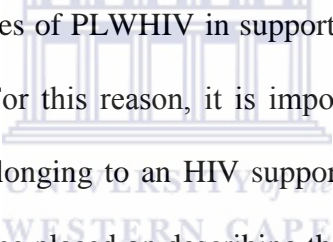


While revealing one's sero-status could be a significant barrier to PLWHIV participating in support groups, respondents interviewed in Skovdal et al's (2013) study in Zimbabwe, saw the idea of both HIV negative and positive people meeting together as a strategy aimed at normalizing the HIV. The authors were of the view that the arrangement enabled members to lead in taking necessary action based on HIV knowledge they received through dialogue without explicitly talking about HIV. On the other hand, although some PLWHIV may want to join support groups, they do not, for fear of being associated with immoral behaviours. This fear is linked to the church teachings which emphasize that the sex is the preserve of a married man and woman; anything outside that is perceived as sin (Campbell, Skovdal and Gibbs, 2011: 5). Another equally important

factor advanced by the authors (2011: 7) that motivates PLWHIV to join or form support groups, is the “sense of the control, ownership and association with externally resourced organizations.” Roberts (2008) affirms that while support groups serve the information needs of their members with neutrality and accuracy without stigma notions, participating in support groups may reveal one’s HIV status to onlookers and inhibit participation.

Chileshe and Bond (2010), also pointed out that while the characteristics of those who seek psychosocial support following an HIV diagnosis have been well documented in Western countries, little is known about those who become engaged with such services in developing countries of the world where comprehensive HIV-related care and prevention systems are still being developed. Correspondingly, in a literature review on support groups for People Living with HIV/AIDS’, Spirig (1998) notes that it is commonly assumed without any evaluation, that support groups in general are helpful for PLWHIV. This view is also shared by Walch, Roetzer and Minnett (2006) who observe that few experimental or quasi-experimental studies of HIV support groups exist and that studies have been limited largely to clinical accounts, anecdotal reports and single group outcome studies. This was reported in a study aimed at examining demographic characteristics and perceived barriers of attenders and non-attenders of HIV support groups via a mail survey. The study results suggested that more than half of the people who expressed interest to participate in the support group were those diagnosed more recently.

In sum, studies show that government and development organizations have employed different interventions to address the diverse needs of PLWHIV. The theme of assistance has been mainly social support which clearly plays an important role in providing a safe and conducive environment beneficial for members' learning and sharing of coping strategies. Literature from the developed world and South Africa, Uganda and Zimbabwe highlight gender, low socio-economic exclusion status and church teachings among others as factors creating enabling or disabling contexts for PLWHIV. Literature also revealed the impact of social networks in facilitating development of strategies in addressing issues that concern them.



The literature describing experiences of PLWHIV in support groups and those who have left is skewed to South Africa. For this reason, it is important to explore PLWHIV's experiences and perceptions of belonging to an HIV support group as envisaged in the aim of the study. More focus will be placed on describing the profile of people who join, what keeps people in them for periods of time, and the balance between material, emotional and informational needs in contexts of poverty.

CHAPTER 3 – METHODOLOGY

1.1. Aim

The aim of the study was to explore and describe the needs, preferences and challenges of PLWHIV in a faith-based HIV support group in Ng’ombe Township in Lusaka, Zambia.

1.2. Objectives

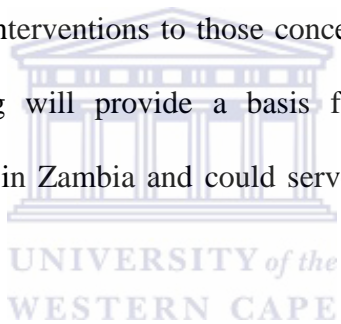
1. To describe the formation and functioning of the Flying Angels Support Group.
2. To describe support needs amongst PLWHIV in the Flying Angels Support Group of Ng’ombe Township.
3. To describe how the different needs of individuals PLWHIV in support groups are addressed.
4. To explore PLWHIV’s experiences of belonging to the Flying Angels Support Group.
5. To explore the barriers and facilitators PLWHIV encountered in participating regularly in a support group.

1.3. Study Design

The study was a descriptive, qualitative case study of the Flying Angels HIV Support Group in Ng’ombe Township formed in 2008.

The case study approach has been selected for its capacity to elucidate the lived experiences of participants in a support group in the context in which the group operates,

with a view to contributing to more effective future support for PLWHIV. Yin (1981: 58) argues that: ‘As a research strategy, the distinguishing characteristic of the case study is that it attempts to examine: (a) a contemporary phenomenon in its real-life context, especially when (b) the boundaries between phenomenon and context are not clearly evident’. Flyvbjerg (2006) argues that case studies provide the means for understanding the nuances of human behaviour within a context, and secondly that ‘concrete, context-dependent experience is ... central ... to professionals learning’ to do, for example, research (Flyvbjerg, 2006: 219). The story-telling nature of the case study offers unique opportunities to understand participants’ experiences more deeply, and form judgments about the appropriateness of the interventions to those concerned (Keen and Packwood, 1995). This better understanding will provide a basis for comparing the existing understandings of support groups in Zambia and could serve as a basis for larger scale research into the phenomenon.



The study involved systematic collection of information using in-depth interviews guided by an open-ended interview guide, and focus group discussions (FGD) to explore the lived experiences of PLWHIV. The approach allowed the participants to tell the story of their needs, experiences and challenges of belonging to the Flying Angels HIV Support Group in their own words (Varkevisser, Indira and Brownlee, 2003). This was helpful in allowing the Researcher to see and understand things from the perspective of the participants and to capture their differing perceptions of their experiences (Baum, 1995).

In addition to the above, reports, registers and other documentary evidence relating to the Flying Angels Support Group were collected.

,1.4. Study Population and Sample

The study used the purposive sampling methodology which focuses on particular characteristics of population that are of interest and which will best answer the questions under study (Patton, 2002). Maximum variation sampling was used to select Support Group member participants with different characteristics of interest to understand experiences from diverse participants' perspectives, and the functionality of the support group in terms of meeting their different needs (Patton, 2002). For example the Researcher was interested in factors that enable continuing participation in the Support Group and assumed that employment status was an important background. The sample consisted of a total of twenty four participants with the following characteristics:

1. Active members, support staff or caregiver of the Flying Angels Support Group
2. Been an active member since 2010 or active member for two years and left prior to the study.
3. Employed or unemployed
4. Man or women
5. Married or single

The study population included the pastor, PLWHIV, caregivers and current and past members of the Flying Angels HIV Support Group who had been associated with the

Flying Angels HIV Support Group in Ng'ombe Township for at least two years at the time of the study in-order to obtain substantial experiences.

1.5. Sampling Process

The Researcher was assisted by the caregiver in-charge of the Flying Angels Support Group to identify support group members who were willing to participate in the study according to the designated characteristics. The Researcher met with the volunteers before the interviews to explain the study, emphasize their voluntary participation and clarify some questions (such as whether they would be rewarded for participating), before obtaining written consent from each one of them. The Researcher met the participants individually and informed them that the information they provide will be anonymized and that their participation would be confidential beyond the group.

1.6. Data Collection and Analysis

Data was collected from fifteen key informants and tape-recorded with their consent: the pastor, caregivers (Support Group coordinators) and current and past Support Group members over a period of seven weeks. A further nine active members of the Support Group participated in a FGD. The same interview guide with open-ended questions was used for both FGD and in-depth interview to guide discussions with key informants (Table 2) which lasted from between forty minutes and one hour. The in-depth interview and FGD were conducted by the Researcher in Bemba, Nyanja and English.

Table 1: Key Informants

	DATA COLLECTION METHODS	KEY INFORMANT	NUMBER OF PARTICIPANTS
1	In-depth Interview	Pastor	1
2	In-depth Interview	Caregivers (Support Group coordinators) (referred to as CG in results)	3
3	In-depth Interview	Support Group members (referred to as SGM in results)	8 – Current 3 – Past
4	Focus Group Discussion	Support Group members (referred to as FGDP in results)	9 - Current

The questions in the in-depth interview guide were elaborated (see appendix 3). One interview guide was used for both the in-depth interview and FGD to ensure consistency and to ensure that the same general areas of information were collected from each interviewee; this provided focus, enabled triangulation of information, without limiting the degree of freedom and adaptability in getting the information from the interviewee.

In an attempt to ensure data quality control, the research instruments were pre- tested on a home based care group in Kaliliki Township, a non-study field area for feasibility, and understandability of questions and quality of data obtained.

Hospice records were reviewed for documentary evidence relating to hospice and support group activities. These included support group attendance registers, activity reports, and

food distribution registers. This data supplemented information obtained from the FGD and in-depth interviews. The information from key informants and documentary evidence were triangulated to maximize the quality of data collected and reduce the chance of bias.

Recordings of the FGD and interviews were translated soon after data collection to minimize researcher recall or memory bias which could affect the validity of findings (Bowling, 2004) and content searched for common themes, otherwise known as thematic content analysis (Green and Thorogood, 2004). The Researcher examined the transcribed set of recorded interviews to identify similar patterns and processes, commonalities and differences between the sub groups namely caregivers, members of the Support group and members who had left the Support group. Following this the Researcher classified the responses, coded and categorized themes according to the most frequent used phrases.

1.7. Rigour

Background sources were searched for the research topic using main concepts and key words in the research question. Maximum variation sampling (Patton, 2002) was used to generate broader views and experiences thereby obtaining rich information to assist in understanding, from the participants' perspective, their needs, preferences and challenges of the group members and not for generalization to all support groups. Pre-testing of the research instrument in a non-study field area of Lusaka was done to check the adequacy of the instrument for completeness, reliability and validity of the results.

The use of audio recordings enabled capture of the key informants' exact words and expressions or to quote evidence which were necessary for accurate interpretation of meanings (Malterud,

2001). The use of quoted evidence (interpretive validity) to support interpretations of information was done to increase dependability of the findings (Green and Thorogood, 2004). Triangulation of data from all data sources assisted in increasing validity by detailing the case setting and ‘thick’ description of the data and context (Malterud, 2001), ensuring the potential for transferability of the findings (validity) to comparable contexts.

Selected member-sharing and validation of draft findings involving some Support group members who participated in FGD and interviews, and two caregivers to check if the findings reflected their views, was done to enhance rigour (Gifford, 1996). The Researcher took back the summary of responses grouped in thematic areas stated below:


1. Formation and functioning of the Support Group
2. Needs of the Support group members
3. Experiences of the belonging to the Support Group
4. Enabling factors to joining the Support group
5. Barriers to joining the Support group
6. Areas of improvement / recommendations.

The three groups’ (FGD, individual members interviewees and caregivers’ responses were read out to the members present asking if they represented each particular group’s views. The outcome of the member-checking process was that results were validated as a true reflection of the responses. More clarification was sought on the whether the Support Group had attempted to access funds from the Constituency Development Fund (CDF) for their Income Generating

Projects. The members explained that they had not done so because they believed that the CDF was intended for partisan politically affiliated individuals and groups.

Finally in order to avoid bias, the Researcher triangulated the data. Being a health professional, the Researcher would have easily been tempted to base conclusions on her previous professional experience working with PLWHIV in different settings such as clinics. For example, the common knowledge that PLWHIV in support groups do not stay long beyond food support. However, in this particular case it was found that food was not the main motivator for remaining in the Support Group (see set Chapter 4 sub section 1.4.) in the case of the Flying Angels HIV Support Group members.

1.8. Ethical Considerations



Each participant gave his/her written consent to participate and permit the Researcher to record the discussion before the interview. The Researcher explained the purpose of the study in each participant's preferred language (Bemba or Nyanja), and explained that participation was voluntary without penalty if one declined or discontinued the interview. Anonymity was maintained throughout the process up to final reporting. Participants were given an opportunity to ask questions to clarify their concerns. The foregoing was done to ensure observance of the ethical principle of beneficence.

1.9. Limitations

The study was conducted on one faith based HIV support group, in Ng'ombe Township and not the whole of Lusaka town. As such, the findings of this research are not

representative of the larger population. The target of eight past members of the Support Group could not be met as there were few people that had left the Support Group.



CHAPTER 4 - FINDINGS

This chapter presents the findings gathered through interviews and documentary evidence. The findings are presented along the study objectives: the formation of the Flying Angels HIV Support Group, PLWHIV's needs and reasons for joining the Support Group, roles and impact of the Support Group as well as the facilitators and barriers to member participation.

1.1. Formation and functioning of the Support Group

According to the pastor and caregivers, the Flying Angels HIV Support Group was established in 2007 to cater for the increasing number of sick people in need of spiritual support, those defaulting on HIV and Tuberculosis treatment as well as deaths occurring in Ng'ombe Township. The first people to work with the Support Group were a doctor and three caregivers, all volunteers from the Flying Angels Hospice. The caregivers explained that the Support Group was formed to fight stigma which led patients to default on treatment for fear of family members and other people knowing that they had tested HIV positive. The doctor and caregivers did this by following the patients in their homes to check on how they were coping with treatment. The pastor also visited the patients to provide spiritual care and support, as part of church evangelism. The Support Group started with fifteen patients who regularly met at the hospice during review visits. Over time, the group grew as more PLWHIV who enrolled in follow up care joined and met with others. The Support Group meets every last Saturday of the month in a classroom

adjacent to the hospice to share experiences and learn from one another. In between meetings, Support Group members do other activities such as extending personal support in cases of family illness and bereavement as well as reminding them to take medicines. This type of support depends on the relationship between individuals.

The Support Group was established exclusively for PLWHIV, although it currently takes in people with chronic conditions such as diabetes mellitus and hypertension. Caregivers from the hospice coordinate the Support Group activities which include home visits and teaching the members on a variety of health and positive living topics. The Support Group members receive packets of food rations monthly, free medical services from the hospice as well as free basic education and food rations for their children who are living with HIV. The total number of registered members on the register was eighty four at the time of study (2013), with an average monthly meeting attendance of forty members. The Support Group has a nine member Executive Committee (evenly divided between men and women) which represents the members and coordinates communication between the caregivers and the Support Group members. The Committee has a Chairperson, Secretary, and Treasurer who are all deputized by vice positions. The Support Group meets every last Saturday of the month from 09hrs to 12hrs. Depending on the starting time and topic of discussion, sometimes the meeting goes beyond the scheduled end time. Caregivers from the Flying Angels Hospice facilitate the meeting activities. During the meeting, members share their day to day experiences, are given information on a range of health topics. Each member is also given 3 rice packs at the end of the meetings.

Members agreed to contribute K1 (20 Cents) monthly, which is kept by the hospice staff after being recorded in a book by the Group Treasurer.

There are no formal written rules governing the Support group. However, there were a number of records kept on the Support Group. They included a food distribution register (listing ninety-five members), a monthly meetings attendance register (showing a total of eighty members), and partially completed Monthly Support Group reports for the period 2009 to 2013.

Support Group membership is open to men, women, both PLWHIV and individuals with chronic conditions such as tuberculosis, cardiac illnesses, and diabetes mellitus and carers' of PLWHIV (who are not necessarily HIV positive themselves). The decision to open the Support Group to non-HIV chronic conditions was made by the care-givers and described by members as an imposition from the caregivers that breached their confidentiality. One member in the Focus Group discussion said,

“We were surprised when we discovered we were not one family because some people who are not HIV positive were among us. Although we have not heard any bad things being said about our Group, we are worried because they listen to our secret stories.” (FGD P ID 1)

1.2. Reasons for Joining the Support Group

With reference to why PLWHIV joined the Support Group, the caregivers were of the view that people joined the support group to receive psychosocial support as well as to obtain information from their colleagues' experiences. The members indicated that the

caregivers were instrumental in influencing them to join the group and meet with other PLWHIV to share experiences and learn how the others were coping. One member explained why she joined the group saying,

“I joined because we learn a lot from the Support Group when we meet; because when you are alone you start thinking how did I get the virus. So like that you can’t live properly if you do not join your friends and exchange ideas on how to live...” (SGM ID 3)

Other members also said,

...“I joined the Support Group because in a support group one can get different forms of assistance such as money to buy baby milk formula when you present your problem to them.”(SGM ID 2)

...“Other people joined the Support Group to access free education for their children especially men who have lost their wives, Secondly others join because they have heard about free medical services provision to PLWHIV in the Support Group.” (FGD P ID 4)

Other reasons cited for joining the support group included encouragement about the importance of ARV medicines and learning about positive living.

1.3. Members’ expectations and needs

The pastor and caregivers believed that members expected to receive money, food, information as well as psychosocial support from the Support Group. They added that *“some patients think that Flying Angels has a lot of money or food and are expecting much but we have explained to them that it is just voluntary”* implying that managing expectations regarding material support was an ongoing part of their role in the Support Group.

One caregiver explained that the group started with a small number of PLWHIV because their primary need was food which the Support Group did not have at the time. Providing food was thus a key part of establishing the Support Group;

“... you know in the community members of a support group are those with HIV and you find that many of them are those who are not even working; and most of them are single parents and you find that when they are on that drug they need something especially food support and we have found that they have literally nothing so those were the challenges when we started the Support Group. We could give them something when they come so they could know that we care.” (CG ID 1)

She went on to say, if this was not done, the patients would not see a reason to attend the meetings.

While food was foremost in the minds of the care-givers, patients described a mix of emotional and material needs. Despite the challenges the Support Group members faced,

those who came said they found companionship out of their common problems and shared experiences to encourage one another.

On the other hand, their material expectations extended well beyond what the Flying Angels Hospice could provide. Members interviewed wanted to be supported with start-up income to undertake income generating projects, such as block making or peanut butter production so they could support their families. The fragile social circumstances of Support Group members was illustrated most vividly by one member in particular, who told of how he was struggling against the lack of an income to enable him to provide for his family's shelter and food needs. He explained that he, his wife and child are all HIV positive. The available work opportunities involved walking about eight kilometers without having taken any food to either dig trenches or mix concrete for builders to be paid twenty five Kwacha (\$5) a day. With hopelessness in his voice, he described how, he opted to skip taking anti-retroviral treatment at times because the medicines made him "weaker than the disease" whenever he takes it without food.

"Even if I am telling you this, I know you think I am not ok upstairs (mentally). But the power (effects) of this medicine is too much that sometimes I do not take it when I have not eaten because the power hits you leaving you feeling worse, it is bad..." (SGM ID 9)

He wished the Support Group had bicycles for members to borrow when they had somewhere far to go as part of assistance. When asked, he indicated he had brought this up during the meetings, but was informed that the Group needed to find a "well-wisher"

if it was to assist in this area. While there was awareness amongst interviewees of community schemes such as the Community Development Fund, available to community based organizations (CBOs) through the Resident Development Committees, the members' view was that since they were not politically affiliated they do not qualify to access the fund. The common practice is that the Area Member of Parliament (MP) through the Constituency Offices has an upper hand in determining the projects to be implemented with these funds.

1.4. Reasons for Continuing Participation

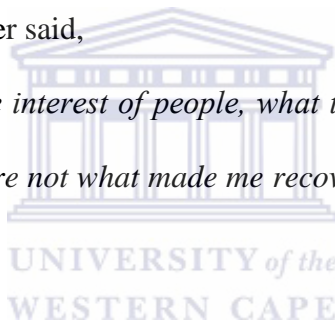
Support Group members receive three packets of rice during the monthly Support Group meetings. They also received free medical care including medicines from the Flying Angels Hospice OPD together with their children under age 8 years. In addition, Support Group members' school-going HIV positive children also receive free education at the Flying Angels Community School where they are also given a weekly rice pack as part of the nutrition support to Orphans Vulnerable Children (OVC). These are donated by "STOP Hunger". The Pastor and Caregivers believed this support was the basis for ongoing participation in the group. The caregivers reported how the Support Group members had before drawn contributions from members during the meetings to hire a vehicle either to the hospice, clinic or hospital when one of them was taken ill, an act they valued.

Apart from the above, Support Group members also receive basic information on HIV which is shared by the group facilitators during the meetings. They said this information

has helped them to manage their health. The following were the topics commonly shared during meetings; positive living, importance of good nutrition, antiretroviral treatment and types of drugs, side effects of ARVS and their management and adherence to treatment.

The positive effect of the caregivers' caring attitude, commitment and hard work was also acknowledged by members. When asked if they would continue participating in the support group activities if the church stopped providing free rice rations, medical services and education, most members said they would because they valued the information they received. For instance, one member said,

“Of course I have seen the interest of people, what they want is to learn. The three packets of rice are not what made me recover from my very sick condition.” (CG ID 2)



Another member said, *“If it was not for the care and support I received from the Flying Angels Caregivers and fellow Support Group members, I would not be alive today.”* (SGM ID 5)

1.5. Constraints to Participation

According to the Caregivers, Support Group meeting time and duration is a disabling factor for members' regular participation especially those who work. Usually these members' jobs demand that they work even at weekends leaving them with little or no time to attend the meetings. For example, watchmen, domestic workers and shop keepers

who work on Saturdays and at night miss some scheduled meetings. Other people feared being seen coming to the Support Group meeting and also described how they took ARVs secretly (indicative of non-disclosure of sero-status) for fear of the spouse and family. All these behaviours were the result of individuals not wanting people around them to know they were HIV positive.

On the whole, however, the members interviewed were not able to identify problems that hindered them from participating in the Support Group particularly after they had joined and been accepted into the group. The members spoke of meeting together with non-HIV positive people and long meeting times as constraints. *“Another thing that brings me down is being in the meeting for a long time, reducing my time to rest before report for casual-overnight work.”* (FGD P ID 1)

1.6. Reasons for dropping out

When asked about reasons for leaving the Group, the caregivers explained that some members leave the Support Group to move when their family relocates to another township or town. Others could be within the same township but distance becomes a barrier as they may be too weak to walk to the meeting sites. However, these were said to rejoin the group when they felt strong enough again. The members interviewed stated that they did not know of anyone who had left the group permanently. Further they said they had not had any experience that made them consider dropping out. Despite other members' displeasure at the group facilitators' imposition on the group of non HIV positive people that have chronic conditions such as cardiac illnesses, diabetes mellitus,

they popularly believed they were better participating in the Support Group than not doing so.

Members interviewed who were not active in the HIV Support Group, said they had not dropped out but rather had been absent due to other necessitating factors. They cited illness and family bereavement which compelled them to temporarily relocate live with other members of the family for assisted care and attending to family matters such as funerals.

1.7. Impact of the Support group

The caregivers alluded to the effectiveness of the Support Group with these words;

“... the big impact is that some patients who were under the Ng’ombe clinic’s support group left because they said that there was nothing taking place there. They said that they were not taught things that are taught here at Flying Angels. At least here, there is a doctor who is teaching us about diseases and always answers and explains any questions we have.” (CG

ID 1)

When asked about the impact of the Support Group, the members explained that the reduction in the levels of stigma in Ng’ombe Township was evidence of the positive impact brought about by the Support Group. Some members acknowledged that stigma could not be eradicated completely as there were some families who hid the patients when they visited them. This was common where the visiting members went in a group and were more easily noticed. Yet when only one person went back later, they would be

allowed to talk to the patient and the carer. When probed further as to how they knew the patient was inside, they said the patients told them in confidence that their carer did not allow them to see her.

They also felt that the migration of their colleagues from other support groups within the township also showed that the work of the Support group had touched the community in a positive way. One member said,

“I have spoken to some of the members from Kondwa centre and Fostina for the Roman Catholic (both community based HIV support organizations in Ng’ombe township) support groups; and they have complained about their support groups saying there is too much conflicts, that’s why they decided to join this Support group. They have seen the difference.”(SGM ID 7)

The members also attributed their ability to counsel and convince other people to go to the clinic for a voluntary test for HIV to the Support Group where they were taught how to talk to community members.

CHAPTER 5 - DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

1.1. Discussion

The premise for the formation of the Flying Angels Support Group was similar to that of other HIV support groups, which is motivated by the expressed or implied need of a group of people with common interests or characteristics. Discussions with key informants from the Flying Angels HIV Support Group confirmed Skovdal et al's (2013) and Mundell et al's (2012) explanation that support groups provide PLWHIV with a space where a combination of instrumental, emotional and informational needs are met, enabling them to cope with the disease after diagnosis. The findings revealed that the learning and sharing among the members and consequent realization that "one was not alone" took away the members' previously held fears of rejection and judgment by the people around them contributing to their continuing participation in the Support Group.

1.1.1. Functioning of the Support Group

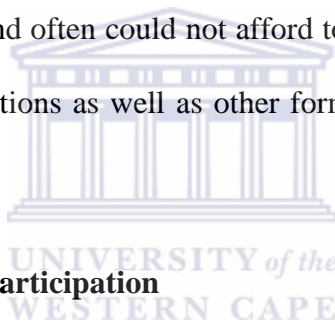
In contrast to other groups in Ng'ombe Township, the Flying Angels HIV Support Group had sustained participation by its members who considered it to be an effective support group. From observations and interviews, the Support Group's functioning was enabled primarily by a sense of ownership and control felt by its membership, who had the freedom to make suggestions (such as introducing monthly contributions).

The Researcher also observed that the Support Group remained a fairly informal structure and did not have clearly defined and written group rules relating to members behaviour. Record keeping systems were in place but only partially complete. The members spoke about meeting schedules and the Executive Committee but had no information on what they could otherwise do or not do for the smooth operation of the Support Group. It is interesting to note the efficiency of the functioning of the Support Group without any overt rules and elaborate systems. However, the Researcher is of the view that the absence of the rules did create some concerns which led to the decision to put in place an Executive Committee to improve communication between the Support Group members and the group facilitators. The relatively informal nature of the group may have served the Support Group well in some respects, but may also represent a limitation in being able to mobilise additional support. For example, the effects of incomplete records were apparently not felt as they group was not required to not submit these to external supporters.

1.1.2. Members' Needs and Expectations

While in theory support groups are a holistic concept addressing a range of needs, in practice members expressed very variable satisfaction of these needs through the Support Group. The Researcher observed that PLWHIV have some needs (such as social belonging) which can easily be addressed through support group interventions. Other needs included information about HIV treatment; management of symptoms; assistance with basic needs like food; shelter and sustainable source of income to be able to provide for household needs, which may be more complex to meet.

People wanted to maintain their esteem by providing for themselves and their families without entirely depending on handouts as implied by the members expressed need for income generating activities. This was especially so for the men interviewed in the study. The disabling effects of the HIV disease on livelihoods may contribute to feelings of inadequacy imposed by the societal norms that ‘a man’ must provide for his families. The men in particular reported joining the Support Group to access free educational services for their children thereby fulfilling their gender roles in caring for their families’ needs. A number of members lived in situations of severe poverty: they were single parents; not earning any income and often could not afford to provide food. These joined the Support Group for the food rations as well as other forms of support that enabled a basic level of survival.



1.1.3. Reasons for Continuing Participation

The members’ continued participation in the Support Group can be attributed to the real role the Support Group played in enabling the members cope with the disease. The fact that support groups are known to provide PLWHIV with both a non-judgmental safe space and some material support ensured continuing participation.

Access to health care is one feature of the Flying Angels HIV Support Group that distinguishes it from other support groups in Ng’ombe Township. While general access to health care at Ng’ombe Clinic is good, a fundamental problem is inadequate provision

of services for PLWHIV which, the Flying Angels HIV Support Group has adequately provided particularly for PLWHIV.

In addition, given the stigma that comes with living with HIV, people joined the Support Group to feel companionship and acceptance, and the caring, positive attitudes of the caregivers. Maslow's (2002) hierarchy of needs theory explains belongingness as what drives human beings into relationships. The need drives people to join groups and in this case, the Support Group. The members alluded to having developed a sense of belonging which came out of sharing their experiences, coping strategies and materials resources leaving them with a sense that others understood what they felt.

In relation to gender, both men and women appeared to participate and benefited equally as evidenced by the equal opportunity for both genders to participate and freely express themselves during the discussion. The findings of other studies (Campbell, Skovdal and Gibbs, 2011) of the stereotyping of HIV positive unmarried (never married or divorced) women as sinners by the church teachings which espouses that sex outside marriage is a sinful act, was not a factor for the women who were interviewed. Rather the church was seen as a source of not only significant the emotional and informational support but also of instrumental support as evidenced by its ability to mobilize food support and free medical and social services to members.

1.1.4. Constraints to Participation

It was evident from some members' views that prolonged meeting times can dissuade one from regular attendance of the meetings. Employed members, particularly those who work at night, said that sometimes the meetings went on for longer than the scheduled time leaving them with no time to rest before returning to work.

Meaningful member participation was also affected by the admission of HIV negative people to the Flying Angels HIV Support Group by the group facilitators. The Researcher observed that as a result of this arrangement, there could have been selective disclosure and discussion of personal problems due to internal stigma (Miller and Rubin, 2007). However, when asked if there had been any disclosure of members' status by the non-HIV positive members, the response was negative. The Researcher further observed that the above concern was not expressed by the individuals during the in-depth-interviewees but by the members in the Focus Group discussion who included representatives of the Support Group Executive Committee.

It is clear that poverty and unemployment perpetuated the members' distress (Shacham et al, 2008) and were factors which were beyond Support Group's control, and so had to be borne by the individual or household. This came alive when members described how they walked long distances in search of work to meet family needs. Individuals in employment had difficulties deciding whether to go to work or attend the Support Group meeting, for fear of forfeiting the much needed day's wage if they decided to attend the meeting.

In spite of assertions that the strategy for bringing together HIV positive and negative people in Zimbabwe (Skovdal et al, 2013) was a way of normalizing HIV, the strategy was not well received in this study with members alleging the act on the part of the group facilitators was a breach of their confidentiality. When people are assured that they have a common problem, they will voluntarily subscribe to the group on that understanding. Their behavior thereafter will be influenced by the perceived benefits they receive from participating.

In this case study there appeared to be no gender constraints to participation in the Support Group, and were not raised by participants. However, the strong cultural belief that women are inferior to men, may be a reason that gender discrimination could not be excluded as it may be seen as normal phenomenon by the members.

1.1.5. Reasons for dropping out

The study was also not able to draw out reasons for dropping out of the Support Group because people who had “dropped out” in fact described themselves as temporarily absent. In the light of the incomplete records of Support Group activities, it was not possible to conclusively state that there were no people that had dropped out especially that the findings revealed that some people who had started work no longer attended the scheduled meetings. Engagement in employment and relocation to and from the Township were the main issues that were identified as reasons for leaving the Flying Angels Support Group. There may be a thin line between dropping out and irregular

participation in meetings. However, it was also evident that the opportunity cost of dropping out and foregoing the support and benefit of continuing was high on the part of the members.

1.1.6. Impact of the Support Group

The members' decision to take on voluntary community care and support work was demonstration of how belonging to the Support Group had helped the members overcome the stigma and discrimination barrier (Mundell et al, 2012) enabling them to extend help by counselling others to go for VCT, seek treatment as well as make informed decisions to join the Support Group. Information is power! Therefore with the information members received from the Support Group, the members utilized it to reclaim their self-esteem and face the world with courage and confidence.

The growth of the Support Group membership base over time as a result of both self-referral as well as invitations to join by old members was indicative of the mark the Group had made in the community. It also pointed to the level of member satisfaction of the services offered by Support Group.

It was also observed that some members were not aware of fund assistance schemes available in the community except the Community Development Fund (CDF); purported to be disbursed on partisan lines as opposed to identified community needs. As such, the Support Group had limited opportunities known to them for resource mobilization for income generating activities.

Some members struggled with problems of non-acceptance (denial) of one's sero-status, stigma, fear of disclosure of one's status to spouse and family even after joining the Support Group. Some members of the Support Group remained fairly peripheral in the group and were yet to cross the relationship building bridge with other Support Group members who would in turn help them to open up, begin to share and learn coping mechanisms.

1.2. Conclusion

The aim of the study was to explore and describe the needs, preferences and challenges of PLWHIV in a faith-based HIV support group in Ng'ombe Township in Lusaka, Zambia. The basic principle behind HIV support groups is that members must see themselves as people in supportive relationships to each other in a safe and conducive environment that enables fulfillment of their diverse needs.

The findings point to evidence that substantiates the relevance and effectiveness of HIV support groups as social support structures where the treatment and care, psychosocial and informational needs of PLWHIV are addressed. However, the support groups are still limited in addressing poverty. As ART has increasingly become available to PLWHIV, individuals accessing the treatment are living longer yet with adverse consequences thrust upon them particularly economic challenges that impact on the quality of their lives. The Support Group members' capacity to negotiate access to resources outside of the Group such as the Community Development Fund or other

schemes that may be available for such groups were seemingly lacking, as were the information and other systems that this would require.

The very nature of some support groups being established and facilitated by individuals who are economically marginalised, limits their capacity to address the members' needs (personal, transportation, food and accommodation costs) arising from poverty.

1.3. Recommendations

The Researcher has identified recommendations for enhanced functioning of HIV support groups to position them to effectively respond to the needs and expectations of the members.

1.3.1. Given the shortage of personnel in existing health facilities, social networks and support groups of PLWHIV should be encouraged in to provide extended care and support services to PLWHIV. Some of the provisions include food rations and dietary supplements and information on positive behavior for the enhancement of their health; health promoting services like mosquito nets and water purification agents.

1.3.2. There is need for a standardized system of documenting relevant support group activity information and feeding it to a central information repository to inform policy and key decision making processes, and to enable access to external funds and resources.

- 1.3.3. It is recommended that the Ministry of Community Development Mother Child Health review the disbursement mechanism of the Community Development Fund (CDF) so PLWHIV collectives can access the funds to deal with issues specific to PLWHIV in a more targeted way.
- 1.3.4. The capacity of HIV support groups to negotiate access to other forms of social protection programmes such as Community Development Funds need to be enhanced.
- 1.3.5. HIV support groups should be oriented to basics of resource mobilization, group facilitation and management of human and material resources.
- 1.3.6. The Ministry of Community Development should consider supporting NZP+ in its coordination role for effective networking, sharing and learning among HIV support groups.
- 1.3.7. The Living Assemblies of God's non-judgmental stance on HIV positive church members and others in the community should be emulated by other churches.
- 1.3.8. Finally, there is a need for future research to further actionable understanding of HIV programming for improved livelihoods.

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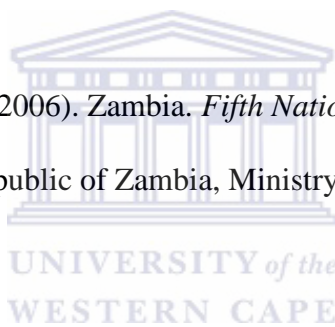
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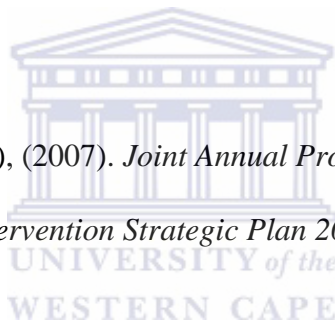
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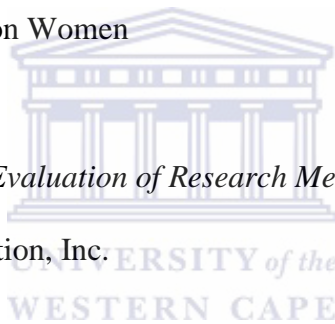
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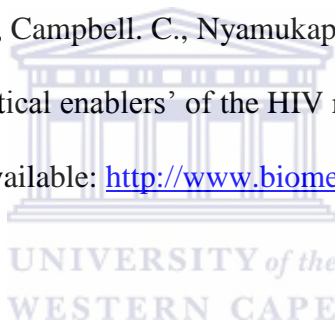
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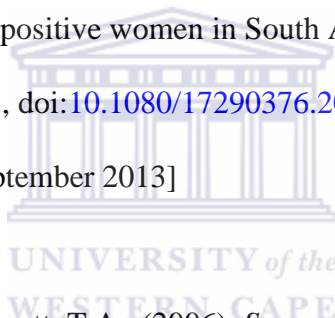
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Appendix 1



UNIVERSITY OF WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa

PARTICIPANT INFORMATION SHEET

Date:

Interviewer: Lumbwe Yuyi Njekwa

UWC Student No: 2616582

Tel: +260 977 778454 **Flying Angels:** +260 977 780280

E-mail: njekwal@yahoo.co.uk

Institution: Palliative Care Association of Zambia

Interviewee's pseudonym: _____

Place at which the interview was conducted: Ng'ombe compound, Lusaka, Zambia

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview. You are asked to give your consent to me on tape when we meet to conduct the interview.

1. INFORMATION ABOUT THE INTERVIEWER

I am Njekwa Lumbwe, a student at the SOPH, University of the Western Cape. As part of my Masters in Public Health pre-qualification requirement, I am undertaking a Research study which is titled *A Case Study of the Flying Angels Support Group for People Living with HIV and AIDS in Ng'ombe Compound, Lusaka, Zambia*

I am accountable to my academic supervisor Professor Helene Schneider who is contactable at C/O SOPH or by e-mail at: hschneider@uwc.ac.za

2. PURPOSE OF INTERVIEW

The purpose of the interviews is to acquire information about the Flying Angels Support Group and about participants' experiences of belonging to support group for individuals living with HIV and AIDS. With this information, I aim to write a descriptive case study which gives insight into the workings of a support group, how it meets members' needs and whether there are ways that it could better suit their needs. Through this knowledge, I hope to contribute to a better understanding of what works best in a support group and the needs of its' members, or what does not work for them.

3. THE INTERVIEW PROCESS

The interviews/focus group discussions are not expected to exceed one hour. I have developed two questions to open up conversations during the interview. However, participants are free to share any information they may feel relevant even if I have not asked for it. I would also like to audio record our interview if you allow me, so that I capture your views and increase the chances of reporting the information as accurately as possible.

4. ANONYMITY OF CONTRIBUTORS

During the interview, I will use a code name which I would like you to choose, so that anything you say will be anonymous. All information obtained and records will be kept locked away at all times to maintain confidentiality.

5. THINGS THAT MAY AFFECT YOUR WILLINGNESS TO PARTICIPATE

If at any time during the interview, you feel offended or prefer not to discuss any issue, please feel free to say so. You may also withdraw from the interview at any time. I will not be offended and there will be no negative consequences if you would prefer not to answer a question.

Please turn over for the Informed Consent Sheet to sign

Thank you

Appendix 2



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INFORMED CONSENT SHEET

A Case Study of the Flying Angels Support Group for People Living with HIV and AIDS in Ng'ombe Compound, Lusaka, Zambia

1. AGREEMENT

1.1 Interviewee's agreement

The study has been fully explained to me. I understand that my identity will not be revealed and the information I give will be used for the purposes of this study, but may be used for published or unpublished research at a later stage without further consent. I have been informed that I will not receive any gift either in material or monetary form for participating in this study as an interviewee. I am under no obligation to consent to the interview and do declare that my participation is voluntary.

Signed: _____ **Or Left hand thumb print:** _____

Date: _____

Place: _____

1.2 Interviewer's agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. Any change from this agreement will be renegotiated with you.

Signed: _____ **Date:** _____

Place: _____

Appendix 3



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INDEPTH INTERVIEW GUIDE – SUPPORT GROUP MEMBERS

A Case Study of the Flying Angels Support Group for People Living with HIV and AIDS in Ng'ombe Compound, Lusaka, Zambia

1. Why did you join this support group?

Probes: Is it different from others? Please explain. What do you like best about it? How did you come to know about it? Did you join alone or with someone?

2. Can you tell me more about the Support Group?

Probes: Services, resources, one to one counseling, information, activities, etc; what does it do for you? Is there anything you need which it cannot provide?

3. Have you encountered any problems in the support group?

Probes: Lack of support, confidentiality, etc? Is it still a problem? Please explain how you overcame them? 4. Is there anything you would want to change in the Flying Angels Support Group?

Probes: membership, size of group, activities, time of meetings, frequency, place, the services and resources offered for PLWHIV by this group?

5. Is there anything you need which the Support Group cannot provide?

6. Is there any other information about support groups you may want to add?

For participants who left

Why did you leave the Support Group? (*applies only to individuals out of the support group*)

CLOSING STATEMENT

I will be analyzing the information you and others have given me and will be happy to send you a copy of the draft report to review if you are interested before I submit it to my school.

Thank you for your time.



Appendix 4



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INDEPTH INTERVIEW GUIDE – KEY INFORMANTS

A Case Study of the Flying Angels Support Group for People Living with HIV and AIDS in Ng'ombe Compound, Lusaka, Zambia

1. Please tell me more about this support group? What brings people to it?

Probes: Services, resources, one to one counseling, information, activities, etc

2. What works well? Please elaborate. What problems do you experience?

3. What effect, if any, do you feel the Flying Angels Support Group has had on members? And do you think it has had any effect on the community in Ng'ombe?

Probes: Reduced stigma and discrimination? Increased acceptance of one's illness? Increased adherence to treatment?

4. When people leave, why do you think they do?

5. What would you do differently in the Flying Angels Support Group? Please explain why.

6. Is there anything more you would like to add?

CLOSING STATEMENT

I will be analyzing the information you and others have given me and will be happy to send you a copy of the draft report to review if you are interested before I submit it to my school.

Thank you for your time.

Appendix 5



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CONFIDENTIALITY BINDING CONTRACT FOR FOCUS GROUP

A Case Study of the Flying Angels Support Group for People Living with HIV and AIDS in Ng'ombe Compound, Lusaka, Zambia

1. AGREEMENT

1.1 Focus Group participant's agreement

I hereby voluntarily consent to be interviewed by the Mrs Njekwa Yuyi Lumbwe, student at the University Western Cape. The purpose of the study has been fully explained to me, and I understand that my identity and the information I give will not be disclosed to anyone else. I also understand that I am under no obligation to answer specific questions and can freely decide to terminate the interview at any point after the interview begins, and this will not negatively affect me in any way. I agree not to disclose what we will discuss to anyone else.

I also understand that the Researcher Mrs Njekwa Lumbwe is the person to contact if I have any questions about the study or about my rights as a study participant. She can be contacted through mobile number 0977 778454.

Participant's signature: _____ **Or Left hand thumb print:** _____

Date: _____ **Place:** _____

Interviewer's signature: _____ **Date:** _____