FACTORS AFFECTING AIDS ORPHANS’ FROM ACCESSING VOLUNTARY COUNSELLING AND TESTING (VCT).

BY

LINEO BERNADETTE MAAMA

Submitted in partial fulfillment of the degree Magister Artium in Social Work (Social Development and Planning) in the Faculty of Health Sciences, Nelson Mandela Metropolitan University

Supervisor: Prof TT Mashologu-Kuse

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ABSTRACT

The study seeks to explore and identify factors that prevent AIDS orphans in presenting themselves for Voluntary Counselling and Testing (VCT). Socio-cultural factors, notably, stigma and the resultant discrimination by community members, have been presented by many researchers as the main aetiological factors that hinder the use of VCT by AIDS orphans. It is on the basis of this that this study was conducted to identify factors that hinder AIDS orphans from accessing VCT. The study used a qualitative approach following an explorative and descriptive, contextual research design and was conducted at Ubuntu Education Fund, Port Elizabeth. Purposive sampling was used to determine a sample of AIDS orphans. Participants of the study had to be orphaned as a result of AIDS, isiXhosa-speaking, between 12-17 years, living in the care of a primary care-giver and had not presented themselves for VCT.

Data was collected by means of semi-structured interviews. Semi-structured interviews are suitable in cases where the researcher is interested in an issue that is complex or personal (De Vos, Strydom, Fouche and Deloport, 2005). Data was analyzed according to the framework provided by Tesch (1990) as described in Creswell (2003). The major findings of this study were that people are locked in a ‘poverty-of-the-mind cycle’, in respect of HIV and AIDS, and this is exacerbated by educational impoverishment and general poverty. The recommendations that emanated from this study are made from policy and service delivery perspectives. It is recommended that in order for AIDS orphans to access VCT they should be developed and empowered through sustainable programmes that enhance their capacities to the utmost realization of their potential. It is also recommended that health and other professionals should encourage AIDS orphans and community members to present themselves for VCT and thus curb the spread of HIV and AIDS.

Key words: HIV and AIDS, AIDS orphans, Voluntary Counselling and Testing (VCT).
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INTERVIEW GUIDE

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2. How long have you been living with your caregiver?

Content questions:

3. What do you and your friends understand by VCT?
4. What discussions have you and your friends had about VCT?
5. What will encourage you and your friends to go for VCT?
6. Have you ever discussed VCT with your primary care giver?
7. What are the factors that stop you from going for VCT?
Dear Sir/ Madam

RE: Request to conduct research with AIDS orphans assisted by Ubuntu Education Fund

I hereby request to be given permission to conduct my study with the participants of Ubuntu Education Fund, as a partial requirement to complete my MA studies in Social Development and Planning. Below are details of the study and the role that will be played by the research participants.

Title of the research project: Factors affecting AIDS orphans from accessing VCT.

The objectives of the study are:

- To explore their views about VCT
- To determine factors that prevent them from accessing VCT.
- Based on the research findings, the study will draw conclusions and make recommendations on appropriate support services in order to encourage AIDS orphans to utilize VCT.

AIDS orphans will participate voluntarily and all the information supplied above will be conveyed to them on the first day of the interviews. Each participant will be given a consent form that will be fully explained to them and this will be to ensure that the participant participates voluntarily. All the information provided during the interviews will be treated confidentially and will not be used for any other research study. After the study is completed the researcher will give Ubuntu Education Fund a copy of the report and share the research findings with the management.
Physical address of the researcher : Renaissance Post-graduate Student Village
: Village 1 Room 9B
: NMMU
: Port Elizabeth

Contact numbers : Cell 0795889429
: Home 041 5044 4137

Your cooperation and that of the AIDS orphans will be highly appreciated.

Yours faithfully

Lineo Maama, MA Research student
APPENDIX III

Research Participant Consent Form

Title of the research: Factors affecting AIDS orphans from accessing VCT.
Reference Number: 207037299 (student number of the researcher)
Researcher: Lineo Maama
: Renaissance Post Graduate Student Village
: Village 1 Room 9B
: NMMU
: Port Elizabeth
Contact Numbers: Cell 0795889429
Home 041 504 4137

Declaration by the research participant:
I, the research participant was invited to participate in the above mentioned research project which is undertaken by Lineo Maama of the Department of Environmental Health and Social Development Professions, Faculty of Health Sciences at Nelson Mandela Metropolitan University.

The objectives of the study are as follows:
- To explore AIDS orphans views about VCT.
- To determine factors that prevent them from accessing VCT.
- Based on the research findings, the study will draw conclusions and make recommendations on appropriate support services in order to encourage AIDS orphans to utilize VCT.

I understand that my participation is voluntary and that I have a right to withdraw from participating at any time without penalty. I understand that confidentiality will be maintained at all times. The person asking me questions will never tell anyone what I told her and my name will not be written down or recorded. My privacy will be maintained in all published and written data resulting from this study.
I know that if I have any questions or complaints about this study I can contact anonymously, the Head Department of Environmental Health and of Social Development Professions, Faculty of Heath Sciences at Nelson Mandela Metropolitan University at 041-504 2353.

I voluntarily agree to participate in this study:

Signature (Participant):  Date:

Signature (Researcher):  Date:
APPENDIX IV

Research Guardian Consent Form

Title of the research: : Factors affecting AIDS orphans from accessing VCT.
Reference Number: : 207037299 (student number of the researcher)

Researcher: : Lineo Maama
: Renaissance Post Graduate Student Village
: Village 1 Room 9B
: NMMU
: Port Elizabeth

Contact Numbers: : Cell 0795889429
: Home 041 504 4137

Declaration by the guardian:

I, the guardian give my child consent to participate in the above mentioned research study which is undertaken by Lineo Maama of the Department of Environmental Health and Social Development Professions, Faculty of Health Sciences at Nelson Mandela Metropolitan University.

The objectives of the study are as follows:

- To explore AIDS orphans views about VCT
- To determine factors that prevent them from accessing VCT.
- Based on the research findings, the study will draw conclusions and make recommendations on appropriate support services in order to encourage AIDS orphans to utilize VCT.

I understand that my child’s participation is voluntary and that he/she has a right to withdraw from participating at any time without penalty. I understand that confidentiality will be maintained at all times. The person asking my child questions will never tell anyone what he/she told her and my child’s name will not be written down or recorded. His/her privacy will be maintained in all published and written data resulting from this study.
I know that if I have any questions or complaints about this study I can contact anonymously, the Head of Department Environmental Health and Social Development Professions, Faculty of Heath Sciences at Nelson Mandela Metropolitan University at 041-504 2353.

I therefore give my child consent to participate in this study:

Signature (guardian):    Date:

Signature (Researcher):  Date:
CHAPTER 1

1. INTRODUCTION AND PROBLEM FORMULATION

1.1 Introduction

1.1.2 Extent of the problem

AIDS has become a global phenomenon with severe challenges that threaten human existence. According to the Joint United Nations Program on HIV and AIDS (UNAIDS) and the World Health Organisation (WHO), by the end of 2002 there was an estimated 42 million people living with HIV and the numbers have increased by 2 million compared to 2001. According to AIDS Epidemic Update (2004:1) and a Report on Global AIDS Epidemic (2004:1), the number of people living with HIV reached its highest level ever in 2004. An estimated 44.3 million people are living with the virus globally, the most affected target groups being women and young adults (AIDS Epidemic Update, 2004). It is estimated that 11.8 million youths are infected and living with HIV and AIDS. About one third of those currently infected with HIV and AIDS are in the age group of 15-24 years. UNAIDS (2002) estimates that 3 million people died of AIDS during 2002 and makes a further estimate world wide that more than 15 million children under 18 have been orphaned as a result of AIDS (UNAIDS, 2006).

Africa is the worst hit by HIV and AIDS (Report on Global AIDS Epidemic, 2004). According to the WHO (2002), since the late 1970s 17 million Africans have died due to AIDS. In 2003 an estimated 3 million people in Africa became newly infected with the virus and 2.2 million died (Report on Global AIDS Epidemic, 2004). Throughout the continent people living in Sub-Saharan Africa are the most infected and affected. In Sub-Saharan Africa an estimated 29.4 million people were living with HIV by the year 2002, while 3.5 million of these were children under 15 years. In four Southern African countries, adult prevalence has been rising beyond expectation, exceeding 30 %:
Botswana 38. %, Lesotho 31 %, Swaziland 33.4 % and Zimbabwe 33.7% (UNAIDS, 2002).

The first reported cases of AIDS in South Africa were of two homosexual men in Johannesburg who died of the disease in 1982 (Catholic Health Care Association of Southern Africa, 2004). By 1990 there were more than 600 cases of AIDS reported in South Africa. It is thought that the main transport routes of Africa were responsible for bringing the virus through sexual contact between truck drivers and commercial sex workers (Catholic Health Care Association of Southern Africa, 2004). During that year, there were 270 AIDS related deaths, and 0.76% of pregnant women were confirmed HIV positive.

In 1991, only 57 cases of the disease were reported to the WHO, the figure increasing to 225 in 1992 and to 552 in 1993. In 1994, the ‘dawn’ of South Africa's first new political dispensation, the number of HIV positive people was estimated at approximately 750 000. This meant that 7.5% of the adult population was infected. This significant increase in infection has continued. By the year 2000, AIDS had become the biggest cause of death in South Africa. By 2001, the prevalence rate was around 25% (UNAIDS, 2004).

South Africa is one of the countries with the highest HIV and AIDS prevalence in the world (AIDS Epidemic Update, 2004:1). According to the National HIV and Syphilis Sero-Prevalence Survey (2003) and the National Department of Health (2004), KwaZulu-Natal province has the highest prevalence rate (37.5%) whilst the Eastern Cape where the study will be conducted is the fifth (27.1%); Northern Cape (16.7%) and Western Cape (13.1%) have the lowest prevalence rates in the country.

1.1.3 Motivation for the study

HIV and AIDS affect AIDS orphans emotionally, educationally, in households in which they live and the ‘stigma’ that is always attached to them. These negative impacts are discussed below.
1.2 The impact of HIV and AIDS on orphans

1.2.1 Emotional Impact

Stein (2003) and Subbarao and Coury (2004) maintain that when the biological parents die children suffer as a result of the death of their parent(s) and the emotional trauma that later occurs. They may then have to adjust to a new situation, with little or no support, and may suffer exploitation and abuse. In a study carried out in rural Uganda, high levels of psychological distress were found in children who had been orphaned by AIDS. Anxiety, depression and anger were found to be more common among AIDS orphans than other children. Twelve percent of AIDS orphans stated that they wished they were dead, compared to 3% of other children interviewed (Atwine, Cantor-Graae & Banjunirwe, 2005). These psychological problems can become more severe if a child is forced to separate from his/her siblings upon becoming orphaned. After the death of parents children are usually cared for by their extended kin (Barnet & Whiteside, 2001). Ansell and Young (2004:3) maintain that many orphans therefore migrate to other areas in order to receive care and support. According to Ansell and Young (2002a: 5) most children find it very stressful and they often struggle to fit into new families and alienated communities.

1.2.2 Household Impact

The loss of a parent to AIDS can have serious consequences for a child’s access to basic necessities such as shelter, food, clothing, health and education. Orphans are more likely than non-orphans to live in large, female-headed households where more people are dependent on fewer income earners (Monasch & Boerma, 2004). According to the Salaam Congressional Research Service (2005), this lack of income puts extra pressure on AIDS orphans to contribute financially to the household, in some cases driving them to the streets to fend for themselves. The majority of children who have lost a parent continue to live in the care of a surviving parent or family member, but often have to take
on the responsibility of doing the housework, looking after siblings and caring for the ill or dying parent. Children who have lost one parent to AIDS are often at risk of losing the other parent as well, since HIV may have been transmitted between the couple through sex (Avert, 2006).

1.2.3 Education

Children orphaned by AIDS may miss out on school enrolment, have their schooling interrupted or perform poorly in school as a result of their situation. Expenses such as school fees and school uniform present major barriers, since many of their caregivers cannot afford these costs (UNICEF, 2005). Matshalaga (2002) maintains that extended families sometimes regard school fees as a major factor in deciding whether, or not, to take on additional children orphaned by AIDS. AIDS orphans may also leave school to attend to ill family members, work or look after young siblings. AIDS orphans may also miss out on valuable life-skills and practical knowledge that would have been passed on to them by their parents. Without this knowledge and a basic school education, children may be more likely to face social, economic and health problems as they grow up.

1.2.4 Stigmatization

Children grieving for dying parents as a result of AIDS are often stigmatised by society. The distress and social isolation experienced by these children, both before and after the death of their parent(s), is strongly exacerbated by the shame, fear, and rejection that often surrounds people affected by HIV and AIDS. Because of this stigma, children may be denied access to schooling and health care. Once a parent dies children may also be denied their inheritance and property (Kimane, 2005: 4). Often children who have lost their parents to AIDS are assumed to be HIV positive themselves, adding to the likelihood that they may face discrimination and risk their future prospects. In this situation children may also be denied access to much needed health care. Sometimes this occurs because it is assumed that they are infected with HIV and their illnesses are untreatable (Avert, 2006).
1.3 Voluntary Counselling and Testing (VCT)

When the HIV test was developed in the mid 1980’s, testing tended to be accompanied by little HIV counselling. However, the growing awareness of HIV infection and AIDS and the recent availability of Antiretoviral Therapy (ART) have resulted in the ‘broadening’ of Voluntary Counselling and Testing. Van Dyk (2005: 103) defines VCT as a process whereby an individual undergoes counselling to enable him/her to make an informed decision about being tested for HIV antibodies. VCT has emerged to be a strategy for prevention of HIV and AIDS world wide. The thrust of VCT is for people to know their HIV status, whether positive or negative. Counselling should be done by trained professionals as it can be harmful if not properly done.

It should be noted that VCT does not simply mean drawing blood and offering counselling. It is more than that because it is the vital entry point to other HIV and AIDS services including prevention and clinical management of HIV-related illnesses, tuberculosis (TB) control, psychological and legal support, and prevention of mother-to-child transmission (Boswell & Baggaley, 2002).

According to Evain (2001:39) and Van Dyk (2005:103), there are always reasons for people to be tested. These reasons vary from one person to another. Common reasons for people to opt for VCT include that they want or are planning to become pregnant or they already are pregnant and they do not want to pass the virus to their babies. The other reason might be that they have anxiety about their lifestyle especially if they are having multiple sexual partners. Some people present for VCT for insurance purposes, while others are planning to get married (South African National HIV prevalence, HIV incidence, Behaviour and Communication Survey, 2005).

While there are risks involved with knowing one’s HIV status, the benefits, both for the individual and the community, lead to increased demand for accessing VCT. According to Ritcher, Griesel, Durrheim, Solomon and Rooyen (1999), VCT helps people to make informed decisions by weighing up the ‘pros and cons’ of going for VCT, that is, what
they would do if tested HIV negative or HIV positive. The authors further maintain that VCT helps people to access information about the personal, medical, social, psychological and legal implications of testing either negative or positive. It is further stated that women who know their HIV status can make informed decisions about contraception or pregnancy. Baggaley (2001) is of the opinion that VCT increases awareness of options for prevention of mother-to-child transmission. Baggaley also maintains that VCT helps to improve health status by providing nutritional advice through counselling. According to Volberding, Lagos and Koch (1990), identifying the virus early helps those infected to be referred for clinical care and psychological care before they become sick, thus improving their quality of life and long-term survival. 

Shangula (2006) maintains that people usually associate HIV with immediate death, have a belief that they are outside the category of getting infected, they fear being labelled and stigmatized by significant others and lack knowledge about available treatment. These are some of the factors that prevent people from testing, and this informs the fundamental premise of this study.

The latest survey conducted by Human Sciences Research Center (HSRC) (2005) found that whilst people in South Africa know about the availability of VCT, the majority still do not present themselves for VCT. Fylkesnes (2002) and Sheron (2000) are of the opinion that in some parts of Africa as well as in South Africa even some of those people who take the initiative of going for VCT are still reluctant to return to VCT for post-counseling. According to Deacon, Stephney and Prosalendis (2005: 60) the reasons for not accessing VCT are at a personal, family and community level. Stigma and discrimination are some of the factors people take into account when it comes to testing.

According to Rose-Innes (2006:1) the stigma attached to HIV seriously hinders preventative efforts and derails HIV positive people from seeking care and support for fear of being discriminated. In South Africa, a study conducted in KwaZulu-Natal found that out of 305 who presented themselves for VCT, only 17 % returned for their results. This may be due to personal, family and community factors underlying HIV and AIDS (Richter, et. al., 1999).
At a personal level, when people realize that they themselves might be HIV positive, they tend to accept stigmatizing ideas presented to them by their immediate families or the community and this on its own prevents them from testing or going for treatment (Deacon et al. 2005: 60). Furthermore, HIV positive people themselves have negative perceptions about the disease. According to Parker, Colvin and Birdsall (2006), people usually blame themselves for being infected and have a feeling that they are being stigmatized even if that is not true. Deacon et al. (2005: 60) further indicate that due to stigma people do not want to spoil the experiences of feeling well by finding out that they are HIV positive especially when there is presently no cure.

At family level, most studies show that people especially women do not present themselves for VCT because they are afraid that they will be stigmatized and discriminated by their children and partners. Gielen, O’ Campo, Faden and Eke (1997) assert that even those who go for testing are still afraid to disclose their status for the same reasons. Thus non-disclosure of HIV positive status has been ascribed to stigma (Deacon et al., 2005: 61). Gielen et al. (1997) is of the opinion that women who disclose their status to their partners are likely to be abused because they might be blamed for infecting their husbands and thus be deserted for other women.

According to the Commission on HIV and AIDS and Governance in Africa (CHG) (2004), until recently available HIV prevention methods put greater emphasis on individual modification and chastity. However, this approach fails to acknowledge that due to some cultural practices there are women who still do not feel free to control their bodies and sexuality. This view is endorsed by studies conducted by UNAIDS (2004) in some African countries which reveal that women in monogamous marriages do not protect themselves and thus get infected. In some African countries it has been found that women who have been married for 15-19 years have higher HIV infection rates than non-married sexually active females of the same age (UNAIDS, 2004). One of the reasons might be that they are not working, therefore economically dependent on their husbands; and so leaving the man will mean hunger and deprivation for the children.
HIV related stigma can also arise at community level. There are a number of reported cases of people who have been harassed by community members because they are HIV positive and they are believed to have brought the disease to other community members by infecting them. Usually such blame in extreme cases is associated with violence and murder. For instance, in South Africa Gugu Dlamini was beaten and stoned to death by neighbours in ‘her’ township near Durban in 1998 because of disclosing her HIV positive status. Also, Nkosi Johnson was denied access to attend school like other children because he was HIV positive (Avert, 2005).

It is important to note that stigma and discrimination are not only presented by family and community members but also by the healthcare system and its professionals. In a study conducted by the Human Science Research Council (HSRC) 2005, most participants stated explicitly that they would go for VCT if confidentiality was maintained. This shows that most people do not go for VCT because they feel that counsellors are responsible for spreading the news or rumors about their HIV status, thus discriminating against them. Another study that was conducted by UNAIDS (2002) in four Nigerian states, revealed shocking results where 10% of doctors and nurses admitted that they refused to take care of HIV and AIDS patients and that they did not admit them to hospital. In the study it was found that the doctors and nurses still have a negative attitude towards people living with HIV and AIDS, and they believe that the appearance of the person portrays his or her status, but the truth is that one cannot just tell by looking at a person if somebody is HIV positive or not. It is only through blood test that a person can know his/her status. According to UNAIDS (2004) and WHO (2001), HIV related stigma by doctors and nurses can be associated with fear of getting infected themselves.

1.3.1 Definition of an AIDS orphan

The term ‘orphan’ has had many definitions from ‘time’ immemorial’. Traditionally, an orphan was a child who had lost both parents, and there was no other person including the extended kin who, for various reasons was willing to take to care of him/her.
A literature search reveals varying definitions of the term ‘orphan’. The World Health Organization (WHO), UNAIDS and UNICEF define orphans due to AIDS as children who lost their mothers before attaining the age of 15 years. Some of these children have lost or will later lose their fathers to AIDS. Maternal orphans are children, younger than 15, who lost their mothers, and perhaps fathers; paternal orphans are children, younger than 15, whose fathers, and perhaps mothers, have died; double orphans are children who are younger than 15 and have lost both parents; total orphans are children younger than age 15, whose mother, father, or both parents have died of AIDS (Avinash, Shetty and Powell, 2003).

For the purpose of this paper, an AIDS orphan is a child between 12-17 years and has lost a mother, and in some cases, a father, to AIDS.

1.4 Conceptual frameworks

1.4.1 Empowerment Theory

Empowerment refers to a process by which people are given power that enables them to be responsible and ‘take charge’ of their adverse conditions (Gray and van Rooyen, 2002). It can be defined as a process by which individuals, families, groups and communities are assisted in order to increase their personal, interpersonal, socio-economic strength and enhance their capacity to improve their circumstances and to shape their destiny. For people to be empowered, their abilities, knowledge and skills must be expanded through capacity building. Gray (1997) is of the opinion that empowerment and capacity building are two components that are significant for professional intervention. These components are the main characteristics of developmental approach in the sense that people’s potential is recognized and nurtured through empowerment and capacity building.

1.4.2 Developmental Approach

Gray (1997) believes that developmental approach is the best method of addressing current welfare problems in South Africa. The developmental approach is a process
involving many stakeholders and different sectors of the community. It targets the poorest of the poor, the most disadvantaged, the least powerful and the most vulnerable, notably, women and children. It is people-centered and seeks to empower people especially women and the disadvantaged. The thrust of the developmental approach is to promote well-being of individuals, families and communities so that they can experience change in their lives and become self-sufficient through empowerment and capacity building. This approach will equip individuals and families with the necessary skills for growth, development and survival (Gray and van Rooyen, 2002).

The thrust of this study is informed by two interlocking frameworks, namely the empowerment theory and the developmental approach. Both these frameworks indicate that people need to be developed and empowered through sustainable programmes that enhance their capacities to the outmost realization of their potential. It is hoped that through this study AIDS orphans will be empowered to make use of VCT in order for them to escape the ‘poverty of the mind cycle’ in which their parents were ‘trapped’. The researcher’s ‘hunch’ is that factors affecting AIDS orphans from accessing VCT, in the context of this study, may be borne out of a multiplicity of factors, including issues relating to child-headed households in the absence of biological parents, lack of education about the pandemic on the part of professionals, and educational impoverishment exacerbated by general poverty.

1.5 Problem formulation

A great deal of research has been conducted on the need for and importance of VCT as a prevention strategy for HIV and AIDS in South Africa and most of it has revealed that knowing one’s status, whether positive or negative, is instrumental in behaviour change and adopting safer sex practices (Mkaya-Mwamburi, Qwana, Williams & Lurie, 2000; Serima & Manyenna, 2000). Van Dyk (2005) maintains that depending on the results of the VCT, people usually take steps to avoid becoming infected or infecting others. Wider access to VCT may lead to greater openness about HIV and AIDS, raise awareness and reduce stigma and discrimination both at family and community levels.
Although VCT has been advocated and found to be the best prevention strategy to HIV and AIDS in South Africa (Van Dyk, 2005:103), so far there is minimal research undertaken to determine factors that prevent AIDS orphans from accessing VCT. Therefore, the study will attempt to investigate factors that affect AIDS orphans in accessing VCT. The study will make a valuable contribution to the existing body of knowledge about factors that affect AIDS orphans in accessing VCT. It is envisaged that the findings of this study would assist in policy development, programs that would build the capacity of AIDS orphans, their families and community members in order to break the barriers to accessing VCT.

A large number of VCT sites are being opened in South Africa. The services provided by these sites are playing an increasingly significant role in the prevention of HIV and AIDS. However previous studies show that there are still barriers that prevent people from taking the test and they include lack of education on VCT culminating to negative perceptions about it, fears with regard to social stigma, discrimination and the resultant negative social relationships, and anxiety about coping after the results have been pronounced positive. It is against this background that this study will be undertaken.

1.6 Research question

The grand tour question to be answered in this study is: “What are the factors that affect AIDS orphans from accessing VCT?

1.7 Aim and objectives of the study

1.7.1 The overall aim of the proposed study is:

1. To gain insight into the factors that affect AIDS orphans’ access to VCT.

1.7.2 Objectives
1. To explore and describe factors that prevent AIDS orphans from presenting themselves for VCT.
2. Based on the research findings, the study will draw conclusions and make recommendations on appropriate policies and support services in order to encourage AIDS orphans to utilize VCT.

1.8 Research design and methodology

1.8.1 Research Design

Research design can be understood as the planning of any scientific research from the first to the last step (Bless & Higson-Smith 1995: 63). Mouton (2001:55) provides a closely related definition by comparing it to a house plan which explains how one intends to build the house from the first to the last step. In this study, a qualitative approach will be adopted. De Vos, Strydom, Fouche and Delport (2005: 268), explain qualitative research as a social interaction that allows the researcher to study the participants in detail thus interpreting the meanings they attach to their lives. By using a qualitative approach the researcher will be able to collect information on how participants think, feel and act, as well as what they believe. The design of this research will be exploratory- descriptive.

The study is firstly explorative because the researcher will be seeking to gain insight into the factors that affect AIDS orphans from accessing VCT. De Vos et al. (2005) describe the aims of exploratory research as establishing the facts, gathering new data and determining whether there are interesting patterns in the data. The advantage of using exploratory research is that it makes initial work with the research data effective. Secondly, the study will be descriptive in nature. According to Bless and Higson-Smith (1995:154) the primary aim of descriptive research is to describe (rather than explain) a particular phenomenon.

1.8.2 Research Methodology
In this section, the research population, sample, data collection methods and data analysis will be discussed. A brief description of the pilot study will also be given.

1.8.3 Research Population and Sampling Methods

Neuman (2000: 201) refers to population as target population and defines it as a specific pool of cases that the researcher wants to study. De Vos et al. (2005) define sampling as taking a portion of the whole population as a representative of that population. De Vos et al. (2005) further states that population is the total from which the units of the study are chosen. The research population of the study consisted of children who have lost both parents due to AIDS in Port Elizabeth. A non-probability purposive sampling method was used to select AIDS orphans. According to Bless and Higson-Smith (1995: 94), this sampling method is based on the judgment of the researcher regarding the characteristics of a representative sample. The sampling method was appropriate since the researcher was interested in selecting the sample on the basis of her knowledge of the population and the aim of the research study.

Based on the judgment of the researcher the criteria for the selection of AIDS orphans was as follows. Participants of the study had to be:

- Youth orphaned as a result of AIDS for a minimum of 2 years and associated with Ubuntu Education Fund;
- Between the age-group 12-17;
- Living in the care of a primary caregiver,
- Have not presented themselves for VCT, and
- Should be schooling.

According to De Vos et al. (2005), once the research population and appropriate sampling strategies have been considered, the researcher then decides on how to gain entry to the research site. The researcher gained entry to Ubuntu Education Fund through the social worker working for the organization. Ubuntu Education Fund is a Non Profit Organization (NPO) that assists children from disadvantaged families in the townships of Port Elizabeth. Ubuntu Education Fund started as a very small organization about 10
years ago but at the moment Ubuntu Education Fund is reaching over 40 000 children with life-saving health and educational resources and services. The researcher made an appointment telephonically with the director of the organization, and then personally presented herself to explain the aims and objectives of the study. The social worker, who later served as a gate-keeper, was requested to assist in approaching possible participants and inform them about the research study as well as determine if they would be willing to participate in the study. Participants who were willing to participate in the study were given a consent form to commit themselves that they will voluntarily participate, but are not obliged to.

A minimum of 8 participants was recruited for this study. The sampling was concluded when it reached a point of data saturation and participants, prepared for termination. According to Siedman (1998) saturation is a point whereby when conducting interviews a researcher begins to hear the same information from all the participants and no longer gains new information.

1.8.4 Data collection methods

According to De Vos et al. (2005), there are three major types of interviews that can be used by a researcher to collect information. These are:

**Structured or standardized interviews:** Here the researcher asks each participant a series of arranged questions with a limited set of responses. There is very little flexibility in the way that questions are asked or answered in a structural interview. De Vos et al. (2005: 292) maintain that this method is preferred when two or more researchers are involved in data collection.

**Unstructured interviews sometimes referred to as open-ended interviews:** De Vos et al. (2005: 292) are of the opinion that unstructured interviews are interested in understanding the experiences of other people and the meaning they make of their experiences. The researcher establishes the direction of the conversation and pursues
specific topics raised by the participant. Initially the participant does most of the talking and the researcher does a lot of probing where the answers are not clear enough (De Vos et al., 2005).

**Semi-structured interviews:** According to De Vos et al. (2005), semi-structured interviews are used when a researcher is interested in gaining a detailed picture of the participant’s beliefs about a particular topic. Semi-structured interviews are suitable in cases where the researcher is interested in an issue that is complex or personal (De Vos, 2005:296). Since people living with HIV and AIDS are usually stigmatized and discriminated against, this study is complex and personal, hence semi-structured interviews were used as the main tool for data collection. The researcher chose this tool because it is flexible to both the interviewer and the interviewee (De Vos et al., 2005). It is flexible to the participant because questions asked are in a systematic and consistent order therefore it becomes easier to answer them. At the same time the interviewer is also allowed freedom, to a certain degree, to probe beyond the prepared and structured questions.

Semi-structured interviews make use of an interview schedule that guides the way in which questions should be asked and thus helps the researcher to stay focused throughout the interview. In addition to that, semi-structured interviews also allow for the discovery of new aspects of the problem by investigating in detail some explanations given by participants (Bless & Higson-Smith, 1995:110). De Vos et al. (2005: 292) assert that with semi-structured interviews a participant is considered to be the expert on the study and therefore should be allowed to do a lot of the talking and to tell his/her story. Although this sampling method was chosen as the most appropriate for the study it has some limitations. Bless and Higson-Smith (1995) state that if the researcher is not competent enough he/she may have biases. According to Beiley (1994:175), the interviewer’s biases can be caused by misunderstanding the answers given by the participants.

Data was collected at Speelman Family Counselling Agency in Zwide Township and interviews were also conducted there. The reason for not conducting interviews at
Ubuntu Education Fund was that the researcher does not want the participants to feel obliged to participate basically on the premise that they are getting professional services from Ubuntu Education Fund. Another reason would be that generally participants have a tendency of not supplying accurate information because they think that by doing so, it might affect their ‘relationship’ with the organization. The selected participants by the researcher were counseled by a social worker, who had been providing the necessary professional services for the past 5 years, to prevent them from being emotionally hurt. Thereafter the social worker had no further involvement with the participants. Their caregivers were asked to give consent to their children’s participation in the study. The selection of the primary caregivers in the absence of the biological parents is a cultural practice of African families in which an adult who accepts responsibility for the upbringing of a child is regarded as a parent and is entrusted with such responsibility.

In this study, the semi-structured interview schedule were used to collect data. An interview schedule was used to guide the researcher when asking questions. In order to address the aim and objectives of the study, five questions were presented to the research participants and they are:

- What do you and your friends understand by the term VCT?
- What discussions have you and your friends had about VCT?
- What will encourage you and your friends to go for VCT?
- Have you ever discussed VCT with your primary care giver?
- What would make it easier for young people to go for VCT?

The researcher requested permission from the participants to audiotape the interview. Tape recording the interview was preferred because it allowed the researcher to return to the collected data in its original form as often as he/she wished. Silverman (2000: 149) summarizes the advantages of using tapes and transcripts compared to other kinds of qualitative data collection methods as that:

- Tapes can be replayed and transcripts improved.
- Tapes maintain the original sequences of talks.
1.9 Pilot study

In order to test the research methods and the data-collection tool, the researcher interviewed one participant who volunteered to participate. He/she had to be orphaned as a result of AIDS for a minimum of 2 years and assisted professionally by Ubuntu Education Fund, should be between 12-17 years old, is attending school, has been living in the care of a primary caregiver and has not presented himself/herself for VCT. According to the Dictionary of Social Work (1995: 45), a pilot study is a process whereby the research method chosen is tested in order to find out if it is appropriate and to check if participants will be able to understand the questions that will be asked. Conducting a pilot study is very important and helpful because it also assists in estimating the time and costs that may be involved in conducting the research (De Vos et al., 2005). Strydom (2002: 337) further points out that it helps to identify the problems that may arise during the actual interviews before they can actually happen. The pilot study conducted assisted the researcher to ‘test’ the research tools, and the feedback used to sharpen and improve the research questions for data collection. The feedback also assisted the researcher to make changes, if necessary.

1.10 Data analysis

De Vos et al. (2005: 333) state that data analysis gives the collected data a meaning, brings it to order and also gives it a suitable structure. In analyzing the data collected during semi-structured interviews, the researcher adopted Tesch’s (1990) framework, as stated in Cresswell (2003).

Below are the steps that were followed:

- The researcher carefully read the transcripts to get a sense of the whole thus jotting down ideas as they come to mind.
• The researcher picked up any transcript of interest. At this stage the researcher should only think about the underlying meaning of the information not about the substance of the information.

• At this stage the researcher made a list of topics /themes. The topics were grouped together according to their similarities. The researcher then put these themes into the columns that were arranged as main topics and sub-topics.

• The researcher went back to the raw data and assigned codes to the data. By doing this the researcher determined whether, or not, new categories and codes emerged.

• The researcher identified the relationship between major and sub categories and thus reflected these as themes.

• At this stage the researcher made final decisions on the abbreviations made from the categories and put the codes in alphabetical order.

• The researcher grouped the categories and started preliminary analysis.

• During this stage, the final stage, the researcher recoded the existing data where necessary.

1.11 Data verification

As the researcher was working alone in the field, the issue of verification became significant. To verify the collected data, Lincoln and Guba’s (1985) model on trustworthiness was adopted. According to Lincoln and Guba’s model (1985) in De Vos et al. (2005: 346) there are four aspects of trustworthiness for verifying qualitative data, namely, applicability, neutrality, truth-value and consistency.
Applicability is defined as the degree to which findings can be applied to another context or setting and this is established through transferability.

Neutrality refers to the “degree to which the findings are a function solely of the informants and conditions of the research and not of other biases, motivation and perspectives” (De Vos, 2005:348). Neutrality is established through conformability.

Truth-value is concerned with the truth of the findings based on the design and the context of the informants. It is the discovery of lived human experiences that assist a researcher to be able to establish the truth value of a study.

Consistency of the data is concerned with whether the findings would be consistent if the research study was to be conducted with the same subjects or in a similar context and this is established though the strategy of dependability.

1.12 Ethical considerations

It is of the outmost importance that one complies with professional ethics when conducting research. Strydom (2002: 24) defines ethics as a set of moral principles which is suggested by an individual or group, and is widely accepted and offers rules and behaviour that is expected about the correct conduct towards the respondents. In this study ethical issues such as informed consent, confidentiality, and voluntary participation, were adhered to.

Voluntary participation

Bless & Higson-Smith (1995:102) maintain that people should not be forced to participate in a research study and they have a right to refuse to participate. The right to privacy demands that direct consent for participation be obtained from people, and in the case of children, from their parents or guardians. In this study, consent for the
participants’ participation was obtained from the primary care giver or legal guardian. A consent form is attached as Appendix II.

Confidentiality

When conducting a research study, a researcher must assure the participants that whatever information given will be treated with confidentiality. That is, they must be assured that the collected data will be only used for the stated purpose of the research study and that no other person will have access to the given information. Assuring the participants that information will be kept confidential can result in the participants giving honest and complete information. In this study interviews were conducted in a counseling room at Speelman Family Counseling Agency located at Zwide and not connected to Ubuntu. To secure further confidentiality the researcher used ‘A and B’, instead of using participants’ names, or pseudo names. After the study was completed all tape records and transcripts were destroyed.

Informed consent

Informed consent involves informing participants about the purpose of the study, risks and benefits that may be associated with participation in the study (Williams, Tutty, & Grinnell (1995: 30). Caregivers were asked to give consent for the participants to participate in the study and the participants were also given a consent form to sign.

Debriefing

It is very important for the researcher to be aware that interviews could have touched on sensitive issues. As such, the researcher made arrangements for assistance as needed. The purpose of debriefing is to reduce any possibility of unforeseen psychological harm, discomfort and misconceptions that might have come during interviews.

1.13 Contextual concept clarification
An AIDS orphan, in the context of this study, means a child who has been orphaned as a result of AIDS (and is aware of such), is living under the care and supervision of a primary care giver and has not presented himself/ herself for VCT.

VCT, in the context of this study, means a process whereby one undergoes pre-counselling which prepares a person for making a decision about being tested for HIV, and also post-counseling after knowing the results, whether positive or negative.

1.14 Dissemination of results

The research findings will be compiled in the form of a treatise and a copy will be placed in the library of Nelson Mandela Metropolitan University. The researcher proposes to share the findings of this study with the management of Ubuntu Education Fund (from where participants were recruited), and thereafter, with the participants of the study.

1.15 Layout of chapter

The final report consists of four chapters:

Chapter 1: Introduction and problem formulation

In chapter 1 the motivation for the study and a brief literature review are presented to provide a background and to contextualize the study. Next, the research aims and objectives are presented as the base for the reader to understand the intended contribution of the study. The research design and methodology of the study are described.

Chapter 2: Research design and methodology
In chapter 2 the researcher describes in detail the research methodology and the process that will be followed in collecting and analyzing data.

**Chapter 3: Discussion of Research findings and literature control**

Chapter 3 reflects the analysis of the data and discusses the research findings. Appropriate literature will be used to endorse or refute the findings.

**Chapter 4: Summary, conclusions and recommendations**

The last chapter highlights the findings of the research study. Recommendations for health and other related professionals in terms of empowering AIDS orphans and community members to present themselves for VCT are presented for further research.

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**CHAPTER 2**

**RESEARCH DESIGN AND METHODOLOGY**

2.1 Introduction

This chapter presents a detailed research methodology that was used in this study. The study adopted a qualitative research design and the rationale for the study is presented. In order to provide a clear idea of how the research results were obtained, sampling, data collection methods as well as analysis of the study are discussed. In addition, the ethical considerations adhered to are discussed.

2.2 Rationale for the study
The idea of this research came as a result of the literature that was reviewed by the researcher on the whole issue of HIV and AIDS, notably AIDS orphans. Most studies have been conducted on the experiences and challenges faced by AIDS orphans, their needs and their rights as AIDS orphans and the relationship between HIV positive parents and their children (UNAIDS, 2005). It is through this process of literature review that the researcher learned that although parents are going for VCT, they find it very difficult to disclose their HIV positive status to their children for a number of reasons that include culture and the stigma attached to the pandemic. Most of the children normally take care of their dying parents and thus put their lives at risk of being infected too. So, far there is minimal research undertaken to determine factors that prevent AIDS orphans from accessing VCT. Therefore, the study attempts to investigate factors that affect AIDS orphans’ access to VCT. The study will make a valuable contribution to the existing body of knowledge about factors that prohibit AIDS orphans’ access to VCT. It is envisaged that the findings will assist in developing policies and programs that would build the capacity of AIDS orphans, their families and community members in order to break the barriers to accessing VCT.

2.3 Objectives of the study

Based on the aforementioned, the researcher presents the objectives of the study as follows:

1. To explore and describe factors that prevents AIDS orphans from presenting themselves for VCT.

2. Based on the research findings, the study will draw conclusions and make recommendations on appropriate policies and support services in order to encourage AIDS orphans to utilize VCT.

2.4 Research paradigm and design

Research design is defined by Bless & Higson-Smith (1995:63) as the planning of any scientific research from the first to the last step. It is the set of procedures that guide the
researcher in collecting, analyzing and interpreting observed facts. Mouton (2001:55) provides a clearly related definition by referring to it as a plan on how a researcher intends to conduct the research. According to De Vos et al. (2005) the first thing a researcher must outline is the paradigm that underpins the study. A paradigm acts as a perspective that provides a rationale for the study and guides the researcher to use particular methods of data collection, observation and interpretation (Blanche and Durrheim, 2002:36).

2.4.1 The qualitative design

In this study, a qualitative paradigm for research has been adopted. De Vos et al. (2005:268), explain qualitative research as a social interaction that allows the researcher to study the participants in detail thus interpreting the meanings they attach to their lives. Marlow (1993) asserts that qualitative research has no statistical methods of inquiry and analysis of social phenomena. It portrays an inductive process in which themes and categories emerge through analysis of the data collected by techniques such as interviews and observations. According to Creswell (1994) there are five underlying assumptions of qualitative research and they are:

1. The focus is on the process and not on the product or outcome.

2. The interest is placed on the meaning that is how people make sense of their life experiences and how they structure their worlds.

3. The mode of inquiry may involve fieldwork, depending on the nature of the study.

4. The process, meaning and understanding are gained through words and pictures.

5. A researcher builds abstracts, concepts, hypothesis from details thus making the inquiry inductive.

In this study, a qualitative research seemed appropriate since the researcher is interested in gaining an in-depth understanding of the HIV and AIDS phenomenon and factors affecting AIDS orphans’ access to VCT.
De Vos et al. (2005:264) explain phenomenology design as “the study that attempts to understand people’s perceptions, perspectives and understanding of a particular situation”. In order to explore factors affecting AIDS orphans’ access to VCT, phenomenological design seemed appropriate. Phenomenological study aims at understanding and interpreting the essence of the meaning that people give to their lives. Interviews are primarily used and themes are sorted on the basis of their similarities. The result is that the different ways in which people experience, conceptualize, perceive or understand aspects of the world are mapped out. The phenomenological design is used because in South Africa there is little information on AIDS orphans and factors affecting them not to present themselves for VCT have not been fully documented. Therefore, the design is appropriate because it allows the researcher to gain insight into the phenomenon of AIDS orphans and the experiences and challenges they are faced with. The main focus for this study was therefore on the essence of the meaning they give to their lives.

2.4.2 Exploratory research

According to Bless and Higson-Smith (1995:42) the main purpose of exploratory research is to gain insight into a situation, phenomenon, community or person. The design of this research is exploratory in nature. Bless and Higson-Smith (1995:42) further state that the need for the study could basically arise because little has been documented on the problem. Therefore, in this particular study exploratory research seemed appropriate because the researcher was seeking to gain insight into the factors that affect AIDS orphans’ access to VCT.

Higson-Smith and Bless (1995:43) state that when using exploratory research, the researcher must become more familiar with the situation in order to formulate a problem or develop a hypothesis. They further state that “it is often very useful to assess the feasibility of the research project, the practical possibilities to carry out, the correctness of some concepts, the adequacy of the method and instrument of measurement by doing a
pilot study.” Therefore exploratory research serves as an initial step before the actual study and thus the subject of investigation may not be precisely determined but left open for adjustment. De Vos et al. (2005) describe the aims of exploratory research as establishing the facts, gathering new data and determining whether there are interesting patterns in data. The advantage of using exploratory research is that it makes initial work with the research data effective.

2.4.3 Contextual research

Contextual research studies phenomena because of its essential and immediate significance (Mouton, 1996:13). This study therefore focused on factors affecting AIDS orphans’ access to VCT in the townships of Port Elizabeth. The researcher attempts to capture the context in which AIDS orphans are living, in order to obtain a holistic picture of their experiences as AIDS orphans.

2.5 Research methodology

2.5.1 Sampling procedures

According to Bless and Higson-Smith (1995: 95), non-probability sampling method is based on the judgment of the researcher regarding the characteristics of a representative sample. Babbie (1989:190) asserts that it is appropriate for the researcher to select a sample on the basis of her knowledge of the population, its elements, and the aims and objectives of the study. A non-probability purposive sampling method was adopted in this study. The researcher used purposive sampling to select eight AIDS orphans and all of them were getting professional help from Ubuntu Education Fund. Since the researcher was interested in selecting the sample on the basis of her knowledge of the population and the aims of the study, purposive sampling seemed appropriate for this study. The criterion for selection of AIDS orphans was the following: Youth orphaned as a result of AIDS for a minimum of 2 years and professionally associated with Ubuntu
Education Fund, between the age-group 12-17; living in the care of a primary caregiver, have not presented themselves for VCT, and are attending schooling.

The researcher gained entry to Ubuntu Education Fund through the social worker who introduced the researcher to a gate-keeper not working for the organization. Ubuntu Education Fund is a Non Profit Organization (NPO) that assists children from disadvantaged families in the townships of Port Elizabeth. Ubuntu Education Fund started as a very small organization about 10 years ago and presently Ubuntu Education Fund is reaching over 40,000 children with life-saving, health and educational resources and services. The researcher and the gate-keeper made individual appointments with the research participants and the venue was at Spleeman Family Counselling Agency. The reason for not conducting interviews at Ubuntu Education Fund was that the researcher did not want the participants to feel obliged to participate basically on the premise that they are receiving professional services from Ubuntu Education Fund. Another reason was that generally participants have a tendency of not supplying accurate information because they think that by doing so, it might affect their professional relationship with the organization.

The aims and objectives of the study were explained to the participants to make sure that they are participating voluntarily and thereafter, were given consent forms to sign.

2.5.2 Data collection methods

According to De Vos et al. (2005) an interview schedule guides the way in which questions are asked and thus helps the researcher to stay focused throughout the interview. The data for this study was collected by means of semi-structured interviews. The interviewees were asked questions in a systematic and consistent order but the interviewers were allowed to probe far beyond the prepared questions. At the beginning of the interviews, the researcher introduced the study to the participants. There are five main questions other than the biographical questions that were posed to the research participants and they are dotted down as follows:
• What do you and your friends understand by the term VCT?
  *Yintoni wena neetshomi zakho eniyaziyo nge VCT?*

• What discussions have you and your friends had about VCT?
  *Yintoni enikhe nithethe ngayo neetshomi zakho nge VCT?*

• What will encourage you and your friends to go for VCT?
  *Yintoni enoncedisana nawe neetshomi zakho ukuze niye kwi VCT?*

• Have you ever discussed VCT with your primary care giver?
  *Wakhe wathetha nge VCT nomntu okuzaloyo?*

• What would make it easier for young people to go for VCT?
  *Yintoni enokwenza kube lula kubantu abatsha ukuya kwi VCT?*

The interviews were conducted in isiXhosa. Each interview lasted for approximately an hour and thirty minutes and all the interviews were conducted in a counselling room where confidentiality was ensured.

2.5.3 Methods of data collection

2.5.3.1 Interviews

**Structured or standardized interviews**: the researcher asks each participant a series of arranged questions with a limited set of responses. There is very little flexibility in the way the questions are asked or answered in a structural interview. De Vos el al. (2005: 292) maintain that this method is preferred when two or more researchers are involved in data collection.

**Unstructured interviews sometimes referred to as open-ended interviews**: De Vos et al. (2005: 292) argue that unstructured interviews are interested in understanding the
experiences of other people and the meaning they make of their experiences. The researcher establishes the direction of the conversation and pursues specific topics raised by the participant. Initially the participant does most of the talking and the researcher thus asks a lot of probing where the answers are not clear enough (De Vos et al., 2005).

**Semi-structured interviews**: According to De Vos et al. (2005), semi-structured interviews are used when a researcher is interested in gaining a detailed picture of the participant’s beliefs about a particular topic. Semi-structured interviews are suitable in cases where the researcher is interested in an issue that is complex or personal (De Vos, 2005:296). Since people living with HIV and AIDS are usually stigmatized and discriminated against, this study is complex and personal hence semi-structured interviews were used as the main tool for data collection. The researcher chose this tool because it is flexible to both the interviewer and the interviewee (De Vos et al., 2005). It is flexible to the participant because questions asked are in a systematic and consistent order therefore it becomes easier to answer them. At the same time the interviewer is also allowed freedom, to a certain degree, to probe beyond the prepared and structured questions.

Semi-structured interviews use an interview schedule that guides the way in which questions should be asked and thus helps the researcher to stay focused throughout the interview. In addition to that, semi-structured interviews also allow for the discovery of new aspects of the problem, as the researcher would hope this study would do, by investigating in detail some explanations given by participants (Bless & Higson-Smith, 1995:110). De Vos et al. (2005: 292) assert that with semi-structured interviews a participant is considered to be the expert on the study and therefore should be allowed to do a lot of the talking and to tell his/her story.

**2.5.3.2 Field notes**

Hesse-Biber & Leavy (2006:271) describe field notes as a written account of the researcher’s everyday experiences in the field; which are written in the field or shortly
after leaving the field. According to De Vos (2005:304) field notes should include both empirical observations and interpretations. The researcher noted and transcribed all the things that she remembered, exactly what took place in the field. The researcher used a tape recorder in order to record the exact words or phrases of participants and transcribed them after the completion of the interview.

2.5.3.3 The role of the researcher

The process of interviewing is a process of communicating, involving, asking, listening and talking (Hesse-Biber and Leavy, 2006:146). The quality of data collected depends on the quality of interviews and observations made by the researcher and that can only be achieved through communication. The premise for inclusion of this is that without communication there can be no interviews. Communication skills required by the researcher will include:

**Responsive listening**, which involves attending to verbal and non-verbal cues. According to Wilson & Kniesi (1992:159) non-verbal cues helps the researcher to judge the reliability of verbal messages more readily, especially in the presence of mixed messages. There is a wide range of non-verbal channels and they include facial expressions, hand gestures, body movements, pitch and volume of the voice and many more.

**Probing**: Hesse-Biber & Leavy (2006:146) describe probing as the researcher’s way of getting a participant to continue with what he or she is talking about, to go further or to explain more, perhaps by virtue of illustrative examples. Sometimes a probe is simply a sign of understanding and interest that the researcher puts forward to the interviewee.

**Reflecting**, involves verbalizing the implied feelings in the participants’ comment i.e expressing a thought and a related feeling. It is further stated that reflection is useful because it encourages the participant to make additional clarifying comments. In this study the researcher identified latent and connotative meanings that may clarify the content.
Clarifying: According to Wilson & Kniesi (1992:150), clarifying is an attempt to understand the basic nature of a participant’s statement. In this study the researcher asked the participants to give an example to clarify a meaning and this helped the researcher to understand the participants intended message better.

Summarizing the session: Involves highlighting the main ideas expressed in an interaction. Both the researcher and the participant benefit from this review of the main themes of the conversation (Wilson & Kniesi, 1992:150). Summarizing is also useful in focusing the participant’s thinking and aiding conscious learning. It is also important because it keeps the participants directed towards a goal. The researcher summarized what was said previously in the first few minutes she has spent with the participant. Early summarizing helped the participant to recall the areas discussed and give the participant the opportunity to see how the researcher has synthesized the content of a previous session.

2.6 Pilot study

According to the Dictionary of Social Work (1995: 45), a pilot study is a process whereby the research method chosen is tested in order to find out if it is appropriate and to check if participants will be able to understand the questions that will be asked. Conducting a pilot study is very important and helpful because it assists in estimating the time and costs that may be involved in conducting the research (De Vos et al., 2005). In order to test the research methods and the data-collection tool, the researcher conducted interviews with two participants who volunteered to participate in the study. The participants that were used for the pilot study were orphaned as a result of AIDS for a minimum of 2 years and assisted through professional intervention by Ubuntu Education Fund, were between 12-17 years old, attending school, were living in the care of a primary caregiver and had not presented themselves for VCT. By conducting the pilot study the researcher learned that the research method used was appropriate although there was a need for her to construct questions appropriately and remove questions that were
not clear. The pilot study also helped the researcher to ensure that there was a flow in a way that questions were asked.

2.7 Ethical considerations

The research proposal was submitted to the NMMU Ethics Committee and was approved by the committee. To comply with professional ethics the researcher adhered to the following aspects:

2.7.1 Informed consent

The informed consent form was submitted to the Nelson Mandela Metropolitan University Ethics Committee as recommended. In order to ensure that participants volunteered to participate in the study before the interviews were conducted, they were given a consent form to sign. Also, the primary caregivers were asked to give permission for their children to participate in the study.

2.7.2 The right to privacy, confidentiality and anonymity

All the interviews were conducted in the counseling room at Spleeman Marriage Counselling Agency where confidentiality was ensured. To secure further confidentiality the researcher used ‘A and B’, instead of using participants’ real names, or pseudo names. After the study was completed, all tape records and transcripts were destroyed.

2.7.3 Permission to conduct the study

Permission to conduct the study was obtained from Ubuntu Education Fund. A letter introducing the study was submitted to the Director of the agency and the researcher had a session with him to explain the aims and objectives of the study.

2.8 Data analysis
De Vos et al. (2005: 333) state that data analysis gives the collected data a meaning, brings it to order and also gives it a suitable structure. As discussed in the first chapter of this study, in analyzing the data collected during semi-structured interviews, the researcher adopted Tesch’s (1990) framework, as stated in Creswell (2003).

Below are the steps that were followed:

- The researcher carefully read the transcripts to get a sense of the whole thus jotting down ideas as they come in mind.
- The researcher picked up any transcript of interest. At this stage the researcher only thought about the underlying meaning of the information not about the substance of the information.
- At this stage the researcher made a list of topics /themes. The topics were grouped together according to their similarities. The researcher put these themes into the columns that were arranged as main topics and sub-topics.
- The researcher went back to the raw data and assigned codes to the data. By doing this the researcher was able to see if new categories and codes emerged.
- The researcher identified the relationship between major and sub categories and thus reflected those as themes.
- At this stage the researcher made final decisions on the abbreviations made from the categories and put the codes in an alphabetical order.
- At this stage the researcher grouped the categories and started preliminary analysis.
- During this stage, the final stage, the researcher recoded the existing data if it was necessary.

2.9 Data verification
As the researcher is working alone in the field, the issue of verification becomes significant. There are different ways in which the soundness of a qualitative study can be tested. For this study Guba’s (1999) model on trustworthiness was adopted. According to Lincoln and Guba’s model (1985) in De Vos et al. (2005: 346), there are four aspects of trustworthiness for verifying qualitative data, namely: applicability, neutrality, truth-value and consistency.

**Applicability** is defined as the degree to which findings can be applied to another context or setting and this is established through transferability. In this study applicability was met since information that was obtained from participants i.e. AIDS orphans was transferred into the context outside the study situation. The researcher hopes that the findings will also be used by other researchers.

**Neutrality** refers to the “degree to which the findings are a function solely of the informants and conditions of the research and not of other biases, motivation and perspectives” (De Vos, 2005:348). Neutrality is established through the strategy of confirmability. In this study this criterion was met since information obtained from participants confirmed the general findings in other studies regarding factors affecting AIDS orphans’ access to VCT.

**Truth-value** is concerned with the truth of the findings based on the design and the context of the informants. It is the discovery of lived human experiences that assists a researcher to be able to establish the truth value of a study. In this study, information that was obtained from participants was the same as information collected with literature review.

**Consistency** of the data is concerned with whether the findings would be consistent if the research study was to be conducted with the same subjects or in a similar context and this is established though the strategy of dependability. In this study this criterion was met
since the same interview schedule was used for all the participants and it is hope that the
same findings will be found.

In this chapter the methodology used was clearly described and the rationale for adopting
such methodology was also given. The chapter was then divided into sections that clearly
indicated the steps followed when conducting the study. A qualitative research paradigm
seemed to be most appropriate for this study and rationale for choosing a qualitative
approach was given. In chapter three, presentation of the research findings will be done
with relevant supportive literature in order to substantiate the findings of the study.

CHAPTER 3

3. DATA ANALYSIS AND LITERATURE CONTROL

3.1 Introduction

The purpose of this study was to explore factors affecting AIDS orphans’ access to VCT.
The overall aim of this study was to gain insight into the factors that affect AIDS
orphans’ access to VCT. The study was conducted from the paradigm of qualitative
research. The research findings of this study are presented in this chapter. The researcher
used purposive sampling technique to select eight AIDS orphans. Data was collected at
Speelman Family Counselling Agency in Zwide Township and interviews were also
conducted there. The reason for not conducting interviews at Ubuntu Education Fund is
that the researcher did not want the participants to feel obliged to participate basically on
the premise that they are receiving professional services from Ubuntu Education Fund.
Another reason would be that generally participants have a tendency of not supplying
accurate information because they think that by doing so it might affect their ‘relationship’ with the organization.

The researcher used an interview schedule to collect data. According to De Vos et al. (2005) an interview schedule guides the way in which questions are asked and thus helps the researcher to stay focused throughout the interview. The interviewees are asked questions in a systematic and consistent order but the interviewers are allowed to probe far beyond the prepared questions. At the beginning of the interviews, the researcher introduced the study to the participants and obtained consent from the participants to tape-record the interviews.

There are five main questions other than the biographical questions that were posed to the research participants and they are:

- What do you and your friends understand by the term VCT?
  
  \(\text{Yintoni wena neetshomi zakho eniyaziyo nge VCT?}\)

- What discussions have you and your friends had about VCT?
  
  \(\text{Yintoni enikhe nithethe ngayo neetshomi zakho nge VCT?}\)

- What will encourage you and your friends to go for VCT?
  
  \(\text{Yintoni enoncedisana nawe neetshomi zakho ukuze niye kwi VCT?}\)

- Have you ever discussed VCT with your primary care giver?
  
  \(\text{Wakhe wathetha nge VCT nomntu okuzaloyo?}\)

- What would make it easier for young people to go for VCT?
  
  \(\text{Yintoni enokwenza kube lula kubantu abatsha ukuya kwi VCT?}\)
3.2 Profile of the participants

This study did not give preference to gender, therefore both females and males (four males and four females) volunteered to participate and the profile of the participants was as follows.

- A child who has been orphaned as a result of AIDS and is aware of such;
- Were getting help from Ubuntu Education Fund;
- Were between the age-group 12-17;
- Were living in the care of a primary caregiver;
- Had not presented themselves for VCT;
- Were attending schooling and
- Were isiXhosa speaking.

For data analysis, the researcher adopted Tesch’s (1990) eight steps of data analysis as described in Creswell (2003). The researcher, assisted by the supervisor of the study, identified the themes and sub-themes from the collected data and an independent coder was appointed to assist in identifying the themes and sub-themes of the study. Below the researcher presents an overview of the themes and sub-themes that emerged from the data analysis process. The themes and sub-themes are supported by relevant literature followed by verbatim quotes from the interviews.

3.3 Presentation of findings

Generally all the participants had heard about AIDS and VCT, and had a fairly good level of knowledge of the basic facts i.e. sleeping with a person who is infected without a condom increase the chances of infection while using a condom reduces the risk of being infected, that people should not use the same sharp objects like needles, and mothers should not breast feed their children if they are HIV positive. However, the children did
not know the difference between HIV and AIDS. Also, they know that VCT is about getting someone’s blood tested for HIV. They also know that testing should be done voluntarily, therefore should not be forced to do it.

Almost all the participants knew where VCT can be accessed but they still experienced difficulty in dealing with the challenge of presenting themselves for VCT even though VCT is provided free of charge in all public sector clinics, hospitals and centers. The participants expressed that there were factors that prohibit them from accessing VCT and they include fear of a positive diagnosis, fear of death and there was also a concern that they do not want to be seen at the VCT health facilities because people will think they are already HIV positive even before they get tested. The implication of this is that they do not want to be stigmatized and discriminated against by the community.

There are factors that the participants felt would enable them to go for VCT, and these included sharing information about HIV and AIDS and VCT with their teachers, classmates and friends. The support that they get from their extended kin, teachers, classmates and friends would enable them to go for VCT.

There are four themes and accompanying sub-themes that were identified from the participants’ responses. These themes and sub-themes came as a result of semi-structured interviews that the researcher had with the participants of the study, during data analysis process and the consensus discussion with an independent coder. All the themes and sub-themes are presented below.

3.3.1 Theme 1: Factors perceived to prohibit AIDS orphans from accessing VCT

3.3.1.1 Sub-theme: Fear of a positive diagnosis (low self-esteem, self-hate, self rejection)
3.3.1.2 Sub-theme: Fear of death
3.3.1.3 Sub-theme: Community attitudes (stigma and discrimination)

3.3.2 Theme 2: Factors that enable access to VCT
3.3.1 Theme 1: Factors perceived to prohibit AIDS orphans from accessing VCT

Eight participants interviewed in a semi-structured fashion revealed that indeed there are factors that prohibit them from accessing VCT. These factors are categorized into three sub-themes namely: fear of a positive diagnosis, fear of death as well as community attitudes, stigma and discrimination.

3.3.1.1 Sub-theme: Fear of a positive diagnosis

From participants’ narrative it becomes evident that they had fear of a positive diagnosis. AIDS orphans expressed their fears of a positive diagnosis as follows:

“People especially those in my age group do not go for VCT because they are scared of being told that they are HIV positive whilst they did not know that”.
“I do not think there is anything that can encourage me to go for VCT because if I know I am HIV positive I know that I am going to die so what is the point of getting tested”?

“My friends do not go for VCT because they are afraid that they are HIV positive”.

“I think if you are not ready anything is possible. You can even collapse when they tell you that you are HIV positive”.

AIDS orphans stated that they are afraid to go for a test due to possible stress that they might experience if they test positive. One participant said:

“Maybe I did not want to stress myself at time”.

It should be noted that children react to stress in many different ways. Many children find it difficult to talk about their worries. They internalize their feelings of stress, believing that they are abnormal in some way, and suffer from low self-esteem which results to self-hate and self-rejection.

According to Stuart and Laraia (2001) low self-esteem has become a major problem for many people who have tested positive or have seen someone suffering due to AIDS. Low self-esteem involves negative self-evaluation and is associated with feelings of being weak, helpless, hopeless, frightened, worthless and inadequate. Low self-esteem indicates self-rejection and self hate, which may be conscious or unconscious process expressed in direct and indirect ways. In this study the participants expressed feelings of low self-esteem and the quotations below bear the testimony to this:

“People think if they go for a test and test positive they are cheap”.

“My friends said if they are HIV positive they will kill themselves”.
According to Mallmann (2003:45) “when a child is orphaned due to AIDS, the home-world is in crisis and turmoil”. His or her identity as a son or a daughter is confused because his or her parent or parents have died of AIDS”. In Erik Erikson's (1970) stages of psychosocial development, the onset of an identity crisis is in the teenage years. This is the stage in which people struggle between feelings of identity versus role confusion.

It becomes clear that in this study AIDS orphans are faced with the developmental task of working out who they are, what their purpose in life is and where they belong. They are preoccupied with changes in their bodies and afraid that their bodies may be harmed. So diseases like HIV and AIDS are very threatening to them; this is so because they are preparing themselves to get involved in life and the idea of their lives being limited or ended by HIV and AIDS is threatening to their partly developed concepts of self and of life (Mallmann, 2003).

Mallmann (2003) argues that it is difficult for many teenagers to find a role in their society. The fact that they are faced with burdens and responsibilities of adults but at the same time are not yet adult men and women is very confusing to them. Not fitting into either group can have a great impact on the adolescent’s sense of self-worth, self-confidence and developing identity. For this reason many adolescents feel hopeless and see no opportunities in the future. Erikson (1970) is of the opinion that only individuals who succeed in resolving the identity crisis will be ready to face future challenges in life. But it should be noted that identity crisis may well be recurring, as the changing world demands us to constantly redefine ourselves.

From this study it is evident that a positive HIV diagnosis does not only affect an individual who has tested positive but it may affect family, friends and children. It is clear that children who have seen the reality of HIV and AIDS in their families are afraid to go for a test, may be because of the suffering that they saw their loved ones going through after a positive diagnosis. One participant added to the aforementioned and expressed her fears of going for a test in the following words:
“Yes I do want to go for a test but I am afraid because before my mother went for a test she was fine but when she was told she was HIV positive, she became a totally different person, she stopped eating and I decided that I will never go for a test in my life because I do not want to be like her”.

In support of the above statement, Barth, Cook, Downs, Switzer & Fischhoff (2002) state that in a study conducted in an American college, students did not present themselves for VCT and STD treatment in general because they were afraid of the negative consequences of testing positive.

This fear of a HIV positive diagnosis indicates that there is still a lot that has to be done, for instance to empower AIDS orphans through counselling and appropriate education so that they will feel confident enough about protecting themselves. It is clear that although the participants seemed to have some knowledge about modes of transmission they still experienced anxiety around contracting HIV, which means prevention programmes would be of benefit to such AIDS orphans. Empowerment may, for example involve knowledge and skills gained in order for AIDS orphans to make realistic choices and to act upon them.

According to Pettifor, Rees, Steffenson, Hlongwa-Madikizela, Macphail, Vermaak-Madikizela and Kleinschmid (2004), in order for young people to take precautions to protect themselves from being infected by HIV, they should be aware of their potential risk of being infected. Indeed in this study the participants stated that they are afraid to go for VCT for different reasons. However, they regard themselves out of the category of being infected as indicated in the following words:

“No there is nothing stopping me from going for VCT but it is because I am not at risk”.

“I do not have a girl friend so I am not at risk of being infected”.
The quotations above collaborate with the findings of the study that was conducted among youth aged between 25-24 in South Africa where 36% of young people reported that they were not at risk of contracting HIV, while 35% reported being at small risk and 12% at moderate risk and 14% at high risk. The fact that AIDS orphans have a low perception of risk could be because some are not sexually active or they think that they are very young to be infected by HIV. To confirm this one participant said:

“I am turning 18 later this year and I think it is the right age to go for VCT because I will be able to make decisions, when I was 16 years I was thinking that I am not at the right age to go for VCT”.

This statement shows that prevention strategies should focus more on teaching AIDS orphans about the risks that they are faced with before they become sexually active. They should also be provided with correct and adequate knowledge about the risks faced by people of their age group.

In this study the fact that participants had a fear of contracting HIV and AIDS indicates that AIDS orphans are not yet confident that they would be able to avoid all possible modes of transmission. This may be due to the gaps in certain areas of their HIV and AIDS knowledge. The quotations below show the gaps that were identified during the interviews.

“I don’t know the difference between HIV and AIDS”.

“There is no difference between HIV and AIDS”.

“An HIV person is a person who keeps getting thinner, and does not want to eat”.

It is therefore important that AIDS orphans are provided with accurate knowledge about HIV and AIDS and VCT. They should be convinced that there are more ‘pros than cons’ to knowing one’s status, be it positive or negative, and that VCT holds more benefits than
disadvantages, therefore the benefits of VCT have to be addressed through educational programmes.

3.3.1.2 Sub-theme: Fear of death

Most participants had a preconceived idea that an HIV positive diagnosis meant death and if they test positive they are going to die. One participant said:

“If I test positive, I know I am going to die so what is the point of getting tested”.

Their fear of death might be based on the slow, degrading and painful death that they had witnessed from their parents and other siblings. All the participants had known of someone in their family or community who had died of AIDS.

There is a widespread belief that children do not take death seriously and therefore are not concerned about it (Dane, 1994:23). People believe children should be protected from death itself. Perhaps this belief that children should be protected from the experience of death sustains the belief that death does not trouble children (Killian & Perrot, 1994:10). However, Kubler Ross (1970:158) argues that although adolescents generally find it difficult to deal with the developmental stage, there is not much difference between the way adults and adolescents experience death. Holland (2001:50) agrees with this point stating that when children are 12 years old they have the same understanding of death close to that of adults. “Their cognitive (intellectual) understanding of death is that of an adult” (Mallmann, 2003:35).

“If one parent is infected with HIV it means that his or her partner will probably also be infected by means of unprotected sexual intercourse. This then results in both parents getting sick and eventually dying. This means that, unlike orphans who have lost a parent due to an accident or non-infectious disease like cancer, AIDS orphans are often confronted with the disease and death of both parents and losing a parent to AIDS and that increases their fears of death” (Mallmann, 2003:1).
According to Mallmann (2003:17) “when a parent dies, it is natural for a child to experience feelings of bereavement like sadness, depression or anger. Grieving is the word used to describe the thoughts and feelings that people have when someone has died”. Kubler Ross (1969) agrees with the above mentioned author and states that when receiving news about death, it is normal for people to go through five stages of grief namely, denial, anger, bargaining, depression and acceptance.

However, according to this theory people do not always experience all of the five grief cycle stages. Some stages might be revisited while others might not be experienced at all. The theory further argues that people are different and therefore each and every one has to pass through their own individual journey of coming to terms with death and bereavement, after which there is generally an acceptance of reality, which then enables the person to cope.

Tilley (1990) adds on, saying that people can react either positively or negatively on receiving death. Those who respond negatively may experience the above mentioned feelings of bereavement. According to Kubler Ross (1969) initially upon hearing death, a person reacts with a shock. Shock is an immediate reaction to something unexpected and it is a normal feeling that people undergo but it is not experienced by everyone. This is evident in this study as some responses of the participants attest to this:

“I was very shocked and did not believe it”.

“I was very shocked because I never thought my father could be HIV positive”.

Kubler Ross (1969) considers denial and shock as normal reactions to loss, as long as they are not prolonged. The next stage that people go through is anger. As the bereaved person comes out of denial they often become angry as they recognize their lack of control over the loss. According to Chapman (2006) in Kubler Ross (1969) anger can
manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them.

The third stage is bargaining. They begin to bargain with whatever God they believe in. In this study AIDS orphans prayed that God does not take their parents but when they realized that this was pointless, they went through a period of depression.

According to Tilley (1990) depression is a medical illness which affects one’s mood, body, thoughts and feelings. “Depression is characterised by prolonged periods of any of the following; sadness and crying, feeling low or despairing, feelings of guilt and lowered self-esteem, a tendency to see only negative things etc”. In this study one participant experienced some kind of depression due to her mother’s death and he expressed his feelings as follows:

“When my mother died, my heart was sore, I used to cry a lot”.

From the above quotation it is evident that the participant has at least begun to accept the reality with emotional attachment.

The final stage is acceptance. Finally, a bereaved person accepts the loss. Although it was not that easy, some participants said they had to accept the death of their parents, as endorsed in the following:

“I stopped crying and granny told me to be strong”.

“After my mother’s death I did not feel bad because I felt that had she not tell us about her status, it would have stressed her a lot and stress could have led to her death”.

One participant stated that he would not have been able to concentrate at school if her mother had disclosed her HIV positive status before she died but later the grandmother told the participant that his mother died of AIDS. When asked what happened to his
concentration after the grandmother told him about his mother’s status, the participant said:

“At that time I was able to concentrate because she was already dead and there was really nothing that I could do”.

The statement above shows that although it is not easy to accept death of a loved one, finally people do come to terms with death and accept it.

From this study it becomes clear that there is a need for HIV positive parents to be provided with knowledge about how to prepare their children for their death. This can be done through workshops. Information provided at the workshop can include ways that parents can arrange with relatives to take care of their children, by drawing a will to provide for their children and by talking to their children about death. This can help AIDS orphans to accept their parents’ death quicker.

Mallmann (2003:14) is of the opinion that children who have not been prepared for the death of their parents are likely to be traumatized thus react with shock and get confused. She further states that it takes longer for the child to understand what has happened and this makes the grieving process more complicated and may cause nightmares, hyperactivity or outburst of anger.

3.3.1.3 Sub-theme: Community attitudes

Research in Africa conducted by the British Organisation ‘Save the Children’ showed the seriousness of community stigma and discrimination. Participants (older children and adolescents) in ‘Save the Children’ study said gossiping about people’s HIV status by members of the community was common. Many adolescents felt hurt by the gossip and felt that their sense of self-worth was affected. The quotations below link up with the aforementioned notion that it is common for community members to gossip about peoples HIV status.
“You can also stay home when you know you are HIV positive because there are lots of gossips out there”.

“People do not change their behaviours before testing because they are thinking of what people will say if they are found to be HIV positive”.

“I do not think of going for VCT because people will say I am positive when they see me there”.

“…I was always asking myself questions like what I am going to say to those people. What I am I testing for”?

“…They hear people who are HIV positive talking about their status and that scarce them. They are thinking of what people will say if they are found to be HIV positive and they are also afraid of the nurses”.

The above quotations not only show the impact that community stigma can have on people especially the youth, but also highlights the reason for AIDS orphans not to present themselves for VCT. In order to break the misconceptions and myths about VCT, community members should be provided with the accurate and updated information so as to raise awareness and help the community to know what to fear and what not to fear.

Preparing communities for VCT so that they understand its benefits and providing support for those testing positive is essential. Communities can be prepared through community education programmes. By providing education, VCT access and acceptability will be limited by fear of discrimination and stigma.

Children grieving for dying or dead parents due to HIV and AIDS are often stigmatized by society through the association with the disease. The distress and social isolation experienced by these children, both before and after the death of their parents is strongly
increased by the shame, fear, and rejection that often surrounds people affected by HIV and AIDS. According to Avert (2005) children who have lost parents to AIDS are often assumed to be infected with HIV themselves. Because of this stigma, and the resultant fear surrounding this disease, AIDS orphans may be afraid to present themselves for VCT because they do not want to be identified as HIV positive. This is apparent in the following statement:

“People especially those in my age group do not go for VCT because they are scared of being seen by community members when they go for VCT”.

From the above quotation it becomes clear that AIDS orphans are concerned with privacy and are fearful that once they are seen at the VCT center, community members will know that they had an HIV test. Therefore, it will helpful to provide a youth friendly VCT service where AIDS orphans will not be seen by their neighbours as fear of being seen might prohibit their use of VCT.

AIDS orphans are not presenting themselves for VCT because they fear being stigmatized and discriminated against by the community. According to Avert (2005), HIV related stigma does not only occur at individual and family levels but can also arise at community level. There are a number of reported cases of people who have been harassed by community members because they are HIV positive and they are believed to have brought the disease to other community members by infecting them (Avert, 2005). Usually such blame in extreme cases is associated with violence and murder. For instance, in South Africa Gugu Dlamini was beaten and stoned to death by neighbours in ‘her’ township near Durban in 1998 because of disclosing her HIV positive status. Also, Nkosi Johnson was denied access to attend school like other children because he was HIV positive (Avert, 2005).

According to UNAIDS (2005), stigma and discrimination continue to accompany the HIV and AIDS epidemic. In cases of stigma, children begin to be rejected early as their parents fall ill with AIDS. Some children maybe teased because their parents have died of
AIDS, while others may lose their friends because it is assumed that relationship that they have with their friends can spread the virus.

Harsh cases of discrimination have been reported in many countries, including India and Trinidad and Tobago, particularly for HIV-infected children. A UNAIDS (2005) study found that HIV-related stigma is particularly high in India, where 36% of the respondents in a survey felt that HIV-positive people should kill themselves, and the same percentage felt they deserved their fate. Another 28% reported that they would not associate with an HIV-infected person.

People living with HIV can also experience a form of internalized stigma (Deacon et al., 2005). According to Deacon et al. (2005) for some time internalized stigma has always been seen as a type of stigma. However the authors argue that internal stigma (self-stigmatisation and perceived stigma) is a response to stigma rather than a type of stigma. Self-stigmatisation and perceived stigma are linked processes rather than distinct kinds of internal stigma. “The combination of external stigma and internal oppression of the self may impose a heavy burden (Deacon et al., 2005:34)”.

3.3.2 Theme 2: Factors that enable access to VCT

In this study, it was established that even though the participants were not presenting themselves for VCT, there are indeed some factors that they believe would enable them to present themselves for VCT. The participants stated that sharing information about HIV and AIDS and VCT with their friends, teachers and school mates would help them go for VCT. To express the importance of sharing information one participant said:

“I think there is nothing that can help people to go for test except for being given information, until they make the decision to go for VCT”. 
Furthermore, the participants stated that if they could get support from their extended kin, teachers, friends and school mates they would be able to go for VCT. These two factors are expatiated below as sub-themes.

3.3.2.1 Sub-theme: Information sharing

From the participants narratives it became evident that they believe that sharing information about HIV and AIDS and VCT with friends is more beneficial because they relate better to their peers than they relate to adults therefore the information they get from their friends would help them make informed decisions about getting tested. The following quotations attest to this:

“Maybe if one of my friends does not know what VCT is and I would tell them about it that it is voluntary and you do it when you want to test if you have HIV or not”.

“Yes, sometimes we do talk about testing but we have never done it. We just wish we could go”.

“Yes, I have a friend he is 18 years old and doing grade eight with me. One day he did not come to school and I asked him why. He told me that he did not come to school because he went to the clinic to test. I asked him, test for what? He said blood. I asked him again, did you touch someone’s blood? He said no but his parents said he should go for a test because he has a girlfriend”.

“I think young people should talk about HIV and AIDS and share all the information they have. People who have already tested should talk about getting tested so that young people will feel free to test”.

From the above quotations it is clear that the participants prefer to share their problems with a friend rather than with an adult; this may be due to the fact that peers support each other and help each other to grow. Peer groups provide a sense of belonging and identity
“Although circumstances may force children to take on adult responsibilities, children are still children. Spending time with peers allows a child to be a child. Together they can share their feeling and discuss life” (Mallmann, 2003:45). Children of a similar age see life differently from how adults see life.

The fact that the participants preferred to discuss HIV and AIDS and VCT with friends is consistent with the findings of Diedericks (2003). In her study the majority of students (92.9%) discussed HIV and AIDS with their friends and more than half (69.9%) discussed it with their parents. It is clear that young adults find it more comfortable to trust people they are familiar with and who are in the same developmental stage as they are. In another study conducted at Malawi in 2006, 29.7% of youth said they discussed VCT with their friends, 27.6% at school, 27.6% at the radio station, 1.4% with parents and 13.7% with others (Mpaya, 2006: 78).

From this study friends are seen as playing a very important role in influencing peers to access VCT services. This is encouraging, as it may help spread information about VCT and that would help the AIDS orphans to make informed decisions about getting tested, preventing transmission of HIV and if diagnosed positive, take treatment early. In this study it is evident that there is a need for spreading accurate and updated information about VCT. The information can be spread through workshops. In the workshops there can be group sessions where group members can share information and their experiences about VCT.

Most of the participants of this study did not have any discussions about AIDS and VCT with their caregivers, the reason being that caregivers are very old and therefore lack knowledge about VCT. One participant said:

“My grandmother knows that VCT is done when you want to test but she does not know much about it”.
The above quotation shows that there is still a need for community education about HIV and AIDS and VCT because it has been discovered that HIV and AIDS is still regarded as a sensitive issue and therefore parents still find it difficult to discuss it with their young children. The need for community education will be discussed later as a suggestion for presenting themselves for VCT.

The aforementioned support the findings of the study that was conducted by Love Life Organisation (2006) in South Africa. In this study it was found that parents had a problem of talking about teenage pregnancy and HIV and AIDS with their children. Although parents are faced with this challenge they are concerned about the need to talk openly about issues concerning their children. However age is the main factor that prevents them because they think their children are very young.

Although caregivers in this study did not have discussions with their children about VCT one participant stated that his grandmother usually talk about teenage pregnancy.

“My grandmother told me not to have a girlfriend because they will give me problems like falling pregnant. She said if I impregnate a girl she will kick me out of her house so I decided to stay away from girls”.

The above statement shows the importance of information sharing between children and their parents. According to Harrison and Steinberg (2002) research has also indicated that open communication with parents about HIV, sex and sexuality appears to reduce risky sexual behaviour.

In Southern Africa when parents die children are usually cared for by the extended kin especially the elderly who are generally poor (Barnett & White, 1999). Some children are left on their own as child-headed households and this is when the school environment becomes a safe haven. At least at school the child knows where he or she belongs and what is expected of him or her (Mallmann, 2003). According to Mallmann (2003) as the number of children orphaned by AIDS increases at schools, the roles of teachers are also
changing. Children who have lost a parent or both parents to AIDS need to say how they feel and what they think. “Expressing one’s feelings is the first step to healing” (Mallmann, 2003: 45). The role of a teacher changes to that of being a good listener and ‘counsellor’. Listening to what children have to say about their lives helps them to express their feelings.

In this study it was established that information sharing between children and their teachers is essential for effectively encouraging and supporting them to present themselves for VCT. Some responses from the participants link up with the aforementioned statement that teachers can play a vital role in encouraging AIDS orphans to present themselves for VCT.

“Maybe I can go for VCT if my teacher tells me to go”.

“My teacher, friend and a person I trust would be able to help me to go for VCT”.

“Maybe if our teachers and everybody who understands about VCT could tell us more about VCT maybe it could make it easier for us to go”.

From this study it becomes evident that AIDS orphans look for extra things from their friends and teachers. Due to their developmental stage, AIDS orphans need guidance from their teachers but also need someone they can trust and someone who is interested in their lives. They need a teacher who will help in times of crisis. For example when one participant who was experiencing a problem with an abusive grandfather was asked by the researcher if she had told anyone about that, the participant said:

“Yes, I told my teacher and she said she will visit my grandfather and try to talk to him. She said I should tell her when he is not drunk so that she can come”.

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They need a teacher who will help them develop self-esteem and self-confidence. The teacher’s role changes from being simply an instructor to being an instructor, a counsellor and an advisor (Mallmann, 2003:7).

3.3.2.2 Sub-theme: Support networks

Social networks are defined differently by different authors and there is no single definition that captures all the elements of social networks (Cohen, Normann & Snyman, 1993). According to Cohen et al. (1993) there are main elements that when combined together explain social networks and these are social integration, the opportunity to nurture others, a sense of reliable alliance, attachment and help, and guidance.

According to a Report on Participatory Workshop (2002:17), there is a need for good support services and support networks. Whether the result is positive or negative, the VCT experience can sometimes be painful, emotional and risky. Even a negative result does not necessarily reduce the stress. Froland (1980) and Litwak (1978) in Cohen et al. (1993) state that there are two types of social support systems, formal and informal social support systems and these two complement each other. Formal social support services are those falling under the support of welfare organizations. In this kind of support there are formal rules and procedures that need to be followed. Examples of these are nurses, doctors, social workers. Informal support system consists of partners, family, teachers, friends and support groups.

As mentioned earlier that the support networks work together, in this study the participants did not mention the need for formal support networks. They specified that informal support networks can play an important role in helping or enabling them to present themselves for VCT. This may be due to the fact that friends, extended families and teachers do not need to follow any formal rules and procedures when providing help, and also participants relate better to their friends, teachers and support group members than to nurses and social workers.
One participant when asked what would make it easier for him and his friends to go for VCT said:

“When there is one of us that we feel is in danger of HIV and AIDS, we would go with the person for VCT to get tested and we will also test”.

From the above statement it is evident that the above mentioned social networks support can play an important role in helping and enabling AIDS orphans to go for VCT. The support that AIDS orphans get from their friends as peer networks can play an important role that can enable them to go for VCT mainly because their friends accept them the way they are, they give them a sense of belonging, identity and values. The participants said their friends are particularly important because they play a vital role in socialization and supporting them especially in the absence of their parents.

One participant told his friends about her sister’s HIV positive status and that he got support from his friends.

“When I told them about my sister’s status, they did not say anything. Even if we were playing and making fun of one another they were not making fun of my sister’s status but maybe would laugh about my big head nothing serious to make someone angry”.

This quotation further shows the support that friends give to one another.

From the findings of this study, friends play a very important role in influencing their peers to access VCT services. It is therefore important to empower young people so that they can provide accurate information to their peers to enable young people to go for VCT.

In sub-Saharan Africa, the HIV and AIDS epidemic has deepened poverty and increased deprivation (Avert, 2005). The responsibility of caring for orphaned children is a major factor in pushing many extended families beyond their ability to cope. With the number
of children that require protection and support, many extended family networks have simply been overwhelmed. These households are often progressively unable to adequately provide for the children in their care.

Besides the challenges and problems mentioned above, in this study, AIDS orphans maintain that extended family networks can play an important role in encouraging them to go for VCT. This may be because the extended family is the second environment in which AIDS orphans experience love after the death of their parents. Also, families have a similar system of values and norms. To confirm these values one participant said:

“If ever I go for VCT and test positive the first person to know would be someone from home because I know people from home would bath me when I am weak and cannot do anything”.

Furthermore, teachers as support networks can encourage AIDS orphans to go for VCT. The following quotation from one participant endorses the above quotation:

“Because going for a test is scary I need someone like my teacher to support me”.

Moreover, participants stated that support groups can encourage them to go for VCT. They stated as follows:

“ There is something known as Grassroots that likes going to our school to talk to the Grade 7 and 9 about things such as HIV and there we get a chance to talk about what we know about VCT and HIV/AIDS”.

From the interviews the researcher had, one participant seemed to have a lot of knowledge about the whole issue of HIV and AIDS and VCT and when asked where she learned about them, she said:
“We have a Support Group with my friends and we usually have workshops on HIV and AIDS, that’s where I learned more about the disease”.

The aforementioned endorses the findings the study conducted by Mpaya (2006), in which young people participating in youth club activities are expected to be more knowledgeable since they have more time and opportunities to discuss sexual and HIV related issues. It can therefore be concluded that being a member of a support group or youth club can encourage AIDS orphans to go for VCT since they will have more ready access to information on regular basis.

3.3.3 Theme 3: Challenges of AIDS orphans

“Families cope with relatives’ death by ensuring that children affected by HIV and AIDS receive care from a substitute caregiver. The extended family support network functions through changes in household composition, with relatives moving into households to care for survivors or AIDS orphans moving out into relatives’ households” (Ansell & Young, 2004: 5). In staying with their caregivers AIDS orphans are faced with some challenges that include the fact that they have to be cared for by their extended kin with a host of problems like being abused, aging caregivers and lack of basic necessities like food. The other challenge faced by AIDS orphans is that they have to take care of their aging grandparents and this means that the roles are being switched, from being a child to being a caregiver. After the death of one or both parents children usually drop out of school for different reasons. It is therefore important to see to it that AIDS orphans are empowered to face the challenges like HIV and AIDS that come in their lives as they are growing. All these challenges are presented below as sub-themes.

3.3.3. Sub-theme: Living with the extended kin

As the number of orphans in community increases, the first traditional choice of caregivers are members of the extended kin, and when they become unavailable, grandparents are recruited into childcare (Foster, 2000 & Foster, Makufa, Drew et al
1996, Beer, 1998). Grandparents are often the first option as caregivers and they agree to take AIDS orphans because other relatives refuse (Mckerrow, 1997). The following quotations confirm this:

“At home, I am staying with my grandmother and my sister”.

“I am staying with my grandmother”.

According to the report by the Institute for International Cooperation Development (2005) the vast majority of AIDS orphans in sub-Saharan Africa are cared for by the extended kin. Here, the extended family has historically formed a resilient system of social security that usually responds quickly to the death of a mother or a father. The selection of a primary caregiver in the absence of the biological parents is a cultural practice of African families in which an adult who accepts responsibility for the upbringing of a child is regarded as a parent and is entrusted with such responsibility.

This is changing because the number of children that are orphaned by AIDS is ever-increasing and therefore the extended families are overstretched and find it difficult to take in more AIDS orphans. It should be noted that households with orphans are more likely to become poorer. This is primarily because of increased dependency ratio, meaning that in these households the income of fewer earning adults is sustaining more dependents.

In this study the fact that all the participants were living in the care of their grandparents and being cared for by their grandparents was not only a positive experience, but also a negative one. AIDS orphans stated that their grandparents are not working therefore they are not able to provide them with basic necessities like food and clothes. They expressed themselves as follows:

“We are staying with my grandmother and she is not working so we are not getting things that we want”.
“We get food from Ubuntu but sometimes they finished before we get another one and it becomes very difficult for us to survive because my grandmother is not working”.

From the above quotations it becomes clear that the fact that grandparents are unemployed prevents them from providing AIDS orphans with basic needs like food and clothing. One participant added to the aforementioned and elaborated as follows about the other problems facing them with regard to being cared for by grandparents:

“…my grandfather drinks a lot and he always insults us, me and my brother when he is drunk. He is a pensioner but he does not buy anything in the house. He sometimes beats us”.

From this it becomes clear that another challenge facing AIDS orphans is abuse or mistreatment. Loneliness at a time when support is needed weighs heavily on many teenagers. It makes them vulnerable to abuse, especially girls.

According to Mallmann (2003:137) children are usually abused by people they know or people who are in authority like a caregiver. It is further stated that children are at high risk of being abused if their caregivers abuse alcohol, are isolated from their families and communities, find it difficult to control their stress and anger, do not seem to have interest in caring for their children and seem to have serious financial or personal problems. The fact that the grandparents are very old was challenging to the participants because they felt they could not have any discussions about things like VCT with their caregivers: One participant when asked if he ever had any discussion about VCT with his grandmother said:

“My grandmother cannot even talk properly because she is very old, is about 78 years”.

From the interviews with AIDS orphans another challenge became evident, namely, taking care of the aging person. This will be discussed next as a sub-theme.
3.3.3.1 Sub-theme: Taking care of the aging person

In many families, older children are taking care of their sick parents or other siblings (old and younger). In this study AIDS orphans stated that they were faced with the challenge of taking care of their HIV positive parents and other siblings. They expressed their experiences as follows:

“When my father was sick, I used to do everything for him”.

“I used to help my mother when she is bathing and also help her eat”.

From the quotations above, it becomes evident that AIDS orphans feel overwhelmed by the huge responsibility of caring for sick parents. They nurse their parents without having been taught how to do it. They risk being infected themselves because they do not know what precautions to take when nursing people with HIV and AIDS. Nursing a bedridden patient is a huge burden even for an adult. It can be exhausting for a child. Therefore, there is a need for AIDS orphans to be empowered with life skills programme in which issues like prevention of HIV transmission can be discussed. This can include awareness about proper use of condoms and gloves.

The older the child is, the more aware he or she will be about what lies ahead. Boys can be caring and responsible caregivers but studies have shown that girls seem to feel more comfortable with this role. Often it is culturally and traditionally more acceptable for women to take on this role than taking over household chores like fetching water and herding animals. Children have to prepare food, take care of other children in the family, do the washing and, most importantly, nurse the sick parent.

3.3.3.2 Sub-theme: Dropping out of school

In this study AIDS orphans did not drop out of school while their parents were still alive.
According to Mallmann (2003) normally after the death of their parents adolesscents tend to be focused on themselves. They apply the consequences of the parent’s death to their own lives and that usually affects their school attendance or even worst result in school drop out. One participant agrees with the above mentioned by the author and worded this challenge as follows:

“I do not know where my sister is. She is leaving around and even dropped out of school”.

From the above quotation, one can conclude that after the death of parents, children are likely to behave in a different way from how they were behaving when their parents were still alive. According to Barnett and Blaike (1992) lack of discipline can be another factor contributing to school drop-outs. These authors further state that it is usually common for orphans not to be disciplined after the death of their parents and this is confirmed by many grandparents in many studies that have been conducted (Barnet and Blaike, 1992).

According to Avert (2005) children are affected by HIV and AIDS before they are orphaned. When a parent develops HIV related symptoms, children often shoulder new responsibilities, these include domestic chores such as cooking, cleaning, carrying water and laundry, care giving activities such as feeding, bathing, toileting, giving medication and accompany relatives for treatment, agricultural or income generating activities and childcare duties. Although many teenagers do this with great commitment and compassion, many children fall behind in their work, start missing school and eventually drop out of school completely (Mallmann, 2003).

During the interviews the researcher became aware that Ubuntu Education Fund is not paying school fees for the participants. Most participants when asked if they have passed said they did not know because they owe school fees therefore, they did not get their reports. In this regard one participant said:
“Grandmother is not working, our school feels are paid by my mother’s sister.

The fact that participants are getting help from their aunts is not guaranteed because some of the aunts are also not working or only have odd jobs. Therefore, there is a need for seriously looking for possible ways of helping the AIDS orphans educationally.

3.3.4 Theme 5: Suggestions put forward by the participants

Although AIDS orphans are not presenting themselves for VCT, they have suggested ways that can help people go for VCT. The participants of the study suggested that people should disclose their HIV status early so that they will get treatment in time. They emphasized the need for them to be encouraged to go for VCT. AIDS has become a global phenomenon and people have been taught about the disease. However, there is still a need for further community education on HIV and AIDS and VCT. AIDS orphans suggested that they also need to be treated with compassion. The above suggestions are discussed below as sub-themes.

3.3.4.1 Sub-theme: Early disclosure

People living with HIV and AIDS are still experiencing problems of disclosing their status due to stigma attached to HIV and AIDS (Deacon et al., 2005). There are some reasons why people especially women find it difficult to disclose their status and they include the following: resultant fear of abandonment and loss of economic support from partners, fear of rejection or discrimination, fear of violence, fear of upsetting family members especially children and fear of accusations of infidelity (Greenberg, 1999).

One of the biggest decisions for people living with HIV is whether or not to tell other people that they are HIV positive. According to South African AIDS Information Dissemination Service (2003) disclosure means giving out of information, which might commonly be kept secret, usually voluntarily, or to be in compliance with legal regulations or work place rules.
The above reasons for failure of disclosing HIV positive status correlates with the findings of the study that was conducted by Notshe (2007) in Gugulethu, Cape Town. In this study the age of children and inability to keep secrets were factors that hinder parents from disclosing their HIV positive status. Parents said they prefer to disclose their status when their children are older and therefore are able to understand. Fear of being stigmatized and then discriminated against was yet another factor that made it difficult for parents to disclose their status.

On the other hand according to WHO (2002), disclosure is an important public health goal for a number of reasons. First, disclosure may motivate partners to seek testing, change behaviour and ultimately decrease transmission of HIV. AIDS orphans also agree with the fact that disclosing HIV positive status have more ‘pros than cons’. They stated that knowing and disclosing one’s status is beneficial because one can get treatment early therefore live for a longer time. They expressed these benefits as follows:

“I did not feel bad when my mother died of AIDS because had she not tell us about her HIV positive status it would have stressed her a lot and it could have led to her death. But because she had told us we supported her and she was fine”.

“My mother would tell people about her HIV positive status. It was not a secret, she took a decision not to hide it but talk about her status”.

“People should disclose their status so that they do not infect others”.

“If I know that I am HIV positive and my boyfriend doesn’t know, I have to tell him and use a condom so that I do not infect him. This means that I have to think about his future also not mine only”.

From the above quotations it becomes clear that disclosing one’s status is beneficial not only to a person living with HIV but to the family members and sexual partners.
Disclosing HIV positive status helps those caring for a sick person to protect themselves by using gloves. Also, disclosing status increases condom use and thus reduces further transmission and re-infection. However, one participant has a different view about knowing one’s status. When asked if there was going to be a difference in his life if his mother had disclosed her HIV positive status before she died, the participant said:

“Yes there would have been a difference. I would not have been able to concentrate at school”.

3.3.4.2 Encourage to go for testing

Some participants said that it is true that youth have enough information about HIV and AIDS and VCT and this can be due to the fact that in South Africa, HIV and AIDS is included in the school curriculum and this has compelled teachers to teach about HIV and AIDS and VCT. Hence more school-going AIDS orphans get VCT information at schools. However, they still need to be encouraged to go for testing. One participant said:

“Youth do know about VCT and the places they can go when they want to test”.

This shows that encouraging people to go for VCT can increase VCT access. People can be encouraged by being given true and appropriate information about knowing one’s status. The need for community education will be discussed below as a sub-theme.

3.3.4.3 Sub-theme: Community education

It is evident in this study that AIDS orphans lack the skills for caring for a HIV positive person, or are fearful or embarrassed to talk with their caregivers about sex. Lack of open discussion and guidance about sexuality is often lacking in their homes, and this may lead to AIDS orphans picking up misinformation from their peers instead and therefore be infected. Thus, there is a need for VCT promotional programmes transmission. VCT
promotional events such as awareness campaigns and educational programmes can encourage communities to know their HIV status and to live positively. At these events, educational material can be distributed and proper and consistent use of condoms can be taught and encouraged. People can also be provided with gloves and condoms so as to reduce the risks of being infected. This community mobilisation and VCT promotion can encourage change in people’s attitude to testing in order to know their status and make informed choices about their lifestyles.

AIDS orphans stated that they fear to be seen at VCT centers because people will think they are HIV positive when they see them there. The researcher asked one participant what would help him to overcome his fears of being seen at the center. The participant said:

“If people know it is a place to test people for HIV”.

The above quotation shows that in the communities there are still some people who do not have correct knowledge about VCT and as such there is need for community education about VCT. Some of the participants also agree that there is a need for community education, as stated below:

“I think there is a need for education about VCT.

“If we are provided with knowledge about VCT we would go”.

However, people who do possess some knowledge about HIV often do not protect themselves because they lack the skills, support or incentives to adopt safe behaviours. High levels of awareness among the youth, a population group particularly vulnerable and significant as regards to the spread of HIV and AIDS, have not led, in many cases, to sufficient behavioural change.
The purpose of this chapter was to present the research findings of this study supported by relevant and appropriate literature. The researcher provided a profile of research participants in order to give the reader some background and contextual information about the study. The research study did not give preference to gender and so both females and males voluntarily participated. The researcher discussed the themes and sub-themes that emerged from the process of data analysis. The last chapter that follows presents the summary, conclusions and recommendations of this study.

CHAPTER 4

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

This chapter provides a summary of the major findings of this study discussed in the previous chapters. Chapters 1 and 2 presented the objectives and aims of the study, as well as the research design and methodology respectively. In chapter 3 the findings of the study through the use of semi-structured interviews were presented and discussed with reference to the themes and sub-themes that emerged during the process of data analysis and the consensus discussions between the supervisor, the researcher and the independent coder.
The purpose of this chapter is to provide a brief summary of the findings, formulate conclusions and make recommendations on the issue of AIDS orphans’ access for VCT and recommendations for future research.

4.1.1 Research Aims and Objectives

The overall aim of this study was to gain insight into the factors that affect AIDS orphans’ access to VCT.

The objectives were:
To explore and describe factors that prevents AIDS orphans from presenting themselves for VCT.

Based on the research findings, the concluding objective of the study was to draw conclusions and make recommendations on appropriate policies and support services in order to encourage AIDS orphans to utilize VCT.

4.2 Summary of the research design and methodology

Chapter 2 of this report outlined the researcher’s choice for the research methodology and the research process followed.

4.2.1 Choosing the research problem

The idea of this research study came as a result of the literature that was reviewed by the researcher on the whole issue of HIV and AIDS, notably AIDS orphans. Most studies have been conducted on the experiences and challenges faced by AIDS orphans, their needs and their rights as AIDS orphans and the relationship between HIV positive parents and their children (UNAIDS, 2005). It is through this period of literature review that the researcher learned that although parents are going for VCT, they find it very difficult to disclose their HIV positive status to their children for a number of reasons that include
culture and the stigma attached to the pandemic. Most of the children normally take care of their dying parents and this puts their lives at risk of being infected too. Due to the aforementioned fact the researcher felt that there was a need to investigate factors that are affecting AIDS orphans’ accessing VCT. The study highlighted both factors that prohibit and enable access for VCT. It is hoped that this study will make a valuable contribution to the existing body of knowledge about factors that prohibit AIDS orphans’ access for VCT. It is envisaged that the findings would assist in developing policies and programs that would build the capacity of AIDS orphans, their families and community members in order to break the barriers to accessing VCT.

4.2.2 The choice of the research design

This study was placed within a qualitative paradigm, exploratory and contextual strategy of inquiry. De Vos et al. (2005:268), explain qualitative research as a social interaction that allows the researcher to study the participants in detail thus interpreting the meanings they attach to their lives. The fact that qualitative research approach is best for research specifically focusing on controversial issues that have not been adequately explored in the past e.g AIDS orphans’ access to VCT, seemed appropriate to adopt the qualitative approach for this study. The qualitative paradigm that is exploratory seemed relevant to this study because the researcher needed to gain insight into the opinions of AIDS orphans about factors that prohibit them from accessing VCT and those that would enable them to access VCT. The researcher captured the context in which AIDS orphans are living, in order to obtain a holistic picture of their experiences as AIDS orphans.

4.2.3 Sampling selection of research participants

Babbie (1989:190) asserts that it is appropriate for the researcher to select a sample on the basis of her knowledge of the population, its elements, and the aims and objectives of the study. A non-probability purposive sampling method was adopted in this study. The researcher used purposive sampling to select eight AIDS orphans, all receiving professional assistance from Ubuntu Education Fund. The study does not give preference
to gender so both males and females orphaned as a result of AIDS for a minimum of two years volunteered to participate in this study. The study included AIDS orphans that have not presented themselves for VCT, living in the care of primary caregivers, attending schooling and isiXhosa speaking. This selection was done with the help of a social worker who have been providing the necessary professional services for the past 5 years at the organization. The researcher gained entry to Ubuntu Education Fund through the same social worker who served as a gate-keeper throughout the empirical study.

4.2.4 Data collection

In order to test the research methods and the data-collection tool, the researcher interviewed one participant who volunteered to participate. According to the Dictionary of Social Work (1995: 45), a pilot study is a process whereby the research method chosen is tested in order to find out if it is appropriate and to check if participants will be able to understand the questions that will be asked. Conducting a pilot study helped the researcher because the feedback she got from the pilot study was used to ‘sharpen’ and improve the research ‘tools’ for data collection. The feedback she received also helped her to make changes where it was necessary.

Semi-structured interviews were conducted in isiXhosa with each participant at Speelman Family Counselling Agency in Zwide Township. The reason for not conducting interviews at Ubuntu Education Fund was that the researcher did not want the participants to feel obliged to participate basically on the premise that they are getting professional services from Ubuntu Education Fund. Another reason was that generally participants have a tendency of not supplying correct information because they think that by doing so, it might affect their ‘relationship’ with the organization. The researcher used an interview schedule and that helped her a lot because AIDS is still regarded as a controversial and personal issue especially to young people so where responses were not clear enough, the researcher was able to probe further beyond prepared questions.
During the process of data collection the researcher assumed the role of a participant-observer. To perform that role the researcher used different communication skills namely, responsive listening, probing, reflecting, clarifying and summarizing the session (Wilson & Kneisi, 1992; Hesse-Biber & Leavy, 2006).

4.2.5 Data analysis

The collected data was analysed according to the eight steps proposed by Tesch (in Creswell, 1994). The independent coder was also consulted and assisted in confirming themes and sub-themes that were identified by the researcher.

4.3 Summary of the research findings

The researcher conducted eight semi-structured interviews and the findings were analysed according to Tesch’s (1990) eight step model of data analysis. During the data analysis process, the themes and sub-themes emerged and the independent coder was appointed to confirm them. The emerged theme and sub-themes were supported by relevant literature with quotations from the transcripts. A summary of findings is presented below. The findings include: Factors that prohibit people from accessing VCT and these factors are fear of a positive diagnosis, fear of death and community attitudes (stigma and discrimination). Factors that enable access to VCT and they include information sharing and support networks. Lastly, there we suggestions that were put forward by the participants and they are early disclosure, encouragement to go for VCT, need for community education and treating AIDS orphans with compassion.

4.3.1 Factors perceived to prohibit AIDS orphans from accessing VCT

When asked the reasons for not presenting themselves for VCT, the research participants expressed that indeed there are number of factors that prohibit them from accessing VCT. Factors perceived to prohibit AIDS orphans from accessing VCT were identified as one of the main themes. This theme was divided into three sub-themes:
• Fear of a positive diagnosis
• Fear of death, and
• Community attitudes.

It is apparent that AIDS orphans did not present themselves for VCT because they were afraid of a positive diagnosis. It became clear from this study that children who have seen the reality of HIV and AIDS in their families were likely to have a low self-esteem which later would result to self-hate and self-rejection. Fear of death was another reason prohibiting AIDS orphans from accessing VCT. This fear of death was based on the slow, degrading and painful death that AIDS orphans had witnessed from their parents. According to Mallmann (2003) when a parent dies, it is natural for a child to experience feelings of bereavement like sadness, depression or anger. Community attitudes towards people living with HIV were yet another factor prohibiting AIDS orphans from accessing VCT. Some participants stated that they were afraid of possible stigma and resultant discrimination from the community members.

4.3.2 Factors that enable access to VCT

In response to the question: “What will encourage you to go for VCT”? the participants came up with a number of responses and these responses were identified as factors that enable access to VCT. These factors were divided into two sub-themes, namely information sharing and support networks. AIDS orphans believed that sharing information about HIV and AIDS and VCT with their teachers and friends would enable them to go for VCT. Teachers and friends were found to be the best people they can share information with about HIV and AIDS and VCT and thus encourage AIDS orphans to go for VCT. This is because the participant had trust in their teachers and also relate better to their friends, so sharing information would be much easier. Some participants felt that social networks like the extended family, teachers and friends do play a vital role in encouraging them to go for VCT.
4.3.3 Challenges of AIDS orphans

The challenges presented by the participants were divided into three sub-themes namely:

- Living with extended kin
- Taking care of an aging person and
- Dropping out of school.

Some participants felt that living in the care of their grandparents and being cared for by the grandparent was not only a positive experience, but also a negative one. Participants stated that the fact that their grandparents were unemployed added to their problems because they were not able to get the basic necessities like food and clothing like they used to when their parent were still alive. The other negative experience of living in the care of parents was that some participants reported cases of abuse. According to Mallmann (2003:137) children are usually abused by people they know or people who are in authority like a caregiver.

Taking care of an aging parent/s was yet another challenge that was faced by AIDS orphans. Some participants stated that they were taking care of their sick parents or siblings. Mallmann (2003) is of the opinion that caring for a sick person can be heavy work even for an adult; it can be very strenuous to a child.

One participant reported that after the death of her parents her sister dropped out of school and did not even know where she was. According to Barnett and Blake (1992) after the death of their parents children usually start to behave in different ways may be due to lack of guidance and discipline and this has been confirmed by grandparents in many studies.

4.3.4 Suggestions put forward
There were suggestions that were put forward by the participants and these suggestions were identified as the fourth theme. The following sub-themes were put forward as suggestions by the research participants and they include; early disclosure, encouraging them to go for testing; community education and treating them with compassion.

Although AIDS orphans have never presented themselves for VCT they felt the need for early disclosure. Participants were aware of the benefits of knowing one’s status; they stated that if a person knows his/her status he/she can get treatment early therefore live for a long time. According to WHO (2002), disclosure is an important public health goal because it may motivate partners to seek testing, change behaviour and eventually decrease transmission of HIV. Some participant agreed that that most of them have enough information about HIV and AIDS however they still need to be encouraged to present themselves for VCT.

Other participants suggested that there was a need for communities to be provided with education about HIV and AIDS and VCT.

5. Major findings of the study

It became evident in this study that there was still lack of education and knowledge about the whole issue of HIV and AIDS and VCT on the part of AIDS orphans and the community at large. Findings of the study have shown that educational impoverishment was associated with a number of factors that included amongst others: general poverty, stigma and the resultant discrimination associated with HIV and AIDS.

According to AIDS Foundation South Africa (2005) approximately 61% of South Africa’s 18 million children live in poverty and 7.9 million people are unemployed. The findings of this study revealed that households caring for AIDS orphans were poverty-stricken grandmothers were unemployed and as such the basic needs like food and clothing were unmet. The fact that households caring for AIDS orphans are the worst hit
by poverty can be traced back to the historical legacy of apartheid that left communities disadvantaged and vulnerable (Gray & Rooyen, 2002:198). The study highlighted that AIDS orphans were more vulnerable to HIV infection because of the “poverty of the mind cycle” in which their parents were “trapped”. Tladi (2006:371) argues that “the extent to which people can protect themselves from HIV infection depends on their knowledge of perceived risk and their capacity to apply that knowledge, the amount of power a person has to negotiate safer sex and the prevailing cultural and societal norms”.

The findings of this study revealed that AIDS orphans were afraid of being stigmatised and discriminated by community members. According to Avert (2005) children who have lost parents to AIDS are often assumed to be infected with HIV themselves. It became apparent that because of this stigma, and the resultant fear surrounding the disease, AIDS orphans were afraid to present themselves for VCT because they did not want to be identified as HIV positive. There are a number of reported cases of people who have been harassed by community members because they are HIV positive and they are believed to have brought the disease to other community members by infecting them (Avert, 2005). Usually such blame in extreme cases is accompanied with violence and murder. For instance, as stated in chapter one, in South Africa Gugu Dlamini was beaten and stoned to death by neighbours in ‘her’ township near Durban in 1998 because of disclosing her HIV positive status. Also, Nkosi Johnson was denied access to attend school like other children because he was HIV positive (Avert, 2005).

As mentioned in chapter one, unless AIDS orphans are developed and empowered through sustainable programmes that enhance their capacities to the utmost realization of their potential, they are likely to become more ‘impoverished’ and thus vulnerable to HIV and AIDS as well as become victims of stigma and discrimination. According to Gray and Rooyen (2002) developmental approach targets the poorest of the poor and seeks to empower people especially women and children. Developing people involves promoting their well-being so that they experience change in their lives and become self-sufficient through empowerment and capacity building. Snyman (2002) in Marais et al.
(2002) sees development as a step-by-step process that should work out at the pace and according to the wishes and needs of the people.

Gray and Rooyen (2002) further state that, for people to be empowered, their skills, knowledge and their abilities must be expanded through capacity building. Alan (2002:56) is of the opinion that capacity building cannot be carried out if the community does not recognize the need for it, and it always has to be negotiated with the community first. In other words for empowerment and capacity building to occur, there is a need for professional intervention. In this study it became evident that although AIDS orphans did not access VCT they needed to be encouraged by their teachers and friends and also be provided with more education about HIV and AIDS and VCT. The role of the community worker is to facilitate the release of this capacity.

According to Saleeby (1997) during the helping process it is significant to concentrate on the strengths, skills, assets, capacities, resilience and resources that individuals, families and communities have, not only on their needs and problems. Strengths perspective states that people know what is best for them, what they want and they have capacity to change their situation. In order for AIDS orphans to be developed and empowered, their strengths and capacities have to be put into action so that they are able to access VCT. Assert-based approach sees the importance of keeping assets register instead of needs studies. The strengths of this approach include the fact that it encourages community grassroots participation. If people take part in projects that involve them, they feel that they own them and are part of the solution. Therefore participation encourages ownership. Because people are experts of their own situations, professionals helping them should be in partnership with people and does not occupy a ‘dominant’ role. In this study, the strengths of the Asset-based approach would be to incorporate grass-roots community-based solutions in relation to programmes that embrace the whole issue of accessing VCT by AIDS orphans.

6. Limitations of the study
While this study has yielded remarkable results, there are some aspects that were regarded as limitations, as stated below:

The research study was restricted to AIDS orphans attending school, therefore the results cannot be generalized to all South African AIDS orphans including the illiterate.

All the participants in this study were living in townships (urban areas) hence the result might not be generalized to AIDS orphans living in rural areas.

7. Conclusions and Recommendations

7.1 Conclusions

The study revealed that there are a number of factors that prohibited AIDS orphans from accessing VCT. One of the prohibiting factors was the fact that AIDS orphans are afraid of what community members will say if they are seen at VCT centers. This implies that community stigma and discrimination is a major problem. Most of the AIDS orphans are not going for VCT because of fear of being told that they are HIV positive. This feeling of fear applies to all those who have seen their parents or other siblings suffering after a positive diagnosis. To some AIDS orphans, a HIV positive diagnosis means death therefore they do not go for testing because they have a fear that if diagnosed positive they are going to die immediately.

Even though it was found that there factors that prohibited AIDS orphans from accessing VCT, it can be concluded that through this study there were also factors that were identified as enabling access to VCT. The support networks, both at family and extended kin levels, were found to play an outstanding role in encouraging AIDS orphans to access VCT. It can be concluded that although extended kin support is overstretched due to increasing number of AIDS orphans, they still can play a major role in guiding AIDS orphans to make informed decisions about accessing VCT. The participants in this study further expressed that sharing information with their teachers and friends does encourage
them to access VCT. AIDS orphans would therefore like to be told by their teachers and friends to go for VCT. Therefore it can be concluded that maintaining a good relationship between teachers and pupils is significant as it increases access to VCT.

It can be concluded that this study found that there are both factors prohibiting and enabling access to VCT. Based on these findings and conclusions, the recommendations below are presented:

7.2 Recommendations

The following recommendations are made from a policy and service delivery perspectives.

- Service delivery perspectives

The role of health and other professionals were seen to play a pivotal role in encouraging AIDS orphans to access VCT. The participants themselves mentioned the important role that health professionals play in encouraging them to make use of VCT. It is therefore recommended that health professional like social workers provide on going counselling to AIDS orphans before and after the death of their parents. Providing counselling can help AIDS orphans make informed decisions about getting tested.

It is also recommended that social workers be equipped with the necessary skills for growth so that they can make a difference in the lives of the vulnerable groups like children.

From this study, it became clear that after the death of their parents AIDS orphans have put all their trust in their teachers. In schools teachers seem to play multiple roles of being counsellors, friends and parents. Teachers have been seen to play a major role in encouraging students to access VCT. Therefore, it is recommended that teachers be empowered through training programmes on child care and development so that they will be able to make informed decisions about accessing VCT and be in a position to shape
their destiny. At the same time teachers should be provided with counselling to prevent burn out.

A wide range of Non Profit Organizations (NPOs) have responded to the HIV and AIDS crisis. They are playing a major role in assisting children from disadvantaged families with training, education, welfare and health service provision. For those NPOs providing VCT services it is recommended that VCT centers be situated in a way that when young people enter the sites they will not be seen by their neighbours as this was mentioned as one of the factors that prohibited them from accessing VCT.

Also it is recommended that NPOs provide a youth friendly VCT service where young people who have already tested can be empowered through capacity building skills and be trained to be peer counsellors and work at VCT centers. Providing training to youth will help as it has been mentioned earlier that peers relate better to one another than to adults so it would be easier for youth to go for VCT where counselling is provided by their peers. “Successful interventions show that a peer educator approach is most appropriate to convey the AIDS message to the target group” (AIDS Foundation South Africa, 2005:4).

The participants of the study stated that they have never touched or be provided with gloves by the organizations that are helping them. It is therefore recommended that children be provided not only with condoms but should also be provided with gloves and proper education on how to use them so that when they care for their HIV positive parents or siblings, they can protect themselves from being infected.

From the this study it became clear that support groups are playing an important roles in empowering AIDS orphans with knowledge and skills that are necessary for helping them to access VCT. According to Health Systems Trust (2006) due to increasing numbers of people who are infected by the virus, resources are overstretched therefore support groups have been seen as the best to respond to the needs of the infected and affected people like AIDS orphans. It is therefore recommended that in their support groups,
AIDS orphans are empowered through sustainable programmes that will enhance their capacities to the utmost realization of their potential. It is also recommended that the support groups provide AIDS orphans with emotional and spiritual support in a way that their well-being will be promoted so that they can experience change in their lives and become self-sufficient and productive members of the society.

It became evident in this study that AIDS orphans are fearful or embarrassed to talk with their caregivers about sex. Therefore it is recommended that in their support groups AIDS orphans are provided with education through workshops aimed at improving their knowledge and skills in relation to the issue of HIV and AIDS and VCT so that they will be able to talk and express themselves fully. Empowering AIDS orphans means regarding them as active members of the community to be involved in decision-making on matters that affect their lives.

Parents should be encouraged to disclose their HIV positive status so that they do not infect those who are caring for them. In order for them to disclose their status, it is recommended that they be provided with ongoing counselling and support so that they will feel comfortable and free to talk about their status to their children. Once comfortable they should engage in public awareness campaigns where they can openly tell the public about the benefits and challenges of disclosing one’s status.

- **Policy perspective**

It has been mentioned in this study that stigma and discrimination are one of the main factors that prohibit AIDS orphans from accessing VCT. Research has shown that providing accurate and comprehensive information to the community regarding the transmission of HIV reduces the degree of stigma and discrimination that accompany an HIV-positive diagnosis. It is therefore recommended that in order to reduce stigma and discrimination the department of Health should provide communities with proper education on HIV and AIDS. In this study community education was mentioned as the best way of improving people’s knowledge about the pandemic. Community education
can be provided through public awareness campaigns where people can be provided with Information Education Communication (IEC) materials. It is only when people understand that HIV and AIDS is a disease like any other disease that levels of fear and animosity can be reduced and thus encourages access to VCT.

It is also recommended that the department provides people living with HIV and AIDS with education about their rights and about how to get help in order to challenge the discrimination and stigmatization they are faced with in their communities. People living with HIV and AIDS and communities members need legal education and access to the justice system to address the violation of their rights.

It is further recommended that the department of education equips its communities with the necessary skills for growth, development and survival. These skills can be provided through educational programmes where people can be taught ways of preventing transmission like proper use of condoms and gloves.

- **For future research**

The findings of this study suggest that future researchers could investigate the following:

- Some researchers can conduct studies on the long-term outcomes for those who have undergone VCT.

- The coping mechanisms for AIDS orphans that test positive.

8. Concluding remarks

The aim of this study was to gain insight into factors affecting AIDS orphans’ access to VCT. It can be concluded that the following were achieved:

Factors that prohibit AIDS orphans from accessing VCT;
Factors that enable access to VCT;
Recommendations based on the research findings were made.
It is very important to note that the findings of this study add to the body of knowledge as existing research has thus far not yet focused on the importance of AIDS orphans’ access to VCT.

REFERENCES


The role of stigma and discrimination in increasing the vulnerability of children and youth affected and infected by HIV/AIDS. 2002. Report on Participatory Workshops. Save the Children UK.


