

AN EXPLORATION OF THE DELIVERY OF COMMUNITY-BASED PSYCHOSOCIAL
SUPPORT SERVICES TO CHILDREN LIVING WITH HIV AND AIDS BY THE SIMBARASHE
NATIONAL NETWORK FOR PEOPLE LIVING WITH HIV AND AIDS IN THE KADOMA DISTRICT,
ZIMBABWE

by

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DECLARATION

I, declare that **AN EXPLORATION OF THE DELIVERY OF COMMUNITY-BASED PSYCHOSOCIAL SUPPORT SERVICES TO CHILDREN LIVING WITH HIV AND AIDS BY THE SIMBARASHE NATIONAL NETWORK FOR PEOPLE LIVING WITH HIV AND AIDS IN THE KADOMA DISTRICT, ZIMBABWE** is my own work, and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Name:

Student number:

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DATE

DEDICATION

This dissertation is dedicated to my husband Tinashe, our two beautiful girls Thandiwe and Nyasha and our son Michael. Your support and patience throughout this process have been amazing!

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I want to firstly thank my Lord and Saviour Jesus Christ for saving me from a tragic situation in my life and for giving me my life back.

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SUMMARY

The delivery of psychosocial support (PSS) services to children living with HIV and AIDS (CLHA) by PSS service providers, such as community-based organisations (CBOs) in resource-poor settings, ensures the availability of consistent and sustainable support to children living with HIV and AIDS. These children face various psychological and social challenges associated with living with HIV and AIDS, such as drug adherence to HIV medication, stigmatisation and distress, among others. This qualitative study explored the critical factors that influence the delivery of community-based PSS services to CLHA younger than 15 years of age in a resource-poor setting by a community-based organisation. Multiple data-collection tools were adopted. The findings revealed the critical factors that contributed to the delivery of community-based PSS services to CLHA, and also ways in which these important services could be improved.

Key words:

Care and support, children, children living with HIV and AIDS, community-based organisations, HIV and AIDS, people living with HIV and AIDS, psychosocial support, Simbarashe National Network for People Living with HIV and AIDS

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LIST OF ACRONYMS

AfriCASO	African Council of AIDS service organisations
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BBC	British Broadcasting Corporation
CLHA	Children Living with HIV and AIDS
CBO	Community-Based Organisation
CSO	Central Statistical Office
HAART	Highly Active Antiretroviral Therapy
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
HOSPAZ	Hospice Association of Zimbabwe
MDG	Millennium Development Goal
MOHCW	Ministry of Health and Child Welfare
MTCT	Mother-to-child transmission
NPS	National Psychosocial Support
PEPFAR	President's Emergency Plan for AIDS Relief
OVC	Orphaned and Vulnerable Children
PLHA	People Living with HIV and AIDS
PSS	Psychosocial Support
REPSSI	Regional Psychosocial Support Initiative
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
ZDHS	Zimbabwe Demographic and Health Survey
ZIMSTAT	Zimbabwe National Statistics Agency

DECLARATION

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SIGNATURE



DATE

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

A number of children have globally been infected with the Human Immunodeficiency Virus (HIV). A total of 3.3 million children below 15 years of age globally were living with HIV in 2011 (WHO, UNAIDS & UNICEF 2012). An estimated 330 000 children were newly infected with HIV in the same year (UNAIDS 2012:42). Sub-Saharan Africa accounted for the highest percentage (90%) of new infections among children in 2011 (UNAIDS 2011:42). Mother-to-child transmission (MTCT) continues to account for most new infections among children globally (UNICEF & WHO 2008:9). In 2011, 230 000 children below the age of 15 years died globally of Acquired Immunodeficiency Syndrome (AIDS)-related causes (WHO, UNAIDS & UNICEF 2012). Many children in sub-Saharan Africa die without receiving an HIV diagnosis or without having received any HIV treatment and care (UNICEF & WHO 2008:9; UNAIDS 2013:42).

The HIV and AIDS epidemics have increasingly destroyed the health and welfare of children, undermining the hard-won gains of child survival. Sub-Saharan Africa has not only experienced the unprecedented loss of health and human life of children, but also of the children's primary caregivers as a result of HIV infection and AIDS-related deaths. This loss of human life in communities has resulted in children being negatively affected as they then receive inadequate or compromised care and support. The provision of adequate care and support to these children is essential for their development (Foster 2005:1). The above statistics – which reflect a high and growing number of HIV infections in recent years – reveal the magnitude of the need to provide sustainable care and support services to vulnerable children in general, and to children living with HIV and AIDS (CLHA) in particular.

Community-based interventions have been identified to play a crucial role in the provision of long-term sustainable social support and resources to vulnerable children (Boler & Johnson 2007:31-32; Foster 2005:5; Ninan & Delion [sa]:213). This is especially critical in order to reach Millennium Development Goal (MDG) 6, which aims to combat HIV and AIDS, malaria and other diseases, and further seeks to halt and reverse the spread of HIV by 2015.

Existing literature points out that social support interventions have repeatedly been linked with contributing to good long-term health outcomes in the case of those affected by chronic diseases and other health-related disorders (Hogan, Linden & Najarian:2002). Guided by the social support theory, this qualitative study seeks to understand the critical factors that contribute to the delivery of community-based psychosocial support to CLHA in a resource-constrained area. The study focuses on the delivery of psychosocial support from the perspective of an organisation working closely with communities in Zimbabwe, namely the Simbarashe National Network of People Living with HIV and AIDS.

This chapter contextualises issues surrounding the delivery of psychosocial support to CLHA in Zimbabwe and explains why there is a need for sustainable community-based psychosocial support services for these children. It highlights some international policy frameworks that guide the provision of care and support services to children living with HIV and AIDS. The chapter further sets out the research objectives and research questions of the study. It gives a brief overview of the research setting, the rationale for the study, the research design and the research methodology of the study, as well as the assumptions of the study. This chapter also defines the key terms used in this study and gives an outline of the four dissertation chapters that follow.

1.2 RESEARCH PROBLEM

1.2.1 Background

In 2012, Zimbabwe recorded a high estimated adult HIV prevalence rate (ages 15 and above) of 14.67%, and in the same year recorded a child HIV prevalence rate (ages below 15) of 3.14% (MOHCW 2012:7). Similarly, in the previous year in 2011, Zimbabwe had recorded a high estimated adult HIV prevalence rate of 13.1% (National AIDS estimates 2010 in National AIDS Council 2011:1).

According to the Central Statistical Office population projections, Zimbabwe in 2011 had an estimated population of 12.7 million people. Of the estimated total HIV infected population of 1,159,097 million people in Zimbabwe recorded that year, an estimated 138,642 (about 10%) of this population were noted to be children below the age of 15 years (Central Statistical Office 2012; MOHCW in National AIDS Council 2011:1,12.) As shown by the statistics above, the continuing high prevalence of HIV in Zimbabwe in recent years is contributing to the large numbers of child HIV infections.

With the significant impact of the AIDS pandemic on individuals, families and communities in Africa, the delivery of psychosocial support has clearly been recognised as a fundamental aspect of care and support. Studies have also noted that the absence of comprehensive and holistic services tailor-made for children will undermine the effectiveness of current care and support efforts. The exclusive provision of medical treatment, while neglecting the psychosocial needs of CLHA, is detrimental as the children's ability to accept and manage the psychological effects of living with HIV infection may inevitably influence their ability to make, for example, informed sexual choices – which may contribute to the reduction or continued spread of HIV communities (Rogers 2006:15).

Psychosocial support (PSS) involves the delivery of services that promote the

emotional, physical, psychological and social well-being of a person. Psychosocial support includes the consistent day-to-day delivery and provision of nurturing and caring relationships that promote love, tolerance and acceptance of an individual, the affected family and the affected community (MOHCW 2009:3). Within the context of HIV and AIDS, PSS for children includes support that directly benefits children and assists them in overcoming the challenges associated with living with HIV and AIDS, such as stigma and the emotional distress associated with the illness (MOHCW 2009:2-3).

Psychosocial support is important because it enables children to cope better in their respective communities. It assists them with laying a good foundation for their emotional and psychological growth. It also assists with their social development and enables them to make positive contributions to society. Children generally need a sense of belonging, stability, affection and reassurance, especially when facing chronic illnesses (Conner, Wilson & Lyon 2006:182; MOHCW 2009:2-5). According to Hodgson, Haamujompa, Mburu and Ross (2011:11), the delivery of appropriate psychosocial support will encourage children living with HIV and AIDS to have a sound understanding of HIV and its implications for expressing sexual feelings.

The current advances in HIV testing and treatment are enabling CLHA in resource-poor settings to live longer and healthier lives. The median life expectancy of CLHA recorded in 2009 was 16 years in comparison to the past 20 years of the history of the AIDS epidemic where children born with HIV would not live past infancy (Anjala, McCleary-Sills, Vujovic, Brakarsh, Dlamini, Namisango, Nasaba & Fritz 2011:17). However, the chronic nature of HIV infection in these children requires the availability of continuous care and support services that also address the critical psychosocial issues that affect them. For instance, the subject of HIV disclosure is important in PSS interventions, as it prepares children to know to whom and when to disclose their HIV status. The availability of services also allows the children to know the benefits or challenges of

disclosure (Anjala et al 2011:17). Due to anti-retroviral treatment, many children living with HIV transition into adolescence and adulthood, and psychosocial support could assist them to cope with living with HIV, and also make them aware of their sexual feelings and future sexual choices. The lack of appropriate support may make them prone to sexual risk-taking behaviour in the future (Hodgson et al 2011:11). Therefore the delivery of appropriate care and support services that promote the physical, mental, emotional and psychological well-being of CLHA could assist in influencing them to adopt healthy sexual behaviour and thus contribute to halting the spread of HIV in the future.

Failure to provide adequate PSS to children living with HIV and AIDS will lead to increased vulnerability, insecurity and reduced development and may have permanent effects on the development of their cognitive and social capacities, which could result in damage to their sense of identity and self-esteem (Richter, Foster & Sherr 2006:13-14).

A global review by the World Health Organization (WHO) of existing psychosocial support (PSS) interventions available for young people living with HIV and AIDS, conducted in 2008, revealed the problems that these young people generally face. The review revealed the priority problems faced by young people living with HIV and AIDS to include adherence to medication, disclosure of the young people's HIV status and the lack of support networks, among others. The review underscored the lack of adequate published research on effective psychosocial interventions, such as those that contribute to improving treatment adherence, minimising the stigma and preventing high-risk behaviour, particularly in the 10 to 24 year age group (WHO 2009:5).

A recent report on addressing the psychological and social challenges related to caring for children living with HIV and AIDS (CLHA) in Africa, released by the United States Agency for International Development (USAID) in 2011, gave an overview of the experiences and the state of well-being of CLHA in sub-Saharan

Africa. The report noted that CLHA still experience more distress than their peers not living with HIV and AIDS because they face multiple stressors such as dealing with their illness, the death of a parent and family insecurity among a number of issues (Anjala et al 2011:18). In addition, the report noted that, although there is a growing awareness of the psychological and social issues faced by these children and their communities, information on this topic is still very limited (Anjala et al 2011:9).

According to Rogers (2006:11-12), children living with HIV and AIDS have specific issues to deal with as a result of their HIV status. For instance, how they became infected is important in PSS provision. Children infected from birth may have to deal with anger towards their parents for infecting them. They may also have to deal with HIV-associated cognitive disorders such as an impaired brain growth and language development delays, among others (Lourie, Pao, Brown & Hunter 2005:182).

Due to the social dynamics presented by vertical transmission¹, children infected at birth may need to deal with caregivers' inability to cope with the pressures associated with caring for them. Studies on youth living with HIV in the United States of America (USA) have indicated that some children infected at birth inevitably assume some responsibility for their own health at a very young age, hence the need for appropriate child-based psychosocial support services at an early stage of life. Those infected during adolescence are also faced with their own unique challenges (Rogers 2006:13; DeLaMora, Aledort & Stavola 2006:1). These may include the disclosure of their HIV status to parents or guardians – an important issue which may affect their ability to access care and support services. Those who have not disclosed their HIV status due to fears of their parents' reactions may find it difficult to request the required financial resources and support that would enable them to visit service providers (Rogers

¹ Vertical transmission is the transmission of the HIV virus from mother-to-child during pregnancy, child birth or breastfeeding (UNAIDS 2009:21).

2006:13,16). Whether infected at infancy, middle-childhood or during adolescence, these children are likely to experience psychosocial problems which adults living with HIV and AIDS may not encounter, hence the need for the delivery of child-related psychosocial support services.

As part of the international response to address issues affecting CLHA, the United Nations Children's Fund (UNICEF) and the World Health Organization in 2008 developed a framework to guide national responses in resource-constrained countries most affected by the HIV and AIDS epidemics to scale-up HIV prevention, diagnosis, treatment and care for children.

Promoting psychosocial support as part of HIV and AIDS care and support services for children living with HIV also corresponds with meeting international goals and agreements such the Convention on the Rights of a Child and the Millennium Development Goals (UNICEF & WHO 2008:12). Every child has the right to life, survival and healthy development, as stipulated in Article 6 of this Convention. In addition, national governments are expected to enact legislature that ensure the protection and realisation of children's rights (Child Rights Information Network [sa]).

The extended family structure, which traditionally would have normally provided support to children affected and infected by HIV and AIDS, is now noted to be greatly over-extended in communities most affected by the HIV and AIDS epidemics, resulting in its reduced capacity to take care of vulnerable and orphaned children (Foster 2005; Van Dyke, as cited in Van Gelder & Kraakman [sa]:3). The AIDS pandemic has resulted in an unexpected emergence of an orphaned and vulnerable generation that has grown at a fast and unexpected rate in the past two decades. This has resulted in the extended family having to over-stretch the limited available resources to assist in taking care of these children. The extended family in resource-constrained communities battles with poverty, among other issues, and the high numbers of children under their care is

beyond their ability to cope in meeting their day-to-day basic needs.

Consequently, one of UNICEF and the WHO's seven strategies for scaling-up interventions included supporting existing community-based organisations (CBO) to identify children who became infected with HIV. Community-based organisations were identified by UNICEF and the WHO to be key players that offer access to essential HIV and AIDS care and support services, among others. The international framework further underscored the role of community-based organisations as providers of accessible follow-up HIV and AIDS care and support to children and their families (UNICEF & WHO 2008:9).

The Government of Zimbabwe has recognised that the provision of psychosocial support services to CLHA is of paramount importance. Since the development of the National Psychosocial Support (NPS) Guidelines in 2009 for children living with HIV and AIDS by the Ministry of Health and Child Welfare (MOHCW), the discussions on PSS for CLHA continue to be part of the national priorities. The main aim of the guidelines was to promote a common understanding of PSS issues for CLHA. The development of these guidelines was influenced by the findings from a national situational analysis conducted by the Ministry of Health and Child Welfare in 2006. The situational analysis is noted to have identified the key issues to be addressed in order to have comprehensive care services such as counselling, palliative care services and access to support groups (among others) to these children by health and community-based workers. With no other recent publications from the MOHCW, these guidelines continue to be the main document that guides the provision of PSS to CLHA in Zimbabwe.

As is the case with other African countries, Zimbabwe is expected to work towards achieving Millennium Development Goals 4 and 6, which underscore the need for countries to have halted new HIV infections by 2015 and commenced reversing its spread (World Bank 2011). The United Nations 65th session General Assembly, Special Session in 2011, saw heads of states and governments,

including Zimbabwe, reaffirm their international commitment in the response to the HIV and AIDS epidemics. The heads of states showed this through making a commitment to the declaration titled the “Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS”. This Declaration of Commitment on HIV and AIDS was initially made in 2001 and again in 2006 thereafter. The 2006 Declaration required nations to have reduced the percentage of infants infected with HIV by the year 2010 (UNAIDS 2011; UNICEF & WHO 2008:12).

This current study will be guided by the conceptual and policy framework of PSS delivery as articulated in Zimbabwe’s National Psychosocial Support Guidelines for Children Living with HIV and AIDS. The document confirmed the nation’s commitment to meeting the needs of those living with HIV and AIDS.

1.2.2 Problem statement

With its relatively high HIV prevalence rate, Zimbabwe has faced various challenges in promoting care and support for those infected and affected by HIV and AIDS. In recent years, the reduced national and international funding towards the HIV and AIDS response in Zimbabwe has continued to threaten Zimbabwe’s efforts of meeting international goals and targets such as those discussed above in section 1.2.1 (Plus news 2009). According to Foster (2005), in order to expand on the delivery of any HIV and AIDS care and support services, additional financial, material and physical resources are also required.

Zimbabwe has been experiencing a decline in HIV and AIDS funding in the last few years due to three major reasons. Firstly, according to Plus News (2009), reduced funding from the international community in the past was mainly due to alleged mismanagement of major international HIV and AIDS donor funds by the Zimbabwean government. The international donor funds included, among others,

the Global Fund² and the United States President's Emergency Plan for AIDS Relief (PEPFAR). In 2008 Zimbabwe received US\$26 million from PEPFAR, ten times less than the funds allocated to neighbouring Zambia, and a quarter of what was allocated to Namibia (Plus news 2009).

Secondly, the prevailing unstable political situation in Zimbabwe has seemingly affected internationally funded non-governmental organisations operating in the country that criticise the ruling government of violating internationally recognised human rights. Operations of humanitarian and human rights organisations in Zimbabwe have in the past experienced unjustified threats of closure, disruptions and state surveillances. Activities of this kind could threaten any sustainable responses to address development challenges such as those posed by the AIDS epidemic (Chinaka 2005; Amnesty International 2005:1-4; Integrated Regional Information Networks 2009). For instance, the political violence experienced during the 2008 national election period saw the emergence of political groups that attacked and interfered with operations of human rights and development and humanitarian organisations suspected to be against the ruling government's policies.

Organisations that were outspoken with regard to human rights violations and the government's failure to meet the basic needs of its people were accused of working with opposition political parties and some were threatened with closure. Since 2009 politically motivated disruption of the work of civil society and humanitarian aid organisations still continues to take place in Zimbabwe. A recent 2011-2012 report released by the Zimbabwe Human Rights NGO forum reported that in February 2012, continued harassment and threats to civil society groups by the government were taking place. The report noted that a provincial level government authority in one of Zimbabwe's largest provinces, Masvingo, announced the ban of 29 non-governmental organisations (NGOs) operating in

² The Global Fund is an international financing institution to fight AIDS, tuberculosis and malaria. Funds are disbursed for national programmes only when country proposals have been successful (Global Fund 2012).

the area in that month alone (Human Rights NGO Forum 2012:6). Such behaviour generally threatens the existence and security of these organisations and undermines their presence in communities (Amnesty International 2005).

Thirdly, the country's inconsistent access to important country HIV and AIDS funding mechanisms, such as the Global Fund, means that vital national prevention, treatment and care programmes funded by these international mechanisms may not be able to continue their operations in communities. According to the African Council of AIDS service organisations (AfriCASO), Zimbabwe did not qualify for the Global Round 10 funding, as it failed to meet the funding requirements. Zimbabwe had applied for US\$170 million for its HIV programmes (AfriCASO2012). This is a major setback for the HIV and AIDS response in the country as Zimbabwe depends heavily on this international funding institution for the implementation and sustenance of its HIV and AIDS programmes.

Currently, there are inadequate psychosocial support (PSS) services available for children living with HIV and AIDS in Zimbabwe. The Ministry of Health and Child Welfare pointed out in the Psychosocial Support (NPS) guidelines that the provision of these services was still lacking (MOHCW 2009:1). The abovementioned challenges and issues reveal the urgent and critical need to consider the promotion of more HIV and AIDS community-based responses to the HIV and AIDS epidemics in Zimbabwe. This could be done through the expansion of existing community-driven initiatives that have minimal dependency on external partners for their future existence.

Foster (2005) points out that studies conducted in sub-Saharan Africa have suggested that a major proportion of AIDS funding and support is provided by local community groups and families. In some countries such as Tanzania, local communities are noted to have had the capacity to provide 90% of the material support given to AIDS-affected households (Foster 2005:5). Consequently,

scaling-up community-based HIV and AIDS care initiatives, as noted by UNICEF and WHO above, could play an important role in promoting sustainable cost-effective care and support services to children living with HIV and AIDS in Zimbabwe.

1.2.3 Focus of the study

As noted above, the HIV and AIDS epidemics have contributed to an increasing number of children living with HIV and AIDS. Children in the Kadoma district of Zimbabwe have not been spared either. While little attention has been given to the psychosocial needs of CLHA, there has been a lot of emphasis on the provision of antiretroviral therapy (ART) and adherence issues (WHO 2009:5).

This study investigates the factors associated with the provision of psychosocial support at community level for children affected by and living with HIV and AIDS. At this point, it is also important to note that for the purposes of this study of limited scope, the focus of the study will mainly be on “psychosocial support” rather than on “psychosocial well-being”. The former focuses on the individual, while the latter is a broader concept which not only focuses on the psychosocial aspects of an individual but also considers the well-being of those who may have a direct influence on that individual, such as his or her family members (REPSSI in MOHCW 2009:3).

The study focuses on the delivery of psychosocial support services by a particular community-based organisation which deals with HIV and AIDS-related issues at community level in Kadoma, Zimbabwe. The identified organisation is the Simbarashe National Network for People Living with HIV and AIDS.

1.3 THE RESEARCH SETTING

The Kadoma district is located in the northern part of Zimbabwe in the

Mashonaland West province. The district is subdivided into three main sub-districts, namely the Kadoma urban district, the Mhondoro-Ngezi district and the Sanyati district. The Kadoma district has a total population of 238 122 of which 66.9% is located in the two rural districts, the Mhondoro-Ngezi and Sanyati districts (MOHCW 2006:1). The Kadoma district's population are mainly involved in informal and formal mining as well as farming activities. The main providers of HIV and AIDS services are government health facilities, community-based organisations, non-governmental organisations and religious groups. According to ZIMSTAT and ICF International (2012:15), the Mashonaland-West province where the Kadoma district is located, recorded a high HIV prevalence of 15% in 2011, as recorded in the 2010-11 Zimbabwe Demographic and Health Survey (ZDHS) survey. The ZDHS survey reveals the existing HIV and AIDS burden in the Kadoma district.

The Simbarashe National Network of People Living with HIV and AIDS operates in the Kadoma rural sub-district of Nhondoro-Ngezi. The Simbarashe National Network of People Living with HIV and AIDS is a community-based organisation that assists communities with information and care and support services that help to reduce the negative impacts of HIV and AIDS. The CBO was founded in 2003 by a couple openly living positively with HIV. The organisation's vision is to improve the lives of those children and adults living with HIV and AIDS. In addition, the organisation provides timely and relevant psychosocial support services to the most vulnerable groups in this community (Simbarashe National Network of People living with HIV and AIDS 2012a).

1.4 RATIONALE FOR THE STUDY

With the magnitude of the impact of the HIV and AIDS epidemics on communities and the increasing number of children living with HIV and AIDS, there is a need to understand the factors associated with the delivery of PSS services for CLHA. This study could be beneficial in that it could reveal some of the critical factors

that could contribute to the expansion of community-based psychosocial services required to meet the PSS needs of CLHA in the Kadoma district. Little is known or has been adequately documented about what has contributed to the successful delivery of PSS services to CLHA in resource-constrained areas in Zimbabwe.

The findings of the study could be useful in informing the activities of various stakeholders advocating for PSS, such as the Kadoma Network of People living with HIV and AIDS, the Ministry of Health and Child Welfare (MOHCW), the Kadoma District AIDS Council and the Kadoma Municipality. These findings could enable them to evaluate whether the existing national policy frameworks on the delivery of PSS services to CLHA are known to or are adequately informing the activities of PSS service providers.

This study could also contribute to existing knowledge regarding the role of community-based organisations as key players in providing an integrated response to promoting care and support in resource-poor settings such as the Kadoma district. Through taking a closer look at the PSS services delivery of the Simbarashe Network of People Living with HIV and AIDS, the study could contribute to existing knowledge on sustainable community-based responses to CLHA in resource-poor settings such as the Kadoma district in Zimbabwe. Community-based organisations are essential players in the national government's response to the HIV and AIDS epidemics in resource-constrained communities.

Notably, the international commitment to respond to the HIV and AIDS epidemics made by Zimbabwe through the United Nations Political Declaration on HIV and AIDS by the year 2010, was not achieved and as indicated by the new and ever-increasing HIV infection statistics recorded each year, this is still to be achieved. Hence, this study's usefulness in adding to existing knowledge on care and support services provision to CLHA in Zimbabwe. This study seeks to establish

the factors associated with the provision of PSS to children living with HIV and AIDS. Through taking a closer look at the operations of a community-based organisation, the study could increase our understanding and give insight into what it takes to deliver such services at community level in resource-constrained areas.

1.5 OBJECTIVES OF THE STUDY

1.5.1 Broad objective

The broad objective of the study is to explore and describe the critical factors that influence the delivery of community-based psychosocial support to children living with HIV and AIDS in a resource-constrained area.

1.5.2 Specific objectives

The specific objectives are as follows:

- To describe the delivery of community-based PSS services to CLHA by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To identify the main factors that influence the delivery of community-based PSS services to CLHA by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To explore caregivers' views on the extent to which the PSS needs of CLHA are being met by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To explore the existing linkages the Simbarashe National Network of People Living with HIV and AIDS has with other PSS service providers in the Kadoma district of Zimbabwe.
- To identify ways in which the delivery of community-based PSS

services to CLHA can be improved by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.

1.6 RESEARCH QUESTIONS

The research questions to be addressed by this study are as follows:

- How are community-based PSS services delivered to CLHA by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe?
- What are the main factors that influence the delivery of community-based PSS services to CLHA the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe?
- To what extent are the PSS needs of CLHA being met by the Simbarashe National Network for People Living with HIV and AIDS in the view of caregivers in the Kadoma district of Zimbabwe?
- What referral linkages exist between the Simbarashe National Network for People Living with HIV and AIDS and other PSS service providers in the Kadoma district of Zimbabwe?
- How can the delivery of community-based PSS services to CLHA by the Simbarashe National Network of People Living with HIV and AIDS be improved in the Kadoma district of Zimbabwe?

1.7 ASSUMPTION OF STUDY

The major assumption of the study is that psychosocial support is essential for promoting the well-being of children living with HIV and AIDS. The other assumptions of the study include the following:

- Resource-poor settings struggle with the delivery of essential HIV and

AIDS services due to limited financial resources.

- There is a basic level of understanding of the concept of PSS in resource-constrained communities.

1.8 RESEARCH DESIGN AND METHODOLOGY

The research design is qualitative in nature. The qualitative research design is selected over a quantitative design because of its flexibility in gathering information on the factors that surround PSS delivery from the perspectives of the selected organisation. The study used a purposive sampling technique to select the research participants for this. Purposive sampling is useful when a researcher requires information-rich data to provide an in-depth understanding on the subject matter (Patton 1990: 169; Neuman 2012:149). The data collection techniques of the study included semi-structured, in-depth interviews and focus group discussions with project personnel of the selected organisation as well as with caregivers of CLHA. In addition, the observation of the delivery of a support group session to CLHA at the CBO's premises and the content analysis of some of the organisation's key documents were undertaken. The methodology of this study is discussed in detail in Chapter 3.

1.9 CONCEPTUAL FRAMEWORK

The study is guided by the social support theory. The social support theory is based on the works of three scholars of the 1970s, namely John Cassel, Gerald Caplan and Sidney Cobb. These scholars laid the foundation of the concept of social support and argued that social support played an important key role in reducing stress disorders in individuals (Vaux 1988:5). The concept of social support refers to processes that can buffer individuals against stressful situations through the interpersonal relationships they have with each other. The social support theory essentially underlines the principles of social support as a buffer to adverse effects of life's challenges (Baum, Taylor & Singer 1984:253).

The delivery of psychosocial support by social groups such as CBOs presents an opportunity for those living with HIV and AIDS to receive support services that reduce the psychological and social effects of the HIV/AIDS epidemics on people living with HIV and AIDS (PLHA). The conceptual framework of this study is discussed in detail in Chapter 2 of this study.

1.10 DEFINITION OF KEY TERMS

The central terms to be used in this study are defined as follows:

1.10.1 Antiretroviral Treatment

“Antiretroviral Treatment” is defined as treatment with medication that inhibits the ability of the Human Immunodeficiency Virus to multiply in the human body (WHO 2010).

1.10.2 Children

The Convention on the Rights of the Child defines “children” as persons up to the age of 18 years (UNICEF).

1.10.3 Community

A “community” can be defined as a group of people with diverse backgrounds who have accepted and transcended their differences and who communicate effectively and work together towards identified goals that benefit them (Hampton 2004). According to Colclough and Sitaraman (2005:477-478), “community” can also refer to single or multiple groups of society that have meaningful social relationships with one another. These social relationships emanate from their shared experiences, which in turn cause the members of the group or groups to create bonds, and to have a sense of responsibility and support toward one

another.

1.10.4 Palliative care

“Palliative care” is defined as the combination of active and compassionate therapy that meets the physical, social, psychological and spiritual needs of the patient and family when medical treatment is no longer possible (Oleske and Czarniecki 1999:1287). It is an approach that focuses on the prevention and relief of further suffering of those diagnosed with life-threatening and incurable diseases through a combination of interventions that can enhance the quality of life for the ill person and his or her family (WHO 2006:1).

1.10.5 Psychosocial

The term “psychosocial” describes dynamic relationships between psychological and social factors which influence an individual (REPSSI 2007 in MOHCW 2009:3).

1.10.6 Psychosocial support

For the purposes of this study, a broad definition of psychosocial support will be used. “Psychosocial support” includes assistance given to meet a person’s social, emotional, psychological and practical needs (Clarke, Mitchell & Sloper 2005:2). Psychosocial support can be further defined to include the provision of both formal and informal services that address one’s psychosocial well-being directly or indirectly. For example, the provision of interpersonal moral support, counselling and spiritual support would be regarded as direct support, while indirect support would include school and nutritional support that could contribute to alleviating stress and worry.

1.10.7 Psychosocial well-being

“Psychosocial well-being” includes meeting the physical, material, psychological, social, cultural and spiritual needs of an individual. However, the well-being of an individual depends on the well-being of others in the household, family and community (MOHCW 2009:3).

1.11 CHAPTER OUTLINE

Chapter 1 presents and introduces the study. The chapter begins with an overview of the recent global HIV and AIDS statistics on CLHA as well as the conceptual issues surrounding the delivery of PSS services to CLHA. This chapter further describes the research problem and the focus of the study. It further provides an overview of the study’s research setting and the rationale for having conducted this study. This is followed by a presentation of the research objectives and the research questions that guided the study. The chapter also sets out the main assumptions of this study and provides a brief introduction to the qualitative research design and methodology used to conduct the study, and also to the conceptual framework of the study. The chapter concludes with the definition of the key working terms used in the study.

Chapter 2 highlights some of the important issues faced by children living with HIV and AIDS globally. Chapter 2 explains why PSS services are essential to address the challenges faced by CLHA. It also discusses the challenges associated with living with HIV and AIDS for children such as treatment adherence, disclosure, and emotional and psychiatric problems. Using examples of experiences in other African countries and developed nations such as the United States of America (USA), the chapter attempts to show that the psychosocial problems of CLHA are unique in comparison to adults living with HIV and AIDS. The chapter further provides examples of an existing community-based PSS service for CLHA in Zimbabwe, such as the Champions for Life

programme. In addition, the social support theory which guided the study is explained in detail.

Chapter 3 explains the qualitative methodological approach used in this study. The chapter discusses the rationale for the use of the qualitative research design and describes the sources of data for this research. This chapter further discusses the multiple-data collection tools used to answer the research questions of the study, namely the individual in-depth interviews, focus group discussions, content analysis and observation. The chapter further elaborates on the non-probability sampling technique used in this study. This is followed by a discussion on how the research data collected during the fieldwork was analysed. The chapter concludes with a detailed discussion on the research setting, the ethical considerations adopted by the study, and ends with a brief discussion on how the pilot study was conducted.

Chapter 4 presents the findings of this study. This chapter discusses in detail the main factors identified by the researcher which have influenced the delivery of PSS to CLHA by the Simbarashe National Network for Children Living with HIV. The factors are categorised by the researcher under six major thematic areas, namely: psychosocial support, human rights, community-based approach, caregivers, integrated HIV and AIDS services, and partnerships.

The study concludes with **Chapter 5**, which provides a summary of the main findings of the study, recommendations for future research and policy development, and also sets out the limitations of the study.

1.12 CONCLUSION

The need for providing PSS services to CLHA in Zimbabwe is crucial as it provides the necessary support required to address the unique challenges faced by these children. An understanding of what influences the delivery of such

services is an important aspect of HIV and AIDS care and support at community level. A summary of the main points highlighted in Chapter 1 include the following:

- Global statistics reveal that new HIV infections among children continue to increase, with sub-Saharan Africa accounting for the highest percentage of new HIV infections in children.
- There is a recognised need for care and support services both globally and locally to deal with the PSS needs of vulnerable children such as CLHA. Care and support services are their basic right, as stipulated in international goals and agreements such the Convention on the Rights of a Child in Article 6. Among a number of issues, CLHA in particular face problems such as treatment adherence, stigma, and stress associated with dealing with their illness.
- The continued donor funding challenges which have affected Zimbabwe's HIV and AIDS response threaten the nation's ability to consistently deliver essential HIV and AIDS services to resource-poor communities and meet the MDG goals and targets. In view of these challenges, the need to promote community-based approaches in the delivery of care and support services to the growing population of people living with HIV and AIDS is crucial.
- The need to understand the critical factors that influence the delivery of community-based PSS to CLHA in resource-constrained communities is important, hence the presentation of this qualitative study. The qualitative study explores the delivery of community-based PSS by the Simbarashe Network of People Living with HIV and AIDS, to CLHA in the Kadoma sub-rural district of Mhondoro-Ngezi of Zimbabwe.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The AIDS pandemic continues to be one of the major health and social concerns globally. Over two decades of global efforts to respond to the AIDS epidemic have now passed, and nations continue to work towards eventually ending the pandemic. Various countries have again reaffirmed their commitment to continue in the response to the HIV and AIDS epidemics at national and community level. The recent global pledge by countries in the 2011 United Nations Political Declaration on HIV and AIDS is evidence of the continued intense battle against these epidemics. The main goal of the 2011 United Nations Political Declaration on HIV and AIDS is to intensify efforts to eliminate the HIV and AIDS epidemics through various strategies, which include attaining the Millennium Development Goals by 2015 (UNAIDS 2012b:6).

The number of people infected with HIV globally remains high and continues to reveal the magnitude of the need for essential HIV and AIDS prevention, treatment and care and support services.

This chapter begins with a discussion on the extent of the HIV and AIDS epidemics among children living with HIV and AIDS globally as well as in sub-Saharan Africa. The chapter discusses in detail the need for PSS services for CLHA as well as the PSS challenges faced by these children. The chapter further points out the differences that exist in managing HIV in adults and in children. This is followed by a discussion on some of the various ways through which PSS services are delivered, for instance through mental health programmes, public schools and palliative care services. The chapter also describes examples of PSS service providers that exist, and concludes with a presentation of the

theoretical framework of this study.

2.2 EXTENT OF THE HIV AND AIDS PANDEMIC AMONG CHILDREN

2.2.1 Global and sub-Saharan perspective

According to UNAIDS (2013:4), at the end of 2012, there were an estimated 35.3 million people recorded globally to be living with HIV. The HIV and AIDS pandemic have affected sub-Saharan Africa more than any other region in the world. Sub-Saharan Africa in 2011 accounted for 69% of the global population (almost two-thirds) of people living with HIV (UNAIDS (2012a:8). Children have not been spared from the impact of this pandemic. The main mode of HIV transmission has been from mother-to-child during pregnancy, child birth or breastfeeding (UNICEF and & WHO 2008:9).

As highlighted in Chapter 1, an estimated 3.3 million children under the age of 15 years were living with HIV and AIDS globally in 2011 (WHO, UNAIDS & UNICEF 2012). Of the estimated 330 000 new HIV infections recorded globally in children under the age of 15 years in 2011, sub-Saharan Africa again accounted for the highest percentage (90%) of new HIV infections, revealing the magnitude of the AIDS pandemic among children in this region (UNAIDS 2011:42).

Although the number of children living with HIV continues to increase globally, there is an evident decline in the number of new HIV infections in children. For instance in 2008, an estimated 2.1 million children under the age of 15 years were living with HIV globally, and an estimated 430 000 new HIV infections in children were recorded globally in this age group in that same year. Of this total, 390 000 of new HIV infections occurred in sub-Saharan Africa (UNAIDS 2009:21). On the other hand, in 2011 there were more children living with HIV, as already noted above. However, in 2011, there was a notable decline in the

number of new HIV infections in children recorded that same year, as there were 330 000 new HIV infections in comparison to the 430 000 new infections previously recorded in 2008. Similarly, the number of new infections in children under the age of 15 years in sub-Saharan Africa was lower, as there were 270 000 new HIV infections in children compared to the 390 000 recorded in 2008 (UNAIDS 2009:21; UNAIDS 2012a). According to UNAIDS (2013:6), the decline in the number of new HIV infections in children can be attributed to the improved coverage of HIV prevention services for pregnant mothers living with HIV. Table 1 below summarises this comparison.

Table 1: Comparison of global statistic of children living with HIV and AIDS: 2008 and 2011

Year	Global number of children living with HIV under 15 years	Global new HIV infections among children under 15 years	Sub-Saharan Africa new HIV infections among children under 15 years
2008	2.1 million children	430 000	390 000
2011	3.3 million children	330 000	270 000

In addition, UNAIDS (2012:42) noted that between 2003 and 2012, there has been a significant decline of 43% in the number of children newly infected with HIV globally. In 2003, a higher figure of 560 000 children were newly infected in comparison to the 330 000 new HIV infections recorded in 2011. Despite the emerging global decline in new HIV infections among children, the statistics still reveal high numbers of children living with HIV in sub-Saharan Africa.

According to UNAIDS, UNICEF and WHO (2008), there is a reported increase of children contracting HIV through sexual activity. The report, however, noted that in sub-Saharan Africa 16% of young females and 12% of young males were reported to have had sex before age 15. Although these percentages may seem to be relatively low, the growing number of HIV infections through sexual transmission in children is a matter of serious concern. Some children have become infected through sexual abuse in some parts of Africa where men living with HIV believe in the myth that HIV can be cured by having sex with a virgin (BBC 2009).

2.2.2 Zimbabwean perspective

With regard to the general characteristics of the population, Zimbabwe's households consist of an average of 4.1 people per household. The households are comprised mainly of children since 43% of household members are children under 15 years of age (ZIMSTAT & ICF International, 2012:15). It is evident that the high HIV prevalence rates recorded in the past 10 years of the history of the AIDS epidemic in Zimbabwe have had a negative impact on the general population as well as the children. According to the Zimbabwean 2010 – 2011 Demographic Health Survey's key findings, there is a significant number of orphaned and vulnerable children, with an estimated one-fifth of children under the age 18 years having lost one or both parents (ZIMSTAT & ICF International, 2012:2).

Zimbabwe recorded a national HIV prevalence rate of 15% in 2011 (ZIMSTAT & ICF International, 2012:15). Although the Ministry of Health and Child Welfare (MOHCW) had projected a lower figure of 13.1% for the same year in the Ministry of Health and Child Welfare national HIV estimates of 2010, it is evident that Zimbabwe's HIV prevalence is still high (MOHCW 2012:2). Using the

Ministry of Health and Child Welfare estimates, a clear picture of the high numbers of those infected and affected by HIV and AIDS in Zimbabwe is highlighted. Table 2 below summarises the national estimates that had been projected for 2011. Although these statistics have changed, they still closely represent the current state of affairs with regard to the HIV and AIDS epidemics in Zimbabwe. Important to note is the high number of children orphaned by AIDS-related deaths in Zimbabwe.

Table 2: Zimbabwean HIV and AIDS National HIV Estimates 2011

Estimated number of people living with HIV and AIDS	1 159097
Annual number of AIDS-related deaths	63765
Number requiring antiretroviral therapy	597293
Number of new HIV infections	46250
Total number of orphans due to AIDS	946547

Adapted from MOHCW (2012:2).

The high numbers in Table 2 above are indicative of the extent of the need for prevention, treatment, care and support services for both those infected and those affected by HIV and AIDS in Zimbabwe.

In addition to the above it is important to note that Zimbabwe is one of the few countries that have experienced a decrease in its national HIV prevalence rate. In 2005 to 2006, the Zimbabwean Demographic Health survey recorded a national HIV prevalence rate of 18% in comparison to the 15% HIV prevalence rate recorded in 2012 (ZIMSTAT & ICF International, 2012:15). The slight decrease in the HIV prevalence rate has been attributed to many reasons, including the successful implementation of prevention programmes as well as AIDS mortality rates, among others.

Another important issue to note about the HIV and AIDS epidemics is that

Zimbabwe's HIV prevalence rate is generally higher in urban areas (18%) compared to rural areas in 2011 (15%). This is mainly due to the population differences between the two areas. Urban areas are densely populated and are generally high HIV-risk areas in comparison to rural areas (ZIMSTAT & ICF International 2012:15).

With regard to Zimbabwe's statistics on children below 15 years living with HIV and AIDS, the high and rising number of children living with HIV and AIDS remains an area of concern. In 2009, Zimbabwe's population of children living with HIV and AIDS was estimated at 150 000 children (UNICEF 2009). In 2011, of the estimated total population recorded to have been living with HIV in 2011, Zimbabwe recorded an estimated population of 200000 children living with HIV (UNAIDS2011).

2.3 THE NEED FOR PSYCHOSOCIAL SERVICES FOR CLHA

Worldwide, a growing number of children are accessing antiretroviral treatment (ART), which is enabling them to live longer and healthier lives in low and middle-income countries. This presents a new public health and delivery of psychological and social services challenge (Domek 2006:1367-1369). The survival of these children into adolescence and adulthood requires that they have to deal not only with issues pertaining to their health, but also with the psychosocial effects of the HIV and AIDS epidemics. These may include dealing with the loss of one or both parents to AIDS-related illnesses. The latter may further contribute to the loss of material and emotional support which the parents may have provided.

In addition, according to Domek (2006:1367-1369), the positive benefits of ART, such as improved quality of life and life expectancy for children in low and middle-income countries in Africa, has brought with it certain social

consequences, such as the lack of the relevant complementing medical, psychological, educational and social services required to address the specific PSS needs of the surviving and growing population of children living with HIV.

The expansion of ART services should therefore be balanced with efforts to redress the underlying inequalities associated with HIV infection such as mode of transmission in children and disclosure (to be discussed in more detail below). Children who acquired HIV through vertical transmission have unique psychosocial challenges compared to children who acquired HIV through other means. A study on the effectiveness of ART among children living with HIV and AIDS in sub-Saharan Africa revealed that a major obstacle in the provision of care to these children in most resource-poor settings is that many of the existing health care facilities have not yet developed policies and protocols to advocate for and guide the delivery of care to children living with HIV and AIDS (Sutcliffe, Van Dijk, Bolton, Persaud & Moss 2005:477-478). The provision of ART should be accompanied by appropriate medical, psychological, educational and social services. Existing ART services in resource-poor settings offer an opportunity for the delivery of parallel psychosocial support services to be conducted under one roof.

The abovementioned statistics and the emergence of new HIV infections are indicative of the growing need of psychosocial support (PSS) for children living with HIV. Psychosocial support for these children will help them respond adequately to the stress related to living with HIV and they could consequently be less likely to develop serious mental health problems. Psychosocial support will further assist those children living with HIV and AIDS in making informed decisions about improving their quality of life and will prevent further transmission of HIV. For those children who have to adhere to tuberculosis treatment, long-term prophylaxis or antiretroviral therapy, psychological counselling is important in order to ensure that they adhere to their treatment regimes (MOHCW 2009:4).

It is imperative that PSS services be expanded at the same rate as the growing access to HIV treatment services.

An explorative study of psychosocial well-being and psychosocial support programmes conducted in 2003-2004 in Bulawayo, Zimbabwe for adolescents affected by HIV and AIDS underscored the importance of understanding issues associated with the promotion of psychosocial well-being in children. The study revealed a conceptual framework that posits that psychosocial well-being could be influenced by three aspects. These aspects are (a) individual factors and experience (such as age and sex, exposure to stress, households structure), (b) contextual factors (such as community support), and (c) one's access to support programmes and services. Thus the concept of psychosocial well-being must be understood according to a person's socio-cultural context, as well as the age and development level of the child (Gilborn, Apicella, Brakarsh, Dube, Jemmison, Kluckow, Smith & Snider 2006:8-10). This is important because this knowledge may determine the success of psychosocial interventions.

According to the MOHCW (2009), psychosocial support involves the provision of services that promote the emotional, physical, psychological and social well-being of a person. As noted in Chapter 1, psychosocial support is defined as the consistent day-to-day provision of nurturing and caring relationships that promote love, tolerance and acceptance of an individual and their respective family and community. Within the context of HIV and AIDS, PSS for children includes support that directly promotes their well-being (MOHCW 2009:2-3).

Psychosocial support refers to two main components, the psychological and the social aspects of life. The psychological aspect has to do with issues associated with the mind, emotions, feelings and behaviour. The social aspects have to do with the environment, the existing interpersonal relationships in families, communities or peers, among others. When referring to PSS for children this involves the provision of a continuum of care and support services which

influence their psychological and social development (REPSSI 2008 in Anjala et al 2011: 19).

Children living with HIV and AIDS experience multiple challenges such as stigma and discrimination, treatment adherence and emotional issues, among others. Various studies have noted that psychosocial support for CLHA helps to build resilience while at the same time meeting the emotional, mental, social and spiritual needs of the child (Anjala et al 2011:18).

With the significant impact of the HIV and AIDS epidemics in Africa in general, and in Zimbabwe in particular, the provision of psychosocial support has been recognised as being a fundamental aspect of care and support.

As has already been noted above, the findings from two major international reports, the WHO's qualitative study on psychosocial support interventions and global report of 2009 and the USAID overview of the situation of CLHA in sub-Saharan Africa's report of 2011 both underscored the need for more PSS initiatives for CLHA. The reports noted that the increasing effectiveness and availability of Highly Active Antiretroviral Treatment (HAART) globally has resulted in the survival of thousands of children born with HIV into adolescence, with unique needs related to adherence to medication, disclosure of status, dealing with stigma and discrimination, and the lack of support services (among others) (Anjala et al 2011:18; WHO 2009:10-15).

While the above studies and many others continue to advocate the provision of psychosocial support, little research has been done on the factors necessary to increase appropriate psychosocial support, particularly for children living with HIV and AIDS. According to the WHO (2009:34), there is a paucity of research on effective psychosocial intervention programmes for adolescents living with HIV. The research that does exist tends to focus on the provision of psychosocial support to children and youth affected by HIV, and rarely focuses specifically on

young people living with HIV.

According to Anjala et al (2011:19), good PSS for a child is one that takes into consideration the local, social and physical environment of the child as well as the available resources and networks which could contribute to the child's continual care. Psychosocial support for CLHA helps to build resilience towards the effects of the HIV disease, while at the same time meeting the emotional, mental, social and spiritual needs of the child (Anjala et al 2011:19).

2.4 CHALLENGES FACED BY CHILDREN LIVING WITH HIV AND AIDS

Children suffering from chronic illnesses related to HIV and AIDS tend to have unique needs which need to be managed differently, such as anger towards their parents for having infected them through pregnancy (Hansell et al 1998, cited in Citron, Brouillette &Beckett 2005:185; Avert 2009). These children may further have to face issues pertaining to treatment adherence, disclosure, stigma and discrimination, among others, as will be discussed in more detail below.

2.4.1 Treatment adherence

With regard to HIV treatment, adherence is a term used to describe the improvement in medical and HIV viral load that would have been made by an individual living with HIV undergoing antiretroviral therapy (WHO 2006:59). According to DeLaMora et al (2006:75), studies have shown that adherence to HIV medication determines whether HIV viral suppression is successful or not. Successful viral suppression occurs when at least 90% to 95% adherence to medication is achieved. Viral suppression is the main goal of HIV treatment

regimens given through anti-retroviral therapy (ART) programmes across the globe (WHO 2006:59).

Although adherence is a common challenge experienced by people living with HIV of all age groups, children living with HIV tend to experience more difficulty in dealing with adherence to HIV treatment (Hodgson et al 2011:23; DeLaMora et al 2006:75). According to WHO (2006:53), treatment adherence in children living with HIV tends to be a challenge due to an array of problems. Some of the common problems include side effects of the ART medication and the burden associated with the continual intake of numerous pills and medication. This is noted to be one of the stressful and burdensome factors for some children living with HIV. A qualitative study conducted by Hodgson et al (2011:23) in Zambia in 2010 to explore the psychosocial, sexual and reproductive needs of adolescents aged 10 to 19 years, revealed some of the treatment adherence challenges they faced. This research noted that, although the adolescents appreciated the benefits of ART in improving their health, they complained of the stresses they were encountering due to the introduction of ART. Hodgson et al (2011:23) highlight the burden of medication uptake and side effects in the following two quotations from his research participants:

“I cannot hang out with my friends because I have to be home by six to take my medicine.”

“I started taking my ART last week and I am still finding it difficult, especially swallowing the pills: I actually throw up.”

Hodgson et al (2011:23, 31-32) state that the above quotations briefly illustrate generic views on the stresses adolescents and young people were experiencing when taking their medication. These authors further note the need for appropriate additional support for CLHA from family members, peers and community groups to assist young people in dealing with treatment adherence and the PSS challenges associated with living with HIV.

In addition to the above issues, the attitudes, involvement and the commitment level of caregivers are important factors contributing to the success of treatment adherence in children living with HIV. The level of success of ART may be heavily dependent on the caregiver. According to WHO (2006:59), treatment adherence may be a challenge, especially when the caregiver is living with HIV and AIDS and is the mother of the child living with HIV. A mother living with HIV and AIDS might compromise the child's ability to deal with treatment adherence challenges if she is failing to cope with similar issues herself. This inevitably compromises the child's health and may contribute to reduced optimal care and support being given to the child. In such cases, the WHO (2006:59) has strongly suggested the need for mothers living with HIV and AIDS to find additional social support through a secondary caregiver or other support services in the community.

A supporting view on caregivers' ability to influence treatment adherence in children is given in a study conducted in a developed nation. Although Naar-King, Arfken, Frey, Harris, Secord and Ellis (2006:621) argue that the stressful life events faced by children living with HIV may not directly affect children's viral load, the study agrees with the above viewpoint on caregivers living with HIV having the ability to influence treatment adherence in children. This was established in a study conducted in the USA on the psychosocial factors contributing to non-adherence to HIV treatment by children. The factors

contributing to non-adherence were associated with the caregiver's personal problems, such as drug and alcohol use, and dealing with their own HIV-positive status. This study suggests that the manner in which caregivers living with HIV and AIDS manage their respective psychosocial needs may play an important role in facilitating adherence to drugs for children living with HIV (Naar-King et al 2006:621).

The studies referred to above clearly point out that the unmet psychological or social needs of caregivers, who may themselves be living with HIV or AIDS, may contribute to CLHA's ability to access additional support services. Similarly, these unmet needs of caregivers living with HIV and AIDS may hinder or promote CLHA's ability to access appropriate social support services that may help them to deal with the stresses of living with HIV and AIDS.

The above discussion is vital to this study as the caregiver's ability to seek social support services to help their children adhere to treatment may similarly show their ability to reach out for other additional social support required by CLHA, such as PSS.

2.4.2 HIV status disclosure

Secondly, with regard to HIV disclosure, one of the most difficult psychosocial issues for parents and professionals revolves around informing a child of his or her HIV status. According to Gillard and Roark (2012:103), disclosure of one's HIV status is beneficial for many reasons, which include contributing to positive health outcomes for those living with HIV and AIDS. Disclosure of one's HIV status contributes to increased social support as it enables one to access essential support services. Several studies reviewed by Gillard and Roark

(2012:103-104) revealed some of the other benefits of disclosure by children and adolescents living with HIV and AIDS. These included, among others: improved self-esteem, reduced depression and engagement in safer sexual practices.

According to Gillard and Roark (2012:102), the fear of stigmatisation, which is one of the strongest factors influencing people's decisions to disclose or not, is a major barrier in HIV and AIDS disclosure. Other common barriers to disclosure in CLHA, as revealed in various studies, include the following fears, namely: the possibility of rejection, stigmatisation (which is one of the strongest factors for or against disclosure), avoidance by community members (as some people view AIDS as a death sentence or being related to beliefs of poor sexual behaviour) rejection, hostility, violence, ostracism and the loss of social support and relationships.

Gillard and Roark's (2012) study noted that some caregivers preferred to tell their children not to disclose their HIV status to anyone, as they just wanted to protect them from the negative effects of disclosure mentioned above.

The issue of caregivers' unresolved emotional issues has been noted as being one of the major barriers in HIV and AIDS disclosure in CLHA. This was underscored by a study on caregivers' roles in the disclosure of an HIV diagnosis to children living with HIV, conducted by Salter-Goldie, King, Smith, Bitnun, Brophy, Fernandes-Penny, Lefebvre, Louch, Macdougall, Moorer and Read (2007:12-16), who noted some reasons for caregivers being potential barriers to disclosure in children. These included concerns for the child's emotional well-being, fear that the child will not keep "the secret" and maternal fears of blame in cases where the virus was transmitted from the mother to the child. The HIV status of the child may be regarded as a secret when there are perceived or real negative consequences that may arise when the HIV status of the child is revealed.

With regard to disclosing the HIV status of CLHA in sub-Saharan Africa, a study conducted in the Democratic Republic of Congo (DRC) revealed that caregivers tended not to provide children with information about their HIV status and their health. Of a total of 259 caregivers of CLHA aged from 5 to 17, only 8 (3%) of the caregivers had informed a child of their HIV status. The study noted that caregivers indeed played a crucial role in disclosing the children's HIV status and stressed the need for social support from others in the community to assist caregivers to know how and when to disclose to CLHA (Vaz, Maman, Eng, Barbarin, Tshikand & Behets 2011:307). According to Funck-Brentanobet al in Vaz et al (2011:313), children who had received partial or detailed information about their HIV status had better psychosocial and health outcomes compared to those where disclosure has not taken place.

Another qualitative study conducted by Kouyoumdjian, Meyers and Mtshizana (2005:285-287) in South Africa in 2001 to understand the barriers to HIV and AIDS disclosure in CLHA, revealed that children often did ask about their illness but caregivers were reluctant to disclose their HIV status to them. This was due to various reasons already noted above such as fear of stigma, the lack of knowledge about the benefits of disclosure and of the communication skills to facilitate the disclosure process. The study identified that some caregivers felt uncomfortable to discussing such issues with their children. The study further noted that caregivers of younger children ranging from 2 to 13 years had never had a discussion about HIV with their children, who were living with HIV. However children are noted to have often questioned why they were regularly visiting health care providers or why they were taking medication when they were not ill. The study further underscored the point that children who knew their HIV status had better self-esteem than those who did not. In addition, the availability of community support from health care and social service providers was noted to be essential in facilitating the disclosure process among CLHA (Kouyoumdjian et al 2005:285).

As children grow older, an accurate and proper understanding of their HIV status and the stages of progression of the disease is important. Not only does it enable them to access essential support services but it also contributes to the reduction in the further spread of HIV, as children are equipped with information to make appropriate decisions about future romantic relationships and sexual activity, among others (Domek 2006:1367-1369).

From the above discussion it is clear that PSS is required by CLHA to address the various priority issues noted above. Gillard and Roark (2012:102) point out that youth living with HIV and AIDS echoed the same sentiments when they frequently mentioned disclosure as one of the key psychosocial issues that they struggled with. Disclosure assisted CLHA to successfully adapt to living with HIV and AIDS (Gillard & Roark 2012:102). The literature also points out that the availability of individuals in the community whom young people could trust could influence young people's decisions to disclose their HIV status. A study by Lam, Sylvie and Wright 2007 (in Gillard & Roark 2012:102-103) notes that the less social support young people have, the higher the HIV viral load was in their body. They also found that not disclosing their HIV status to more mature and trained people, such as mature family members and service providers, resulted in young people suffering more from mental health problems.

2.4.3 Emotional challenges

Thirdly, as in the case of adults living with HIV and AIDS, children living with HIV and AIDS have to deal with emotional challenges such as dealing with grief over the loss of loved ones, depression, anger towards parents for vertically transmitting the virus, and consequences of discrimination from family, peers and school teachers, among other issues (Avert2009). Children living with HIV and AIDS commonly experience depression. This depression is as a result of the challenges of living with chronic illnesses related to AIDS, which brings with it

some of the negative emotional feelings and social outcomes highlighted above. According to Sinclair & Whyte (1987:9), children with long-term illnesses such as those related to HIV and AIDS, tend to suffer emotional and social stresses associated with the illness.

Generally CLHA experience continual and significant distress associated with living with HIV and AIDS when compared to uninfected children (Hansell et al 1998 cited in Citron, Brouillette &Beckett 2005:185). According to DeLaMora et al (2006:76), many of the CLHA who acquired HIV through vertical transmission were noted to find it more difficult to openly mourn and express their emotions at the loss of their parents or siblings, especially in families where there was stigma and secrecy about the family members' HIV statuses. This challenge resulted in some of the CLHA living with unresolved issues of grief and loss and having a sense of guilt for having survived longer than other family members. Such challenges resulted in these children experiencing enormous stress levels in comparison to grieving CLHA infected in other ways (DeLaMora et al 2006:76).

Children living with HIV and AIDS may also suffer emotional distress caused by the physical signs of the illness such as dermatological issues, for example skin rashes and weight loss problems. These visible body changes may result in depression for some children, who may then have to deal with emotional distress and challenges such as stigmatisation, forced disclosure or general worry about medical prognosis (that is, they have concerns about the medical outcomes of their illness) (Citron et al. 2005:185).

Depression appears to be another huge emotional problem faced by children living with HIV and AIDS which needs to be dealt with by providing appropriate support. The depth of the problem is illustrated in the quotation presented below which details a young girl's experience with depression. Her story highlights the real trauma that a young child goes through, particularly when having to deal with watching the rapid death of their parents due to AIDS-related illnesses and

sicknesses caused by antiretroviral medication.

“Tamika, a 16year old girl with vertically transmitted HIV, presents to the primary care clinic complaining of hopelessness. She expresses suicidal ideation with a plan to overdose.

Prior to this, Tamika has been generally healthy. Despite a tumultuous social history, she continues to attend high school and hold a parttime job at the mall. Tamika, who lived with her mother until she died, has no contact with her father and now lives with her aunt. Having witnessed her mother’s rapid death from AIDS, Tamika has become depressed. She was also recently hospitalized for the first time with medication-related pancreatitis. While in hospital, she agrees to start an antidepressant but refuses to resume antiretroviral medications which made her feel sicker. After being discharged, Tamika is unable to return to school. She cries frequently and sleeps most of the day. She complains of poor concentration and memory lapses, and fears she is developing ‘AIDS dementia’.”(Citron et al 2005:185).

Tamika’s case described above reveals the experiences and emotional state of a young person living with HIV. According to various studies reviewed by Steele, Nelson and Cole (2007:61), children living with HIV tend to suffer high rates of behavioural and emotional problems. The studies also noted that, in addition to depression, these children suffered high rates of anxiety and lower involvement in social activities when compared to uninfected children. Such experiences affect the quality of life of these children, and hence PSS is required to assist them to cope with and adjust to the various life experiences they encountered. According to Citron et al (2005:185), the failure to address the emotional needs of young people living with HIV and AIDS may cause them to end up engaging in risky sexual behaviours and or substance abuse, and they may also struggle with receiving medical care.

2.4.4 Psychiatric challenges

Paediatric AIDS-related illness continues to be an important area of research as the illness has gradually shifted from being an acute terminal childhood disease to a chronic long-term disease. A study on psychiatric challenges in paediatric HIV and AIDS cases revealed the emergence of neurocognitive disorders commonly seen in children living with HIV. These children may develop cognitive disorders such as HIV-associated cognitive motor complex (HACM). HIV-associated cognitive motor complex occurs when cognitive, motor and behavioural changes in children manifest as impaired brain growth, continual motor dysfunction and the plateauing of developmental milestones. Some of these children may have challenges coping at school due to difficulties with concentrating or poor eye vision (Citron et al 2005:182). Generally speaking, it appears that HIV affects the cognitive development of children, and progressive cognitive impairments are normally indicative of the worsening of HIV-related diseases, hence the need for early and regular comprehensive medical, psychiatric and social evaluations (Citron et al 2005:182-184).

2.5 DIFFERENCES IN MANAGING HIV IN CHILDREN AND ADULTS

Living with HIV and AIDS impacts differently on adults and children. Rodgers (2006:5) identified three differences on the basis of their study of the HIV epidemic in the USA. These differences, which also apply in the African context, included the mode of HIV transmission, clinical progression of the HIV infection in an individual and the special service needs of young people. In addition, disclosure of HIV status was an area of concern to the children living with HIV and AIDS and to others in the community in some African countries. An overview of these differences is highlighted in detail below.

The mode of HIV infection in the majority of children and young people is commonly through mother-to-child transmission. This in itself poses a challenge for them as they inevitably have to deal and cope with the psychosocial challenges associated with living with HIV and AIDS from a much earlier stage in their lives (Steele et al 2007:58; Rodgers 2006:5). Studies conducted in the USA revealed that those babies living with HIV who survived into adulthood (predominantly those infected in the 1980s and early 1990s) suffered from various physical and development challenges, such as experiencing delays in the commencement of puberty. Their physical, social and sexual development lagged far behind compared to their peers. The studies further noted that, having been exposed to HIV at a very early stage of life, most of these children suffered high levels of psychological distress, including depression, anxiety due to the multiple loss of family members, isolation from peers in an attempt to keep “family secrets”, repeated hospitalisation as well as the stigmatisation associated with living with HIV and AIDS. Although these experiences can also be encountered in an adult living with HIV, children living with HIV tend to experience more difficulties in managing the negative impacts associated with the HIV and AIDS (Rodgers 2006:5).

As far as the clinical progression of HIV infection in young people is concerned, HIV affects young people’s physical bodies more than it does their adult counterparts living with HIV. This is because the clinical progression of the HIV virus begins earlier in young people and also presents another challenge of the virus attacking and damaging body functions of the endocrine system, as well as altering the functioning of the essential hormonal systems required for growth and pubertal development processes in young people (Rodgers 2006:5). Results from large cohort studies conducted in the USA revealed that the age at which an individual becomes infected with HIV is important in determining the duration for an AIDS diagnosis. In other words, the younger the age of HIV infection, the

longer the time period the individual will experience living with and managing the chronic illness.

Common to the African context is the issue of the difficulties faced by caregivers regarding disclosure to the CLHA the children's HIV status. This is an issue which adults living with HIV and AIDS do not usually face as they are usually told directly about their HIV status. Studies conducted in various HIV high prevalence countries, such as Uganda, South Africa and Zimbabwe, stressed the issue of disclosure in children as being an area of difficulty for many caregivers (Anjala et al. 2011:23; Kouyoumdjian et al 2005:285). According to Kouyoumdjian et al (2005:285) studies in the developed world have shown that early HIV status disclosure to CLHA will contribute to better self-esteem and lower depression rates in children, as they would most likely have "opened up" emotionally at an earlier age and accessed appropriate social support.

However, various studies have indicated that disclosing a child's HIV status is still a major challenge in some African studies. As already highlighted above, disclosure to CLHA is affected by various factors, such as the caregivers' ability to cope with their own illness. According to Kouyoumdjian et al (2005:286), results from a qualitative study conducted in 2001 in South Africa that aimed to understand the barriers to HIV disclosure in children, revealed that children were never told about their HIV status by health authorities after HIV testing had been conducted. Only the caregivers were given this information. Disclosure of the HIV status is the opposite in the case of adults who are normally told of their HIV status results immediately after an HIV test has been done.

In another study conducted in rural Chimanimani (located in the eastern part of Zimbabwe) to investigate the challenges in HIV disclosure in CLHA, similar

results to those of the above-mentioned South African study were revealed. According to De Baets, Sifovo, Parsons and Pazvakavambwa (2008), disclosure to infected children was a major challenge for adults. The majority of interviewed respondents (56%) preferred that disclosure of status to CLHA be actually done by community workers such as healthcare providers rather than by themselves. In addition, the results of the study indicated that disclosure to children had to be age-specific. The study participants preferred that disclosure of HIV status should occur from ages 10 to 14 years (De Baets et al 2008). In addition, the capacity of children living with HIV and AIDS to further disclose their status to others around them may be determined by whether or not they have been given consent by the adults who take care of them. For instance, children infected with HIV through vertical transmission may require consent from caregivers first, before they can disclose their HIV status to others in the community. This unique situation, which adults living with HIV and AIDS usually do not have to deal with, may put CLHA in the difficult position where they are not able to seek support services on their own. According to Calabrese, Martin, Wolters, Toledo-Tamula, Brennan and Wood (2012:1092), children and adolescents who became infected through vertical transmission may not have full autonomy over the decision to disclose, as they may face pressure from their mothers and caregivers to keep their HIV and AIDS status a secret. This is because this could inevitably expose the HIV status of the child's mother.

The above discussion highlights some of the important factors and social dynamics that should be considered when dealing specifically with young people living with HIV and AIDS.

Young people infected with HIV during infancy have to deal with a different set of challenges compared to those who get infected later on in their lives. For example, they may need to assume responsibility for their own healthcare at a young age, an issue which can be complicated when the family fails to disclose the HIV status of the child to the child. Children living with HIV at a younger age

require additional medical assistance and services to enable them to handle the transition from paediatric healthcare to youth-friendly services where their emerging needs can be better addressed and they are enabled to acquire other skills (Rodgers 2006:13).

In summary, young people living with HIV – whether, infected at birth or later on in their lives – are affected differently compared to adults, and therefore require appropriate comprehensive care and support services that would address and respond to the many challenges they endure. Neglecting to provide care to these young people is detrimental to communities' progress in providing comprehensive care and support services to vulnerable groups.

2.6 THE PROVISION OF PSYCHOSOCIAL SUPPORT

The World Health Organization (WHO:2009) global review titled “*A qualitative review of psychosocial support interventions for young people living with HIV*” explored interventions such as the provision of mental health services, referrals and support groups (among others) implemented by organisations providing psychosocial support for young people living with HIV in 2008. The review also revealed that young people in the 10 to 24 year age group were the most vulnerable and yet the most overlooked population category when it came to the provision of psychosocial support globally.

The consultation report by Anjala et al (2012) on the provision of PSS to CLHA in Africa revealed the key priority areas to be considered in PSS provision to CLHA. Particularly in the case of CLHA in sub-Saharan Africa aged 0 to 12 years, the report noted that good PSS had to take into consideration the following priority issues for CLHA. These included PSS initiatives that addressed the following:

- HIV disclosure to the child
- Coping with emotional issues such as grief and bereavement
- Treatment adherence
- Child-centred activities such as forums for children to interact, “kid’s camps” and support groups, among others (Anjala et al 2011:23-25).

A UNAIDS (2001) study on psychosocial support for children affected by HIV and AIDS in Zimbabwe and the United Republic of Tanzania revealed some of the factors that need to be considered in the provision of psychosocial support for children affected by the epidemic in these two countries. These included the recognition by public and private institutions, civil society and communities that psychosocial support is an important aspect of children’s rights, as contained in the United Nation’s Convention on the Rights of the Child of 1990 (UNAIDS 2001:6). The Convention underscores the need to involve children in the development of initiatives by allowing them to express their feelings and experiences about how they have been affected by HIV and AIDS. Children have a right to be heard concerning their needs for education, affection, cultural identity and other care and support services such as health care, counselling and recreational facilities. The study emphasised the need for improved networking of stakeholders in the provision of comprehensive and complementary psychosocial support because of this lack (UNAIDS 2001:6).

A study conducted by Alidri, Acidri, Mawejje and Ireland (2002) revealed that, as the number of children living with HIV infections increases, the need to provide appropriate psychosocial support for both infected and affected children is inevitably growing. The study also emphasised the need to provide appropriate psychosocial support for children by ensuring children’s involvement in the provision of such support. Its strength was that it highlighted the need for psychosocial support initiatives to meaningfully engage children in developing and implementing such initiatives. It is important to engage children because firstly, children have a right to be heard in any proceedings that concern them, as

stated in the United Nations Convention on the Rights of the Child, Article 12. Secondly, the meaningful participation of children has been noted to be an effective way of identifying their respective needs (UNAIDS 2006:63).

2.6.1 Provision of PSS through mental health programmes

In view of the above challenges, attempts to address the emerging PSS needs of CLHA include the implementation of mental health programmes that would provide psychological community-based support, by empowering influential community members such as teachers, religious leaders and health staff with skills to recognise and respond to the behavioural difficulties these children experience. Additionally, there can be the integration of mental health care into primary health care systems by educating primary health care workers to recognise childhood psychological problems. This means that in the first entry level of obtaining healthcare in communities from health facilities such as clinics, the staff will be equipped to understand this aspect of psychosocial support Domek (2006:1367-1369).

2.6.2 Provision of PSS through public schools

Public schools may also need to be prepared to address the psychosocial needs of children living with HIV and AIDS, as many children receiving ART are attending school, and this raises concerns about the preparedness of school officials to handle issues related to appropriate disclosure, absenteeism due to illness and doctor's appointments (Domek 2006:1367-1369). Findings from a survey to establish the proportion of children in Zimbabwe accessing HIV care and support services conducted in 2008 noted that one of the reasons for poor drug adherence among young people enrolled in boarding schools was the absence of someone in the school system to supervise the taking of HIV-related medication (Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurungi, Gibb, Munyati, Williams & Corbett 2010:430). Although this is an issue that may

be compounded by the caregivers' lack of disclosure of the child's HIV status to the school authorities, the education sector in high HIV prevalence countries needs to be aware of the emerging PSS needs of the growing population of CLHA. According to Petersen, Bhana, Myeza, Alicea, John, Holst, McKay and Mellins (2010), when caregivers disclosed the HIV status of their child to school authorities, it resulted in the children receiving greater academic support. This in itself protected the children from stigmatisation. In addition, the stigma perpetrators were dealt with by the school authorities.

2.6.3 Provision of PSS through palliative services for children

Psychosocial support for children with chronic illnesses related to AIDS has been offered in some African countries through palliative care services and hospices. The World Health Organization's definition of "palliative care" for children is that palliative care is the active total care of a child's body, mind and spirit. It begins when the illness is diagnosed and continues, irrespective of whether the child is receiving treatment for the respective disease or not (WHO [sa]).

Palliative care aims to improve the quality of life of patients facing life-threatening illnesses through various interventions, which include psychosocial support among others (Liben, Papadatou & Wolfe 2008:852). South Africa has seen the emergence of hospices caring for ill children who are dying of AIDS-related diseases. However, with the increased access to ART, many hospices have become children's homes and have brought up fairly healthy children who need to be integrated back into the community. This therefore underscores the role of the community in the provision of psychosocial care and support (Domek 2006:1367-1369).

The provision of psychosocial services to these children enables them to have control of their emotions and gives them hope for the future. It seems that the

concept of palliative care is aimed at promoting both psychosocial support and the psychosocial well-being of chronic patients.

In Zimbabwe a training manual for communities on palliative care for children living with HIV was developed in 2006. The purpose of the manual was to equip community-based care providers with the skills and knowledge required for the provision of quality home-based care to CLHA. The manual provides information on how to talk with children about dying and dealing with grief. In the manual's chapter on community support, information is given on how community mobilisation for palliative care in children should be conducted. The manual also gives guidelines on how community volunteers are to be selected. In addition, the Palliative Care for Children manual emphasises the need for community-based care providers to adopt a multi-sector approach through networking and referral. The development of this manual was a positive step in the provision of psychosocial support for these children (Hospaz, MOHCW & UNICEF 2006:114-119). The manual continues to this very day to provide national guidance to communities on the provision of palliative care to CLHA in Zimbabwe.

When one considers the provision of care for children with other chronic illnesses such as cancer, the findings of an explorative study that was conducted in the United Kingdom are important. This study investigated the views of parents and patients with regard to psychosocial service provision for children and young people living with cancer. The study revealed that while psychosocial support was satisfactory, counselling, psychosocial, emotional and practical support for family members and not just the chronically ill patients, was lacking (Clarke, Mitchell & Sloper 2005:1).

In view of the above, it seems that in the developed world psychosocial support services for children with chronic illnesses appear to be more advanced than those in developing countries, with treatment centres staffed with medical teams and social workers on site. However, in comparison, in a developing country like

Zimbabwe, children with chronic illnesses related to AIDS or cancer appear not to have access to relevant and adequate psychosocial support, as will be illustrated in more detail in subsection 2.7.2.

2.7 PROVIDERS OF PSYCHOSOCIAL SUPPORT

A national situational analysis conducted in 2006 in Zimbabwe on comprehensive care for children living with HIV and AIDS revealed that psychosocial support was being provided only by a minority of service providers. In this regard, existing services were frequently rated as poor or non-existent. A common understanding of psychosocial support concepts and the needs of these children by organisations, health workers and communities were identified as key factors in ensuring the provision of such services (MOHCW 2009).

According to Hodgson et al (2011:46-47), in a resource-poor setting formal health care and social support services are distributed in a fragmented manner or are inaccessible to children and young people. Despite these challenges, Hodgson et al (2011) recommends increased advocacy work to promote the benefits of community-based social support as well as deliberate targeting of these young people to access services. In addition, CBOs are encouraged to share information on PSS provision and to facilitate the strengthening of linkages between the health care and social support providers in communities (Hodgson et al 2011:46-47).

According to Bronfenbrenne (cited in Richter et al 2006:27), providers of care and support can be classified into four major categories, namely: policy developers such as government departments, community support, family networks, and caregivers.

2.7.1 Family networks and caregivers

It has been further noted by Richter et al (2006) that the effective enhancement of the well-being of children within the context of HIV and AIDS is improved by providing quality care to the affected children by those closest to them.

With increasing numbers in children living with HIV and AIDS and new HIV infections among children globally, caregivers, families and communities who are in close proximity to these children are best placed to provide long-term PSS. According to a global online support network for vulnerable children, called the OVC Support Net, PSS addresses the various aspects of human development (emotional, social, mental and spiritual needs), elements which are normally found in the family home or from external resources in the community.

Families are the primary duty-bearers of children's rights and the providers of security, and thus the best interests of the child are served when they are the centre of concern of a caring family that exists within a supportive community (UNICEF 2006:10).

On the other hand, children living in extended family networks may actually experience more psychosocial problems. This was concluded in a longitudinal study which examined differences in psychosocial problems between children living with HIV and on ART and children not living with HIV in South Africa. The study revealed that children who lived with extended family members were experiencing more psychosocial problems when compared to children who were living with their parents or were in orphanages. The study pointed to the resulting overburdening of the extended family which has had to bear the brunt of the AIDS epidemic. Extended family members, who may already be dealing with health and financial challenges among others, have the responsibility to look after children of deceased relatives, often leading to more stress in the household, such as more mouths to feed or dealing with a grieving or depressed

child (Van Gelder & Kraakman [sa]:14). Generally speaking, some caregivers may not be equipped with the necessary knowledge and skills to effectively deal with the negative behaviours or attitudes presented by the vulnerable child. This in itself may be stressful and in turn affects the living conditions of the child living with HIV.

2.7.2 Community-based responses to CLHA

According to Richter et al (2006:11-23), there is a need for an integrated response from care and support providers, which has been noted to be best provided by locallybased organisations.

In a four-country study on channelling resources to communities responding to OVCs in Southern Africa, Foster (2005) highlights the crucial role of community-based responses to the challenges faced by children affected by the AIDS epidemic. Communities play a crucial role in providing support to those in need. This is because despite the lack of availability of essential services in many areas in sub-Saharan Africa, communities have a known history of developing appropriate safety nets to assist those who are faced with difficulties such as illness or death (Luzze 2002, cited in Foster 2005).

According to Foster (2005:5), some of the reasons to promote the role of community responses to address the impact of the HIV and AIDS epidemics on children in Africa include the recognition of community-based organisations and structures' known role and ability to offer the appropriate support long-term to vulnerable children. In addition, the study noted their ability to promote community child-focused support that offers an appropriate blend of material and psychosocial support. Finally, the financial, human and material resources required to undertake community-based initiatives can be mobilised more rapidly than those of larger organisations. Community-based initiatives also have

another advantage of normally incurring low administrative costs in the running of their activities, as the community members themselves may provide the human and material resources required to undertake activities. According to Foster (2005:6), community and faith-based organisations have comparative advantages over international, non-governmental organisations in that they are able to deliver services to a number of beneficiaries at lower costs.

The Framework for the Protection, Care and Support for Orphans and Vulnerable Children Living in a World with HIV and AIDS endorsed by UNICEF in 2004, identified five key strategies to guide support to children at community level (Foster 2005:6),. The five strategies are summarised as follows:

- Strengthening the capacity of families to protect and care for OVCs by prolonging the lives of their parents and by providing economic, psychosocial and other support.
- Mobilisation of and support for community-based responses.
- Ensuring access to essential services such as education, health care and other services for OVCs.
- Ensuring that government protects the most vulnerable children through improved policy, legislation and through channelling resources to families and communities.
- Raising awareness of OVCs' plight through advocacy and social mobilisation so as to create a supportive environment for children and families affected by HIV and AIDS.

As noted above, the first strategy emphasises the need for strengthening the capacity of families to protect and care for their children. This was noted to be done through the provision of PSS among other support to vulnerable children, as one of the ways families are capacitated to protect and care for these children.

The second strategy underscored the need to mobilise and support community-based responses. This is because communities in Africa were already responding with community initiatives that were appropriate, child-focused and flexible. According to the Catholic Relief Services Zimbabwe Report highlighted in Foster's study (2005:6), communities can be mobilised quickly when there is a need for them to respond to an emerging challenge. In addition, the study noted that the administrative cost for support activities run by CBOs are generally low, because most community initiatives are funded by the community members themselves. This ability to deliver services to beneficiaries in a cost effective manner was noted by Foster (2005) to be an advantage CBOs had over International NGOs.

Foster's study (2005) underscores the important role of community-based responses for CHLA, noting that while progress has indeed been made in responding to their needs, the scale of these responses remains inadequate when compared to the growing numbers of children affected by the HIV and AIDS epidemics.

2.7.2.1 Examples of existing PSS initiatives for CLHA in Africa

An example of a community-based initiative offering psychosocial support to children living with and affected by HIV and AIDS is the 'Champions for Life' programme pioneered by a faith-based organisation in Zimbabwe. The programme, as described in the quotation below, works with local communities in the mobilisation of resources for their respective activities. Its major strength is the strong linkages it has with clinics and hospitals offering ART which assist in the identification and referral of children in need of psychosocial support (Reid 2010).

“A faith-based organisation, Celebration Ministries International, developed a programme mainly for young people living with HIV and AIDS in Zimbabwe. The programme which has been progressing in its development has been implemented for the past 5 years and is coordinated by the church which works in partnership with local church leaders, health care staff at local health institutions and the young people living with HIV and AIDS in their respective communities. The main goal of this initiative which has reached over 2000 children in urban and rural areas is to offer spiritually-based psychosocial support activities which cover different topics on positive living, dealing with depression, adherence to drugs amongst others. The Champions for Life programme targets children infected at birth and those on ART through working closely with health staff at opportunistic infection clinics at local health centres. The programme has been introduced in over 5 towns including Kadoma. The Kadoma programme is implemented by the church on a monthly basis since 2010 with an average of 70 children per session” (Reid 2010:1).

The technical reviews by Anjala et al (2011) of PSS providers in African countries also identified a few organisations in sub-Saharan Africa delivering programmes. One of these programmes, the Baylor International Pediatric AIDS Initiative is offered from Kampala, Uganda. Located in a hospital in Kampala, the programme delivers care and treatment to 5 000 children living with HIV and AIDS and their family members. The main activities involve provision of medical and community care activities which include psychosocial support services. The PSS activities include counselling activities by trained therapists, support groups for children and adolescents, recreational and play therapy activities as well as camps for children. One of the key elements that contribute to the successful delivery of these services was noted to include the availability of community volunteers who facilitated the on-going care and support for children. A weakness of the programme was noted to be the weak external referral network

system to non-clinical organisations. This was -regarded as important if children were to access comprehensive services that could enable them to meet other important needs, such as livelihood support (Anjala et al 2011:92-93). Although the Baylor International Pediatric AIDS Initiative is a huge organisation with thousands of children under the programme, the findings from the review by Anjala et al (2011) highlighted the existence of community volunteers as key in the success of the delivery of care and support. Community volunteers were the ones who ensured the continual delivery of PSS to CLHA.

Another organisation reviewed by Anjala et al (2011:41, 71-73) was the Butterfly House, Drakenstein Palliative Hospice located in an informal settlement in the Western Cape in South Africa. The organisation is run as a community resource centre that has adopted a community-based approach with a vision to provide quality and holistic care for the community. The organisation provides services to children living with HIV and children not living with HIV. The organisation has donor-funded projects which include the delivery of palliative nursing and palliative psychosocial care for both adults and children. With regard to children living with HIV, the hospice provides care services to 54 children. The programme also runs a school programme for children up to 9 years of age. Some of the major strengths of the care and support programme were identified to include the adoption of:

- child-friendly approaches such as drama and games
- a team of dedicated care workers who provide a multidisciplinary follow-up and management strategy of children
- a holistic approach that meets the medical, emotional, social needs and basic needs such as education and food.

One of the major weaknesses of this programme was identified to be the weak referral links the organisation has with other care service providers in the community. From the organisations cited above, it is evident that although

referral networks existed, the linkages between organisations and other care providers in the community were weak. Referral networks were noted to be crucial in helping children access the required care service from elsewhere, when the organisation they had visited did not have the capacity or resources to do so (Anjala et al 2011:28).

The conceptual framework which guided this study is set out in the section that follows.

2.8 CONCEPTUAL FRAMEWORK

2.8.1 Social support theory

The social support theory forms the conceptual framework for this study. A detailed discussion of this theory and its link to HIV and AIDS is provided in the sub-sections below.

2.8.1.1 Social support

Social support is a term that refers to the positive interrelations in an individual's social environment (family, friends, social workers among others) in which he or she lives (Maguire 1991:2).

According to Vaux (1988:5), the social support theory is based on much of the groundwork done by three scholars during the 1970s, namely John Cassel, Gerald Caplan and Sidney Cobb. These scholars laid the foundation with regard to the concept of social support. They argued that psychosocial processes are of considerable importance in disease etiology and that social support plays a key role in reducing stress disorders. Although Cassel did not clearly define social support, he viewed social support as being provided by primary groups such as

those most important to an individual (for example, parents or extended families, friendship groups) and who serve an important protective function of buffering or cushioning the individual from somatic or psychological consequences of stressful experiences. Cassel (as cited in Vaux 1988:5) advocated for the mobilisation of social support as a feasible intervention rather than attempting to reduce exposure to environmental stress. Generally, the existence of social and psychological support is noted to have a direct correlation with positive health outcomes (Hogan et al 2000).

Cassel placed considerable importance on disease etiology and noted that psychosocial support, in particular, plays a key role in reducing stress-related disorders. This viewpoint has persisted for decades and forms the underlying backbone of much of the work done on social support (Vaux 1988:5).

According to Vaux's (1988:5) historical narration on the conceptualisation of the social support theory, Gerald Caplan further incorporated Cassel's views in his work in psychiatry and community mental health, and constantly referred to the term "support system" in defining his viewpoints. Although he did not expand on the characteristics of this system or how it was developed, he emphasised the importance of reciprocity and durability of relationships as he believed that others had a role to play in influencing the course and outcome of a crisis in an individual's life. That is, an individual's existing social relationships were a key factor in influencing how he or she coped in difficult situations. Caplan further elaborated on three kinds of activities offered in a support system. These included: helping one mobilise psychosocial resources to manage emotional problems; sharing demanding tasks; and providing material and financial skills and guidance to help an individual deal with stressful situations. Vaux (1998:5) explained that Caplan's work underscored the importance of support systems in protecting the well-being of individuals when they have to face the daily demands of life and situational crises. However, the major emphasis of Cobb's work (as cited in Vaux 1988:7) was that social supporters, that is those providing social

support, were key stress buffers. He concluded that adequate social support could protect people in a crisis from a variety of physical and psychological disorders, presumably through the facilitation of coping and adaptation mechanisms.

In addition to the above, Maguire (1991) also noted that a major advantage of social support is its ability to protect people from the effects of stress. Without social support, people become isolated and could easily succumb to the effects of a stressful situation. The three main forms of assistance offered through social support, as identified by Caplain in Maguire (1991), include:

- The help offered to empower an individual to use his or her own psychological resources to deal with stressful situations and overcome them.
- The sharing of tasks by individuals with the aim of showing care and concern and reducing the levels of stress to the overburdened individual.
- Giving the individual extra resources such as money or skills to help them in handling the situation better.

In summary, social support systems assist in the reduction of negative stressful situations and improve the general health of an individual. This is because social support influences an individual to cope better in stressful situations. Social support also serves as a buffer against the effects of stress and thus protects individuals from psychological reactions such as depression and self-blame, among others (House 1981, in Maguire 1991).

2.8.1.2 Social support and the buffering hypothesis

The concept of social support has been used to refer to processes that can buffer someone against a stressful situation through the interpersonal relationships they have. This potential protective effect of social support is what is referred to as the buffering hypothesis. The buffering hypothesis is the basis of the social support theory and points out that a person with little or no support will experience negative effects on their health and well-being, compared to a person with some form of support system. The hypothesis underscores the role of social support in reducing or eliminating the effects of a stressful situation (Baum et al 1984:253).

In further elaborating on the buffering hypothesis, Baum et al (1984) identified two buffering mechanisms through which social support could occur. These include psychological and non-psychological support, as distinguished by Caplan (1979), Cobb (1976) and Pinneau (1975). Cobb (1976, as cited in Baum et al 1984:253), noted that non-psychological support referred to providing tangible support such as material aid, while psychological support refers to provision of information. Psychological support was further noted to include appraisal support, which contributes to cognitive support as well as emotional support, and assists in meeting one's emotional needs.

Hogan et al (2002), in their study on social support interventions, conceptualised social support by devising a three-tier classification scheme or categorisation. Social support can firstly be categorised in terms of whether it is provided in an individual or group setting, for instance through a support group. Secondly, social support can be categorised in terms of whether the support provided was direct, such as the provision of emotional or informational support, or indirect. Indirect social support produces enduring changes, for example, support that equips an individual with skills to cope with long-term situations. This consequently

contributes to improving the individual's health and well-being. Thirdly, support was categorised in terms of the source or provider of the social support, that is, whether it is provided by professional medical staff or family members, friends or others in similar circumstances (Hogan et al 2002:384). In summary, the abovementioned authors argue that the buffering process includes the provision of tangible support, appraisal support and emotional support to assist one in dealing with the stressful situation (Baum et al 1984:255-261).

According to Baum et al (1984), effective social support is provided when existing interpersonal relationships are able to provide the appropriate form of support that will operate as an effective buffer to the existing stressful situation. Social support systems play a crucial role in enabling one to cope and respond to a particular situation.

Table 3 below presents a model developed by Baum et al (1984) to explain how a person's support can allow or prevent a negative reaction to a stressful event. The model is based on findings of a research analysis that identified the mechanisms involved in the buffering process. The mechanisms included a principal idea of the belief that when one has resources they must correlate directly or correspond with coping requirements of the prevailing situation in order to be regarded as effective. According to Baum et al (1984), the model states that a situation may require multiple support sources in order to deal with stresses effectively. They cited an example of the death of a spouse who provided a large portion of the family income; this family would then require tangible support (financial aid), appraisal support (psychological support), and emotional support (interpersonal relationships with other family members). Baum et al (1984) highlighted the complexity of effectively meeting one's social support needs in complex situations. The model highlights the importance of understanding the nature of the stressor as the latter determines the nature of the social support required to buffer the negative effects of a given stressful situation. Therefore, in order to fully understand the buffering process, one needs

to comprehend the nature of the stressor as well as the possible potential support that can be accessed.

Table 3: Stressors and Support model

Support Mechanism	Applicable Stressors	Applicable Source of Support
Tangible	Situations where the provision of tangible aid will help one cope with stressful situation. Some examples include illness, disabilities that often accompany aging and loss of income.	Any source viewed as appropriate by the recipient.
Appraisal	Especially those stressors involving primarily psychological as opposed to universal sources of stress. Socially acceptable stressors not involving feelings of guilt or shame	Others in similar situations are presumed to be optimal, especially those who have or are experiencing the same or similar situation.
Emotional		Others in similar situations are presumed to be optimal, especially those providing positive comparison
Self-esteem	Stressors that can result in a self-attribution of failure or inadequacy	
Belonging	Separation from those with whom one has interpersonal relationships, especially close relations e.g. spouse and children	Those providing the opportunity for close, relatively intimate relationships are presumed to be most effective

Adapted from Baum et al (1984:262)

2.8.1.3 Social support and HIV and AIDS

The social support theory clearly underlines the principles of social support as a buffer to adverse effects of life's challenges. With the advent of the HIV and AIDS epidemic, provision of adequate psychosocial support by social groups such as community-based organisations, is key to reducing the psychological effects of these epidemics on people living with HIV and AIDS.

The HIV and AIDS epidemics among young people is associated with social, psychological and behavioral stressors that affect coping patterns, psychosocial factors and the health status associated with an individual (Conner et al 2006:182). Young people have noted that social support is crucial in helping them go through life as it helps them to cope and experience positive outcomes in the process of living with HIV and AIDS. According to Conner et al (2006:182), the absence of reliable positive psychosocial support has a direct correlation with young people experiencing deleterious social and emotional effects in their lives. Studies have indicated that the presence of social support can be linked with good long-term health outcomes (Hogan et al 2002: 381).

2.9 CONCLUSION

In this chapter, a brief overview was given of the extent of the HIV and AIDS epidemics, globally and in sub-Saharan Africa. This was followed by various discussions on the plight of CLHA and their need for PSS services. Using various studies, the chapter illustrated the importance of PSS for CLHA, and how PSS services to CLHA were delivered by the different categories of PSS service providers. The chapter also discussed the current HIV and AIDS funding challenges that Zimbabwe was facing and the important role of community-based

responses to the country's HIV and AIDS epidemics. The chapter also discussed the social support theory, which forms the conceptual framework that guided this study.

The following chapter will describe the methodological approach used in this study. Chapter 3 begins with an overview of the qualitative research design that was used in this study. The chapter then gives an overview of the study's data sources. This is followed by a detailed description of the multiple data collection techniques that were used in this study. The chapter then proceeds to explain the study's sampling procedures and the data analysis and interpretation processes are set out, followed by a discussion of the ethical considerations that were taken into account when conducting the fieldwork for this study. This chapter ends with an overview of the research setting where the fieldwork was conducted.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter details the methodological approach and tools that were used to obtain the in-depth information that attempted to provide answers to the research questions, whose main aim was to explore and describe the critical factors that influence the delivery of PSS to children living with HIV and AIDS by the Simbarashe National Network for People Living with HIV and AIDS in a resource-constrained area in the Kadoma district of Zimbabwe.

This chapter begins with a discussion on the qualitative research design used in this study and provides the rationale for its use. This is followed by a detailed discussion on the study's data sources as well as the multiple data collection tools adopted in the study. The chapter further elaborates on the study's use of the purposive sampling technique in the selection of the Simbarashe National Network for People Living with HIV and AIDS. It then gives a brief overview of the study's data analysis and interpretation processes, and then further describes the research setting where the study was conducted. This is followed by discussions on issues regarding the trustworthiness of the research data as well as the ethical considerations of the study. The chapter concludes with a brief discussion on how the pilot study of the research was conducted.

3.2 RESEARCH DESIGN

A qualitative research design was used in this study because of the nature of this study's research objectives. Qualitative research is a type of social scientific research that seeks to understand a research problem from the perspective of the identified local population. It collects evidence from individuals about their opinions and behaviours as well as their social contexts (Family Health

International 2005:1). Qualitative researchers study selected issues in depth and in detail with the aim of providing information-rich cases of a smaller number of people, resulting in an increased understanding of a particular issue (Patton 1990:14). In other words, qualitative research studies people in terms of their own definitions of the world around them. An advantage of a qualitative research design over a quantitative approach is its degree of flexibility which allows for greater spontaneity between the researcher and study participants. It allows the researcher to adjust the study design according to what is learned during the data collection process (Family Health International 2005:3).

The reason for the selection of a qualitative research design for this study was because the researcher wanted to gather detailed descriptive information that could provide a better understanding of the critical factors that influenced the delivery of PSS services to CLHA by community-based organisations in a resource-poor setting. The researcher decided to explore and describe the activities of the Simbarashe National Network for People Living with HIV and AIDS because of this CBO's active involvement in the implementation of community-based PSS activities for CLHA in the Mhondoro-Ngezi sub district of Kadoma. Various data collection methods, such as observation, content analysis and interviewing, were used in order to provide rich in-depth information and evidence on this topic (Tesch 1990:69; Babbie 2012:309-310). A qualitative research methodology was useful to capture the experiences of selected individuals and this particular community-based organisation on the delivery of PSS to CLHA in the Kadoma District.

3.2.1 Rationale for qualitative research design

There are a number of approaches that provide a foundation to qualitative research such as ethnography, phenomenology, ethnomethodology, heuristic inquiry, symbolic interactionism, and grounded theory (Patton 1990:66-75; Tesch 1990; Babbie 2012:304-307). This study investigated the PSS needs of CLHA

and issues surrounding its delivery at community level by a PSS service provider. Some of the issues discussed above in Chapter 2 included the emotional impact of the AIDS pandemic on children and the recognition of the role played by the key drivers for PSS delivery. Such aspects, for instance, can be investigated through phenomenology. The qualitative research method in this study was informed by the concepts of the phenomenological approach.

Phenomenology can be viewed as a philosophical and social science perspective which was influenced by the initial works of the German philosopher Edmund H. Husserl (1859-1938), and later by others such as Alfred Schutz (1899-1959). Husserl defined phenomenology as the study of how people define their situations and experiences and create meanings. It seeks to understand and explain how the particular experience being investigated has occurred and also seeks to understand what has contributed to its occurrence. Phenomenology focuses on how the particular phenomenon people experience has been brought about (Patton 1990:69). According to Farganis (1996:318), phenomenological sociology basically seeks to understand the world from the viewpoint of the research participants themselves and not from the perspective of the researcher.

In the case of this study, the phenomenon that required understanding was the delivery of PSS services by the Simbarashe National Network for People Living with HIV and AIDS to CLHA. This approach allows the researcher to come to an understanding of what people experience and how they interpret this experience.

Qualitative research does permit the use of a small sample size – see the discussion below on sampling in section 3.5 – because its focus is not on representativeness but on the information the researcher wishes to capture. There are generally no rules regarding sample size in qualitative research as the sample size depends on the purpose of the study, and on whether the research findings are believable, that is if the research were to be replicated by another researcher they would still arrive at the same conclusions (Patton 1990:184;

Hoyle, Harris & Judd 2002:418). The sample size in qualitative research also depends on what can be done within the available time and resources (Patton 1990:184; Fisher, Foreit, Laing, Stoeckel & Townsend 2002:59). Patton (1990:184) underscores the issue of breadth and depth in qualitative research designs, highlighting that in capturing in-depth information, a small sample can be used to provide the required information-rich cases.

3.3 DATA SOURCES

The Simbarashe National Network for People Living with HIV and AIDS was an important source of data for this study. This CBO served as a source of data since the researcher studied a number of the organisation's key documents, interviewed the project staff and fieldworkers of the organisation and observed the delivery of a PSS session. Another important source of data was the recipients of the CBO's PSS services, namely a selected group of caregivers of CLHA.

It is important to note that the researcher had no pre-existing relationship whatsoever with the organisation, which was selected purely on the basis of its service delivery to CLHA in this particular geographical location. The CBO is the only organisation delivering PSS specifically to CLHA in the Mhondoro-Ngezi sub district.

In order to get access to the research setting, the researcher firstly held informal meetings with the National AIDS Council representatives, to obtain information and contacts of the main organisations that delivered PSS services to CLHA in the Kadoma district. Upon gathering this information, the researcher proceeded to make direct contact with the CBO through a written request from the University of South Africa, requesting access from the CBO to allow the researcher to undertake the research. The letter requesting access from the CBO to undertake the research is attached in Annexure A. The letter from the CBO granting the

researcher access to the CBO is attached in Annexure B.

The participants selected to participate in this study were those who could enable the researcher to answer the study's research questions as they were either directly involved in the delivery of PSS (key informants and field workers) or were the recipients of the CBO's PSS services (caregivers). The selected participants were relevant to the study as the study allowed them to reflect on their experiences on PSS delivery at community level. This was in line with the defining characteristic of qualitative research which permits the participants to relate their stories and experiences, enabling the researcher to generate themes that bring understanding of the study topic (Hoyle, Harris & Judd 2002:394).

The key informants who participated in this study were the organisation's project staff operating at senior management and field level, as well as a group of caregivers who were the beneficiaries of the services provided by this organisation. The organisation's senior project staff was selected because they were the key decision makers in the organisation and were also the key catalysts in initiating change, such as prioritising discussions and activities that advocate for increased PSS for CLHA. The project staff working directly with CLHA was regarded as being in a key position to provide accounts of actual experiences and perceptions on PSS delivery. All the participants were requested to complete the consent form attached in Annexure C. The focus group discussion with caregivers revealed information on the perceptions and experiences of caregivers with regard to PSS service delivery to the children and understanding whether their needs had been met. These discussions were further used to capture their testimonials on the benefits of PSS.

3.4 DATA-COLLECTION TECHNIQUES

The data-collection techniques used were semi-structured, in-depth open-ended interviews and focus group discussions. Content analysis of the organisation's reports and publications was done as well as observation of one session where PSS was delivered. According to Patton (1990:10; Fisher et al 2002:78; Hoyle et al 2002:394), interviews, direct observation and content analysis of written documentation are three kinds of data-collection techniques that may be used in qualitative research. Analysis of the written documentation in qualitative research is referred to as content analysis. Five in-depth open-ended interviews were conducted with senior project personnel of the CBO, and three focus group discussions were conducted with other project staff of the community-based organisation. A fourth focus group discussion was held with six caregivers of the CLHA.

In other words, this study employed a combination of data collection techniques, a process also referred to as "triangulation" in order to strengthen the research design. Patton (1990:188) states that combining techniques such as interviewing, observation and document analysis is common in social science research. The use of only one technique makes the research more at risk of having loaded interview questions or biased responses. Patton underscored that the use of combined techniques is useful in reducing research errors and providing cross-data validity checks. Denzin (1978, as cited in Patton 1990:187) stresses that as a qualitative methodological rule, multiple methods should be employed in every investigation.

The reason for the selection of the particular data-collection techniques used in this study was that in-depth open-ended interviews and focus group discussions yielded data in the form of the words of the participants themselves about their experiences, opinions, feelings and knowledge on an issue (Patton 1990:10). The content analysis sought to provide information on the CBO's community

meetings and activities such as the VCT campaigns and the case management of CLHA, and also to reveal the existing partnerships the Simbarashe National Network for People Living with HIV and AIDS had with other community groups in the delivery of PSS, such as the local traditional and non-governmental organisations. On the other hand, observation was used to provide data about how PSS was delivered to CLHA through support group sessions, and also to provide additional information which might have been missed during the individual, in-depth, open-ended semi-structured interviews, focus group discussions and the content analysis. Observation also served to validate the information gathered.

A detailed discussion of each of the data collection techniques highlighted above now follows.

3.4.1 Individual semi-structured in-depth open-ended interviews

According to Patton (1990:10:288), the purpose of open-ended questions is not to put ideas in someone's mind but to find out what is in and on their mind. Thus the use of open-ended questions during the in-depth interviews and the focus group discussions allowed the researcher to discover the research participant's perspectives on various issues. It is believed that the combined use of in-depth interviews and focus groups allows the researcher to capture comprehensive data on the identified thematic areas. The strengths of interviews which use this tool are that participants are able to respond to the same topics and questions but not necessarily in the exact same order and way. This flexibility allowed the researcher to probe further on emerging issues, in comparison to other tools such as informal conversational interviews and observation approaches. The individual in-depth interview schedule is attached as Annexure D.

The individual in-depth interviews were conducted in two geographic locations. The interview with one of the key informants was conducted at the National AIDS

Council offices at the organisation's district headquarters in the Kadoma urban district, while the other four interviews and all the focus group discussions were conducted in one of the offices at the CBO's premises in the Mhondoro-Ngezi district. The reason why the CBO premises were used as the venue, was because all the CBO staff who participated in the research were more accessible to the researcher during their normal working hours at the CBO's premises, and thus the CBO was a convenient location for these meetings to take place.

In order to arrange the interviews, the researcher travelled to the CBO's premises a week before the field work was conducted. The purpose of the visit was to introduce the research and the objective of the field work to the CBO's director and also to explain the types of participants who were required to participate in the research. This process enabled the key informants to specifically schedule time for their individual interviews, which were conducted during their normal working hours. The average time it took for the interviews to be conducted was 30 to 40 minutes for each participant. The interviews were conducted over a time period of three days. All the interviews were tape-recorded after the participants had given their written consent to participate in the research. In addition, all the interviews except in the case of one key informant, were conducted in the English language. The one key informant indicated that he did not speak English fluently and expressed his viewpoints freely in the Shona language. All the interview recordings and transcripts were locked up in a safe location known only to the researcher.

3.4.2 Focus groups

Focus groups are defined as structured interviews with a small group of individuals to discuss a topic under the guidance of a moderator who, in this case, was the researcher (Hoyle et al 2002:401). Focus groups are often used to supplement semi-structured, in-depth interviews. They are used to gather additional information, producing concentrated amounts of data on the topic.

While semi-structured interviews with open-ended questions are typically done with individuals, focus group discussions assist in providing access to forms of data not easily obtained in individual interviews, such as the observation of the verbal interactions among participants during a discussion which could reveal a variety of points of view within the same period of time (Morgan 1997:2, 8). Three focus group discussions were conducted to probe for additional relevant information that emerged during the individual interviews with the community-based organisation's project personnel. A fourth focus group discussion was conducted with the beneficiaries of the organisation's services, namely the caregivers of a group of CLHA. This latter focus group discussion revealed information on the perspectives of the beneficiaries with regard to PSS service delivery for the children.

The average number of people participating in each of the focus groups was six. According to Morgan (1997:42-43), the number of people that participate in a focus group discussion is determined by the amount of information each participant has to contribute. The basic rule of thumb for the size of focus groups specifies the range to be between 6 to and 10 people. A number below 6 may result in difficulty to sustain discussions, and above 10 may result in difficulty to control the group. Although the number of groups to be held is determined by the size of the research team available, the common rule of thumb is 3 to 5 groups so as to provide meaningful new insights. With regard to this study, 3 focus group discussions were conducted to discuss a range of identified thematic areas and other issues that may emanate during the research process.

Depending on the proficiency in English of the research participants, the focus group discussions were conducted in either English or the local language, Shona. All the focus group discussions, except for the one conducted with the CBO's senior project personnel, and the PSS delivery session observed by the researcher, were conducted in Shona. As with the interviews, the selection criteria for all the participants were those who worked directly with or were the

caregivers of CLHA under 15 years of age.

A major strength of focus groups is that they rely on the researcher's ability to coordinate and foster interaction among participants in order to produce concentrated amounts of data (Morgan 1997:13). The questions used to guide the focus group discussions are attached in Annexures E and F for the project staff and caregivers respectively.

Overall, the discussions and the verbal activities undertaken during the research were tape-recorded and transcribed and where necessary, translated into English. The transcribed texts from the focus group discussions and interviews as well as the field notes from the observation and content analysis were locked up and kept in a safe location.

3.4.3 Content analysis

Document analysis or content analysis was used to capture information from the organisation's reports and documents with regard to their PSS activities. Content analysis studies are usually used to analyse recorded human communications. In this study they revealed information on the factors that influence PSS service provision to CLHA (Babbie 2009:333). This method is commonly used together with other methods in HIV and AIDS studies (Fisher et al 2002:78). It provides a "behind-the scenes" look at activities and how they are conceptualised, planned and implemented. Documented information provides data which may not be easily observed or which interviews may not capture. This method is useful in providing a stimulus for generating questions that can be pursued during observation, individual interviews and focus group discussions. Confidentiality was respected by having negotiated with the organisation which documents could be analysed (Patton 1990:234-235). The researcher analysed a number of project reports and minutes of meetings that had been formally documented and were available during the period the research was conducted.

The following documents were analysed by the researcher:

- The Simbarashe National Network for People Living with HIV and AIDS Organisational profile 2010.
- Simbarashe National Network organisational profile 2012.
- The Simbarashe National Network-Mhondoro-Ngezi safe parks draft concept and planning paper 2012.
- Letter from HOSPAZ dated 15 December 2011 to the CBO Director on the disbursement of funds amounting to US\$ 1710.00 from HOSPAZ (NGO) for CBO's conduct 2011 December activities.
- Letter dated 4 April 2007 on Chief Mlambo's 6 hectare land donation to executive director of Simbarashe National Network for PLHA.
- Report on the Simbarashe National Network PLHA Integrated Model for The Simbarashe National Network Paediatric AIDS and Care treatment programme report for June 2012.
- Chart showing support group attendance for CLHA and those not living with HIV in 2010 and 2011.
- Chart showing an organogram of structural levels of the CBO's leadership.
- Chart on the statistics of the support group for children attendance from 2010 to 2012.
- Trustees, Board and Management 2011 report.
- Meeting minutes dated 16/12/11 on year end programme review on PSS offered to OVCs
- Meeting minutes of IMPACT Caregivers monthly reports covering January 2012 to June 2012 time period.

3.4.4 Observation

Finally, the observation of PSS services and activities delivered to CLHA by the Simbarashe National Network for People Living with HIV and AIDS was done by the researcher. Field notes were taken by the researcher to record what she saw or heard during an identified PSS delivery session by the CBO to a group of children. The observation was conducted at the CBO premises, in one of the CBO's classrooms. The observation took place on the day the CBO was closing for school holidays, hence the researcher was permitted to observe the PSS activities within a limited time period as the children had to be dismissed early on that particular day. However, this did not in any way hinder the researcher as she was able to collect adequate data for the study.

The purpose of the field observation notes was to capture data that described the study's research setting (that is the physical environment), the CBO's PSS activities, the social interactions and the behaviours of the research participants during a support group session. This data provided an understanding of service provision through witnessing the actual activities and their impact and this enhanced the validity of the data gathered during the in-depth interviews (Patton 1990:202-245). The observation of the delivery of a PSS activity at the CBO offered the researcher first-hand experience of the research setting and context within which activities were undertaken. The observation also offered an opportunity to see how the research participants themselves behaved during the delivery of a PSS session, and this enabled the researcher to have detailed data and better understanding of the beneficiaries' response to the PSS services delivered to them.

Table 4 below summarises the above-mentioned data collection methods and how they related to the research objectives.

Table 4: Summary of data collection methods

Research objective	Data-collection method
<p>To describe the delivery of community-based PSS services to CLHA by the Simbarashe Network of People Living with HIV and AIDS in the Kadoma district.</p>	<ol style="list-style-type: none"> 1. Observation 2. Semi-structured, in-depth open-ended interviews and focus groups with project personnel 3. Content analysis of project reports and publications
<p>To identify the main factors that influences the delivery of PSS services to CLHA by the Simbarashe National Network for People Living with HIV and AIDS.</p>	<ol style="list-style-type: none"> 1. Semi-structured, in-depth open-ended interviews and focus groups with project personnel 2. Content analysis of project reports and publications
<p>To explore the caregivers' views on the extent to which the PSS needs of CLHA are being met by the Simbarashe National Network for People Living with HIV and AIDS.</p>	<ol style="list-style-type: none"> 1. Semi-structured, in-depth open-ended interviews and focus groups with project personnel 2. Focus group with caregivers 3. Observation of activities and service delivery
<p>To explore the existing linkages the Simbarashe Network for People Living with HIV and AIDS has with other PSS service providers in the Kadoma district.</p>	<ol style="list-style-type: none"> 1. Semi-structured, in-depth open-ended interviews, focus groups with project personnel 2. Content analysis of letters, minutes, reports and financial records
<p>To identify ways in which the delivery of PSS services to CLHA by the Simbarashe National Network for People Living with HIV and AIDS can be improved.</p>	<ol style="list-style-type: none"> 1. Semi-structured, in-depth open-ended interviews and focus groups with project personnel 2. Focus group with caregivers 3. Observation of sessions of PSS service delivery

3.5 SAMPLING TECHNIQUES

Purposive or judgemental sampling was used to select the Simbarashe National Network for People Living with HIV and AIDS in that it was the only CBO active in the delivery of PSS to CLHA in the resource-poor rural setting of the Mhondoro-Ngezi sub-district of Kadoma. Furthermore, only one CBO was purposively selected in view of the researcher's limited time and financial resources.

Purposive sampling is defined as a type of non-probability sampling method in which the research sample or cases under investigation are selected based on the researcher's judgement or prior knowledge on its usefulness to the purpose of the study (Babbie 2012:193; Neuman 2012:149; Bless et al 2006:106). Purposive sampling often leads to non-representative samples or cases. According to Neuman (2012:149), this method is a most appropriate method for a researcher in the following three situations: when the researcher seeks to select a unique case that is informative; when the researcher seeks to find a difficult-to-reach group; or when the researcher just desires to identify a particular case for in-depth investigation.

In non-probability sampling, the sample size is rarely determined in advance due to the researcher's limited knowledge of the population from which the sample is taken (Neuman 2012:147). As qualitative inquiry focuses in-depth on relatively small samples selected purposefully, the logic of purposeful sampling relies on selecting information-rich cases. Information-rich cases can be used to learn a great deal about a particular issue related to the study (Patton 1990:169; Neuman 2012:21).

The sampling technique that was used to identify the focus group discussion participants and the participants for the individual in-depth, semi-structured interviews was also purposive sampling. As noted in sub-section 3.3 above, the

research participants of this study were the organisation's project staff operating at senior management and field level, as well as caregivers of CLHA benefiting from the CBO's PSS activities. The four senior project personnel who participated in the interviews and the focus group discussions were purposely selected because of their vast experience in the actual delivery of PSS to CLHA. The Director of the CBO and his wife are founders of the CBO and provided rich and detailed information on the overall activities of the CBO with regard to PSS delivery.

The NAC representative was selected based on his role as advisor and provider of all the technical support given to the CBO in the development and management of the CBO's PSS programme.

The criterion that was used for the other three individual key informant in-depth, semi-structured interviews and the three focus group discussions with field officers, was that only project staff who were involved in the delivery of PSS to CLHA specifically under 15 years of age were selected.

3.6 DATA ANALYSIS AND INTERPRETATION

Data analysis and interpretation basically involves making sense of all the data collected by the researcher during the field work, identifying patterns and themes. The raw data for analysis was the actual written information gathered from the CBO's documents, the researcher's observation notes and the word-for-word transcripts of the interviews and focus group discussions (Patton 1990:347). Data analysis allows the researcher to arrange and present the collected data to identify patterns and themes and explore whether these are consistent with the conceptual framework that has been selected to guide the study. In this study, the researcher analysed the data by systematically arranging and presenting it in a manner that highlighted patterns and also explored whether linkages to the social support theory could be identified (Hoyle et al 2002:425).

The analysis of the data gathered for this study was guided by the phenomenological analysis stages, summarised by Patton (1990:407-408) as follows:

3.6.1 Epoche

This is the first step of an on-going analysis process whereby researchers acknowledge their personal biases and subjectivity, and focuses on the evidential data of the study. In this study the researcher ensured that her previous knowledge of the information gathered in the literature review in no way brought any personal bias to the actual findings collected during the fieldwork. All the tape-recorded data was transcribed in the manner to reflect the research participants' own viewpoints.

3.6.2 Phenomenological reduction

This process involves the researcher “bracketing” the data by further inspection of the data. Its aim is to take a closer look at the data, dissecting it further to identify elements, key phrases and statements that relate to the phenomenon. The researcher interprets the meanings of these and offers a statement of the recurring essential elements of the phenomenon. In addition, the data is organised and grouped into meaningful clusters to allow for a process of removing repetitive and overlapping information (Patton 1990:408). In this study the researcher categorised the findings in terms of the research questions, and identified in this way themes and sub-themes.

3.6.3 Imaginative variation

Following the above “delimitation activity” is another step termed the “imaginative variation” step, whereby the researcher identifies invariant themes within the

data. The researcher performs an “imaginative variation” on each identified theme, a bit like looking closely at the same issue from different perspectives. Imaginative variation allows for an expanded and enhanced view of the identified invariant theme (Patton 1990:408). In this study the researcher took a closer look at the information that had been categorised in the meaningful clusters to creatively come up with the main thematic areas that were emerging during the data analysis process. This allowed the researcher to further categorise and match the data under various sub-headings (sub-themes) of the various thematic areas.

3.6.4 Synthesis

This is the final stage involves the development of a structural synthesis. A structural synthesis is a synthesis of the actual experiences of participants that carry the deeper meaning and depth of what is encountered. In this stage the researcher reveals the essence of the phenomenon under study (Patton 1990:409). After the overall framework of the categorised data had been laid out in this study and the researcher had confidence in the themes that had emerged, the researcher proceeded to write up the overall research findings. Each identified thematic issue and emerging issues were further substantiated by the quotations of participants from the interviews and focus group discussions, as well the observation notes and the content analysis. The researcher then proceeded to systematically present the categorised data.

3.7 THE RESEARCH SETTING

As briefly described in Chapter 1 above, the study was set in the Kadoma district, Zimbabwe. The Kadoma district is located in the northern part of Zimbabwe in the Mashonaland West province. It is situated 140 kilometers south-west of Harare, Zimbabwe’s capital. The district is subdivided into three main sub-districts, namely the Kadoma urban district, the Mhondoro-Ngezi district and the

Sanyati district. The Kadoma district has a total population of 238 122 of which 66.9% is located in the two rural districts, the Mhondoro-Ngezi and Sanyati districts (MOHCW 2006:1). With regard to the day-to-day activities of the district population, the district is dominated by informal and formal mining as well as farming activities.

The Kadoma district has a total of 35 health centres that provide some form of HIV and AIDS prevention, treatment, care and support services to communities. Other main HIV and AIDS services provided by community-based organisations, non-governmental organisations and religious groups in the district include orphaned and vulnerable children's programmes, food supplement projects and support groups for adults living with HIV and AIDS, among others (MOHCW 2006:1).

According to the 2010-11 Zimbabwe Demographic and Health Survey (ZDHS) report, the HIV prevalence rate for the Mashonaland West province was 15% for that time period (ZIMSTAT & ICF International 2012:15). This high HIV prevalence rate reveals the existing HIV and AIDS burden in this province where the Kadoma district is located and points to the extent to which this epidemic has negatively affected this district.

The study was done in the Mhondoro-Ngezi district where the Simbarashe National Network for People Living with HIV and AIDS is situated. The CBO is situated in the Murambwa growth point area, a peasant farming area located approximately 120 kms from the Kadoma urban area.

3.8 TRUSTWORTHINESS OF THE DATA

Trustworthiness of the data has to do with whether the research data that has been collected by the researcher is dependable and consistent (Babbie 2012:150; Neuman 2012:125; Fisher et al 2002:45-46; Hoyle et al 2002:151).

According to Neuman (2012:126), researchers conducting qualitative studies can achieve trustworthiness by using a range of data sources and multiple data-collection methods so as to produce distinctive results which can be considered to be reliable. As noted above, multiple methods of data collection were used to enhance the trustworthiness of the collected data. Combining methods in qualitative research increases the validity of data as the strength of one method could compensate for the weaknesses of another (Patton 1990:244).

In order to achieve trustworthiness of the data collected in this study the researcher had an obligation of ensuring that the data collected was also valid. According to Neuman (2012:125-126) and Fisher et al (2002:46), the term validity is defined as the level of truthfulness of the collected data. In other words, validity refers to data that is both truthful and accurate. The core principle for qualitative researchers is to be truthful and this can be achieved when a researcher provides research accounts that are not false or distorted. Qualitative researchers achieve validity by providing data which portrays a real description of the social life that is regarded as true to the experience of the research participants themselves (Neuman 2012:125). In this study trustworthiness of the data was also achieved by using the participants' home language, which allowed the participants to freely express their views. As noted above, the researcher tape-recorded the interviews and focus group discussions in order to capture the exact words of the participants. The content analysis and the observation notes further provided the researcher the opportunity to verify the data collected from the participants. In addition, the trustworthiness of data was achieved by the researcher asking the participants similar questions a second time to check whether the same responses would be given (Fisher et al 2002:46). According to Hoyle et al (2002:46), designing studies which can check for validity in the research study results can enable the researcher to check for consistency or dependability of the answers given by the research participants.

Validity and trustworthiness are concepts that complement each other and qualitative research designs aim to collect data that is accurate and truthful (Neuman 2012:126). The overall purpose of selecting a study design is to minimise the errors and bias that can occur by maximising both the truthfulness and validity of the data (Fisher et al 2002:45).

3.9 ETHICAL CONSIDERATIONS

Ethics aims to protect all persons involved in a study (Black 2002:62). All research work involving the participation of research participants should protect their human rights, safety and dignity (Hoyle et al 2002:70). Ethical approval of this study was obtained from the University of South Africa's Higher Degrees Committee of the Department of Sociology. The approval was granted through a process which had involved the initial submission of the research proposal to the committee by the researcher, seeking ethical clearance and permission to proceed and conduct the field work. The researcher proceeded to undertake the field work only after receiving a letter with formal communication from the committee, granting the ethical clearance. The letter of approval is attached as Annexure G.

The study considered the following ethical issues, which were adhered to:

3.9.1 Informed consent

Researchers are required to obtain informed consent from participants. According to Family Health International (2005:9-11), informed consent is a fundamental principle of research. It is the mechanism that ensures that research participants understand what it means to participate in the study. It enables them to make a conscious and deliberate decision whether to participate in research. Informed consent ensures respect for people. Where data-collection with an

individual requires more than a casual interaction, consent is to be sought directly from them.

Written consent to participate in the study was obtained from each participant through the consent form attached as Annexure C. The consent form describes the research conditions and requests each participant to sign the form to document his or her voluntary consent to participate in the study (Fisher et al: 2002:83). The consent forms were signed by the research participants in one of the offices at the CBO's premises. The forms were then placed in the researcher's private folder and kept in a secure place accessible only to the researcher.

3.9.2 Confidentiality

According to Babbie (1990:342), confidentiality involves the protection of the research respondent's interests, well-being, concerns and identity. The main aim of confidentiality is to protect the respondent's identity during and after the research process. Thus, confidentiality ensures that no person or institution should be identifiable from a research report, unless there is a good reason to do so and permission from the research participant has been secured (Black 2002:62).

The researcher adhered to the principle of confidentiality by adopting the techniques highlighted in Babbie (1990:342), such as creating a master identification file which replaced the respondent's names with identification numbers. Only those respondents who indicated that their identity could be exposed were referred to by means of their work titles. In this study only three respondents identities are exposed, firstly the director of the Simbarashe National Network for People Living with HIV and AIDS, secondly his wife, who is the co-founder, and thirdly the National AIDS Council advisor to the CBO are exposed with their permission. The director and his wife are openly living with

HIV.

In addition, the researcher did not disclose information obtained from one respondent to another during the data collection process. The identity of each respondent is not disclosed to anyone except the study's supervisor, who had oversight of the study.

3.9.3 No harm

“No harm” refers to avoiding injury to respondents by revealing information that could in anyway raise negative emotions or circumstances such as endangering their life, jobs or friendships (Babbie 1990:240).

According to Babbie (1990:340-341), the possibility of harming respondents should be guarded against, not only during data collection but also during data analysis and reporting. Although there is no way to ensure against all possibilities of harm to respondents, the researcher was sensitive to respondents' reactions during the data gathering process and in so doing, minimised harm to respondents. In order to adhere to this principle, the researcher was mindful to use respectful language that did not promote the stigmatisation and discrimination of the CLHA. This was a point also stressed to the researcher by the National AIDS Council representative prior to the field visits to the CBO.

3.9.4 Debriefing

According to Babbie (2012:70), “debriefing” is defined as the process of interviewing the research participants after the research has been conducted to learn about their experiences in participating in the research. The main goal of debriefing is to ascertain whether the research could have caused any possible problems or harm to the participants so that the problems may be addressed.

Debriefing is also an important process that can assist the researcher to learn the thoughts and feelings of the research participants about the study and how their view of the study could have affected their behaviour during data-collection (Neuman 2012:233).

In this study the researcher conducted a debriefing session with the research participants who expressed their gratitude for the opportunity to have participated in study. The participants further noted that this study had made them realise that the Simbarashe National Network for People Living with AIDS was indeed an information-rich source of knowledge and experiences with regard to PSS delivery to CLHA. The participants added that this realisation had inspired them to begin a process of properly documenting information on their activities. There were no expressions of the possibility of the research having caused any problems or harm to any of the research participants.

3.10 PILOT STUDY

According to Polit and Hungler (1993:443), a “pilot study” is defined as a small-scale version of the research to be undertaken or a study trial conducted in preparation for the main study. The benefit of a pilot study is that it assists the researcher in improving the reliability and validity of the research data to be collected. This is done through the development of one or several preliminary drafts of the research interview schedules which are then tried out before a final draft is developed (Neuman 2012:123). The researcher conducted a pilot study using semi-structured, open-ended interview questions. The pilot study was conducted with one staff member of the CBO, who was not involved in the final study. After the pilot findings were analysed, the researcher realised that some questions were yielding one-word answers, were too technical or deemed vague and repetitive. For example, the question in the initial interview schedule which had been phrased in the following manner: “*What are the psychosocial issues CLHA face?*” was changed to “*Describe some of the behaviours of CLHA you*

have noticed which are associated with their HIV status". The latter seemed more appropriate and simpler to understand than the former. After the adjustments to the interview schedule was done, a second individual pilot interview was done. This interview was not found to be problematic and was consequently used in the final study. Also, a pilot focus group discussion was conducted with the staff of the CBO – also no serious problems were identified and this case and this focus group discussion was included in the final study.

3.11 CONCLUSION

In conclusion, this chapter has presented the methodological approach that was used in the study. The use of the qualitative research design was justified as the most suitable for providing the information-rich data that could provide answers to the research questions. The chapter began with a discussion of the qualitative study design and introduced the data sources of the study. This chapter further discussed the data collection techniques that were used, namely individual in-depth interviews, focus group discussions, content analysis and observation. This was followed by a discussion on the sampling technique used as well as how the research data was analysed. This chapter also described the research setting where the study was undertaken and further discussed the ethical considerations as they relate to informed consent, confidentiality, "no harm" to participants, and debriefing. This chapter then concluded with a discussion on how the pilot study was conducted.

The next chapter presents the research findings and reflects the application of this chapter's research methodology.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

4.1 INTRODUCTION

This chapter presents the findings of this qualitative study. The phenomenological analysis stages, summarised by Patton (1990:407-408) and discussed in Chapter 3, guided the analysis and interpretation of this study's findings.

In order to answer the research questions of the study a variety of research techniques, which included semi-structured, in-depth interviews with key project personnel, and focus group discussions with project personnel as well as beneficiaries of PSS services were employed. In addition, content analysis of key project documents and observation of a support group session with children were part of the key data-gathering techniques of this study.

This chapter firstly presents the research participants' demographic and social characteristics. This is followed by a presentation of the findings that address the research questions. The chapter presents the six main thematic areas that emerged from analysis of the field work with regard to the main factors that influence the delivery of PSS to CLHA by the Simbarashe National Network for Children Living with HIV and AIDS. These thematic areas were categorised and discussed by the researcher under the following themes: namely; Psychosocial challenges experienced by CLHA, Human rights, Community volunteers, Caregivers, Integrated HIV and AIDS services, and Partnerships

4.2 DEMOGRAPHIC CHARACTERISTICS OF THE RESEARCH

PARTICIPANTS

A summary of the demographic and socioeconomic profiles of the caregivers of CLHA who participated in this study are presented below in Tables 5 and 6.

Table 5: Demographic and socio-economic characteristics of caregivers

Name of caregiver	Age	Gender	Household size	No of children in household	No of CLHA in household	Means of livelihood	Monthly income
Buhle	53	Female	6	2	1	Hand-outs	-
Jackie	48	Female	7	3	1	Informal Trader	US\$10
Sophia	50	Female	6	4	1	Community volunteer	US\$50
Yvonne	55	Female	5	3	2	None	-
Mutsa	54	Female	7	3	2	None	-
Betty	58	Female	5	2	2	None	-

The focus group discussion with six caregivers of the CLHA revealed that only two out of the six caregivers were employed. The responses on how the caregivers made a living ranged from no employment to informal employment and community work. The caregivers who did not have any means of livelihood, such as caregivers 4, 5 and 6, depended on donations from their respective family members. Caregiver1 was a widow and solely depended on hand-outs from well-wishers in the community. Caregiver 3 received a monthly stipend of

US\$50 from the Simbarashe National Network for People Living with HIV and AIDS. Caregiver 2 was an informal trader who sold vegetables for a living and made a minimal US\$10 profit per month.

In addition, Table 5 above shows that the household sizes ranged from 5 to 7 people per household. The focus group discussion with caregivers revealed that not all the children living with HIV and AIDS were their biological children. These children had lost their parents due to AIDS-related illnesses, which resulted in the children being adopted into the extended families of their late parents. The caregivers were either aunts or grandmothers of the CLHA. Responding to a question on the relationship the caregivers had with the CLHA, the respondents revealed the following:

Buhle: "I am staying with my nephew, both his parents are dead. The mother of his father is dead and also the mother of his mother. I am a niece, a daughter-in-law to his grandfather."

Jackie: "I am living with the children of my husband's sister."

Sophia: "I am a grandmother to the child. The child's mother is dead."

Yvonne: "Mine is the child of my young sister. Both parents are dead."

Mutsa: "The one I am staying with, I am the wife to the brother of the child's mother. So I am the child's grandmother [plays the role of grandmother according to the Zimbabwean Shona culture]. Her grandmother is very old, she can't take care of the child."

Betty: "The one I am staying with is the child of my husband's brother, both parents are dead."

With regard to the age and sex profile of the CLHA, caregivers revealed the ages of the children to be between 7 and 12 years. The age ranges of these children, who are also beneficiaries of the Simbarashe National Network for Children Living with HIV and AIDS PSS programme, are presented below in Table 6. Among these children, five were boys and four were girls.

Since the researcher decided not to interview children living with HIV and AIDS below 15 years on the basis of ethical grounds, the respective caregivers of these children provided the data during a focus group discussion about the various PSS issues that affected them.

Table 6: Children’s age groups

Ages	0 – 4 years	5 – 9 years	10 – 15 years
Number of children	0	3	6

4.3 SIMBARASHE NATIONAL NETWORK OF PEOPLE LIVING WITH HIV AND AIDS

4.3.1 Background

The background of the Simbarashe National Network for People Living with HIV and AIDS is that it was established 10 years ago by a couple who publicly disclosed that they are living with HIV. Narrating how the work at the CBO began, the founder and director of the CBO Robert and his wife Paida explained below:

Robert: “Okay, thank you. My name is Robert. Like you mentioned, the founder of Simbarashe National Network. Simbarashe was born out of illness. About a decade ago I was well employed with the Zimbabwean public police and early in 2001 I started ailing, then I retired back home,

here in the rural area. It's like that time as early 2001 they had no treatment for HIV, so when I came here we were all ailing myself and my wife. We were not well at all. This meant that my duties which demanded physic [physical activity], I could not execute my duties, so I retired on medical grounds. But when we were here my wife was in her early pregnancy. So like you know, all mothers that are expecting they need the attention of a doctor, so that's when my wife go to St Michaels Mission Hospital for her to see a doctor for registering the pregnancy. When she went there she found out there was a programme called PMTCT, Prevention of Mother-to-Child Transmission, then there they asked her consent to take blood samples for HIV test, which she consented to and was tested, and when the results came she was HIV positive. That time it was not that easy and my character myself was not that good. I mean when you look at my type of work I used to do I had a bad character. She actually had to go. She ran away she went to her rural home. She was saying 'how do I tell my husband that we are HIV positive?' What then happened is that I discovered that my wife was not coming back home and I had to make a follow- up, only discovering [only to discover] that she had gone to her parents, but before that, she went home and left a small note which said that 'I have been HIV tested at St Michaels Hospital and have been found to be HIV positive. I know you well and it's far difficult for me to break this news. I have just written this note and I have gone to my place but the doctor wants you to go for a test.' I was furious, I went to St Michaels Mission Hospital. Not that I was furious that we were found living with HIV, but my concern was 'how could you [hospital staff] then test my wife without my consent?' So when I arrived at St Michael's Mission Hospital the then Doctor Bertha and other players there convinced me to take the test. I succumbed and it revealed that I was also living with HIV. That's when it all started."

Paida: "A-ah, it started when I was pregnant in 2003/2002. Then at that

time I was tested. There is a programme that tests pregnant women. It was scary for you to accept but I went on to get tested. E-eh it was very difficult for me to tell my husband. I then went to get tested and I was found to be living with HIV. What I then did was I wrote a small letter to my husband and I left it on the table and left for my rural home. From there my husband was hurt, why did this happen and how did it happen? We then talked about it, my husband and I, and he also went to go and get tested. I delivered my child with the help of Doctors. From there I started looking at the number of people who get tested and wondering how they are surviving. E-eh, we started conducting support groups for people living with HIV and AIDS at St Michaels's. We were teaching each other since there was no medication available."

In addition to the above narrations, the content analysis of reviewed project documents revealed the following:

"SNN [Simbarashe National Network] was formed in the year 2002 by Robert after having tested positive [living with HIV]" (Simbarashe National Network for People Living with HIV and AIDS Organisational profile 2012:2).

"It was in 2000 when an ordinary couple from Mahachi village under Chief Mlambo decided to visit their local clinic ... The two, that is, both the wife and the husband had visible signs of ill health... This resulted in the couple accepting a blood test [HIV test] which the hospital staff duly performed. All along Robert had been suspecting it could be HIV. No sooner than later was Robert's fears confirmed ... In 2003 he finally grouped together people who were living with HIV and an organisation was born at the initiation of Robert. That was the beginning of a Network that was going to take care of people who are living with HIV" (Simbarashe National Network for People Living with HIV and AIDS Organisation background

2010:2-3).

“The Simbarashe National Network for People Living with HIV and AIDS is a community-based organisation based in the Mhondoro-Ngezi district. The CBO was founded by a couple living with HIV, Paida and Robert, who decided to come out about their status [publicly disclose their HIV status] and established a charity [organisation] to serve the community” (Simbarashe National Network National Network for People Living with HIV and AIDS concept paper 2012:1).

4.3.2 Mission and Vision

The CBO delivers prevention, care and support services to both adults and children living with HIV and AIDS. As explained in the CBO’s project documents, by Ben, the National AIDS Council advisor to the CBO and two of the CBO’s field officers Petros and Chipso below:

“Simbarashe’s mission is to curtail the spread and impact of HIV in communities through information dissemination, access to basic health, as well as providing children and youth with basic education and skills.”

“Vision statement: To improve the lives of people living with HIV and provide underprivileged children with basic education” (Simbarashe National Network for People Living with HIV and AIDS organisational profile (2012:1).

Ben: “This is a CBO, a community-based organisation, which is into AIDS programming which does a number of programmes in response to the HIV and AIDS epidemics in the community. It does awareness campaigns targeting women with prevention messages, mitigation support for people living with HIV, and also does a lot of PSS for its members who are living

with HIV and AIDS as well as children who are living with HIV within the community of Mhondoro-Ngezi ... They [CBO personnel] are running PSS especially for children who are on ART or who are living with HIV, to ensure they are well integrated within the community and they are part and parcel of the social life in Mhondoro-Ngezi, [so that] they don't feel neglected."

Petros: "Here at Simbarashe our aim is taking care of children, especially those who are living with HIV. When we see children like these, maybe they are poor in so many ways, they don't have anything in their lives, their well-being is poor or they have poor social networks, we try by all means to explain to them, teaching them, that it happens in life. So we do this in order to fit them well into the society."

Chipso: "Children and adults, all of them, we deal with them here [CBO] ..."

4.3.3 Organisational structure

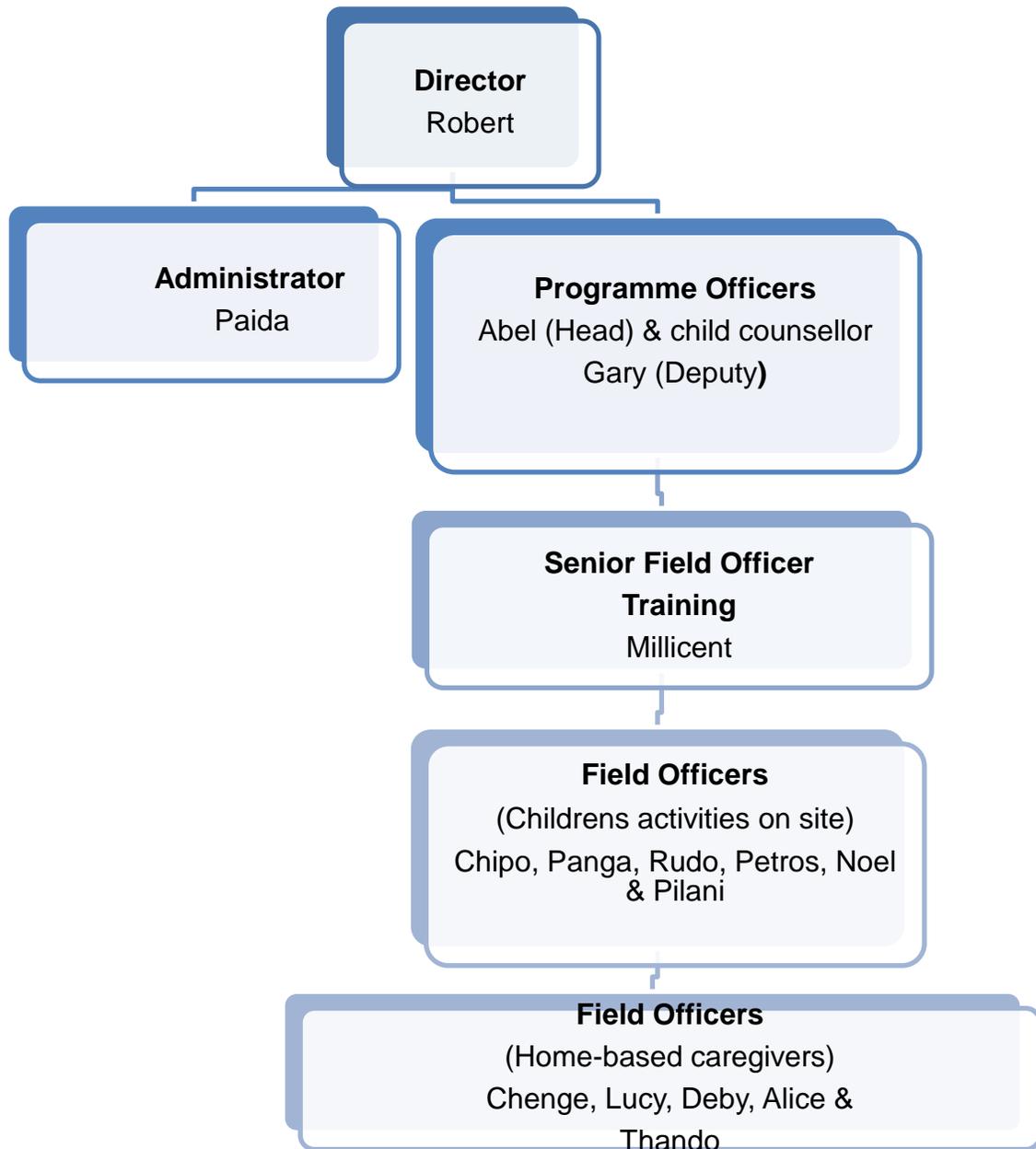
In the content analysis of a hand-written chart of the Simbarashe National Network for People Living with HIV and AIDS organisation's organogram, the study established that the CBO's project personnel who contributed to the delivery of PSS services and other HIV and AIDS care and support initiatives to CLHA, were categorised into five main operational levels.

As illustrated in the organogram below, which shows the CBO's organisational structure, having five levels of project staff, the highest level indicated the founder of the CBO as the director of the CBO. His wife Paida, who is involved in the administration of the organisation and other activities of the CBO's school programme, is on the second level. She does this with two senior project personnel. These personnel comprised of a Programmes Officer and his assistant, the Deputy Programmes Officer, were on the second operational level.

The Programmes Officer is also the CBO's child counsellor. The third level included a senior field officer involved in the training activities of the CBO's field officers.

These field officers are categorised into two operational levels, namely the fourth and fifth levels. The fourth level included a group of field officers who dealt with the children who would have been brought directly to the CBO's premises for assistance by the fifth level field officers, who are community volunteers. The fifth level officers, also referred to as home-based caregivers, were noted during the focus group discussions as the officers directly responsible for going directly into the community to raise awareness on HIV and AIDS. They also provided HIV and AIDS prevention, treatment, care and support services to CLHA. As discussed in further detail in the sub-sections that follow, these are the same field officers involved in the actual identification of vulnerable children in the community for HIV voluntary testing, and thereafter for the enrolment of these children into the CBO's support groups and case management programme.

Diagram 1: Organogram of the Simbarashe National Network Organisational structure



Source: Simbarashe National Network for People Living with HIV and AIDS Organogram (2012).

The study established that the main difference between the fourth and fifth levels of field officers was that the former group were the referral point on site at the CBO's premises for children identified in the community as requiring assistance, while the latter group are the officers who directly went into the community conducting the home visits. The following are some of the statements made by the CBO's project personnel to illustrate their varied roles in the delivery of PSS to CLHA and the training they had undergone to perform their roles:

Paida: "My name is Paida and I am 36 years old ... At Simbarashe I am a facilitator and the administrator too."

Abel: "My name is Abel and I am 24 years old ... currently I am the programme head at this organisation."

Abel further shared on his other role in the CBO:

Abel: "Yes I am also a child counsellor, actually I went to college for this counselling programme ..."

Gary: "I am the Deputy Programmes Officer and I am 30 years old ... My role is to formulate programmes and we lead programs with children mostly in support groups."

Millicent: "My name is Millicent, I am the home-based care (HBC) trainer."

During a focus group discussion, Millicent further shared on some of the training she had undergone:

Millicent: "In fact, from the beginning when I became a training officer, I did a palliative care course ..."

The fourth level officers' responses on their roles in the CBO's PSS delivery to CLHA were as follows:

Rudo: "What we do, the caregivers [fifth-level field officers] are the ones who talk to the children at first, then they come to us field officers [fourth level], giving us the child and telling us that this child is like this, he or she is sick, the food is not enough ... even clothing is not enough plus the way of living, it will be a problem. So we take those children when they come [to the CBO premises], we sit them down and explain to them as we talk with them, telling them how they must live together in love amongst others."

Noel: "Alright, we usually discuss with the caregiver about the condition of the children [Noel is referring to here to the CBO's home-based care givers also termed the fifth-level officer] I am a field officer [fourth level]. When we are given a problem to resolve by the caregiver who works directly with the children, there are some problems which they can see that they are not able to solve, so they come with them here to the centre. After that we will sit and discuss those problems which the children are facing that were given to us by the caregiver [CBO fifth-level field officer]."

Petros: "Our job exactly is to work between caregivers [Home-based Field Officers] and Simbarashe. We, I have an office here. What we do when we are at home, if the caregivers find out information about a child out there, they bring it to us then we bring the issue here [CBO premises]."

The fifth level field officers' responses on their roles at the CBO were as follows:

Nathan: "My name is Nathan. I am an HBC here. I work with children living with HIV and AIDS. Not only these, but others who also attend support

groups.”

Alice: “My name is Alice. I work with young children who are living with HIV ...”

Lucy: “My name is Lucy. I am a caregiver at Simbarashe.”

Chenge: “We go out in the community; we speak to children and their parents in terms of getting tested for HIV and AIDS.”

4.4 DELIVERY OF PSYCHOSOCIAL SUPPORT TO CHILDREN LIVING WITH HIV AND AIDS

The study found that the delivery of PSS by the Simbarashe National Network for People Living with HIV and AIDS below 15 years of age could be categorised as being part of a seven-staged process. Depending on the specific PSS needs, a child may not necessarily go through all seven stages. A more detailed description of how the CBO delivers PSS through this process is provided in the following sub-sections.

The seven main stages of the PSS delivery processes are as follows:

1. Identification of children requiring PSS
2. Voluntary counselling and testing of children to establish their HIV status at local health facility
3. Disclosure of child’s HIV status
4. Support groups
5. Case management

6. Transitory school for out-of-school orphaned and vulnerable children
7. Child-friendly rights-based approach

A detailed overview of this delivery process is described in the sub-sections below.

4.4.1 Identification of children in need of PSS

The PSS delivery process begins with the identification of children in the community who may be perceived to be in need of PSS. This is in line with one of the goals of the CBO, as noted in the organisation's profile document:

"2.2.1 To identify and locate people living with HIV and AIDS regardless of their colour, sex, creed, religious or political orientation or socio-economic status" (Simbarashe National Network for People Living with HIV and AIDS Organisational profile document 2012:2).

This process of identifying CLHA is done by the trained fifth-level CBO project staff, also referred to as the home-based caregivers, who move from door-to-door, raising awareness on HIV and AIDS and its effects on the community.

Asked to actually explain how PSS was delivered to CLHA by the home-based care field officers [fifth-level field officers], a field officer explained during a focus group discussion that it began by the process of identifying the children in need of VCT during home visits in the community, and thereafter their enrolment into the CBO's support groups session and case management programme. In Petros's words:

Petros: "The first thing, after you have discovered what is happening to the child, you ... don't just attack the child, but first you'll talk to the parents because they own that child, so after you have talked to them, if they

understand personally they can go and have the child tested. After the test results, if they are positive, the child will go on to medication. But only when they give you the permission of doing the job, it will be up to you again to take that child and go with the child for testing. After the child has been tested ... it will be you again who will take the child to the lessons [support group sessions], because the child will be supposed to attend the lessons. With those lessons, you will be busy again, but since we will have committed ourselves to the work and will be already involved, there is nothing we can do, that's how we work."

During these visits, a caregiver may encounter a household with a sickly child who may be requiring medical attention. The deputy programmes officer, Gary and field officers Deby, Chipo and Noel explained:

Gary: "As I have said, we have trained caregivers who work in the communities. So we tasked them to identify children at random where they just go and look for children, and they liaise with the parents as they will tell them the agenda of this programme. Then the parents give you consent to take the children to the hospital [The CBO caregivers take the children to the hospital for Voluntary Counselling and Testing]"

Deby: "The home visits that we do, help when it comes to identifying children in need, since I would have walked door-to-door ... When I do 3 or 4 visits, as I speak to the parents they refer me to other children who are in need, whether they are asthmatic, diabetic or have TB [Tuberculosis], as well as HIV and AIDS. Then we collect the names and record them in a book which we bring to the centre. So when they come they come to the support [groups], they are mixed up to avoid stigma. So both [HIV] negative and positive children attend the support group"

Chipo: "So what we do, when we identify a problem among the children we come here, we play with them, teaching them how to live in the society. If a child is HIV positive [living with HIV], that child has to be taken care of, discussing with the child, eating food, you have to eat together with them, we don't allow discrimination. That's how we work."

Noel: "What usually happens is this, our structure [CBO operational structure] is very, very efficient. When the caregivers identify a child, sometimes if there is no problem, they will identify that ... there might be other problems like now the child is on medication, but we are failing to get enough food, or else there is discrimination at home. Now me as the field officer will see to this and I will create a friendly relationship with the child's family. After creating that friendship I will now be able to talk to them ..."

Another field officer, Lucy, shared a testimony of how she identified that her neighbour's child living with HIV, aged 12 years, required PSS. She explained as follows:

Lucy: "I once came across a case like that when this child was saying, people tell me that I am living with HIV because of my parents. So I explained to him so that he could understand. He could not eat food at his mother's home, he used to ask for food at my place to the point where the mother came to ask me about this. Then I went to talk with her and told her that her child was eating at my house, because he is saying he feels bitter because his parents gave him HIV. I reached the point where I had to explain to that child until he could understand and I said look, there is a child, a small child with HIV, and this child is 6 years, you are better because you can be treated and get well. So he accepted until today. He usually comes to me to ask if he is going to get well and I encourage him to keep praying, taking his medication as prescribed. Telling God that 'I do not want this sickness'. It can be suppressed forever. So he has accepted

and can now eat at his home with others, and also he is now free with them.”

At times the local community members themselves may tip or inform the CBO's field officers of a household with vulnerable children in need of support.

Paída: “... So here at Simbarashe we have home-based caregivers who also stay with the headman. The headman is the one who stays with these caregivers so they [headman] are then able to identify children ... ‘That child is not going to school, why is that so?’ This caregiver is then able to go together with the headman to the parents of the child. This then helps the child to get treatment or for her to go to school and also get support from Simbarashe or from elsewhere. This because the chief and the headman intervened. So at the end of the day you see that the child gets the proper attention that is needed ...”

The CBO's co-founder, Paída, elaborates on the role of the local chief in the identification of children:

Paída: “That issue of awareness campaigns that we talked about. The chief is capable of making people group together under the Msasa tree; then we go and speak about HIV and AIDS to the people who are gathered there ... the chief helped us a lot in identifying households with disadvantaged children.”

Upon arrival at the household, the community-based officers raise awareness on various HIV and AIDS issues affecting children, and encourage the caregivers of the vulnerable or sickly child to consider having the child tested to establish the HIV status of their child. The various benefits of this are explained and if the caregivers agree, the CBO field officers take the children to the Voluntary Counselling Centre (VCT) at the local clinic or hospital. This process was noted

to be a very useful strategy in promoting the existing HIV prevention, treatment, and care and support services in the community. The outcomes of the identification process are heavily reliant on the attitude of the CLHA's caregiver about the child being tested. As explained below by Betty, a caregivers of a CLHA:

Betty: "... so when we are at home, caregivers [CBO field officers] move around discussing what is happening at Robert's place [CBO premises], telling us to go and see what is happening and listen to what is being said about the children whose parents are dead, and they tell us that we can even take the children for testing. They used to explain things right from the start, bit by bit, until we could understand and get the knowledge to help these children, so we were not against them, but we thanked them and told them that we will take the children for testing. But before I took the child for testing I went to Simbarashe Network so that they could explain what they had said to me. So I came here and the Director clearly explained everything to me. Then after that, I took the child to the hospital and he was tested."

A junior field officer, Lucy, explained some of the challenges faced by field officers during the identification process and the reasons for this:

Lucy: "Some parents would get offended as to why and how the caregivers would have identified if their child had HIV and AIDS or not. Yet it will only be encouraging the parents to get their child tested. Some of them would actually go to the Chief to complain. In extreme cases they would not consent to the HIV and AIDS programmes."

Two explanations for the above challenges were given by a fifth-level field officer Deby and by Millicent, as follows:

Deby: "They [caregivers of CLHA] did not comprehend as far as the psychosocial support initiatives are concerned. But however, they now have an understanding of caregiver initiatives."

Millicent: "The other issue was that most people were shy. And they didn't want to be associated with living with HIV and AIDS. They were afraid of being stigmatised and isolated within the community."

4.4.2 Voluntary Counselling and Testing of children

According to the founders of the CBO, there was a realisation a few years ago that the HIV and AIDS testing and treatment services at their local health facilities had only focused on adults and not children. In addition, their own child was sick and upon being tested and being found to be living with HIV, this prompted the couple to start VCT campaigns for children in their local community. As explained below:

Paida: "We then realised that it is only the adults that are getting treated, what about the children? 'Why then don't we deal with the children?' That is when we started speaking with the parents of the children so that they could also go and get tested. That is when we started to get the children tested."

Robert: "Then the issue of children, we then discovered that we were concentrating on awareness as adults, forgetting our children. It all started with myself when I discovered that one of my children was ailing and I said to my wife, why are we not taking some tests for this child, and that's when we took the child for an HIV test and we discovered that the child was HIV positive, and at some stage we are to blame for not taking her to hospital early. So quickly I then started talking to our members, saying,

gentlemen let us concentrate on our children that they be tested as well. That's when we partnered with the children first programme, which was then being spearheaded by HOSPAZ. Then we teamed up and started a VCT programme, that is, in 2011 in February, that's when we started the programme for children. Then this VCT when we launched it, we started doing a sensitisation programme with the whole community, parents, headmen, everybody to sensitise that this is what we want to do, and we have thought of this because we were leaving our children behind. After this sensitisation we had to seek consent from the parents of the children. When consent was granted the children were then taken to the nearest clinics."

The director of the CBO further explained how the community was encouraged to take their children for VCT at the nearest clinic:

Robert: "What we then did was to sensitise the parents on how bad HIV is, and that we were expediting the death of our future generations ... So after educating the community, there was acceptance in the community that we needed to protect our children. When we started we had no target group as such; we were just saying from zero [age], any child has to go for a test and then it was agreed. But then we later saw that a number of children we were seeing were from 5 to 16 years who quickly responded to the call and were tested. Some of them, we have them here [CBO premises], some of them are in their relevant schools, and some of them live where they live."

According to two of the CBO's field officers, the child or children requiring VCT services are escorted to the local health centre by the child's own caregiver or by the Simbarashe National Network for People Living with HIV and AIDS's community-based caregivers. The officer only does this with the consent of the child's caregiver. At the local health centre, only the trained and qualified health

centre personnel conduct the VCT session with the child. Through this strategy the CBO saw many children in their local community get tested for HIV and AIDS.

Chenge: "Then we take the parents together with the children to the hospital. If they are living with HIV, that is when they start coming to support group programmes."

Thando: "We also take children whose parents are deceased because of HIV and AIDS for testing. If they are living with HIV we bring them back to support groups."

One caregiver of CLHA explained how their children went for VCT during a focus group discussion:

Mutsa: "When the testing programme [VCT] started, I went with the child for testing and was found to be living with HIV; then automatically the child went on medication. Right now the child is strong."

The CBO director and founder explained the outcome of the CBO's community VCT campaigns for children as follows:

Robert: "To tell you, in that month of February we tested about 700 children just in one clinic, this one Muramba Clinic, but we had about 5 clinics doing the same work and all these clinics ran out of testing kits. Then we discovered that we have around 150 children living with HIV, and it was a cause of concern."

In addition, the content analysis of the CBO's Simbarashe organisation profile document revealed the following statistics with regard to the VCT outreach for children during 2011:

“In February 2011, the organisation [Simbarashe National Network for People Living with HIV and AIDS] in collaboration with HOSPAZ and Children First organisation, embarked on the IMPACT programme with the main objective of accessing the children living with HIV and AIDS (CLHA) to ART. Through this programme, the organisation has managed to reach out to many people in the Mhondoro-Ngezi district and has managed to access 1 164 children. 206 of them tested HIV positive [living with HIV]” (Simbarashe National Network for people living with HIV and AIDS organisation profile document 2012:3-4).

4.4.3 Disclosure of the child’s HIV status

The local health personnel from the health facility disclose the results of the HIV test to the caregiver or to the CBO’s level-five field officer who would have escorted the child on behalf of the caregiver. At the health centre, the nurses empower the caregiver of the CLHA or the CBO officer with information on how to disclose the VCT results to the child. In addition, the CBO’s field officers also provide the caregivers with information on the available PSS support available for children who would be living with HIV at the health facilities.

An explanation of how the disclosure process takes place by the CBO’s deputy programmes officer is given below:

Gary: “Yeah it is like when a child is identified as living with HIV, we know the caregiver [CBO field officer] has been given consent to go with the child to go and get tested and so on. Then the nurse will just say child A, B, C, D have been identified positive and child E, F, and so on have been identified negative. Then it is quite hard for a caregiver at the clinic ... and say John has been identified to be living with HIV, then Peter has no HIV.

So it is like they have to go back to the parents then explain the results to the parents ... Then break the news. Then you get the consent from the parent to allow the child to be enrolled into this programme after having explained to the parent the benefits of the child being involved in the programme [After the benefits of enrolling the child into the CBO PSS programme are explained and they agree for their children to enrol, the children start the PSS programme].”

Gary further explained the benefits the CBO field officers told to caregivers of the CLHA who chose to enrol in the CBO PSS programme as follows:

Gary: “Yeah mostly we have no material benefit but, but it is all about this psychosocial support, positive living, HIV Literacy, child protection. Everything to do with a child, getting a child empowered about HIV information ...”

Answering a question on how CLHA came to know that they were living with HIV, one caregiver of a CLHA during the focus group discussion explained how the child’s HIV status was disclosed by a health worker directly to the child when they were collecting their medication:

Mutsa: “My child knows because she is in grade 4 ... The person who talked to her did so when she went to collect her tablets ... She was 9 years.”

The disclosure process was noted to be made easier when parents themselves had been tested for HIV. A field officer and the CBO’s co-founder Paida explained below:

Millicent: “In most cases parents who know that they are HIV positive [living with HIV] are quick to respond and they agree for their children to

be tested. And when the child is tested positive it does not come as a shock, and it is easy to incorporate the child or children into support groups.”

“Paida: “... Yeah, I saw that the children were quick to accept their status because it was difficult for the adults to go and get tested, because we had to explain bit by bit until they began to understand. But for the children whose parents would have been tested, they would actually help you to speak to the children.”

4.4.4 Support groups

Support groups for CLHA are key to the organisation’s PSS delivery to CLHA:

“The beginning of 2011 has seen Simbarashe Network establishing support groups for children ranging from five to sixteen years. The network facilitates VCT for these children. Our key stakeholders in the support groups are the Ministry of Health, HOSPAZ and Children First” (Simbarashe organisation background document 2012:8-9).

“To fully assist the 206 children who are living with HIV and AIDS, the organisation established 6 support groups, where children both infected [living with HIV] and affected meet for psychosocial support, adherence support, positive living, children’s rights awareness and HIV literacy” (Simbarashe organisational profile 2012:4).

The above quotations also clearly show that delivery of psychosocial support to CLHA aged 5 to 16 years was through the support groups, which involved child-friendly activities such as sporting activities, discussion sessions on children’s rights awareness, positive living and HIV education, among others.

As noted above, caregivers of the children who were tested to be living with HIV, are constantly encouraged by the CBO's project personnel to allow their children to join the children's support groups offered by the Simbarashe Network for People Living with HIV and AIDS. The CBO conducts weekly support group meetings, held every Saturday, for the children. Responses on what PSS was giving to CLHA from senior project personnel Paida and Abel, field officer Petros, as well as the caregivers of CLHA were as follows:

Paida: "We do support group every Saturday."

Abel: As an organisation [Simbarashe National Network for People Living with HIV and AIDS] we do support group meetings and under those platforms we engage the children in playing the games ..."

Betty: "There are support groups, they play together, they act dramas, they are being taught how things are like and how to cope when you are on ART. They are being taught everything that we do together, playing ball with others, doing this together as one."

Petros: "... here at Simbarashe there are support groups, we had not talked about it, those support groups ... every Friday or every Saturday they meet here, dealing with different kinds of children with different problems, so we touch so many issues."

Caregivers of CLHA [answering all at once]: "They [CLHA] come once a week to support groups ..."

The organisation offers this service both to CLHA and to those who are not living with HIV, mainly because they want to reach out to all vulnerable children in the community and in addition want to reduce stigmatisation and discrimination. The

CBO founder explained that, after the VCT for children had been conducted, he realised the need for the formation of support groups for the CLHA, which later integrated children living without HIV and AIDS. Recalling a statement he made to community members on setting up support groups for children, he stated:

Robert: "... let them [referring to children who had undergone VCT and were found to be living with HIV] then start PSS programmes. 'How then?' Let's formulate support groups for these children,' and we immediately formulated support groups, 6 support groups. Then we discovered that we were isolating the children now to say those living with HIV only, because we then create a stigma. So then we then said support groups will involve those living with and those without HIV. So every Saturday now children will group for a sporting activity ... which we would call "kicking out HIV through sport". Then we could play sports with them and would then sit down with them again for a session of drug adherence now that they are on treatment ..."

Although the meetings cater for both children living with HIV and AIDS and those without, the CBO project personnel noted that the support group sessions covered various topics, such as HIV treatment and drug adherence, healthy eating, sexual abuse, children's rights, HIV prevention, and stigmatisation and discrimination, specifically assisting CLHA and at the same time empowering those not infected with knowledge and information. The case management system in place at the CBO then further helped to target those children specifically living with HIV and AIDS. The founder of the CBO, Robert, was asked whether children living without HIV had ever asked why they were being taught topics such as drug adherence when it did not affect them. Robert explained:

Robert: "They haven't, because when it's being taught it's not targeted. It's like being taught as a subject, something you have to know. Then there is the case management issue of targeting those who are actually on

medication. You get what I mean?"

In order to have an in-depth understanding of how the support groups of the CBO contributed to the delivery of PSS to CLHA, the researcher observed the delivery of one of the CBO's support group sessions offered to children at the CBO. The support group session was for both children living with HIV and those who were not. As noted above in a quotation by Robert, the support groups accommodate children living with HIV and AIDS as well as those not living with HIV and AIDS. The support groups include other vulnerable children who have been affected by the HIV and AIDS epidemics. This is done so as to avoid stigmatisation and discrimination through segregation. Before the support group session observed by the researcher began, the researcher was informed by the CBO project officer conducting the session, that the majority of the children attending the session were CLHA. Part of the observation notes taken by the researcher during the support group session, which began with on a discussion on the topic of sexual abuse, are as follows:

"A support group discussion for the children is conducted in a small brick-walled classroom directly opposite the CBO wooden cabin office block. There are 12 children in this room, which could accommodate another 12. Of these, 6 are girls and 6 boys. Their ages range from 7 to 13. The children are seated on wooden benches in an L-shape pattern. There are 11 benches in the room and the children are seated on 5 of them. The room is full of colourful manila charts with English and mathematical illustrations. There are two huge blackboards on the wall. The floor is cemented and was in a good condition (Observation notes).

The meeting begins by the teacher Abel [who is one of the CBO's Senior field officers], who is in his late twenties and communicates and connects very well with the children, telling them that the topic of the day is on abuse, the different types of abuse (Observation notes).

The teacher asked the children what is abuse and no one answered, and he picks a boy named John. John's response: 'when someone sleeps with someone'. The teacher then adds that this is when one is forced to have sex. He asks another question, 'who can do this?' The children gave different answers such as uncles, fathers, brothers. Another child puts up his hand and mentions that abuse is when someone is beaten for no reason. The teacher then said the focus of the topic of the day was on physical and sexual abuse. He adds, 'does anyone know such a person, no names and I will not ask their names'. Only one child slowly raised her hand. Another child raises their hand and asked the teacher 'do you mean from our group?' The teacher notes it could be anyone they know from their community and 5 children raised their hands. He further asked how they felt when they saw such children then the majority said they felt pity for them. One of the children said if they had a home of their own they would have taken them and looked after them (Observation notes).

The support groups are structured in such a way that children participate in the PSS delivery. Older children are appointed as group leaders of younger children and are empowered to assist the CBO's project personnel in managing the support group activities. As further noted by a senior project officer, Abel:

Abel: "We train them to be support group leaders so that they can be able to offer peer-to-peer counselling, peer-to-peer leadership, so they won't need much of elders' guidance. They can solve some of the little issues that they come across."

Another part of the observation notes from the support group discussion observed by the researcher are given below. In this part of the support group discussion the facilitator continues the discussion on sexual abuse and further discusses topics on healthy eating and HIV prevention:

“After 20 minutes of the support group session, the facilitator shifts the discussion to the effects of sexual abuse and HIV infection in children. He asks a question on what a person living with HIV must do in his life. At this stage many of the children who were active seem uncomfortable as they move away from glaring straight at the facilitator and start to look downwards. One girl who is very shy answers “one should go to the clinic.” Another boy adds ‘to get tested.’ The facilitator then emphasises that testing is done at the hospital. One boy who has been keeping his hand up adds that ‘people that are tested should eat good food.’ Then the facilitator asks what kind of food should be eaten?’ and all the children lighten up, and most of them raise their hands, giving answers such as vegetables, fruits and traditional foods known in the area. Another boy shouts ‘sweets’ and all the other children burst into laughter, shouting ‘that is not healthy.’ One of the children adds ‘they taste nice but they are not healthy.’

Facilitator: I am now on medication and I am now growing up and I am in my puberty stage ... let’s say the child is a girl and she is going through puberty. Her breasts and hips begin to develop, or if the child is a boy and he is going through puberty his voice deepens and he starts to develop a muscular shaped body, and I have these sexual attractions towards a girl, what is it that you can tell me that can help me so that I do not infect my partner with HIV?

Child 1: You can use a condom ...

Facilitator: What if I haven’t had intercourse with her but I want to fall in love her. Is there a word that I am supposed to know? We once talked about this word and we said it starts with ‘A’?

Child 5: And ends with what?

Facilitator: With an ‘E’.

Children: M-mm ... (Thinking)

Facilitator Teacher: Let’s start at the beginning.

Child 2: Acquired ...

Teacher: Not acquired ... (children laugh). The word starts with A and finishes with E. If I had a chalk I would write the name in jumbled letters so that you can try and get the correct answer. So whoever gets it correct will get a round of applause from the rest of the class, right? Let me give you a tip whilst you think, the word has 10 letters. I will give the meaning of the word: I am grown-up and I have not yet engaged in sexual intercourse and remember that I am HIV positive and I want to preserve myself, but at the same time I love my partner. (The facilitator starts writing the letters of the word on the chalkboard)

Child 2: (shouts) Abstinence!

Facilitator: Yes, abstinence. Let's clap hands for him. (The class claps hands) ... Right, we said that abstinence means that you are not supposed to have sex until you are mature enough. We can get condoms when you are grown-up, isn't it? ... the use of condoms is another way to prevent HIV transmission" (Observation notes).

The delivery of PSS conducted through the above support group emphasised the need for CLHA to prevent the further spread of HIV in the community. The discussion also encouraged all the children to delay sexual activity, especially the children who were below 15 years of age.

4.4.5 Case management

The case management of CLHA by the CBO came about after the CBO realised that many of the children required additional support to adhere to their HIV medication. As explained by the CBO's Director below:

Robert: "That's when we said we need to monitor these children to ensure that these children are on medication, we need to ensure that these

children receive PSS, we need to ensure these children take their drugs, we need to ensure that these children are being monitored. That's when we took up our home-based caregivers for case management. We have around 150 children living with HIV who have been tested and found to be living with HIV. [Then we said] what we have to do here then is to take them for a CD4 count and ensure medication has been given to them."

Asked how case management was conducted, the responses from a home-based caregiver field officer during the focus group discussion were noted as follows:

Alice: "In the area where I am staying, I have a number of children I am taking care of. I visit them frequently, Monday to Friday, assessing their health. I also carry medication in the form of pills which I will give them if they have for example, sores on the head."

Asked to specify the types of drugs they distributed, the field officer stated the following:

Alice: "To give the children, for example, paracetamol."

Asked how often they conducted the visits to children, another field officer explained:

Chenge: We go on Monday, then Friday.

Reseacher: Every week, the whole year?

Chenge: Yes.

Asked on how the case management was actually done when they arrived at the home of the CLHA, and whether it was done in the presence or absence of the

caregiver of the CLHA, the field officers responded:

Alice: "Usually we want the parent to be there so that they will help with taking their medication, because some of the children need help on the time to take their medication,"

Millicent: "Okay. I wanted to say it also depends on the child's age and their level of understanding. U-ummmh ... because some of them can understand and are able to read a watch and see that 'it is now 6 o'clock, I have to take my medication' or if the child is staying with granny, granny cannot read a time watch, and so if the child is too young we need to explain to the parents on how they should be cared for in relation to the child's illness."

When asked to further explain what age groups the field officers considered young, another field officer stated:

Deby: "From 1 year to 10 years."

Discussing what the case management of the identified child involved, a field officer, Petros, explained as follows:

Petros: "Then after that, you will keep on with the programme, making sure the child is on medication and is the child adhering to that medication? – meaning to say, 'is the child properly taking the medication?', especially the girls who are mature. What usually happens is that, sometimes when they are feeling better they might think of leaving the medication, so you have to follow-up so that you monitor them every time, but usually you give the support to those who stay with the child to watch if the child is taking their medication properly."

In addition, the content analysis of the CBO's organisation profile document revealed that in 2011 the CBO trained 50 of its field officers to specifically provide case management to the 206 children who had undergone tests and were found to be living with HIV:

“This programme has 50 trained caregivers [CBO home-based care field officers] who case-managed the 206 children with HIV” (Simbarashe organisation profile document 2012:4).

The content analysis notes established that the following published resources found on the CBO library were used as reference material for the case management:

- *The Integrated Management of Paediatric AIDS/HIV care and treatment and PMTCT(IMPACT): A Bantwana Model Facilitators manual*
- *Case management guidelines for secondary caregivers (Hospice and Palliative Care Association of Zimbabwe (HOSPAZ)).*

4.4.6 Transitory school for OVCs

The study established that the Simbarashe National Network for People Living with HIV and AIDS delivers PSS to CLHA through a nursery facility and transitory school for out-of-school OVCs. The transitory school located on the CBO's premises was birthed from an idea by the CBO's founders to have an Out-of-School Study Group (OSSG) project for disadvantaged children in the community. This transitory school is also referred to as a 'Safe Park' by the CBO, as it provides social protection services and the OSSG for children. The school was birthed after a realisation of the social needs of vulnerable children in the community. As stated below by Robert and the CBO's project documents:

Robert: "... we discovered a missing link that these children had been identified as those that had not been tested [but now they have been tested] and are now receiving their ARVs and they are now being case-managed, but further to the effects [of HIV and AIDS] these children are not going to school. But we cannot open up schools ourselves. Let's then start to talk to the government for a transitional camp where we say we build up community learning centres in preparation to re-integrate these children back into formal education. Then we grouped the children involved in the government correspondence schools with their syllabus, so that they would get the little they could, for basic primary education to the children, whilst we source funding to re-integrate these children back into formal education. This was received and we started doing that programme.

"The idea of the OSSG led to the idea of the establishment of a transitory facility at Simbarashe resource centre in Chief Mlambo's area, where out-of-school children come for OSSG. Simbarashe is now running two such facilities catering for about 250 children, with the second facility at Jompani site" (Simbarashe National Network for People Living with HIV and AIDS concept paper 2012:1).

"Simbarashe was moved to think Out-of-School Study Group (OSSG) project to cater for the disadvantaged children ... The OSSG would contribute towards a holistic package for vulnerable children who were receiving other social services such as voluntary counselling and testing (VCT) for HIV, psychosocial support and food and nutrition support ..." (Simbarashe National Network for People Living with HIV and AIDS concept paper 2012:1).

The main goal of this facility is to provide educational services to these children while they await re-integration into the formal education system, when the CBO and the government Department of Social Services have the capacity to do so.

Re-integration of the children was at the mercy of on the availability of funding from the government:

“The [transitory schools] facilities are ‘Safe Parks’ in the sense that children who come to them are protected, receive social protection services that Simbarashe is involved in, and also attend OSSG with [the] aim of being re-integrated into the formal school system” (Simbarashe National Network for People Living with HIV and AIDS concept and paper plan 2012:1).

As explained in another project document below and by the co-founder of the CBO, many of the children enrolled in the CBO’s school facilities were OVCs and some had been out-of-school due to poverty:

“The Network [CBO] has established a crèche for sixty (60) pre-school children and most of whom are orphans, while others are living with HIV. Tuition is free of charge” (Simbarashe National Network organisation background paper 2010:8).

Paيدا: “... when we saw that the children were getting tested, that is when we realised that some of the children are not going to school ... We then wrote to the Ministry of Health and Child Welfare. And we realised the reason why the children were not going to school was because of money, they did not have, their parents are poor and some of the parents have passed away because of HIV and AIDS. So then we started a start group at Simbarashe, so from there we started working with the children, teaching them, conducting support groups and teaching them about living with HIV and AIDS, wondering, can the children accept their status at a young age?”

The CBO school also benefits CLHA that would have faced abuse from their

caregivers and would not be receiving any form of education. A field officer during a focus group discussion related a case of how two children living with HIV, who were identified by field officers as being abused by their grandmother at home, eventually ended up being enrolled at the CBO school where they are now receiving education rather than staying at home. The existence of the CBO school has helped to improve these children's lives. In addition, through the intervention of the CBO personnel in dealing with this case, the grandmother's treatment of the CLHA has improved. The field officer related the story as follows:

Noel: "Mine is about abuse. There are children who lived with their granny. Granny was very old and the children were very young. All the parents were dead. There were four of them and two were living with HIV virus, but the other two were not. The way these children were treated, those living with HIV, were not good at all. They were badly treated. When we heard about this, we tried to talk to the grandmother to make her amend her ways so that she treated the children like their own children. They were her daughter's children all four of them, but she showed a very big difference, a very big difference [in the way she treated them], which could be seen by even small children that she was ill-treating those children who were living with HIV. When we tried talking to her, things changed for the better for a short while ... we discovered that she was going on with that behaviour again, and we ended up forwarding the issue to the directors and it was like things got better. So right now you cannot see the problem anymore. They are now being treated well like the other two children. She has changed her behaviour because she was helped to amend her ways ... the ones [children] who were being ill-treated [were aged] eight and below ... Right now they attend the school with others, they participate in the activities done here [at CBO]. Here at this school they come to learn with the others."

The founders of the CBO also stated the numbers of the children attending the school and the role she played in delivering educational and PSS services to the children who attended the school:

Robert: "As I speak to you now, we get over 250 children who are receiving PSS and who are receiving basic primary education, receiving sports to get to the Millennium Development Goal (MDG) [MDG 2 Achieving universal primary education]. So this is what we are doing together with the government of Zimbabwe, the Ministry of Education ..."

Paida: "At this point in time we have about 281 children who are attending our school at Simbarashe. I am the facilitator in level 1 for the start groups here at Simbarashe."

Asked to explain what she meant by being the "facilitator in level 1", Paيدا further explained:

Paida: "A-ah, when I say I am the facilitator, I will be teaching the children that, that and this, even this how one can live if they are living with HIV. And also if you are HIV positive it does not mean that you are going to die. Furthermore, I also teach them what is taught in schools, also I teach them vocational skills. We teach them how to write, some are not able to say ... 'My name is ...' We actually do step-by-step since the child will be just sitting at home doing nothing. So we do step-by-step ... how A is written, how B is written."

Caregivers of CLHA were requested to explain why they specifically brought their children to the CBO school facility, and why they did not take them to the formal education facilities in the community. They explained:

Sophia: "It's because we have nothing [financial resources]. At school

[referring to formal schools] they need uniforms, books, pencils, rulers, but here they are given everything. They don't need money here, like this year things are so hard (u-um) people have nothing, even food, so it's like when we find there is food and children also going to school and they find on the table when they're back, we are happy."

Buhle: "That's the same: you cannot find money for school and buy food for the child also."

Jackie: "I want to add something, that at school [referring to CBO school] when a child gets sick I don't pay money for hospital [fees]. The child is treated for free, so it helps me in a way that my child's health is always taken care of."

Asked to explain further on their previous experiences with the formal school system when their CLHA had fallen ill, two caregivers of CLHA explained:

Jackie: "The teachers could only give a letter to go to the parents and go to the hospital for treatment, because they said the child couldn't mix with others when they were sick."

Yvonne: "Here [CBO School] the school takes them to the hospital, Mr Robert [CBO Director] assists."

The caregiver of a CLHA further explained that, even if the formal school authorities decided to take the responsibility of taking a sick CLHA to the clinic, in the formal school system the school authorities would still send the child home with a letter requesting the child's caregivers to cover the medical costs that would have been charged. A caregiver explains what the formal school authorities had said to the CLHA:

Yvonne: “Go and get some money’ [what formal school authorities told CLHA]. The child is given a letter and they will take the letter to the clinic and there they want a treatment fee of \$2. They [health authorities] send the child back to the parent for the treatment fee but if they see that it’s serious, they treat the child but the US\$2 is required to be paid there and then.”

Another caregiver of a CLHA adds:

Jackie: “Plus at school [formal school system] the headmaster will just write a letter and tell the child to go home and get treated, even when the child is sick. He will give some days so that the child will stay at home receiving treatment, but he doesn’t offer any kind of help, but just a letter to the parent to take the child to the hospital.”

4.4.7 Child-friendly rights-based approach

Embedded in the CBO’s core objectives is the CBO’s commitment to the delivery of rights-based HIV and AIDS services to children living with HIV and AIDS and those affected by HIV and AIDS. The content analysis of the CBO’s concept plan document affirmed this through the following statement:

“It [Simbarashe National Network for People Living with HIV and AIDS] has a set of core values that point to its objectives, that include:

- a. To provide equal community access to health services,*
- b. Promote and advocate for children’s rights in the community, and*
- c. Provision of non-discriminatory access to basic education to all the vulnerable, the disabled and the children living with HIV and*

affected children and youth” (Simbarashe National Network for People Living with HIV and AIDS concept paper 2012:1).

The study further established that PSS was also delivered through child-friendly rights-based approaches. The CBO uses various electronic and published resources from NGOs, such as the *“Psychosocial well-being series: Facilitating Care and support through kids clubs* authored by REPSSI, play cards, CD stories, as well as games and sports to educate and deliver messages on various PSS issues affecting CLHA in the community. As explained by the CBO Director:

Robert: “Okay, we have a CD listener programme, which has very nice educational stories where they listen to, like ‘ngano’ [folk tales] for instance, but this story will be educational ... Then general games like fish-fish [skipping rope game], it does good to their minds. We have got a way that they play with their play cards; we have got quite a number of playing cards. Here which method of playing is designed very well with the facilitator, who does the day-to-day work in groups. So they will then run and do some kind of competition in their playing cards, and obviously soccer, netball, ‘dunhu’ [a local Zimbabwean game]. They have quite a lot of these games and are part of their psychosocial support. Then obviously they are actually taught ‘what is HIV?’, ‘What are these drugs for?’ ‘How then do you take them?’ That kind of thing ...”

In addition, the children’s games are designed to loosen up and engage the children regarding various PSS-related issues. As further explained by the CBO’s Director and co-founder:

Robert: “We design quite a variety of games and they open up at the end of the day. Children like to play, remember, and we have very little time to sit with them and maybe educate them. But the games are designed in such a way that they are educational plays. So they open up at the end of

the day these activities are the remedy for denial, withdrawnness ...”

Paida: “We can say to them play soccer, skipping rope games, play card games. All this helps the child to loosen up.”

Another senior project personnel explained:

Abel: “Yes, as an organisation we received comic books from one of our partners, that is, World Education with information on children’s rights, responsibilities and duties. So by involving these children now to participate in children rights, promotion and responsibilities you would then say that they gradually learn the best ways on how a child can behave in the society.”

The study established that the approach used by the CBO has also assisted in meeting the basic human rights of children, such as education. The co-founder of the CBO shared a testimony of James, a 14 year-old boy, who had dropped out of school when he was young but was now enrolled at the CBO’s school, where he is enjoying the child-friendly activities:

Paida: “We have a child who is 14 years. This child last went to school at grade 5. So he basically used to go and herd cattle, so he used to go to school here and there. So at the moment I see that his life has changed. Whenever we got clothes we would give him and he would go home very happy. So [currently] he is taught at school [the CBO school], at support groups and he plays with other children. He is also now able to write. At the present moment he has gone to Harare to play soccer and since he had never used modern-day public transport, so we see that this experience has indeed changed his life. His name is James and he is 14 years.”

Caregivers of CLHA commented on the kind of services delivered by the CBO that met their children's PSS needs. The caregivers commented on how joyful their children were after attending PSS activities, and how their CLHA also enjoyed the children's snacks and food offered to them at the CBO. A caregiver during a focus group discussion explained:

Jackie: "What I realised is that this programme for the children is very free, so after the children have come here [CBO premises], when we are discussing with them doing this and that, they are now feeling free to say out whatever will be troubling them. So when they are playing [at the CBO] they are given Zapnax and Maputi [Zapnax and Maputi are popular snack foods for children in Zimbabwe], they play house, they play ball. So you could see that the child is free and is happy, that he is being looked after very well."

Jackie: "[What the CBO offers children] Drinks, Mazoe [a popular Zimbabwean drink], biscuits then from there they go and play ball at the grounds, after that they are given sadza [maize meal] and after eating they go home. They feel very happy, such that they start exchanging hugs even with those who are not sick. They feel happy because they know that if they come [to the CBO premises for activities], they will eat, you hear them saying there is 'lumo' [slang word meaning food] (laughing)."

4.5 CRITICAL FACTORS INFLUENCING DELIVERY OF PSS

The study established that the critical factors that influence the delivery of PSS to CLHA by the Simbarashe National Network for People Living with HIV and AIDS can be categorised under six major thematic areas, namely: psychosocial challenges experienced by CLHA, human rights, community-based approach, caregivers, integrated HIV and AIDS services, and partnerships. These thematic areas and the corresponding factors are summarised in Table 7 below:

Table 7: Critical factors that influence PSS delivery

THEME	FACTORS
1. Psychosocial challenges experienced by CLHA	<p>Recognition that CLHA have PSS needs associated with:</p> <ul style="list-style-type: none"> i. Drug adherence ii. Denial of HIV status iii. Disclosure iv. Isolation and or depression v. Bereavement vi. Stigmatisation and discrimination vii. Poverty viii. Stress
2. Human rights	<p>Commitment to human rights</p> <ul style="list-style-type: none"> i. Children's rights ii. Child protection
3. Community-based approach	<p>Adoption of a community-based approach through involvement of community members:</p> <ul style="list-style-type: none"> i. Committed community-based volunteers ii. Local traditional leadership (chief and headman) iii. People Living with HIV and AIDS
4. Caregivers	<p>Caregivers' attitudes towards:</p> <ul style="list-style-type: none"> i. VCT
5. Integrated HIV and AIDS services	<p>Availability and access to HIV services</p> <ul style="list-style-type: none"> i. Availability and access to HIV prevention, treatment care and support services
6. Partnerships	<p>Partnerships with external partners</p> <ul style="list-style-type: none"> i. National AIDS Council ii. NGOs iii. Government departments

4.5.1 Psychosocial challenges experienced by CLHA

4.5.1.1 Recognition that CLHA have PSS needs

The study revealed that the CLHA involved with the Simbarashe National Network for People Living with HIV and AIDS have various psychosocial needs associated with their HIV and AIDS infection. Some of the main PSS issues in CLHA were associated with dealing with drug adherence, denial of HIV status, disclosure, isolation or depression, stigmatisation and discrimination, stress, bereavement and poverty.

A few of the issues highlighted by the key informants are further discussed in detail in the sub-sections that follow:

4.5.1.1.1 Drug adherence

With regard to drug adherence, the study noted that the CBO recognised that this was an important issue that had to be addressed, as some CLHA had struggled with this issue. The struggle with drug adherence was because of the absence of supervision by the caregivers of CLHA. When asked to relate the PSS challenges faced by CLHA, the CBO's senior project personnel Robert, Paida, Gary, and the field officers Petros and Pilani explained that some children struggled with drug adherence issues because they were laughed at by their peers when they were seen to be taking HIV-related medication. Although the CBO explained to CLHA the importance of drug adherence as well as the dangers of non-adherence to drugs, some children were noted to stop taking their medication when their health had improved and they were feeling much better. This challenge of drug adherence has resulted in the problem of the children getting sick often. As explained below:

Robert: "They also lack adherence in taking their medication, of course you would have taken the children to the hospital but they do not have a primary caregiver who is competent at home, as they need day-in day-out supervision, which this organisation is offering through the case management programme, where we are then saying, 'Where is Catherine? Did Catherine take her drugs today?' ... We educate on the medication they are taking."

Paيدا: "Here one can say that he or she does not want to take his or her medication, because he or she is afraid to be laughed at by his or her peers. So we teach, teach them, encouraging them to take their medication as prescribed."

Gary: "Then we would rather talk of adherence support [explaining to the children] 'Why it is important for you to adhere to medication as prescribed, and what are the dangers [of not adhering to the drugs].'"

Petros: "What usually happens is that, sometimes when they are feeling much better they might think of stopping their medication, so you have to follow up so that you monitor them every time, but usually you give the support to those who live with the child to watch if the child is taking medication properly ..."

Pilani: "... some of them they had problems of getting sick again and again, so they would end up going to the hospital to be told what to do. Here we could only teach them adherence to ... to their medication, how important it is so that they will not get sick every time ..."

The senior project personnel Paيدا noted that drug adherence for young children living with HIV did not seem to bother them until they were at puberty stage, particularly when they were now getting attracted to the opposite sex. This issue

had led to some children becoming ashamed of their HIV status, which in turn affected how they adhered to their HIV medication. She explained below:

Paída: "... that child can be 10 years and will be happily taking her medication but at 13, 14 years she starts getting interested in boys and then she gets embarrassed to be seen in the queue for going to take ARVs, and she might say, 'people will say that I am sick' – so then she will stop taking her medication or the grandmother will go and collect her medication. But at the same time, if someone collects her medication for her, it is tricky as she must also consult the doctor or the nurse. So when their peers laugh at them it discourages them and makes them unhappy."

In addition, the support group session discussion observed by the researcher covered the topic of drug adherence and illustrated that this was an important issue recognised by the CBO affecting CLHA. Children who participated in this session were able to even name the drugs given to CLHA. A brief discussion on drug adherence observed by the researcher was as follows:

"Facilitator: Let's say that I am 10 years old and I am HIV positive and I am eating my traditional vegetables. If I do that ... is it enough? I have eaten traditional vegetables. Remember that I am HIV positive, even though I have been raped ... What else do I do?"

Child 1: You take your medication.

Facilitator: What is the name given to the medication?

Child 2: Lamivudine ...

Facilitator: Yes ... all the tablets are called ARVs but she gave us the name of one drug. What are the names of the other drugs? Is there anyone else who knows the other names?

Child 2: There is Zidovudine and Stalanev" (Observation notes).

4.5.1.1.2 Denial of HIV status

Some children struggled with accepting their HIV status, particularly those who had discovered their HIV status when they were much older or were infected through mother-to-child transmission. As previously discussed, the VCT campaigns conducted by the CBO resulted in a number of children being tested for HIV. Acceptance of the HIV results for some children was noted as a PSS issue that the CBO had recognised. When asked to discuss some of the common behaviour in CLHA, project personnel Abel and the Director Robert noted the issue of denial as illustrated by the following statements:

Abel: "... there is also denial. Especially in children who might find out that they are living with HIV and AIDS maybe after being sick, like 10 year olds, 12 years, then suddenly he or she falls sick and upon being tested for HIV, then the result is positive, denial takes place. That denial might lead the child to behave in various delinquencies like prostitution, early initiation into sex, because remember, HIV in our community is attached with promiscuity. So maybe because of their failure to have resilience the child might conform to what the community says about HIV."

Explaining on the issue of denial, the Director noted the following:

Robert: "Yeah, [yes] in denial you try to talk to the child, try to lift up her or his spirits for him or her to participate with others. Then you will see at the end of the day that this child is still withdrawn. 'Are you not feeling well?' 'No, I'm okay, I'm alright.' 'Are you hungry?' 'No, I ate something. I'm alright.' 'Then what is it?' If it cannot come out then you can later see that the child is in denial because of the status. We continue to talk to the child, lifting the spirits, then gradually, slowly, maybe she will come round like that in the morning you will see that this child is far withdrawn, then maybe around 10 or so you will see that she is speaking now. That's how I can

explain this denial.”

Commenting on the issue of denial, another senior project officer Gary noted the following:

Gary: “Okay. Mostly those who are in support groups, in the first days they were in some sort of denial.”

A caregiver of a child living with HIV, Buhle, explained how their child had initially struggled with accepting his HIV status:

Buhle: “The child that I stay with did not easily accept it [HIV status]. It was because the child was still young and began to notice that my own children did not take this medication except him. So he once asked me, saying ‘why is it that I am the only one who is taking these tablets in this house?’ Then I took him and explained to him that you are the only one taking tablets because you are always sick, so that is why I always take you to the Doctor, and these other children are not sick. Can’t you see that now you have recovered, you are now better? And he even said ‘Yes mama, I am now better’ but it took him time to accept that he was the only one in the house taking medication.”

Another caregiver, Betty, explained how their child came to accept her HIV status and how this contributed to her improved drug adherence:

Betty: “My child knew when she was 10 years ... luckily enough at home I have my aunts ... who came to talk to her because she used to take her time if you asked her to take her tablets. It would take her time to respond. After explaining things to her she began to cheer up, and then one other time she came to me and said, ‘Look, I am taking the same medication as brother Dickson,’ and I said, ‘You see, I always tell you that.’ That is when

she accepted, from then on and takes her tablets ... When she was supposed to go to St Michaels [hospital], she told me to stay behind and said she was going together with Dickson.”

4.5.1.1.3 Disclosure

With regard to HIV disclosure, there was recognition by the CBO's Director Robert that this was not an easy issue to deal with for CLHA. He explained:

Robert: “And are they aware they are living with HIV? That’s one hell of an issue, so we try to ensure that disclosure is done to them at an early age that they would grow up knowing. That’s when they start accepting themselves and become bold and stand firm.”

Other senior project personnel such as Gary commented on the issue of disclosure, noting that some of the children, upon starting their support group sessions, had difficulty in talking about issues associated with their HIV status. The children would whisper when talking to the CBO's project personnel, not wanting the next person to know about their conversation. This point was strongly emphasised by Gary in the following quotation:

Gary: “They did not want to disclose their status or they did not want their counterparts to know their status. So we kept on sensitising them, telling them why it is good for someone who is near you to know your status. So they developed resilience and their behaviour changed. They are now different people.”

The project personnel further explained why some of the CLHA struggled with disclosing their HIV status. He noted that some CLHA struggled with disclosure because they were either in fear of the unknown or were afraid of being ridiculed

by the effects of stigmatisation and discrimination in the community:

Gary: "Okay. Firstly, it is like fear of the unknown, that is why they do not want to disclose. They do not even want someone who is nearby to know. Maybe you want to laugh at her and so on. And at the same time they thought there is an element of humiliation in them, if someone knows that this is Patience who is HIV positive, yes this is Tanaka who is HIV positive. They thought the whole community will laugh at them and so on ..."

4.5.1.1.4 Isolation and or depression

Asked about what the other common behavioural issues were that the CBO staff had picked up in CLHA, responses included that the children struggled with depression and either isolated themselves constantly from other children or withdrew from what was taking place. As noted by the CBO's senior project personnel, Robert and Abel:

Robert: "Very withdrawn, very withdrawn. You will immediately tell that the child is thinking and is not concentrating, and the reason is 'what then shall I do with HIV?' It's like a kind of a drug [addiction], a lot of misconceptions which at the end of the day becomes then our duty to iron out, to explain, to give hope, to say no, no it's not like that, HIV is like any other disease. You don't have to worry. So with time now we measure if the child is still withdrawn, if the child is in denial, if the child is isolating himself or herself, they just want to be on their own ... We then have to say 'no, no, no, that's not how it is, it's not like that ... did you know that I am just like you? Think of it, I'm just like you. So she say's 'no you are not like me' and I say 'why? Why do you say I am not like you? I am also HIV positive like you, and I'm doing A, B, C, D and everything is moving'. So

they start to open up and they start to mingle with other children who are like them who have actually accepted and life goes on. So it's like when you measure you are able to see that they are improving and they return to normal."

Robert further explained the results of this tendency to withdraw:

Robert: "Obviously that child when it's withdrawn and it's not participating ... it's psychologically damaging."

Abel: "Yes, you would find [there is] the issue of denial and withdrawal from their peers. You would find that in their minds things are not well and because things are not well, the child will be having some questions that will be impacting on his or her behaviour, causing him or her to withdraw herself from others. And also choosing to be alone, and you will find that it is also part of the psycho-motor [psychological behaviour which affects their ability to become active] of the child. These are issues that have impact on the child because, remember, a child does not have much to think about but it is difficult to...it takes time for a child to forget. So what he or she comes across at the period when he or she is HIV positive, you know it really plays a major role in making the child becoming someone who is ready to fight the war or someone who will chicken out [give up] or give in."

A caregiver of a CLHA also described this tendency to withdraw:

Buhle: "I observed that he usually sat alone quietly. He could not play with others. I used to force him to go and play, so I thought there was something bothering him [were maybe he was asking himself] 'what's happening in my life exactly. So I could talk to him nicely, explaining things bit by bit, asking him and make him happy."

Field officers Petros and Pilani described the behaviour of loneliness in CLHA because they did not want to interact with other children:

Petros: "When they first came here [to the CBO], they used to be lonely, they could sit alone like what they do at home, not wanting to mix with others. But through educating them they ended up mixing together ..."

Pilani: "Others used to withdraw themselves ..."

4.5.1.1.5 Bereavement

The CBO recognises the effects of bereavement on CLHA, particularly those who had lost one or both parents. The Director of the CBO noted the following:

Robert: "We discovered that quite a lot of these children have got no parents. They passed away either of HIV or something else."

A field officer during the focus group discussion also noted the following about the CLHA:

Pilani: "... most of those children are orphans ..."

While explaining the reason why CLHA did not want to disclose their HIV status, a senior project personnel Gary noted the effects of bereavement on CLHA, particularly those who had lost their parents due to AIDS-related illnesses. He noted that these children moved into the homes of extended family members where they often suffered ill-treatment and child labour at the hands of foster parents. This realisation has enabled the CBO to conduct child counselling sessions as part of the PSS to address the issues associated with bereavement

and orphanhood. As explained below:

Gary: “There are situations where, like a child is born today, both parents die, then he is brought up by grandparents or foster parents. So at times you just know how these parents treat these minors. It is not a new thing and some of us came from such situations, so you just know the ill-treatment they get. So it is painful for them to narrate what they went through. So mostly they do not like to talk about it. To make matters worse, he is orphaned. For a child to continue saying ‘my mother died of HIV’ ... aah [sighs] it becomes painful, especially for the children.”

4.5.1.1.6 Stigmatisation and discrimination

The study established that stigmatisation and discrimination towards people living with HIV and AIDS in general was a challenge faced in the community. As already noted above, HIV was often seen as a disease associated with promiscuity, and so even CLHA growing up in this community were affected by the negative perceptions of those around them. Ben (from the National AIDS Council) noted that the stigmatisation and discrimination against CLHA was emanating from community members who lacked an understanding of HIV and AIDS. The stigmatisation and discrimination affected the emotional and psychological well-being of CLHA. He explained as follows:

Ben: “These children, because of HIV and AIDS, they ... they have experienced stigma and discrimination within the community ...”

In another quotation Ben commented:

Ben: “... it’s [referring to the stigmatisation and discrimination] coming also from the general community as well as within their households, where the

households or families don't understand issues to do with HIV and AIDS. Hence they tend to stigmatise and they don't understand the life experiences of these children, hence the children having to suffer emotionally and psychologically."

Explaining further, particularly on the emotional challenges faced by CLHA of the feelings of neglect, lack of love and appreciation, which affected the children's self-esteem, Ben noted:

Ben: "We are looking at families or households which do not understand or appreciate that a child living with HIV is just like a child ... is just like any other child who is not living with HIV, and they tend to fail to give them enough love to appreciate them and also... they tend to stigmatise them and they are separated from other children ... And those experiences make children feel neglected and brings down their esteem and actually, finally, it will affect their emotional being as well as psychosocial, you know emotional well-being ..."

Field officers Noel and Lucy and a caregiver of a child living with HIV, Betty, also noted the challenge of stigmatisation and discrimination against CLHA, from the community members as well as from themselves:

Noel: "... the other problem is that there is discrimination, it happens a lot here. A child can be discriminated by others or can discriminate him or herself. He and she can be afraid to mix up with others because of what he or she is. So there is need to teach them that there is no difference. Your sickness is like someone with sugar disease [diabetes], cause someone with sugar disease [diabetes] can also mix up with other people even in the bus, in the combis [commuter omnibuses] and can also go to the same school as others. Even those with blood pressure, they are everywhere, so even you can also be everywhere. So it will help the child

not to look down upon him or herself, like when it comes to the issue of school. Like here when all the children come [gather together] they have time to discuss [such issues] with the Directors. They are taught to avoid stigma. Like if there is a child with wounds, they must not be condemned ...”

Lucy: “To some it is the issue of stigma; they feel bitter because some fellow students from school will be calling him names or saying he or she has AIDS, so that child will feel out of place and feel different, thereby he or she will be troubled at all times.”

Betty: “Because these children were going to school, you see when they were playing at school, some of our children will be having wounds and so others would not play with him, because they will say that ‘he is sick’...,so these other children end up not participating in activities or mingling with our children who have head wounds or something, or are even coughing severely. Someone can even say ‘hey you are boring me [irritating], go and do your coughing somewhere else.”

When asked about the specific care and support topics they discussed under the CBO’s programme for CLHA, another senior project personnel, Gary, responded by pointing out the issues of stigmatisation and discrimination:

Gary: “Okay. We have to tell them how best they can live with HIV. How best should they do or should they deal with discrimination and stigma. So when we talk about psychosocial support it is about the psychological and social aspect. So mostly it is discrimination and stigma which affects the psychological part of the child and the social part of the child. So mostly we were teaching them how to deal with stigma and discrimination.”

Gary was asked to further explain the exact information the CBO provided to the

children to help them deal with stigmatisation and discrimination. He responded as follows:

Gary: “Yeah, [yes] we had to teach them, we had to let them know how the community views someone who is HIV positive, as our community is not really informed about HIV. Of course we know that we have had HIV programmes in the community but the level of understanding with the community is different. So we are trying to take the children to our level of understanding, removing them from the community’s level of understanding. So we had to teach them how these people view them and what is really stigma and what really discrimination is. Also teaching them what are the negative impacts of discrimination and stigmatisation ...”

4.5.1.1.7 Poverty

Poverty was noted as a common issue that affected children living with HIV and AIDS in the community. The CBO regarded poverty as a social issue because it affected the children’s access to food and social services such as education and health care. Poverty was also noted specifically by Abel to affect access to sanitary supplies such as menstrual pads for the girl-child living with HIV and AIDS. Some of the children were in a state of poverty because they were orphans and were coming from child-headed households. As discussed by the CBO’s project staff below:

Abel: “Some of them are living under child-headed households and others are even more vulnerable [are in a very helpless state making them susceptible to danger].”

Robert: “That’s another very serious issue of malnutrition where you find out that where they are coming from there is no food, there is no

breadwinner to actually look after them. So now that she is HIV positive and at home, there is no actual breadwinner, things are not well at home.”

Thando: “Sometimes there will be no food in the house so when the child is sick and there is no food in the house, that child will think of many things in their mind [becomes troubled].”

Pilani: “... their well-being, their clothes, their food, all are low class so that’s the biggest problem that we have at the present moment. When things are like that, the child will not be going to school as there will be no-one to pay for the fees, so this child becomes poor for the most of his or her time of life.”

Paida: “Furthermore, the availability of food is yet another big problem since the medication also needs food. You will find a situation whereby the grandmother is unemployed and has to go to do piece jobs, and then when she comes back home with little food, she will then say to the grandchild ‘you will eat in the morning.’ So this is indeed a big challenge.”

The founder of the CBO and the NAC advisor during the semi-structured individual interviews mentioned the struggle of the caregivers of CLHA to assist their children to access school facilities. This was because they did not have the necessary financial resources due to poverty. Robert and Ben explained:

Robert: “Children living with the virus, their issues, as I mentioned earlier, some of them could be orphaned; they lack parenthood at their respective places [homes], because possibly they could be living with an elderly granny who no longer has time to give guidance. So these children they need ... guidance, they need education.”

Robert: “They are actually orphans and they are staying with their

grannies, so the reality is no one is able to pay school fees for these children.”

Ben: “This is mostly due to issues of income within their households or in the families which are taking care of these children, where the parents or guardians do not have enough money to pay for the fees or meet the educational costs of those children.”

In another quotation he further explained:

Ben: “... I think maybe we can sum it up to say it’s because of poverty that the households or the families do not have sufficient income to meet the school needs of these children ...”

The CLHA issue of the lack of sanitary pad supplies for young teenage girls in puberty was explained by Abel. He recalled an incident when a young girl living with HIV began her menstrual periods and did not have the appropriate sanitary supplies. The child was evidently psychologically disturbed by the issue. When the grandmother of the child was approached by the CBO’s field officer to address the issue, the officer was informed that the grandmother, who was the sole caregiver, did not have any financial resources to purchase sanitary pads for the child. The issue of the lack of sanitary wear was noted as an issue that affects the girl-child living with HIV and AIDS, as she was constantly aware of her HIV status and feared being stigmatised by other children because her blood was infected. As alluded to by the senior project personnel Abel, who explained the above paraphrased issue:

Abel: “We do come across situations like those ones, like for instance we have a 15 year old girl who is in form 2 at the nearby secondary school. When we received a report that she was not coming to school, we then sent the caregivers to find the reasons why she was not attending school.

We were then made to understand that the reason was because she was having her periods [menstruating] and not having [did not have] sanitary pads. So to us it became a challenge now to say okay, now even though you want to assist but for how long will you be able to assist, because we do not have enough resources to assist and what if this is a sign, that there are more children who are absconding school because they also do not have sanitary pads?”

When asked to clarify whether the above issue was only a case of just the inability to access sanitary wear, or whether it was because the girl was living with HIV and was avoiding people around her who feared infected blood, he explained:

Abel: “It is both ways, but the part that really affects us is the part that the child knows her HIV status and that one of the ways one can contract HIV is through blood, and just imagine during break time then the blood flow starts to happen. What kind of scenario will it become?”

Abel also explained how this child living with HIV had been affected emotionally and psychologically because of this issue:

Abel: “... on Saturday she came to the support group meeting and you know she was disturbed. She even preferred to be lonely [alone]. Being HIV positive is one issue but also poverty comes into play and it negatively impacts the child’s behaviour ... she feels like an outcast. So these are some of the issues affecting especially the girl-child who is living with HIV and AIDS.”

Abel was asked to also explain whether the issue of lacking sanitary wear was an area of greater concern in girls living with HIV compared to girls not living with HIV. He responded as follows:

Abel: “Yes, it is an issue but you would find that to those not living with HIV and AIDS, they are open to share [their problems] with others ... They help each other, they advise each other, but not this one now, just because the [HIV] status is known ...”

4.5.1.1.8 Stress

The study established that CLHA below 15 years of age struggled with the challenges associated with living with a chronic illness such as HIV and AIDS, and worried about various issues, such as the availability of food and getting married in the future. When asked about some of the common PSS issues CLHA discussed or complained about, the Director recalled some common statements made by CLHA to include the following:

Robert: “I’m always not feeling well, I’m always sick’ and it’s like some say ‘when I get [take] my medication I feel very hungry. At home there is no food you see, my granny possibly does not understand this medicine, and other children from other schools ask me why I always drink these tablets’. Things [questions] like that. Quite a lot of things like that they ask.”

Another senior project member, Abel, noted:

Abel: “Yes, one of the major questions that the children always ask is like ‘okay, for how long will I live and even if I live ... for the girls their fear is ... will I be able to have a family of my own?’ You know, some of the issues really touches even you as a caregiver, as a counsellor. Because of this, the child is really concerned about his or her future ...”

Field officers Millicent and Lucy also noted that the CLHA would be in deep

thought constantly, especially concerning the issue of marriage. As explained below:

Millicent: "When you talk to them, if it is a girl the issue is about getting married. If it is a boy the story is just the same, so we try to explain to them, telling them that it is possible, you can get married and have your home, and it makes them happy knowing that having this kind of disease does not mean that one is dying. So they keep on asking about this marriage thing and we tell them you can have a wedding ..."

Lucy: "... the other thing is about marriage, especially the girls. They think that they will never get married because of their status, thereby not knowing that she can be married and have a white wedding despite being positive."

A field officer, Pilani, explained the violent behaviour he had observed in CLHA:

Pilani: "... at first, children used to mock each other, so others became violent such that they used to fight each other."

Commenting on the CLHA attending school at the premises of the CBO, field officers Chipo and Pilani discussed situations at the school that caused some children to suffer stress, because they were in constant thought as to why other children laughed at them during school activities such as dramas. Starting that discussion was Chipo, who had initially noted the following:

Chipo: "Others were not even good at school because of shyness and the fear of being laughed at."

When Chipo was asked to clarify whether the children were being laughed at because they had failed to give a correct answer in class, or because they were

living with HIV and AIDS, another field officer Pilani interjected and explained as follows:

Pilani: "... no, it was because of different reasons, because sometimes when a child gets to know his or her status, that child will start to think 'I was the one who caused it'. So when he or she now knows, there are dramas, poems which they are taught so that they will know that it was sometimes because of their parents or because of what they themselves used to portray during the dramas. HIV can infect you in weird ways so. Before that child had understanding, he or she would be concerned of what people were saying about them, thinking that 'maybe I did prostitution' and yet that child is only 8 years or 14 years or 12 years. So when they laugh at each other, the child will say 'these people think that I did this also' [whatever is being portrayed in their drama activities]. So the child, the child withdraws from people or will become violent, so that is where it starts."

Related to the above discussion, field officers during the focus group discussion were asked whether CLHA were regarded as being emotionally sensitive and which age group was most affected by this issue. Only one field officer responded:

Pilani: "Very sensitive because of their ages, that age is a tender age, so he or she is sensitive to different things ... It starts at teenage."

During the key informant interview the Director was asked about whether CLHA suffered mental challenges because of their HIV status. The Director responded that that this was not the case. As noted below:

Robert: "We have not met [encountered] the mental part. They are quite well and they do not have mental problems. No."

Although CLHA were noted not to suffer any mental challenges, some were noted to suffer physical growth challenges. The reason for these growth challenges were unknown and were blamed on malnutrition. As noted by the Director during the key informant interview:

Robert: "Yeah, [yes], that we have encountered that you will see that we have some children whom you will wonder why they are not growing. Yeah we have them. They were very bad when we started with them, but you can see that they are very happy now. But you can always say your child is not growing – why? We end up thinking it is because of malnutrition or what? We don't know."

During the individual semi-structured interview, Ben commented on an observation he had made on CLHA:

Ben: "... there is general retardation in terms of their development and welfare."

When asked to explain what he meant by "general retardation", Ben noted the following:

Ben: "... we are basically talking about the physical growth of children ... where you observe that their growth is not as good as those who are not living with HIV."

4.5.2 Human rights approach

4.5.2.1 Commitment to human rights

The CBO recognises that PSS is a human right for all children, whether infected

with HIV or not, and has adopted a rights-based approach in the delivery of its PSS activities. The CBO mainly focuses on raising the children's awareness of their basic human rights and on child protection issues. Using a child-friendly, rights-based approach in the delivery of PSS to CLHA enables the CBO to address both children's rights and child protection issues affecting CLHA in this community, such as violence and sexual abuse. The Director, Robert noted the following:

Robert: "Under that same CD listener [activity] we will also be telling them their rights, what rights do they have as children. So there are a lot of plays in the CDs. They listen to those CDs, we have got quite a number of CDs. And we have comic books, protection against child abuse and torture. When they need help there are some stories inside where they read in these books or they hear them in a CD, like it's a drama form and it's interesting, they laugh through. We will ask them to portray, to do the same thing on their own, to discover whether they have understood the psychosocial support part of it, and you will then notice that if you then ask them their rights, they will quickly tell you that our rights are A, B, C."

When asked to explain the support provided to the CBO by the National AIDS Council to address the issue of children's rights, the NAC representative, Ben, explained that NAC provided technical support and training to the CBO's project staff on children's rights issues. In addition, Ben noted that the CBO has received support over the years to commemorate the day of the African Child. Ben explained as follows :

Ben: "On rights, we train the CBO staff, we have provided technical assistance in knowledge on children's rights issues and also, more importantly, we have also been supporting them [CBO] in commemorating the day of the African child, which is a very important commemoration and which raises awareness about the fundamental rights of children for the

organisation and for the community at large. We have partnered them, we have been supporting them, and we have been partnering with them for the past few years in commemorating such events, especially which recognise the value and the rights of children within the community.”

4.5.2.1.1 Children’s rights

According to one senior personnel member of the CBO, CLHA were noted to be dealing with negative behavioural issues such as bullying, sexual abuse and lack of formal education. The problem of bullying was noted to be emanating from children who had been sexually abused and contracted HIV. Children from child-headed households attending the support group sessions were also noted to be bullies and seemed to no longer have any recognition for authority figures; they seemed to have lost respect for other people around them. Abel noted the following during the semi-structured interview:

Abel: “Yes, the issue of bullying in some of our children might be a cause of the background they are coming from ... they will be living as children under child-headed households. So you will notice that the issues of respect it’s not important to them. So when they are at a support group meeting, you will find that if there is an issue or even a single issue that needs little attention and reasoning, you would find that they will solve the issues by bullying each other, start telling some other children some vulgar words, and you would notice that the child would have lost the respect for humanity.”

When asked to further explain on the issue of bullying, he added:

Abel: “... and also some of them are bullies, because some of them have been sexually abused and contracted HIV.”

In another semi-structured interview, Ben highlighted the issues which violated the human rights of CLHA, such as abuse, neglect from their guardians and their inability to attend educational facilities such as schools. Ben explained as follows:

Ben: "... we have children who are living with HIV who have been abused. We have children who are living with HIV who have been neglected by their guardians, who have not been loved, who have been ... who have not been accepted by their families or their households or by the community. We have children who are living with HIV who have not been ... who have not been able to go to school. These are some of the specific needs, we have children who are living with HIV who have not been ... who have had specific emotional and psychosocial needs, maybe due to the unwelcoming environment where they are coming from."

Ben further described the kind of abuse he was referring to:

Ben: "We are looking at emotional abuse of children. You, know this might be verbally because the parents are not living ... they no longer have parents. You know we are looking at children who have been sexually abused. We are looking at children who are physically abused, who are involved in child labour, mostly because there are no parents and guardians who are taking good care of these children."

On the issue of lack of education, the co-founder of the CBO, Paida, noted that some CLHA were sitting at home as they were unable to attend school and thus were unable to proceed with their education. Paida explained as follows:

Paida: "Some children are sited at home doing nothing. You find 16- year olds and above who last did grade 7 as they could not proceed with their

education. The grandmother does not have money to send the child to school, and you find that the mother of the child passed away so the child is then told to go and work at 16 years when in actual fact the child is supposed to be at school.”

4.5.2.1.2 Child protection

With regard to child protection, the CBO recognises the need for CLHA and other OVCs in the community to be provided with general social protection. Senior project member, Gary, explained during the semi-structured individual interview:

Gary: “Okay. It is like as I have said, we mainstream in child protection ... So we would be telling a child, teaching a child, telling him what really child protection is. What really is a child? How do you define you as a child? You yourself, how you ... how you would define yourself as a child. All that will enable a child to know what rights are, what her responsibilities are.”

The CBO does child protection through its case management of CLHA and through its transitory school. According to the Simbarashe National Network for People Living with HIV and AIDS Concept Note (2012:3), when cases such as sexual abuse or child labour have been identified at the CBO’s transitory school or by the field officers conducting case management in the community, the CBO ensures the child is protected from further harm by immediately referring cases to relevant child protection departments such as the Zimbabwe Republic Police Victim- Friendly Unit. Citing a case of child abuse in the community which the CBO had dealt with, field officer Petros explained that upon receiving a report that a 15 year old girl was being sexually abused by her grandfather, the CBO got involved by ensuring the child was protected from further harm. The end result was that the perpetrator was arrested and jailed. As explained by Petros:

Petros: “The second incident is about a rape case in the community ... what happened is that this child was staying at Marimire [neighbourhood], and the child lived with the grandfather. While living with her, he took advantage of her, then raped her. So what happened is this, he used to frighten the child saying ‘whatever happens is our secret, if anyone hears about it, which will be the end of your life’. So she couldn’t do what? Release the information? But it so happened that one day that grandfather went away and the grandmother stayed behind with the child. So the child talked to who? To her grandmother. And told her all that had been happening. So granny couldn’t wait to question the grandfather and she quickly sought help. She did very well, she talked to a caregiver [CBO field officer] (interruption) ... so after speaking to the caregiver about the story, it was further reported to Simbarashe and was dealt with.”

Explaining further on how the CBO had dealt with this case, Petros added:

Petros: “After the story was dealt with, this man was put behind bars, and how about the child? The child is being kept at a safe place.”

4.5.3 Community-based approach

4.5.3.1 Adoption of a community-based approach

The study established that the adoption of a community-based approach in delivering its PSS services to CLHA was done through the involvement and participation of committed community members such as the fifth-level field officers, the local traditional leadership and those adult members of the community living with HIV.

As noted in section 4.3.3 above, the CBO’s fifth-level field officers are community

volunteers. The participation of these community workers in the CBO's PSS delivery activities to CLHA, has enabled the CBO to adopt a community-based approach.

Questioned on what a community-based approach is and whether or not the Simbarashe National Network for People Living with HIV and AIDS had adopted a community-based approach in the delivery of PSS to CLHA, key informant Ben during the semi-structured interviews responded by saying:

Ben: "Community-based approach, it is an approach which is grounded in the community, which is driven by the community as the agents of the programme, as the actors in the programme, as the change agents as well as the beneficiaries of the programme. This is a community; it is a programme which is based in the capacity and the resource base of the community, addressing the needs of the community."

On whether the Simbarashe Network follows a community-based approach, he further explained:

Ben: "Yeah [yes] it follows a community-based-approach and more, so this is a community-based organisation which is located in the community where it is reaching out to its community members."

Ben: "There is general community support were Simbarashe is meeting the community needs and the community is seeing value to their programmes, hence they are supporting their programmes. As a community they engaged the Village heads, Chiefs, the Councillors, you know the various community leaders and the general community population ... I think that has been the cornerstone of their success ..."

4.5.3.1.1 Committed community-based volunteers

An underlying principle of the CBO's success in its PSS delivery to CLHA is the involvement of the community members in the delivery of its PSS services. Ben clearly explained that the availability of the community volunteers were a critical factor in the successful delivery of PSS to CLHA by the Simbarashe National Network for People Living with HIV and AIDS. Ben explains:

Ben: "... I think one of the underlying principles or ... the underlying base for their [CBO] success remains the sheer or the mere will from the members to just serve their community without expecting much from them in terms of being paid, and so I think that has really made, that really has been the backbone of their programmes."

When asked to clarify on which 'members' he was referring to, Ben explained:

Ben: "We are looking at the caregivers [CBO field officers] who are mostly doing the bulk of the work, who are volunteers doing the work without being paid, and they have been doing the work for quite a number of years."

When a group of six field officers (home-based caregivers) were asked during a focus group discussion what made them join the organisation and the benefits they received from being part of the programme for CLHA, their responses included the following:

Alice: "As for myself, the love for children, love – especially for children – made me appreciate this programme ... when I look at these poor children I feel pity, but since I am poor I do not have anything I can give out to help them, so that is what made me join this programme to identify children with problems in the village and bring them here to the centre."

Lucy: "I was happy with this programme though my [HIV] status is negative. I saw many children, children with problems, yet their parents do not understand that when a child takes medication he or she can live long. I came to Simbarashe so that I may learn a lot of things, like love, to show love to positive people [people living with HIV and AIDS] ..."

Alice also added:

Alice: "I can just say that we gain knowledge together with the children, and they also teach us [learning from them] here, so we gain knowledge."

The other field officers Deby noted and Thando noted the following:

Deby: "We use that knowledge that we get to take care of our own children [CLHA]."

Thando: "Another thing is about counselling. I have learnt ... I have learnt a lot about children. It's like some children cannot express their problems because they feel bitter, so because of counselling you will reach a certain point to where you will make him or her understand and feel like opening up, even to his or her parents ."

Revealing their care and commitment in ensuring drug adherence in CLHA during case management visits, Alice further explained what the voluntary field officers did when they arrived at the home of CLHA, and how they provided support in the presence of the caregivers of CLHA:

Alice: "Usually we want the parent to be there so that they will help with taking their medication."

After explaining some of the difficulties they encountered in terms of harsh

treatment and resistance from some members of the community they had visited, the voluntary field officers during the focus group discussion noted that it was the passion for children that made them overcome these obstacles and continue with their work. As explained by Millicent:

Millicent: "... it's about passion and how committed you were as a caregiver, since it is voluntary work. So it is all about pursuing the children's parents until they give in."

In order to further ascertain their commitment level to the CBO's activities for CLHA, the field officers were asked what made them become voluntary field officers at the CBO. The responses varied from some being PLHA who wanted to do something meaningful for the community, to some having joined because of the benefits of merely enhancing their knowledge on HIV and AIDS. As explained below:

Millicent: "... as for me, I am also HIV positive so I just thought it better to come and join this organisation ... I learn a lot from other people u-um, such that I don't keep straining myself with the issue of being positive ..."

When Abel was asked about what the critical factors were for PSS delivery by the CBO, the response was given as follows:

Abel: "We don't have much funding, but because of the passion of the community and commitment, I would like to believe that we are really making some progress and the community now claims to be the owners of the project."

Commenting on the community's volunteer's contribution to PSS delivery, Ben noted the following:

Ben: "... firstly we are looking at human resources, the volunteers or the caregivers. These are major ... are a major asset in the programme and they are a major resource in the programme."

4.5.3.1.2 Local traditional leadership

The study established that the local traditional leadership, which consists of the local Chief and the Headman, were actively involved in the establishment and delivery of PSS to CLHA. Reiterating a quotation cited earlier where the Director, in his account of how the CBO's first HIV awareness campaign took place, highlighted that it was because of the local Chief's consent that he was able to have access to the local community:

Robert: "... I talked to the Chief, that I would want about 3 000 or more people within his jurisdiction, and he consented, and I asked him to put up cattle to slaughter that day, and he accepted. And Dr Bertha had to bring rice and things like that. Around 3 600 people gathered at St Michaels Mission for an HIV awareness campaigns, spearheaded by Robert who was then to come out as living with HIV ..."

The content analysis of the CBO's profile document revealed that indeed, the Chief's support had enabled Robert to conduct HIV and AIDS activities in the Chief's jurisdiction. As explained by a quotation below from one of the key documents:

"The Chief duly yielded to Robert's request to identify other people with the same HIV positive status. Little did Robert know that the Chief was going to be a major player in the whole game of identifying people who had been tested and found to be HIV positive" (Simbarashe National Network for People Living with HIV and AIDS profile document 2010:3).

Following several successful HIV and AIDS campaign meetings by the CBO, the

local leadership also assisted the founder and Director to acquire a piece of land from the government, at no cost. This is the piece of land where the Simbarashe National Network of People Living with HIV and AIDS is currently located. It is the land where the support group sessions and other care and support services to CLHA are delivered.

The study further examined the contents of a letter from the local Chief to the CBO's Director and Founder on the donation of the 6 hectares of land in the Mhondoro-Ngezi district. The letter stated that the land had been donated for the purposes of continuing the CBO's work in meeting the needs of PLHA and for the personal development of the founder of the CBO. A line quoted from the letter dated 4 April 2007 read:

“In donating this land to you Mr. Robert it is my hope that you will establish your resource centre from which to operate” (Letter from Chief 2007).

In addition to the above demonstration of the involvement of the local traditional leadership in various PSS-related activities and processes, the local traditional leadership also played a part in the identification of CLHA requiring PSS support. From the various discussions held with the CBO's project staff, the study established that the local leadership were able to influence the community and thus contributed to the successful delivery of PSS activities. While explaining how the community had ownership of the CBO's programme, Abel noted the following:

Abel: “It's like there is community project ownership, to say now it's not just our [CBO] responsibility to deliver the programme to the community children population, but now it's like even if you are not attached to the organisation as staff or as a caregiver, but just because of the understanding that you have towards the programme, you are involved. The psychosocial support programme involves the village leaders. It is

part of their [village leaders'] responsibility to see how the child will be living ... and also to communicate with the caregivers [caregivers of CLHA] to say 'now there is a problem'. They will notify the caregiver and the caregiver notifies the organisation, and now [then] we map the way forward on how best we can assist the child, to maybe refer the problem the child is facing to the Clinic, to the Social Welfare Department and to the District Council, or even to the Chief, depending on the type of problem that the child is facing."

While explaining the role of community members in ensuring a successful PSS programme to CLHA, Ben identified the local community leaders as being important:

Ben: "We are looking at community leaders, traditional leaders, village heads, chiefs supporting the programme, as well as community volunteers, caregivers, village health workers. These are very important community cadres whom we need to ensure a successful programme."

4.5.3.1.3 People Living with HIV and AIDS

The study established that the involvement of PLHA, particularly adults living with HIV and AIDS, in the delivery of PSS to CLHA, is another factor which influences PSS delivery to these children. As has already been discussed in section 4.3 above, the existence of the CBO in itself is a result of the founder who had tested positive for HIV and who decided to use his life experiences to help others in the community, including CLHA.

With regard to this CBO involving PLHA in its PSS activities, Robert explained:

Robert: "... we are an organisation for people living with HIV and we are in the same plight with them [referring to the CLHA]. It makes them understand us better because they see us living, they see nothing

changing, [and] they see life going on. So they kind of say, we can do it also, so they are now ...”

Explaining the importance of the involvement of people living with HIV in the delivery of PSS to CLHA, the NAC advisor explained:

Ben: “... that has also been a major factor, the meaningful involvement of People Living with HIV ... That has been a major factor also in improving the uptake of psychosocial support of children, especially for parents who are living with HIV. They have got better appreciation of HIV and AIDS issues and also they value the importance of the support service.”

When a group of project staff were asked why they had joined the Simbarashe National Network for People Living with HIV and AIDS PSS programme for CLHA, one project member, Millicent, revealed that she was living with HIV, hence she joined the CBO. As stated below:

Millicent: “... as for me, I am also HIV-positive, so I just thought it better to come and join this organisation ...”

4.5.4 Caregivers’ attitudes

4.5.4.1 Caregivers’ attitudes towards VCT

The study established that the caregivers’ responsiveness to the CBO’s VCT campaigns for children in the community and their willingness to disclose their child’s status determined whether or not PSS could be delivered to CLHA. As noted above, the CBO’s entry point to PSS delivery, after the identification of children by field officers, was the VCT process, which was conducted only with the caregiver’s consent.

Reiterating a quotation already cited in section 4.1, where Robert illustrated the important role of caregivers in CLHA accessing VCT services:

“Robert: “After this sensitisation we had to seek consent from the parents of the children. When consent was granted the children were then taken to the nearest clinics. To tell you in that month of February, we tested about 700 children just in one clinic ...”

As already noted above, the CBO conducted a VCT campaign session which saw 700 getting tested at their local health facility. VCT is important because it establishes the HIV status of a child and enables caregivers of CLHA to seek further care and support services. Accessing any services to assist CLHA was only possible when the caregivers of CLHA showed concern for the child in their care. The study established that caregivers who had identified health-related problems in their children were prompted to take them to their local health facility for assistance – as explained below by caregivers of CLHA Jackie, Buhle, Sophia, Mutsa and Betty.

Caregivers of a child living with HIV during the focus group discussion further described the action they took after their child fell ill:

Jackie: “I saw that the child had stomach problems, especially after eating you could see the child being troubled, so that’s when I realised that the child had a problem in his life. I took him to the hospital and he was tested. The results were positive. I was happy with the Network programme here [CBO PSS programme], so I asked if I could find some help so that I would know what to do with the child.”

Buhle: “He used to sleep at any time, feeling very weak and also could not play with others, so I noticed that something was bothering him. That is

why I felt for him and took him in and started going with him to the hospital ...”

Sophia: “When I took in the child, the child could not even eat or go to play with others or bath ... but when we went to the hospital and the child started taking medication, I saw a change. The child is now so strong that you would not think that he was sick. The child is now strong.”

Mutsa: “When the testing programme [VCT] started, I went with the child for testing and was found positive; then automatically the child went on medication ... and right now, the child is strong.”

Betty: “When I saw the child, he had ringworms, continuous flu, coughing, loss of weight, was skinny and could not eat. That is when I took him for testing [VCT] and the results were positive. Right now there is some change in the body and he can now eat.”

However, despite the above success which took place because of the positive attitudes of caregivers who consented towards seeking health care and VCT for their children, the CBO’s project staff revealed that there were still other caregivers who refused for their children to undergo VCT. This was seen as one of the biggest challenges that threatened PSS delivery in the community. The focus group discussion with six key senior project personnel revealed that there were still caregivers who were reluctant to give consent to the CBO and those delivering VCT to deliver this service to their children. One of the reasons given for this was fear that the secret of their own HIV status would be exposed once their child had tested positive, and was seen to be frequently visiting the CBO’s premises for services. As explained by senior project personnel, Abel and Robert:

Abel: “Guardians and parents were resisting to get children tested for HIV,

and by that you would notice that the child mortality rate was going up because HIV was increasing.”

Robert: “We asked the Population Services International (PSI) to come and a lot of children got tested with the consent of their parents ...”

In another quotation Robert noted the following:

Robert: “... we are seeing that a lot [of children] are suffering because of their parents. You find that the child wants to get tested but the parents do not want because the parents know what they have done ... So it is hampering our psychosocial support. Children want to come but the parents ... they do not want to see those children closer to those gates [CBO premises], because they fear that their secret will come out.”

Stressing this point, the project personnel further explained that several children who wanted to get tested when a VCT service provider, the Population Service International (PSI), had visited the community to provide VCT services, had to be turned away. This was because the children had not been given the required consent from their caregivers to do so. As further explained by Robert below:

Robert: “... PSI even refused to test a lot of children here and they went back untested. Parents do not want to turn up. It is really a major challenge because even if I call PSI ... and we go to that school there and say, those who want to get tested we are testing tomorrow, please bring your parents as early as eight o'clock – we will see children waiting, parents do not come ...”

4.5.5 Availability and access to HIV services

4.5.5.1 Access through VCT services

As has already been pointed out above, the availability of HIV and AIDS prevention and treatment services to the community had enabled CLHA to access PSS services from the CBO. The successful HIV prevention initiatives delivered through the VCT campaigns enabled 150 children in 2012 who had tested positive for HIV after a VCT campaign to not only then receive ART from the local health facilities, but to also receive HIV and AIDS care and support services from the CBO.

The study established the availability of these key services to be an important factor in facilitating the delivery of PSS to CLHA by the Simbarashe Network for People Living with HIV and AIDS. The CBO did not work in isolation, but was dependent on the Ministry of Health and Child Welfare, who provided medical care services to the community. Illustrating the point that the CBO did not work in isolation, the Director Robert explained:

Robert: "... I always talk about sensitisation programmes within the community, where you talk to them, tell them exactly what it is that they are supposed to do [and where] to get assistance."

The NAC Advisor to the Simbarashe National Network for People Living with HIV and AIDS, Ben, discussed in detail the role of the Ministry of Health and Child Welfare in the delivery of PSS to CLHA. He noted the following:

Ben: "These are supporting partners to the programme, to Simbarashe. I think basically that's its [MOHCW] major role; in addition to technical support, the Ministry of Health is meeting the medical or health-related needs of children living with HIV."

Ben also underscored the importance of the availability and accessibility of these

services in influencing PSS delivery. According to the Kadoma district National AIDS Council monitoring and evaluation reports, the coverage of PSS delivery to CLHA in the district could be estimated at 30%. This percentage represents the contribution of the Simbarashe National Network only, as this is the only organisation in the district currently providing such a service to CLHA. This in itself means the delivery of PSS is only limited to those in close proximity to the CBO.

As noted by Ben below:

Ben: "... I can say the 30% which we are talking about is mostly coming from them (Simbarashe), because they are the ones which are doing the bulk of the work, especially when focusing on children living with HIV and AIDS."

4.5.5.2 Access through the PMTCT programme

In addition to the above issue, it was noted that prevention services to pregnant mothers through the PMTCT programme in the district was threatened by pregnant women who were not visiting the health facilities and were delivering babies in their homes. The reasons for these home deliveries were because these women could not access or afford maternity fees or had spiritual beliefs that promoted home deliveries. Ben explained below:

Ben: "... quite a number of mothers are still delivering from their homes due to a number of reasons. There are costs associated with going to the clinic as well as the maternity fees which pregnant mothers have to pay. Quite a number cannot afford to meet or to pay those fees, user fees which are required by clinics or hospitals. Then of course there are quite a number of mothers who don't go to clinics or to hospitals for spiritual or traditional beliefs which require them to give birth from their homes."

Ben: "... the user fees, they vary from one hospital to another, but they range between \$20-30. In addition, mothers might require, might be requested to bring in other necessities such as cotton wool when they come to deliver and also these have got cost implications for them.

Ben: "... I can say our surveillance data shows that Mhondoro-Ngezi, especially for the last year, our home deliveries constituted around 19% of the total deliveries within the district, which is quite high."

The NAC advisor also noted that some women in the district could not go to the clinic as they had to walk long distances ranging from 15 to 18 kms to access the nearest clinic. Other women did not have the resources to cover any transport costs (ranging from US\$ 12-14 for a two-way trip) as well as the required hospital fees, which ranged from US\$ 20 - 30.

Ben: "... you will find that households and families at times do not have enough income to meet the costs or to pay the bus fares. On average we are looking at \$6-7 per single trip for one way maybe, that's around \$12-14 two way, and also in addition to that, a mother would need additional income or additional money also to eat and for other needs at the hospital."

Asked to explain what the link was between PMTCT and PSS delivery to CLHA at the Simbarashe National Network, the NAC advisor responded by saying:

Ben: "... a number of challenges, because when we fail to reach out to a number of mothers with PMCT it means that those mothers are going to deliver children who are going to be living with HIV, and also where mothers fail to take PMCT services due to costs, distance and other reasons, they are also more likely to fail to uptake psychosocial support

services which might be provided in the community, due to the same reasons.”

The study further established that the failure to access PMTCT services by some women was of concern to the National AIDS Council, as vertical transmission from mother to child remained the major mode of HIV transmission in the Mhondoro-Ngezi district. As explained below:

Ben: “The common mode of infection, especially for children, remains the vertical transmission of the HIV virus, that is from mother to child transmission for children.”

In addition, the Mashonaland West province where the Simbarashe Network is located had a recorded 15% HIV prevalence rate, as recorded in the 2010 - 2011 Zimbabwe Demographic health survey. As explained by Ben below:

Ben: “The 2010-2011 Zimbabwe Demographic Health Survey, that’s the one which is telling us that our prevalence for Mashonaland West province [where the CBO is located] is 15%.”

4.5.6 Partnerships

Through the content analysis of central documents of the CBO, the focus group discussions and the semi-structured individual interviews, the study established that in order to deliver PSS to CLHA, the Simbarashe National Network for People Living with HIV and AIDS had various partnerships with external organisations. These were categorised by the researcher as follows:

- National AIDS Council
- NGOs
- Government departments

The NAC Advisor to the CBO, Ben, noted that the support the CBO had received from other organisations was a critical factor that had assisted the CBO to conduct their activities within the required stipulated standards. When Ben was asked about what he thought had contributed to the successful delivery of PSS by the CBO, he responded as follows:

Ben: "... I could add that the support from other organisations, other non-governmental organisations in areas to do with HIV and AIDS, in areas to do with children's rights, in areas to do with the welfare of children, as well as government departments such as the Ministry of Health, the Ministry of Education, the National AIDS Council, which have [all] been supporting Simbarashe as a CBO to ensure that their programmes meet the required standards and are in line with the standards for provision [of PSS] and the of technical support and advice given to their programmes."

Ben further commented that networking amongst organisations and partnerships with others is what enabled CBO's operating in resource-constrained areas to receive support to conduct and sustain their activities. He explained:

Ben: "... networking or partnerships help to support or sustain organisations who are operating in a resource-constrained environment ..."

Table 8 below summarises these partnerships and the services they offered to the CBO as revealed by the study.

Table 8: Summary CBO's Main Partnerships in PSS delivery to CLHA

Name of partner	Nature of partnership	Description of services offered
National AIDS Council	Technical capacity building and coordination.	<p>Provide technical support and advise on PSS activities.</p> <p>Trains CBO field officers in resource and community mobilisation and HIV and AIDS prevention treatment, care and support initiatives.</p> <p>Monitoring and evaluation of CBO's activities.</p>
<p>NGOs</p> <ul style="list-style-type: none"> • HOSPAZ • Children First • World Education Programme First • Population Services International • SAFAIDS 	<ul style="list-style-type: none"> • Provide funding, capacity building, VCT and resource materials. 	<ul style="list-style-type: none"> • HOSPAZ offers funding for CBO's PSS activities. Provides training on palliative care to field officers. • Children First and the World Education Programme provides educational materials used in the transitory school as well as comics, CDs and posters on human rights issues. • PSI conducts VCT for children. • SAFAIDS provides various information materials on HIV and AIDS.
<p>Government departments</p> <ul style="list-style-type: none"> • Ministry of Health and Child Welfare • Ministry of Labour and Social Services and the Police. 	Providers of health and social services.	<ul style="list-style-type: none"> • MOHCW provides VCT and ART to children as well as training sessions on HIV- related issues and Palliative Care services. • Ministry of Labour and Social Services and the Police work closely with the CBO to provide child protection to vulnerable children.

Source: Simbarashe National Network for People Living with HIV and AIDS Organisational profile (2012).

The following subsections discuss the three broad categories of partnerships in more detail.

4.5.6.1 National AIDS Council

Through the National AIDS Council's (NAC) decentralised local structures, called the Provincial AIDS Action Committees (PAAC) and the District AIDS Action Committee (DAAC), the CBO is able to create relationships with various stakeholders in the community. The National AIDS Council is the coordinating structure of all HIV and AIDS responses in Zimbabwe. The CBO benefits from its relationship with the NAC as it is able to use its various decentralised platforms to acquire and disseminate information on its activities to other organisations in the district. The senior project member, Abel, noted the following about the important role of the decentralised NAC structures, the DAAC and PAAC, in PSS delivery:

Abel: "... we are an organisation that has a vision of being a campaigner for disseminating HIV and AIDS-related information in the community. So being a partner to the National AIDS Council through the DAAC and Provincial AIDS Action Committees (PAAC), you notice that we get a lot of information [literature] from them, and hence we improve our dissemination of accurate information, correcting the misconceptions on HIV and AIDS."

Explaining the role of NAC in supporting the CBO's PSS delivery to CLHA, Ben noted the following:

Ben: "... we coordinate their programmes. We give a lot of technical support to their programmes ... that includes monitoring and evaluation supporting, technical support to programme implementation, design, and

at times we give funding to their programmes to make sure they succeed. In commemorations, normally we provide funding for those commemorations and also technical support ... [support is provided in] planning it as well as giving recommendations ...”

Discussing further how the NAC had supported the CBO to commemorate an HIV and AIDS activity and how much funding had been awarded to the CBO, Ben noted that the Simbarashe National Network had benefited from a larger portion of NAC’s funding in the district. He noted that in 2011, 40 to 45% of their funds had been allocated to the CBO to support its activities. Ben noted the following:

Ben: “... the last commemoration we had last year [2011] we provided a lot of IEC [Information, Educational and Communication] material pertaining to issues to do with HIV and AIDS, children’s rights ... and we have also provided funding ...”

Responding to a question on how much funding had been allocated to the CBO, he stated:

Ben: “... we have committed quite a large amount to Simbarashe. What I can say for 2012, 2011 Simbarashe was the biggest beneficiary in terms of community organisations that received our funding. I think most of our funding went to Simbarashe being a bigger CBO with a number of programmes ... I think out of the funding we got in 2011, I think close to 40-45% of that funding went to ... Simbarashe.”

In addition to the above, the NAC also provided material support for the CBO’s children’s activities:

Ben: "We have provided a number of sporting equipment, sporting material for the children. We have also provided a number of Information, educational and communication (IEC) material, reading materials for children to raise their knowledge levels you know, to familiarise themselves with a number of life issues and also to build their esteem. We have also funded a number of child-related activities for issues to do with the show events like songs, dances done by children mostly living with HIV and AIDS. Then at the same time we have also supported the establishment of support groups for children living with HIV."

NAC has also provided the CBO with technical support regarding the support groups for children. The NAC and other organisations have provided specialised training in PSS activities to the CBO's staff members. Ben noted the following:

Ben: "... the caregivers have been trained in the various trainings ... we [NAC] have supported some of the trainings. Some of them we have conducted, then there are others which have been conducted by other organisations, specialised organisations which deal with issues pertaining to children such as Hospice of Zimbabwe [HOSPAZ], whose main focus is caregiving."

In another quotation Ben added:

Ben: "We have trained them, in what we call community mobilisation. Community mobilization in food access, to the care and treatment package. It's a training package for community volunteers which aims to build their capacity so that they deliver their services to the best of the community, and also reach out to the community and also they address the needs of the community. That's one training which we have supported."

NAC also conducts the monitoring and evaluation of the CBO's PSS activities and have developed the main PSS delivery indicators. Ben explained:

Ben: "We do have many indicators which focus on psychosocial support, which looks at the number of children, the number of new children who would have received psychosocial support from Simbarashe ... which we track each and every month from Simbarashe, especially for psychosocial support."

4.5.6.2 Non-Governmental Organisations

The CBO's founder commented on the role played by three non-governmental organisations: HOSPAZ, Children First, and the World Education Programme in the training of the CBO's project personnel:

Robert: "... the trained facilitators of this organisation and trained caregivers will then do the case management of these children, [they have been] trained by HOSPAZ [Hospice and Palliative Care Association of Zimbabwe], trained by Children First, trained by the World Education Programme, trained [also] by the Ministry of Health."

Abel: "... as an organisation we received comic books from one of our partners, that is World Education ... also we have a major partner that is SAFAIDS, which is a very big organisation ... we have benefited much from their literature ..."

Millicent and Abel explained the role of another non-governmental organisation, CONNECT that is providing training in counselling services to the CBO:

Millicent: "... things like counselling we have CONNECT, they come here and train the caregivers. So where there are sensitive issues which we cannot deal with ... that is when we [CBO] have those who train [coming

to assist].”

Abel: “... as an organisation we work with CONNECT with their [CONNECT’S] systematic counselling programme, and they [Connect] have enhanced our knowledge in offering child counselling to our kids who are in the psychosocial support programme.”

Table 9 below is an extract from information gathered during the content analysis of a letter dated 15 December 2011, revealing the support the CBO received from an NGO. The Table reveals the close partnership between HOSPAZ and the CBO. In 2011, HOSPAZ provided financial support for the CBO’s support group and child protection meetings. In addition, these funds were used by the CBO to cover the transportation costs of CLHA.

Table 9: NGO support to CBO

Type of document	Date	Contents
Letter	15 December 2011	Letter to CBO Director on the disbursement of funds amounting to US\$ 1710.00 from HOSPAZ (an NGO) to conduct 2011 December activities. Letter included budget breakdown as follows: <ul style="list-style-type: none"> • 5 support group meetings – US\$ 150.00 • Access to ART funds 1 month (Funds used to cover transport costs of CLHA and caregivers to travel to health centre to access ART medication) US\$ 440.00 • 1 child protection community meeting – US\$ 70 • Administrative costs (for CBO) – US\$ 720.00

Source: HOSPAZ letter (2011)

4.5.6.3 Government departments

As discussed in various sections above, the Ministry of Health and other government departments work in close collaboration with the CBO in providing VCT, ART and other care and support services to CLHA. When Ben was asked about what kind of relationships the CBO had with the Opportunistic Infection (OI) and Antiretroviral therapy (ART) clinic, and with palliative care providers in the Kadoma district and other health centres close to them, he responded as follows:

Ben: "... I can say they have a working relationship with these health service centres because Simbarashe or beneficiaries from the Simbarashe are also beneficiaries from these health service centres. They are all, they are being serviced by the OI clinics from these hospitals and they are also being leased out by the clinics for OI/ART services ... The palliative care providers. Some of them are the volunteers [the CBO's voluntary field officers] whom they are working with and also others may be ... from the Ministry of Health whereby they are working together to reach out to children in the community."

In addition to the MOHCW, the NAC advisor to the CBO also discussed the role of the Ministry of Labour and Social Services in the CBO's PSS delivery. He explained:

Ben: "... the Department [referring to Ministry of Labour and Social Services Departments] also provides technical support and also provides some monitoring and support activities to the psychosocial support programme being done by Simbarashe ..."

With regard to the role of the Rural District Council and other partners in the

delivery of PSS to CLHA, Ben explained their contribution to the CBO's PSS delivery:

Ben: "Being the local authorities ... [they are] the regulating body which regularises the establishment of community-based organisations or registers their existence."

Ben also noted the role of other community groups such as churches in the CBO's delivery of PSS to CLHA:

Ben: "Churches, schools also do play a supportive role to Simbarashe as well as the business community by providing a number of donations of materials which might be required."

4.6 MEETING THE PSS NEEDS OF CLHA

In order to establish whether or not the CBO was meeting the needs of CLHA, questions in this regard were asked to senior project personnel and field officers. In addition, a separate focus group with six caregivers of children living with HIV and AIDS who received services from the CBO, was conducted to explore their views on this issue. Furthermore, the observation of the support group delivery session illustrated how the PSS needs of CLHA were being met.

When the caregivers of CLHA were asked about which of the CBO's activities were meeting the PSS needs of children, they responded by highlighting how some of the PSS activities, such as support groups, had led to HIV disclosure in CLHA and treatment adherence. Their various responses included the following:

Betty: "There are support groups [here where] they play together, they act dramas, they are being taught how things are like and how to cope when

you are on ART.”

Mutsa: “Now I can see through learning, children are happy even to talk about themselves ... [saying] ‘my parents are both dead and I am living with HIV’ ... They are now free to talk about it.”

Sophia: “My child is also disclosing his status by himself, he was really satisfied with the counselling ... At times he will say, granny where is my food, you know I am one of those taking medication ...”

Asked about how long it took for children to start openly disclosing their HIV status after they had been receiving PSS support, Sophia responded:

Sophia: “It took him a month when he started disclosing himself.”

Another caregiver, Mutsa, noted that the children received information that helped to promote drug adherence:

Mutsa: “They are taught [at CBO] to understand that it [HIV and AIDS] will not kill them if you take your treatment as prescribed. You can live longer than those who are not taking the medication.”

During the individual, semi-structured in-depth interviews, the CBO's founders noted how CLHA were being helped by the CBO's PSS programme which provided guidance, love and comfort:

Paيدا: “The behaviours that we have noticed here at Simbarashe are as follows: some children start engaging in relationship with boys, especially those that are around 16 years [old] and above, and yet they will not be knowing their [HIV] status. So here we teach them to go and get tested and know their HIV status ... We teach them not rush and to abstain

sexually until they are ready for a relationship ...”

Paída: “Under 15 years? On that programme we help them so that they can live and cope as well as accepting their condition. Especially the youth, because it is the youth who are at high risk.”

Robert: “... we try to give as much love as possible; that you will notice when you are saying the day is over and they are going home, some of them won’t be happy that they are going home. Like for instance, they were closing [end of school term], we told them schools are being closed which means that we also have to close [take a break]. And they said ‘oh no we didn’t want to close’. It’s that kind of thing, it’s like we have become their parents, their solace providers, they tell us their problems and we try to work on the problems one by one, gradually.”

Children living with HIV and AIDS receive also counselling services from the CBO’s field officers. Field officers Chipo and Noel noted the following during the focus group discussion:

Chipo: “... as field workers we can counsel them, here, they get counselling.”

Noel: “I wanted to add on the issue of counselling ... the caregivers [lower-level field officers] and field officers together with facilitators [senior project personnel] were given basic training of what? Of counselling, so from there, it can happen that you find a case which does not need a lot of deep-deep [higher level] of counselling. You can counsel that child and he or she will become a better person, for instance when they want to kill themselves, maybe the child is in abuse or maybe it can be something else.”

Asked to explain what PSS that the CBO offered to children living with HIV who were dealing with the issue of bereavement, a senior project member, Gary, explained:

Gary: "Okay. In fact bereavement continues until that child gets some kind of support, some kind of counselling. So here we are trained as counsellors so we can continue to counsel them. Eeeh, trying to offset that element of bereavement ... so we continued to explain to them that there is still life to go, there is still hope, more hope to come. So at times as you go, with time, with age they get changed, they get resilience, they bounce back, but it is gradual and it is not automatic."

When asked to further elaborate on whether the CBO specifically dealt with the topic of bereavement, Gary further explained:

Gary: "Yes, mostly it is just covered within a broader context because there are some sensitive issues just like bereavement issues, death, orphanhood, ill-treatment. They are issues that you cannot spend 30 minutes or one hour with a bereaving child, talking about death of a parent, with an abused child talking about abuse, with an ill-treated ... So you just include the element of bereavement in a broader context ..."

Commenting on the main psychosocial topics the CBO covered during the delivery of support group sessions to CLHA, a senior project officer Abel and field officer Pilani noted the following:

Abel: "We usually discuss stress issues ... status acceptance issues, also about the behaviour of a child, as a human being and not as an HIV positive child or an HIV negative child, because to us as an organisation we believe that being positive or negative, one should just live as a human"

being, because the journey or the fight that we are fighting is to achieve zero immune infections, zero HIV-related deaths. Everyone needs to participate, not just some ... everyone should be involved in the fighting so that we can achieve. And it is also not their cause [fault] for them to be living with HIV and AIDS, we always tell them it is not the right time to look 'who is responsible for my status' but to say 'this is my status, I have accepted my status, and I am willing to fight because no one else will' ..."

Pilani: "Right there is the other thing which we talk about, to make the child know and understand what AIDS really is, how it is acquired, how to prevent it and if you have it, how you can live with it. How the medication is taken, that when you start you don't have to stop, because the tablets are for life. From there, the children are taught to understand that when they are in the community; they are not different from the other child. They must always know how they ought to be behaving in the community, that they must behave just like other children. We teach them to pass information to the other children, so that they teach each other, so that they will all know about this sickness. From there again, here the children come to learn here at the school, just like any other child, they must go to school, have their education so that they will have a brighter future in their lives. So they are encouraged to go to school because without education life won't be easy for them, and will be easily tempted to do bad jobs like selling their bodies."

As already noted above, the CBO offers CLHA play and sporting activities as part of the PSS delivery to them. The CBO offered a place and opportunity for CLHA to play with other children in the community. Sporting activities were noted by Betty to be one of the favourite activities loved by CLHA which helped them to deal with their problems. Another caregiver Sophia confessed that her child was constantly used to do household chores by his grandfather, but was happy the child found a chance to play with others when he came to the CBO. Betty and

Sophia explained:

Betty: "My child enjoys playing ball ... That's the most wanted activity."

Sophia: "My child was mostly disturbed by cattle duties, but here [CBO] there is a chance that he is now able to play ball, then after he will come for the cattle. So at home his grandfather will be sending him to collect the cattle saying "go and collect the cattle."

Robert: "Children like games, they agree to games ... We design quite a variety of games and they open up at the end of the day. Children like to play, remember, and we have very little time to sit with them and maybe educate them but the games are designed in such a way that they are educational plays. So they open up at the end of the day and are the remedy for denial, withdrawnness and these sports, the games and mingling, the meetings help them ..."

The CBO's PSS activities were noted by Ben to address the issue of malnutrition and the problem of stigmatisation and discrimination among CLHA. He noted the following:

Ben: "... for general physical development of children ... the organisation [referring to CBO] is also introducing some feeding scheme for children to ensure that they are well nourished and also develop well, and [so that] they grow just like any [of the] other children in the community ... Then for stigma, stigma and discrimination, the children, they do a number of activities, play related activities, song, dance, music, well you know, sport. All these are part of the activities. They tell stories which build their esteem and confidence ... so that they feel that they are part and parcel of the bigger community."

The support group session observed by the researcher also illustrated that the

CBO was meeting the PSS needs of CLHA in that the CLHA were able to clearly articulate what they had been taught about how a child living with HIV was to behave in the community. An extract from the researcher's observation notes reads as follows:

[Facilitator]: "Let's say today you meet another child and this child is growing up with HIV. What would you teach him or her? Please give me three things? The children are divided into two groups with group 1 emerging as being the most active and talkative group compared to some members of group 2, who seem distant from what is taking place."

Answers from the group sessions are given as follows:

Group 1 answer

- 1. He should not be sexually active or have many partners.*
- 2. He or she should eat healthy food.*
- 3. He or she should take their medication in time.*

Group 2 answer

We will encourage them to go and get tested. [The children in this group struggled but after the teacher emphasised that the person has already been tested and are found to be HIV-positive, the children give similar answers to those given by group 1.]

The support group session ends after 40 minutes, with the facilitator summarising what had been covered in the support group session and emphasising that whether a child had been raped or grew up with HIV, it was important that they abstained from sexual intercourse until they were mature and ready to do so, in order to prevent the further spread of HIV and AIDS in the community."

The CBO's PSS programme contributed to the reduction of mortality rates among PLHA in the community. When a group of the CBO's field officers were asked

about what would happen if the CBO's PSS no longer existed or if it had never existed at all, Lucy responded as follows:

Lucy: "Yes, there would be a difference because people used to die at a high rate, but because they were now accepting this programme, the rate slowed down and is lower. If this programme stops, people will die again like before."

The field officer further explained why people would die in the absence of a PSS programme:

Lucy: "Because they were not taking any medication, so now they are taking medication following what they are told to do, so the rate at which they were dying has slowed down. In addition when we go into the community we explain to them, so that they accept and they understand that if you are HIV-positive and taking medication, it does not mean that you are dying ..."

As explained above, the CBO uses various activities to meet the PSS needs of CHLA below 15 years of age. When the NAC advisor Ben was specifically questioned about whether the CBO was meeting the needs of CLHA, he made the following remark:

Ben: "I think they have managed to meet the psychosocial support needs of the children ..."

4.7 REFERRAL LINKAGES

Through the content analysis and the individual, semi-structured interviews, the study established that the CBO did not have a formalised and structured referral

system in place with regard to external PSS service providers. The CBO's main external links were with the local police office that offered child protection services to children who had been abused in the community. Another external link was with the local health facilities, the hospital and clinics, which offered VCT and antiretroviral treatment services to CLHA.

Asked about what referral linkages the CBO had with other PSS providers in the district, Ben gave a detailed discussion, which highlighted the following issues:

Ben: "I think their referral for psychosocial support is a bit weak because there are not many players which are offering psychosocial support and the referrals to other services which children might need. These are mostly medical services which are provided by the clinic, hospitals and other service providers, but for psychosocial support the referral is weak because there are not as many players which are provided in the district."

Ben described what a relevant referral structure in a community-based setting for PSS delivery to CLHA should look like:

Ben: "We are looking at a referral system which starts from the households to the village to the wards and to the organisation, and in this case it's Simbarashe [CBO]. Then beyond Simbarashe we are looking at the capacity as it becomes limited because there aren't any other organisations. Other organisations are based in Harare, which is the capital, and these are quite far away ..."

This key informant explained that the Simbarashe National Network for People Living with HIV and AIDS did have the capacity to handle certain PSS issues in CLHA that required professional counselling services or child rehabilitation, for instance. Such professional services were only available in the capital city, Harare, which was inaccessible for many of the community members. The issue

of weak referral linkages was a challenge:

Ben: "... especially for children who might need professional counselling, who might need rehabilitation because of emotional or physical abuse ..."

In addition, Ben added that the Mhondoro-Ngezi district did not have basic child-friendly services for vulnerable children, such as a child-friendly court. The absence of a child-friendly court for children revealed the limited effectiveness of the existing referral linkages in the district for vulnerable children. He further explained:

Ben: "... unfortunately we don't have the child-friendly court here in Kadoma. The nearest is found in Chinhoyi which is some hundreds of kilometers away ... There are quite a number of children who are victims of sexual and physical abuse, irrespective of their HIV status. So these children will require the services, especially of the child-friendly court that is not found in the district."

4.8 IMPROVING COMMUNITY-BASED PSS DELIVERY TO CLHA

In view of the rate of new HIV infections among CLHA, the participants in this study were requested to give their views on how PSS delivery to CLHA in the district could be improved and scaled-up. The responses were categorised as follows:

4.8.1 Scale-up uptake of HIV prevention services for children

The study established that the delivery of PSS to CLHA was dependent on the existence of children who had undergone VCT or received HIV prevention services such as HIV awareness campaigns. The need for more VCT campaigns

would assist in identifying CLHA who would then receive PSS services. Responding to questions on how PSS delivery could be improved in the district, the CBO's Director, Robert stressed:

Robert: "... intensify the general HIV awareness campaigns. At least one each month ... Awareness campaigns, they have to be increased in schools and VCT following [should follow] ... they [referring to PMTCT and VCT] have to be intensified and then yield results that's the birth [initial entry point] of all that we are doing."

4.8.2 Reduction of the legal age for VCT for children

As pointed out above, although many children in the community wanted to know their HIV status, they were denied this opportunity as they did not get the required formal consent from their caregivers. The study established that some caregivers were reluctant to give consent to their children for VCT to take place as they feared their own HIV status would be revealed. In order to address this issue, the Director of the CBO advocated that the age for VCT consent be reduced from 17 years to 15 years. The director argued that children below 15 years were becoming sexually active at a much younger age and so the current age stipulation needed to be reduced so that many children would get tested. The Director explained:

Robert: "There is [a] law of consent which says a child of 16 years has to wait until 17 years so that he or she can get tested, which must be lifted ... they [authorities] must go down a bit so that the child is able to go and get tested ... We are saying let them be able, say at an age of 15 years, to go and get an HIV test. They are suffering because you see at 15 some of them are sexually active ... and we continue calling them children but they themselves do not view themselves as that ... Yet they are sexually active, they can make decisions and are you are aware that some at 9

years, they already have their child? ... So are you telling me that that child with her own child will wait for an HIV test after the parents' consent? This is what I am saying. That is where my point is ... I am saying our children today they are indulging [in sex] early ..."

Robert: "Once they [children] know their status and then they are quickly treated if they are positive and quickly taught."

4.8.3 Production and dissemination by NGOs of culturally sensitive and age-specific PSS information, educational and communications (IEC) material

Abel explained that, although the resource materials received from NGOs was useful in the delivery of PSS, the CBO would prefer more culturally sensitive and more age-specific resource material. Specific reference was made regarding the following: that the PSS material be developed in the vernacular language and that the contents address the specific cultural challenges of CLHA in resource-poor communities, such as alcohol abuse and dealing with orphanhood, among others. As stressed by Abel in the quotations below:

Abel: "... as a nation there has to be material that has to be designed basically for psychosocial support, mainly targeting all children of all types, considering the fact that some of the children in our community they do not understand English ... the material should be produced in vernacular [language] so that it can accommodate everyone."

Abel: "... And at that time [at times] you will be having a child 9 years old and a child 11 years old, their understanding capacity [level of understanding] is different, hence at times it is difficult to assess and to measure if all have managed to grasp the concept of HIV and AIDS and the acceptance of their status ... We have literature but not much literature

targeting the children [referring to child-friendly literature] ... and also the language that is used in designing literature is not in vernacular language, because you would find that the level of understanding of the children in our community is low and they would then maybe appreciate if they can have literature that is produced in vernacular languages, maybe in Shona, Ndebele, so that maybe apart from English literature they can choose which language literature they prefer better because we want to empower ...”

Gary also pointed to the need for and importance of child-friendly IEC material for the improvement of PSS delivery to CLHA in resource-constrained communities:

Gary: “... if IEC materials can be developed which are child-friendly, which the children would like to use, that would really help us.”

When asked to further explain on the type of IEC material in psychosocial support, Gary added:

Gary: “It is like IEC materials, these are some sort of books, charts, pamphlets on what we have been talking about, positive living, psychosocial support, adolescence and so forth. They will be written as literature ... in a language with a pitch that suits the level of the children and their level of understanding [and] considering [taking into consideration] their environment. We talk about Kadoma district, we talk about this rural setup, because you find that the material we wanna [want to] get is more complicated. Those who develop the material will just assume that every child is gonna [going to] read and understand what is written ... So we have discovered that most of the children can hardly comprehend what is written.”

4.8.4 Improve coverage of stakeholders delivering PSS to CLHA

With regard to how the coverage of PSS services could be improved and scaled-up, Paida, Ben and Gary commented that coverage could be improved with increased numbers of PSS support centres, community volunteers as well as support group activities for CLHA. This increased number of centres could improve accessibility, especially for those who have to travel long distances to access the currently available PSS services. They explained below:

Paída: "We would be happy to see more Centres like Simbarashe being built because children who come here to the school are from Ward 1. Ward 2 and 3 are far away."

Ben: "I think we need to train and have more community-based volunteers or caregivers that will improve the psychosocial support services within the community."

Gary pointed out the need to promote more support groups in the district, as he noted that this was the only activity that captured the attention of children:

Gary: "We have to intensify the support groups because this is the only way you can get children gathered as children. That is when they enjoy their childhood, because it is not only about having the children and you say 'okay, sit down' and start writing and preaching and so forth. No, we do a lot of activities such as soccer, playing cards, high jump, and dramas, everything that entertains a child. So we have to design what entertains [design programmes that children enjoy] ... then intensify that to the whole district so that you get all the children involved living with HIV or not."

In addition to the above, Ben noted the need for the involvement of more partners in the delivery of PSS to CLHA in the district:

Ben: "I feel we need to scale-up the provision of psychosocial support. We need to build the capacity of other organisations so that they develop specific programmes of psychosocial support for children. We also need to build the capacity of all the health service centres, clinics and hospitals in the entire district so that they deliver psychosocial support services especially for children. I think that will enhance and also improve the provision of psychosocial support for children living with HIV ... We are looking at the other NGOs ... which are operating in the district such as Tsungirirai, ZIMPAM, as well as clinics from the Ministry of Health ... We would like to see these other organisations or clinics having their own volunteers or enrolling also volunteers specifically for psychosocial support or to support psychosocial support for children."

During the focus group discussion, some of the CBO's senior members, Gary and Abel, advocated for the expansion of PSS delivery services to CLHA through the establishment of various platforms where children could be assisted:

Gary: "... maybe start establishing school centres and social clubs in church settings as well as community-based organisations so that we can assist all children at all platforms in the community."

Abel: "... I think it is an issue that even at churches there is need that youth-friendly centres [that address PSS needs of CLHA] be established so that even if the child does not want to go to a support group at a health centre, he can go to a community-based organisation or at a church. One way or the other, information can get to them."

4.8.5 Dissemination of information about the Ministry of Health and Child Welfare's national manual and guidelines on PSS and CLHA

Throughout the data-collection process, the study established that the CBO's project personnel had little knowledge on the existing national PSS delivery documents. During the semi-structured individual interviews, only one key informant referred to the Ministry of Health and Child Welfare's national manual guidelines on PSS for CLHA in Zimbabwe. This participant was the National AIDS Council representative, Ben. The other key informants at the senior management level of the CBO noted they had never seen or heard of the manual, which was developed in 2009. As discussed in Chapter 1, the manual is the main national document that guides all PSS service provision to CLHA in Zimbabwe. When Ben was asked about the existence of standards that guided the delivery of PSS Zimbabwe, he responded as follows:

Ben: "Yes, there are standards being developed by the Ministry of Health ... they, they define what PSS is and how it should be conducted. They also provide guidelines on ethical issues when dealing with children. They also provide the specific issues for child counselling, you know handling child welfare issues, the issues to do with rights of children all those things ..."

When Ben was asked whether he was referring to National Psychosocial Support 2009 Guidelines for Children living with HIV, developed by the Ministry of Health, he responded:

Ben: "Yes, that's the one ..."

Although the National AIDS Council advisor to the Simbarashe National Network of People Living with HIV and AIDS noted that the CBO was aware of the existing standards, the semi-structured interviews with the CBO's key project

personnel revealed that the CBO did not make reference to any national documents in the delivery of their PSS activities. Ben explained:

Ben: "... I'm sure they are aware of these guidelines and more so because that they have been working with government departments, they have been working with other established international and local NGOs who have produced and who are also using these manuals as reference material."

However when Abel, the CBO's programme officer and child counsellor, was asked whether the CBO had any literature on the national PSS guidelines on working with children living with HIV that they utilised, he commented:

Abel: "For psychosocial support specifically we do not have literature ..."

In addition to the above quotations, when Millicent, who had indicated that she was in charge of training field officers, was asked whether she had received any training specifically on PSS to CLHA, she responded:

Millicent: "... no."

Commenting on the importance of CBOs to make use of the national documents, the NAC advisor explained:

Ben: "I can say they [national documents that guide PSS delivery to CLHA] are very very important, especially for community-based organisations, you know, more so because these are community-based organisations which don't have much in terms of professionals, in terms of the institutional capacity and resources, so the manuals or policy guidelines, books, they provide a reference in terms of guiding psychosocial support ... and it entails the do's and the don'ts of the

psychosocial support programme and I think they provide the much needed technical know-how about delivering the programme in the absence of a professional who could be doing that work. So I think they are quite empowering to the community, to the volunteers who do the job.”

4.9 CONCLUSION

The findings of this study have been presented in this chapter. The chapter began with a presentation of the demographic and socioeconomic information of the CLHA and their respective caregivers as they were the main focus of the study. This was followed by an introductory discussion of the Simbarashe National Network for People Living with HIV and AIDS organisation. The chapter provided an overview on the background of the CBO's establishment, its mission and vision as well as its organisational structure. The chapter then proceeded to discuss in detail the seven main processes identified to describe PSS service delivery to CLHA by the CBO, namely: identification of children requiring PSS, voluntary counselling and testing of children, disclosure of child's HIV status, support groups, case management, transitory school for out-of-school OVCs, and the adoption of a child-friendly rights-based approach. This was followed by a discussion of the critical factors that influenced the delivery of PSS by the CBO to CLHA. The critical factors were categorised into six main themes, namely: psychosocial challenges experienced by CLHA, human rights, community-based approach, caregivers, integrated HIV and AIDS services, and partnerships. The chapter then discussed how the CBO was meeting the PSS needs of CLHA. This was followed by a presentation of issues on referral linkages and ways in which PSS delivery for CLHA could be improved.

The following chapter concludes this research by summarising the research findings and briefly discussing recommendations and implications for future research and policy. The limitations of the study are also highlighted.

CHAPTER 5

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

This chapter gives an overall conclusion of this study, whose broad objective was to explore the critical factors that influenced the delivery of community-based psychosocial support to children living with HIV and AIDS in a resource-constrained area. This chapter begins with a summary of the main findings of this study, as they relate to each of the research objectives. This chapter then discusses recommendations for policy and practice as well as for future research. The chapter ends with a discussion on the limitations of this study and some final concluding remarks.

5.2 SUMMARY OF RESEARCH FINDINGS

As highlighted above, the purpose of this study was to explore the critical factors that influence the delivery of community-based PSS to CLHA in a resource-constrained area. This qualitative study focused in particular on exploring the critical factors that influenced PSS delivery to CLHA by the Simbarashe National Network of People Living with HIV and AIDS. Guided by the social support theory, this study used multiple data-collection techniques to address the study's research objectives. The data-collection techniques used included semi-structured, in-depth individual interviews with five key informants, three focus group discussions with project personnel of the Simbarashe National Network of People Living with HIV and AIDS who operate on different structural levels, as well as one focus group with caregivers of CLHA. In addition, content analysis on some of the CBO's project documents were done, and observation of a PSS delivery session to CLHA was also done.

The specific objectives of this study were:

- To describe the delivery of community-based PSS services to CLHA by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To identify the main factors that influence the delivery of community-based PSS services to CLHA by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To explore caregivers' views on the extent to which the PSS needs of CLHA are being met by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.
- To explore the existing linkages the Simbarashe National Network of People Living with HIV and AIDS has with other PSS service providers in the Kadoma district of Zimbabwe.
- To identify ways in which the delivery of community-based PSS services to CLHA can be improved by the Simbarashe National Network of People Living with HIV and AIDS in the Kadoma district of Zimbabwe.

The study's findings will be summarised below in terms of each of the research objectives.

5.2.1 Research objective 1: Delivery of community-based PSS services to CLHA

This study found that the delivery of PSS services by the Simbarashe National Network for People Living with HIV and AIDS to CLHA was done through various activities. The aim of these activities was to ensure that CLHA received relevant psychological and social support services. The study established that, although the CBO did not follow a specific model in its PSS services delivery, the CBO had adopted concepts of the social support theory discussed in Chapter 2. The social support theory emphasises the presence of social support systems such as those provided by the CBO assist individuals in buffering themselves against

negative issues such as those presented by the HIV and AIDS epidemics.

The founders of the CBO, a couple openly living with HIV in the community, have used their life experiences to inspire and harness whatever community resources were at their disposal to establish and deliver PSS to CLHA. The findings of the study revealed that the Simbarashe Network for People Living with HIV and AIDS delivered its PSS to CLHA below 15 years through various processes, categorised into the following six stages as identified by the researcher:

1. Identification of children requiring PSS
2. Voluntary counselling and testing of children
3. Disclosure of child's HIV status
4. Support groups
5. Case management
6. Transitory school for out of school OVCs

5.2.1.1 Identification of children requiring PSS

The study established that the entry point for children into the delivery process of the CBO's PSS services began with the identification of children in the community, perceived to be in need of PSS. This CBO intentionally identified CLHA in the community through a group of community volunteers known as home-based caregivers or fifth-level field officers. The identification process was in line with one of the CBO's goals, namely identifying and locating individuals in the community in need of PSS. This was also in agreement with the studies done by Foster (2005) that clearly identified the role of community members or those in close proximity to CLHA in facilitating the delivery or access to HIV-related care and support services. The findings from the four-country study on channelling resources to communities responding to OVCs in Southern Africa emphasised the crucial role of community-based responses to the challenges faced by children affected by the HIV and AIDS epidemic, through the community's known history of developing appropriate safety nets to assist those who are faced with difficulties such as illness or death (Foster 2005).

Other studies such as the Richter et al (2006) global report titled '*Meeting the psychosocial needs of younger children in the context of HIV and AIDS*' and the UNICEF 2006 global report on '*Caring for children affected by HIV and AIDS*', also emphasised the important role of those in close proximity to children in need of PSS, such as caregivers, families and communities, to be the ones to provide long-term PSS services. However, these studies, in contrast to this study, did not specifically point out the ability of community members or groups to intentionally play a facilitator role in the identification of children in need of PSS. This study established that the CBO's ability to identify children in need of PSS was as a result of the strengths and active involvement of the CBO's founders, and of the CBO's voluntary field officers.

5.2.1.2 Voluntary counselling and testing of children

The study established that following the identification of children in need of PSS also entailed the process of ensuring that the identified children underwent voluntary HIV counselling and testing, in order to establish their HIV status at a local health facility.

Voluntary counselling and testing campaigns by the CBO, which advocated for HIV testing in children, was one of the major activities commonly done by the CBO, as it was recognised by the CBO's project staff as the entry point and in the strategy for caregivers and younger children born with HIV to finally acquire knowledge about their HIV status. This knowledge, only obtainable through VCT, enabled caregivers to further access the existing HIV treatment, care and support services for their children. Similarly, the studies by Anjala et al (2011:17) on equipping parents and health providers to address the psychological and social challenges of children living with HIV in Africa, pointed out that the current advancements in both HIV testing and treatment were enabling CLHA in resource-poor settings to live longer and healthier, as they were able to further seek out existing and appropriate care and support services in their communities

at an earlier stage of their lives.

5.2.1.3 Disclosure of the child's HIV status

The next stage of the CBO's PSS delivery process is the disclosure of the child's HIV status. This study established that the CBO's home-based care field officers were trained and empowered with skills to share with caregivers of CLHA information on HIV disclosure and its benefits for children living with HIV. The study revealed that some caregivers of CLHA struggled with disclosing the child's HIV status to him or her. The involvement of the field officers in the disclosure process was the CBO's strategy of ensuring that children who underwent VCT had knowledge of their HIV status. This knowledge then enabled the children to further participate freely in the CBO's support group sessions.

Similarly, the studies reviewed in Chapter 2 on HIV disclosure in CLHA, such as the study done by Calabrese et al (2012:1092), also noted that children and adolescents who became infected with HIV through vertical transmission did not have full autonomy over the decision to disclose their status, as some children faced pressure from their mothers and caregivers to keep their HIV status "a secret". The study by Calabrese et al (2012:1092) further pointed out that children and adolescents who acquired HIV through vertical transmission required consent from caregivers first before they can disclose their HIV status to others in the community. This unique situation, which adults living with HIV and AIDS did not have to deal with, was noted by Calabrese et al (2012): CLHA were in the difficult position where they had to seek support services on their own.

5.2.1.4 Support groups

This study also revealed that the Simbarashe National Network for People Living with HIV and AIDS delivered PSS to CLHA through weekly support group meetings conducted on the CBO's premises. The CBO's support group sessions for CLHA included child-friendly activities such as sports, play, drama, poetry, as

well as discussions on issues that affected CLHA such as drug adherence, sexual abuse, healthy eating, stigmatisation and discrimination. Similarly, the common use of support groups in PSS delivery to CLHA was pointed out in the consultation report by Anjala et al (2012) on the provision on PSS to CLHA in Africa, as well as the World Health Organization global review report on *psychosocial support interventions for young people living with HIV*, both which underscored the use of child-friendly strategies such as support in PSS delivery to CLHA.

5.2.1.5 Case management

This study revealed that PSS was further delivered to CLHA through the CBO's case management activities. The case management activities involved the home-based care field officers conducting community home visits 3 to 4 times a week, to monitor the children's health progress and also as well as to provide support to these children in taking their HIV-related medication. Case management of CLHA was an activity the CBO undertook as part of its efforts to promote drug adherence. Similar studies confirming this point included the research conducted in Zimbabwe to establish the proportion of children in Zimbabwe accessing HIV care and support services in 2008, which pointed out that one of the reasons for poor drug adherence among young people enrolled in schools was because of the absence of someone to supervise children in their taking of HIV-related medication (Ferrand et al 2010:430).

5.2.1.6 Transitory school

The study established that the Simbarashe National Network for People Living with HIV and AIDS delivered PSS to CLHA through a transitory school. A transitory school was established on the CBO's premises for out-of-school OVCs; it sought to deliver a comprehensive package which addressed the educational, social and health needs of these children. The transitory school came about after

the realisation by the founders of the CBO that CLHA in the community had unmet educational needs, as many of them were either not enrolled in school due to lack of resources from extended family caregivers or due to constant absents in the formal school system as a result of their chronic illness.

The study found that CLHA enrolled in the CBO's transitory school were offered PSS support during school hours, as they were able to receive counselling and medical support from the CBO's field officers as and when they needed it. The field officers were able to escort sick children to seek medical attention and bring them back to class. The CBO's founders noted that this unique ability to have a school that understood the long-term chronic nature of the AIDS-related illnesses was in contrast with the formal education system where CLHA are merely sent home when they became ill. Although other studies reviewed did not highlight the role of transitory school systems that specifically met the unique PSS needs of CLHA in schools, the report by Kaneshathasan et al (2011) did point out that in resource-constrained settings, good PSS for a child living with HIV was one that recognised the social and physical challenges faced by these children, as well their need for consistent social support and continual care in any geographic location.

5.2.2 Research objective 2: Main factors influencing delivery of PSS to CLHA

The study established the critical factors which influence the delivery of PSS to CLHA by the Simbarashe Network for People Living with HIV and AIDS to be as follows:

1. Recognition that CLHA experience psychosocial challenges
2. Commitment to achieving human rights
3. Adoption of a community-based approach through involvement of community members, community volunteers, local traditional leadership, and people living with HIV and AIDS

4. Caregivers' attitudes towards VCT
5. Availability and access to HIV prevention, treatment care and support services
6. Partnerships with external partners: National AIDS Council, NGOs and government departments

This study found that the recognition of the existing PSS challenges is what had inspired the CBO to deliver specific PSS programmes to them. The study established that the challenges the Simbarashe National Network for People Living with HIV and AIDS had identified in CLHA included challenges associated with drug adherence, denial of HIV status, disclosure, isolation and or depression, bereavement, stigmatisation and discrimination, and poverty. Thus the CBO's ability to recognise the unique challenges presented at the CBO by CLHA who had contracted HIV through vertical transmission, is one of the factors that had influenced the development and implementation of the CBO's PSS programme to CLHA.

This finding concurs with findings of the studies conducted by The World Health Organization (WHO: 2009) and the consultation report findings by Anjala et al (2012) that pointed out similar challenges.

The findings of this study also established that the delivery of specific PSS programmes to meet the PSS needs of CLHA was influenced by the CBO's strong commitment to ensuring that the human rights of children in the community were met. This was illustrated by the CBO's activities on human rights awareness, commemoration of human rights celebrations such as the "Day of the African child", as well as through meeting their social needs. There were no specific references made in the literature reviewed to any link between PSS service delivery and human rights.

Another factor identified by the study to influence PSS delivery was the CBO's

adoption of a community-based approach in its PSS delivery activities to CLHA. The study findings revealed that the CBO did this through involvement of community members who included the CBO's community volunteers. As already mentioned above, the fifth-level field officers delivered the bulk of the PSS services to CLHA. These community-based volunteers conducted activities which included identifying children in need of PSS in communities, assisting caregivers to disclose the child's HIV status, integrating children into support groups after VCT, case management of CLHA through the home visits, and escorting sick children enrolled at the transitory school to the local clinic.

Other important members who contributed to the CBO's PSS delivery were the local traditional leadership, such as the chief and headman. The study found that these local leaders are people of great influence, particularly with advocacy to mobilising community members and resources for the CBO's activities. The study established that the local chief where the CBO is located had donated the very piece of land where the CBO currently delivered its PSS services. Thus this study revealed the local traditional leadership as being influential in the establishment of PSS delivery structures, as well as in the uptake of these services. There was no specific reference in literature reviewed to the influential role played by local traditional leadership in PSS delivery services to CLHA.

The study further revealed that the meaningful involvement of people living with HIV and AIDS, particularly adults, facilitated the delivery of PSS to CLHA. As noted above, the founders of the CBO are people living with HIV themselves, and they have used their testimony of their experiences as people living with HIV to assist CLHA in the community. In addition, the CBO has also employed staff members as well as community volunteers living with HIV to assist in its PSS delivery activities to CLHA. Although the literature reviewed did not point out the specific role of people living with HIV and AIDS in being influential in the delivery of PSS services to CLHA, the studies on care and support interventions for children living and affected by HIV, conducted by Boler and Johnson (2007:31-

32), Foster (2005:5), and Ninan and Delion ([sa]:213), concurred with this study's finding on the important role of community-based interventions in the provision of long-term sustainable social support and resources to vulnerable children in resource-constrained communities.

Another critical factor identified in the study was the caregivers' attitudes towards VCT. As already explained above, VCT was important in establishing the HIV status of children as it inevitably determined whether or not they could further access the CBO's PSS activities. This study pointed out that the CBO's major challenge was caregivers' attitude towards VCT. This is in contradiction to the reviewed studies, which placed more emphasis on caregivers' attitudes towards HIV disclosure per se. Studies such as the WHO (2009) global review on PSS interventions in young people underscored the global challenge of HIV disclosure challenges as a result of caregivers' inability to cope with their own drug adherence issues.

Another critical factor that influenced the CBO's ability to deliver PSS services was the availability and accessibility of HIV and AIDS prevention, treatment and care services within the reach of caregivers and their children. The study revealed that, although the local community health centres did not offer any PSS activities to children after they had undergone VCT and were found to be living with HIV, the presence of the CBO close to the health centres had facilitated quick uptake of PSS services from the CBO by these children. Thus the absence of care and support services close to VCT centres of health facilities hinders PSS delivery as there will be no children to deliver services to. This concurs with the findings of the study on the effectiveness of ART among children living with HIV and AIDS in sub-Saharan Africa, which revealed that a major obstacle in the provision of care services to children living with HIV in most resource-poor settings was the absence of these services at many of the existing health care facilities (Sutcliffe et al 2005:477-478). The study underscores the importance of having available and accessible care and support services close to HIV treatment

centres. This is particularly important in resource-constrained areas where health facilities may be the most common available structure in communities.

Another critical factor established by this study was the existing partnerships that the CBO had with three main categories of bodies which had assisted the CBO to deliver its PSS services. These partners included the National AIDS Council, non-governmental organisations and government departments. These partners were key in influencing the delivery of PSS activities, as they provided the CBO with technical support services, IEC materials, as well as the financial resources to conduct their activities. The study findings revealed that the National AIDS Council, decentralised structures, namely the provincial and district AIDS committees (PAACs) and (DAACs), were critical structures that provided platforms for the CBO to have conducted PSS advocacy, networking and information dissemination activities. Thus the study revealed that the strong partnerships with other key external partners, in particular with the NAC, which is the National Coordinating structure for all HIV and AIDS responses in Zimbabwe, had contributed to the CBO's PSS delivery activities. Although the literature reviewed highlighted the role of the various categories of PSS service providers, previous studies did not point out the influential role of partnerships, particularly with the National AIDS co-coordinating structures.

5.2.3 Research objective 3: Caregivers' views on the CBO's ability to meet the PSS needs of CLHA

This study found that the caregivers who participated in the study were of the opinion that the PSS needs of CLHA were to a large degree being met by the CBO. Caregivers explained that their CLHA had changed remarkably since they began participating in the CBO's support groups, drama, poetry and sporting activities. The caregivers described how their children were now able to confidently and comfortably disclose and talk about their HIV status and other issues when they returned home from attending a PSS session. This finding

confirms the findings of previous studies which also showed that psychosocial support for CLHA helped to build their resilience, and that psychosocial support met the emotional, mental, social and spiritual needs of these children and contributed to good long-term health outcomes (Hogan et al 2002:381; Lyon & D'Angelo 2006:182).

Caregivers of CLHA also added that the support groups at the Simbarashe National Network for People Living with HIV and AIDS offered opportunities for CLHA to form and maintain relationships that contributed to reducing the stress associated with living with HIV and AIDS. As noted by Baum et al. (1984), effective social support is where existing interpersonal relationships are able to provide the appropriate form of support that will operate as an effective buffer to the negative effects of the existing situation. The social support provided through the CBO's PSS activities essentially played a crucial role in assisting the children to cope with living with HIV and AIDS.

In addition, the CBO was noted to have been addressing problems related to malnutrition through feeding the children, and also addressed their educational needs through the transitory school. The study findings revealed that caregivers of CLHA in their care were extended family members who were struggling to provide the basics due to poverty. It was pointed out by Foster (2005) and Van Dyke (as cited in Van Gelder & Kraakman [sa]:3) that the extended family structures in Africa which used to provide support to vulnerable family members, are struggling as they have now become greatly over-extended in communities most affected by the HIV and AIDS epidemics, resulting in the families having reduced capacity to take care of vulnerable and orphaned children.

5.2.4 Research objective 4: Existing referral links of the CBO with other PSS providers

Another important finding of this study was that the CBO's referral links included

mainly the local health facilities (in cases where children were identified as requiring health care) and the local police (where issues of child protection and sexual abuse required their involvement). However, the study established that the CBO did not have a formal and structured referral system to further deal with emerging PSS needs that were beyond their capacity. The findings indicated that there were specifically no referrals for CLHA who may have required professional counselling or rehabilitation services. The main reason given for this was the absence of relevant specialised services in this particular resource-poor setting. Coverage of such services was noted to be mainly concentrated in the capital city, Harare, which was inaccessible to the majority of the rural community.

The issue of weak referral systems is not unique to the Simbarashe National Network for PLHA alone. Other organisations delivering PSS, whether big or small in Africa, also face this challenge. The literature review noted that the issue of a weak referral system was also an issue to two organisations such as the Butterfly House, Drakenstein Palliative Hospice located in an informal settlement in the Western Cape in South Africa, and the Baylor Taylor International Initiative – a huge organisation with thousands of children under its PSS programme in Uganda (Anjala et al 2011:41, 71-73, 92-93).

5.2.5 Research objective 5: Improving the delivery of community-based PSS services to CLHA

The CBO's main recommendations for the improvement of PSS delivery services to CLHA centred on three main areas; namely increased HIV prevention services targeting children, the development and or dissemination of PSS service delivery-related publications and increased coverage of PSS service delivery centres.

This study's findings highlighted the need for the expansion of HIV prevention services for children in resource constrained areas. The main prevention service

highlighted by this study was VCT, as this service was regarded by the CBO as the door-way for children further accessing PSS services after their HIV status had been established. In addition the findings of this study pointed out the need for the reduction of the current legal age of consent for children to be tested for HIV to be reduced from 17 years to 15 years of age.

In addition, this study also found that there is a need for the development and or dissemination of more PSS service delivery-related publications and material resources for PSS services providers operating in resource-constrained areas. Specific mention in the findings was made with regard to the need for the relevant government authorities to disseminate key policy documents such as the national PSS guidelines that guide the provision of PSS service to CLHA, as well as the need for the relevant authorities and advocates for PSS service delivery for CLHA to develop IEC resources that were language, culture and age specific to the kind of children found in resource-poor settings.

The study findings also highlighted the need for improved coverage of PSS services to CLHA by community groups. This would address the problem of the availability of few and sparsely located care and support services. None of the studies reviewed on PSS services delivery highlighted the above in specific reference to reducing the age legal age of consent for VCT in children and the need for more relevant PSS publications.

5.3 RECOMMENDATIONS FOR FUTURE RESEARCH

Although the CBO personnel and caregivers of CLHA acknowledged that PSS delivery to CLHA was influenced by a multitude of factors, ranging from the mere recognition of the PSS needs of CLHA to the availability of community-based volunteers in PSS delivery, there is a need for more research to understand the factors which influence the uptake by communities of existing community-based PSS for CLHA below 15 years.

Based on the findings of this study it is clear that communities in poor-resource

settings are influenced by traditional leaders, people living with HIV and AIDS and the availability and accessibility of other HIV and AIDS services, such as VCT services. An understanding of PSS services uptake by communities could reveal the perceptions of communities to the various care and support initiatives available to them.

Another area of research could investigate the role and influence of VCT services for children in PSS delivery and uptake by CLHA. The study's findings revealed that VCT was the entry point for PSS service delivery to CLHA and that caregivers who were reluctant to give consent to their children to undergo VCT were also hindering access to PSS services for their children, who may be infected with HIV in communities. Another area for research could be an in-depth exploration of the actual role and contribution of community-based volunteers in PSS delivery to CLHA. An understanding of their influence and the actual amount of time and human resources they contribute, could give an understanding of the contribution of these community members in the HIV and AIDS response.

5.4 RECOMMENDATIONS FOR POLICY AND PRACTICE

Based on the findings of this study, the following recommendations should be considered for PSS policy and practice.

5.4.1 Scaling-up of initiatives that promote community-based PSS to CLHA

The study findings revealed that community-based PSS service providers were limited in terms of numbers and coverage in resource-constrained areas. Already the general population was noted to travel long distances to access HIV and AIDS services such as VCT and PMTCT from health facilities such as clinics and hospitals. In this regard, the researcher recommends that:

- I. PSS delivery to CLHA be mainstreamed into existing HIV and AIDS treatment and care support services found already at existing local health structures. This would enable children already visiting health services to enrol in ART treatment or coming to collect their monthly medication, to receive PSS services. This could be done through the establishment of child-friendly support groups conducted on site at health facilities. Currently, health personnel are trained in VCT and PMTCT. PSS for CLHA could also be mainstreamed into their programmes.
- II. The government could encourage the district local government structures such as Rural District Councils to assist in the establishment and registration of more community-based organisations delivering PSS to CLHA. This would improve coverage of services, especially in rural areas where there are few basic health services and these are often out of reach for many community members, who end up walking long distances.
- III. Advocacy by government for more community organisations to be involved in the delivery of partial or comprehensive PSS services. These community organisations could include schools and churches which have a good coverage and are already in existence and within reach of communities.

5.4.2 Dissemination of information and training on the Ministry of Health and Child Welfare National PSS guidelines and manual for PSS delivery to CLHA

The study established that, although this policy document was the main PSS policy document that guided the delivery of any PSS to CLHA in Zimbabwe, limited knowledge of this policy document existed, even at the major PSS provider in the Mhondoro-Ngezi district. In this regard, the researcher recommends that the relevant ministry disseminate information on this national document. The researcher further recommends that this 2009 document be

updated and more copies of the policy be distributed to those delivering PSS to CLHA. This could be done with the assistance of the National AIDS Council structures. The National AIDS Council is the main coordinating body of all HIV and AIDS responses in Zimbabwe and should therefore be engaged in the dissemination of this key document.

5.5 RECOMMENDATIONS TO THE CBO ON IMPROVING PSS SERVICES DELIVERY TO CLHA

In view of the research findings, the researcher recommends three ways in which the Simbarashe National Network for People Living with HIV and AIDS could improve to an even greater extent the important services they are providing to CLHA.

The first recommendation is for the creation and adoption of a documentation and filing system which will capture all the relevant personal information and actual PSS services the children will be receiving from the CBO at any given time. This documentation and filing system could also enable the CBO staff to capture important information on the PSS challenges each child could have as well as the progress the child will be making as a result of the services being provided to them. Such a system could improve the monitoring and evaluation of the effectiveness of the CBO's activities, as factual and historical evidence-based information from children's records would now be available to any of the staff members.

The second recommendation is for the CBO to make contact with the relevant Ministry of Health and Child Welfare department in charge of PSS delivery services to CLHA in the district. This will enable the Simbarashe National Network for People Living with HIV and AIDS to receive information and more relevant technical support services such as trainings and manuals on the ways of effectively delivering PSS services from the respective government department.

Finally, the researcher recommends that the founders of the CBO document and publicise the CBO's activities and their experiences in providing PSS services to CLHA in a resource constrained areas This could be done through publishing an article through the National AIDS council newsletters and website or through the creation, funds permitting, of brochures by the CBO. This sharing of information could assist in promoting the CBO's visibility and could assist in creating a platform to exchange vital information on effective ways to improve PSS delivery to CLHA. As noted above, the CBO is located in a rural setting and any form of visibility could enable the CBO to engage debate on PSS delivery issues and foster relationships with other PSS service providers or experts that could assist them with more ways to better improve their PSS delivery services to CLHA.

5.6 LIMITATIONS OF THE STUDY

Firstly, the researcher could explore the delivery of PSS to CLHA by only one CBO, due to limited time and financial constraints. The researcher's choices were also limited due to the lack of PSS service providers for CLHA in this particular district. However, despite this limitation, the selected CBO proved to be an information-rich source for the research.

Secondly, the researcher was not able to conduct a thorough content analysis of all the CBO's documents. This was mainly because most of the documents of the Simbarashe Network for People Living with HIV and AIDS were handwritten documents, some of which were not legible to the researcher. However, the organisation did have a few typed documents which were utilised in this study.

5.7 CONCLUSION

The findings of this study have revealed that in resource-constrained areas, the delivery of PSS services to CLHA depends on multiple interconnected factors. The critical factors that influenced PSS delivery were not only dependant on the

recognition that CLHA had specific needs, that PSS was a human right or that caregivers' attitudes mattered. The findings of this study revealed other factors such as VCT being the main entry point, not only to HIV treatment but also to PSS services. Caregivers who were reluctant to take their children to VCT limited the CBO's ability to deliver PSS services to CLHA.

In addition, the study also revealed that the local traditional leadership in resource-constrained areas were a key player in ensuring that any PSS delivery to CLHA took place. These traditional leaders were noted to influence the communities' decision on and perception of PSS services. In addition, partnerships with the National AIDS Council and relevant government departments as well as non-governmental organisations, which provided both technical and financial resources, were identified as another critical factor. The study indeed concurred with earlier studies that community-based responses through the active involvement of community members offered the continual social support and social capital required for relevant and sustainable PSS delivery to CLHA in resource-constrained areas.

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ANNEXURE A: LETTER REQUESTING ACCESS TO DO RESEARCH

2010/09/01

To whom it may concern

RE: Letter of access for research

This is to confirm that Ms Memory Zulu (Student number: 41514629) is an enrolled student with the University of South Africa (UNISA). As part of the requirements for the Master's degree, she has to undertake research activities to complete a dissertation of limited scope.

The letter requests that you allow Ms Zulu access to conduct research in your organisation and obtain access to information for the purposes of this research. Her topic is "**An Investigation of Existing Community-Based Psychosocial Support Services for Children Living with HIV and AIDS in the Kadoma District, Zimbabwe**". Please note that Ms Zulu will not start the research until your organisation has furnished her with a letter granting her such access.

While undertaking the research, Ms Zulu will remain accountable to her supervisor, Ms Elize Koen. In this regard, she is bound to policies of ethical research conduct as set by the University of South Africa.

MsZulu will observe propriety in dealing with staff, visitors, equipment and premises and act appropriately, responsibly and professionally at all times.

She will ensure that all information regarding your organisation or furnished by your organisation remains secure and strictly confidential at all times.

Yours sincerely

Mr Leon Roets
Programme Convener
Department of Sociology

**ANNEXURE B: LETTER FROM CBO GRANTING ACCESS TO
RESEARCHER**

ANNEXURE C: CONSENT FORM

(CAREGIVERS AND KEY INFORMANTS)

As part of fulfilling the requirements of the University of South Africa MA Behavioural Studies (HIV & AIDS) degree, Miss Memory Zulu Student Number 41514629 wishes to undertake a qualitative research study of your organisation.

Please note the following conditions of the research:

- All the information collected by the researcher will only be used for purposes of meeting the requirements for the Master's degree.
- All information gathered will be submitted to the University and is regarded as the property of the University.
- Your personal identity will not be disclosed to anyone else. Only the researcher will have access to this information.
- You are allowed to withdraw from the research at any given time during the research process. Please note that no questions will be asked by the researcher.
- The researcher or the University of South Africa will not offer any benefits (material or financial resources) to the research participants.
- Any emotional or psychological distress experienced by the research participants that may arise due to their participation in the research will be dealt with. The researcher will arrange for counselling or debriefing to be provided by a professional.

If you are in agreement with the above conditions and consent to participate in this study, please sign your name and provide the date on the line below.

Name in full..... Signature and date.....

ANNEXURE D: IN-DEPTH INTERVIEW GUIDE

IN-DEPTH INTERVIEW GUIDE

Category of population:

CBO concerned:

Characteristics:

Representatives of the community-based organisation whose opinion on the delivery of psychosocial support to children living with HIV and AIDS in Kadoma District.

Points to consider:

- Personal background
- Organisation background
- Perspectives on the delivery of PSS to CLHA
- Understanding of PSS delivery model/approach used
- Understanding of PSS needs of CLHA
- Factors that promote PSS delivery by the CBO
- Factors that hinder PSS delivery by the CBO
- Knowledge and utilisation of frameworks and policy that support PSS for CLHA
- Participation of CLHA in CBO PSS activities
- Existence and functionality of referral systems to other services
- Understanding the role of the community-based approach in PSS delivery
- Ways to improve PSS delivery to CLHA

Questions:

Personal background

1. What is your name and age?
2. What is your role in the delivery of PSS to CLHA in this organisation?
3. How long have you been with this organisation?
4. Why did you join this organisation?
5. Has joining this organisation changed your life in any way? Please explain.
6. What is your level of education?
7. Do you have any specialised training for this role?

8. How would you describe your community in terms of social and economic activities?

Organisation background

9. What is the full name of your organisation?
10. When and how was the organisation established?
11. What is the vision and mission of your organisation?
12. What are the main goals and objectives of your organisation with regard to PSS delivery?

PSS delivery to children under 15 years

13. How does your organisation define PSS?
14. Describe how you deliver PSS services to CLHA under 15 years?
15. Do you use a model/approach for your PSS deliver to CLHA? Please describe in detail.
16. What are the critical components required for the delivery of PSS to CLHA?
17. What does a successful PSS delivery look like?
18. With which indicators do you measure this success?
19. How do you document your PSS delivery?
20. How many children benefit from your programme?

Recognised care & support frameworks supporting PSS delivery for CLHA

21. Are you aware of the existing international and national policy documents and frameworks that guide PSS delivery to CLHA in Zimbabwe, such as the International framework for HIV Care and Support for Children framework and the National PSS guidelines for CLHA?
22. Describe how you have benefited from the use of these?
23. Explain which sections of the documents have been useful in the implementation of PSS delivery?
24. If you have not used any such documents, kindly explain why you have not used them?
25. What else do you use to guide your PSS delivery to CLHA?

Understanding the specific PSS needs of CLHA

26. What are the main PSS needs of CLHA below 15 years in your organisation?
27. How are they different from the PSS needs of adults living with HIV and AIDS?
28. How does your organisation identify and recruit CLHA below 15 years for your activities?

Existing links with other PSS providers

29. What relationships does your organisation have with the OI-ART clinic at Kadoma District Hospital?
30. What relationships does your organisation have with palliative care providers in the community?

31. What referral links do you have with other PSS providers? Specify which ones.
32. Describe what kind of relationship your organisation has specifically with caregivers and families of CLHA you offer services to?
33. Describe the referral system you have put in place to ensure the comprehensive delivery of PSS for CLHA?

Participation of Caregivers and CLHA in PSS delivery

34. How has your organisation involved CLHA in PSS activities, design, implementation, monitoring and evaluation?
35. How has your organisation involved caregivers of CLHA in PSS activities, design, implementation, monitoring and evaluation?
36. In your opinion, how has this involvement improved PSS service delivery for CLHA?
37. If they were not involved, what were your reasons?

Effectiveness of existing services delivery

38. In your opinion, what is the effectiveness of your CBO in meeting the PSS needs of CLHA and their families?
39. As an organisation, how do you know when you have effectively delivered a service to a child in need?
40. In your opinion, is there a link between PSS service delivery and good health results? Explain

Importance of community-based approach to PSS delivery

41. In your opinion, what is a “community-based approach”?
42. Do you feel your organisation follows a community-based approach?
43. What is the importance of the delivery of community-based PSS to CLHA in your district?
44. To what extent does the local community participate in the delivery of PSS?
45. How have you worked closely with them to deliver PSS to children? Give examples.
46. Did you involve them in the development phase of the project? Explain in more detail.
47. What are the benefits of this community-based approach with regard to the delivery of PSS services?
48. What are the challenges of this community-based approach with regard to the delivery of PSS services?

Improvement of community-based PSS delivery for CLHA in the district

49. In your opinion, what is the extent of the need for community-based PSS delivery to CLHA in the Kadoma district?

50. In your opinion, what is the role of the Ministry of Health, Rural district council, National Council, schools, churches and business people, among others, in supporting the delivery of comprehensive community-based PSS to CLHA in Kadoma district? Please specify.
51. What is the role of other stakeholders in the delivery of sustainable PSS to these CLHA in Kadoma district? Specify.
52. Despite the rise in the number of children living with HIV and AIDS, the provision of community-based PSS activities for CLHA remains inadequate. In your opinion, despite financial resources, what else can be done to improve the delivery of such services in resource-constrained areas?

ANNEXURE E: FOCUS GROUP DISCUSSIONS GUIDE

Category of population: Key Informants (project personnel to include different categories of volunteers)

Points to consider:

- **Description of PSS needs of CLHA**
- **Actual PSS services delivered**
- **Description of PSS delivery model used**
- **Participation of the community in PSS delivery**
- **Testimonials of delivery success on children**
- **Existence and functionality of referral system**
- **Critical factors for PSS delivery in resource-poor setting**
- **Service delivery improvement**

Questions:

Discussion points for the focus group discussions with project staff of the CBO

- What are the goal and objectives of this CBO?
- Describe the children you deal with.
- How does your CBO define PSS?
- How many children does your PSS service benefit?
- Describe the PSS delivery services you offer to CLHA.
- Do you use a specific model/approach to deliver your PSS services?
- Give specific testimonials of children's lives that have been changed since receiving PSS services.
- In what ways are caregivers and children involved in the development of this project?
- In what ways do you work with the community in the delivery of PSS to CLHA?
- What are the critical factors that have enabled you to deliver PSS services?
- How critical is the community in the delivery of PSS services to CLHA?
- What are your key indicators you use to measure successful PSS delivery to CLHA?
- What has made you succeed in the delivery of PSS to CLHA?
- What has hindered your success?

- Do you have a referral system in place?
- When your CBO is unable to deal with a particular PSS issue, what do you do?
- How can the referral system between the CBO and other PSS service providers be improved?
- In your view, what is the extent of the need for community-based PSS for CLHA?
- What then are the critical factors for community-based PSS to take place in a poorly resourced community?
- Besides financial resources, how can PSS provision by your organisation for CLHA in your area be improved and scaled-up in view of the increasing number of children?
- Despite the rise in the number of children living with HIV and AIDS, the provision of community-initiated PSS activities for them remains inadequate. In your opinion, what limits the delivery of community-based PSS besides financial resource?
- How can community-based PSS for CLHA be improved in general?

ANNEXURE F: FOCUS GROUP DISCUSSION GUIDE

Category of population: Caregivers of CLHA

- Personal background of caregivers and children
- Understanding of PSS
- Details of PSS needs of their children
- How they came to know about the CBO and its services
- Details of the actual services the children receive
- Perspectives on the changes PSS services delivery has made to CLHA
- Benefits the service has brought to caregivers' lives
- Participation of caregivers in PSS service delivery
- Existence and functionality of referral systems
- Ways service delivery can be improved

Questions:

Discussion points for focus group with caregivers of CHLA

1) Please give the following information about yourself:

Personal Information

AGE	Number of people in household		Sex M/F number
16-30			
31-45			
46-60			
60+			

2) Income Category per month US\$

Income category	Number in household
Below 100	
Above 100 +	

3) Personal Information about your child/children

AGE	number		Sex M/F number
Below 5 years			
5-10			
10-15			

Description of PSS needs of children

- 4) Describe in detail the specific problems your children deal with daily because of their HIV or AIDS status?

PSS Services received by children

- 5) Describe in detail the specific services your child receives from this CBO which helps them to deal with their HIV or AIDS status?
- 6) What are your children's favourite activities when they come to the CBO?
- 7) How long have you been receiving PSS services?
- 8) How often do your children receive services from the CBO?
- 9) Explain how you came to know about this CBO?
- 10) Are you aware that your child's PSS needs are recognised by the government as advocated for in the National PSS Guidelines for CLHA?

Benefits of CBO PSS services to children

- 11) In your opinion, has the PSS service of the CBO brought about significant changes to your children? Give specific testimonials, giving the name, sex and age of your child.
- 12) If this CBO did not exist would you manage to deal with the PSS needs of your child on your own or with other extended family member? Give reasons.

Role of caregivers in PSS delivery of CBO

- 13) Did you or your children participate in the development of this community PSS programme? Give details.
- 14) Are you involved in the running of this PSS programme? Give details.

- 15) What are the important steps you took as a caregiver that have enabled you to succeed in accessing this particular community service?
- 16) What has hindered you from fully accessing this particular community service?
- 17) In your opinion, what role does the local community play in the success of community-initiated PSS for CLHA?

Referrals by the CBO

- 18) Does the CBO offer you information on where else to get PSS services when they are unable to provide the service your child requires? Please give examples.
- 19) How and who do you think can be involved from your community to improve the delivery of PSS by this CBO?

Improvement of PSS delivery by CBOs

- 20) In your opinion, how can community PSS delivery for CLHA be improved and scaled-up in view of the increasing number of children?

ANNEXURE G: ETHICAL CLEARANCE

**ANNEXURE B: LETTER FROM CBO GRANTING ACCESS TO
RESEARCHER**



Simbarash Network For P.L.W.HIV

CBO No 2006/1

To Ms Memory Zulu

Cc Mr. Leon Rosi

Programme Convenor

Department of Sociology

**PERMISSION TO CONDUCT RESEARCH ON OUR PSYCHOSOCIAL SUPPORT
PROGRAMME**

I do hereby grant permission to Ms Zulu conduct her research on our psychosocial support programme. We are in agreement with her proposed methodology for the study and she will have access to all relevant documents and reports about our programme

Yours Faithfully

Richman Rangwani

Founder and Director

Simbarashe Network for P.L.W.HIV.

ANNEXURE G: ETHICAL CLEARANCE

Proposed title: An Investigation of existing community-based psychosocial support services for children living with HIV and AIDS in the Kadoma District, Zimbabwe.

Principal investigator: Ms Memory Zulu (Student number 4151-462-9)

Reviewed and processed as: Class approval (see paragraph 10.7 of the UNISA. Guidelines for Ethics Review)

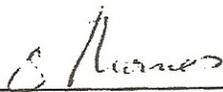
Approval status recommended by reviewers: Approved

The Higher Degrees Committee of the Department of Sociology in the College of Human Sciences at the University of South Africa has reviewed the proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the candidate should heed the following guidelines:

- To only start this research study after obtaining informed consent
- To carry out the research according to good research practice and in an ethical manner
- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy
- To work in close collaboration with her supervisor and to record the way in which the ethical guidelines as suggested in her proposal has been implemented in her research
- To notify the committee in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change
- To notify the committee in writing immediately if any adverse event occurs.

Kind regards



Dr Chris Thomas
Chair: Department of Sociology
Tel + 2712 429 6301